



## DEMENTIA CARE SERIES

Michigan Department of Community Health

CARING SHEETS: THOUGHTS & SUGGESTIONS FOR CARING

# Caring Sheet #13: Frontotemporal Dementia:

A Summary of Information and Intervention Suggestions with an Emphasis on Cognition

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## Introduction

This caring sheet focuses on Frontotemporal Dementia, with an emphasis on cognition.

Caring sheets #11 and #12 summarize information and intervention suggestions regarding Alzheimer's Disease (caring sheet #11) and Dementia with Lewy Bodies (caring sheet #12). All three outline the brain changes in each type of dementia, the impact these changes have on cognition and behavior, and implications for effective intervention.

The three caring sheets (#11, #12, and #13) are written as companion pieces in outline form with virtually each line of one caring sheet corresponding with each line of the other two. The three can be laid out side by side, and compared almost line by line.

Other caring sheets describe the cognitive and behavioral changes and specific interventions for these dementias in more detail. Caring Sheet #2 in particular describes the characteristics of dementia, and the relationship between the brain changes and changes in cognition.

Dementia is a decline in a person's cognition. This decline occurs because of changes in the brain.

If the cognitive decline is caused by treatable disorders such as a urinary tract infection, vitamin deficiency, reactions to medications, or depression, it is likely **temporary** and **treatable** (e.g., delirium).

In other cases the brain changes and resulting cognitive decline are **irreversible** and **progressive** (i.e., increasingly severe). They are caused by disorders such as Alzheimer's Disease, vascular disorders (e.g., ministrokes), Creutzfeldt-Jakob Disease, Dementia with Lewy Bodies, or Frontotemporal disorders. There are over 80 different disorders that cause this type of progressive dementia. Frontotemporal Dementia is one of these disorders.



## **FRONTOTEMPORAL DEMENTIA (FTD)**

AD refers to Alzheimer's Disease

### **CHARACTERISTICS**

Brain disorder

Most obvious symptoms: behavior and personality changes

Progression: increasing severity of symptoms over time (a progressive dementia)

Onset: insidious; age 40-65 usually, (average age about 60)

Duration: slightly longer than for AD

Cause unknown

Cure: no cure at this time, but there is treatment to reduce symptoms

Diagnosis supported by structural imaging (e.g., CT, MRI) or functional imaging (e.g., PET, SPECT) of person's brain before death

Fairly common cause of dementia (10-15% of all dementia cases)

About 140,000 – 350,000 people in United States have FTD

Only known risk factor is family history

May be hereditary in 38-60% of cases (chromosome 17, or less often chromosome 3)

Course: behavior and personality changes are first and most obvious symptoms throughout course. Course varies with individual. Slower course than AD, usually.

Name is based on location of neuropathology. A variety of diseases cause FTD.

### **NEUROPATHOLOGY**

Varies with type/cause: (e.g., Pick bodies are found in 20% of cases at autopsy)

Atrophy (i.e., loss) of brain tissue; cell death

No neuritic plaques

No neurofibrillary tangles

No Lewy bodies

No significant changes in Acetylcholine

No changes in EEG even in late stages

### **LOCATION OF CORTICAL BRAIN CHANGES**

Cortical refers to the cortex (i.e., the outer layer) of the brain

Changes (pathological abnormalities) occur in the cortex and in internal (subcortical) structures of the brain

Changes (pathological abnormalities) occur on both sides of the brain

Cortical brain structures affected:

Frontal lobe

Temporal lobe (anterior)



## **COGNITIVE CHANGES**

Preserved in early part of course:

- visual & auditory perception
- spatial perception
- orientation
- praxis
- memory
- time orientation

Preserved in later part of course:

- spatial orientation (e.g., don't get lost as often as do persons with AD)

Insight impaired early in the course

Impairment in speech: very obvious symptom; impaired in early part of course;  
increasingly impaired throughout course:

- Reduced spontaneity
- Fewer words used
- Repetition of limited variety of words, phrases, themes
- Clichés used; difficulty individualizing speech to situation
- Echolalia (person says words or phrases she/he just heard)
- Perseveration (person repeats an action or speech)
- Mutism (lack of speech) eventually, often
- Comprehension often less impaired than speech

Impaired earlier in the course than in AD, with increased impairment over time:

- Perseveration
- Mental rigidity and inflexibility
- Concentration impaired
- Distractibility
- Impulsivity
- Reasoning impaired
- Judgment impaired
- Abstract thinking impaired
- Lack of concern for accuracy
- Initiation impaired
- Sense of time impaired
- Ability to empathize with others impaired
- Ability to monitor self impaired
- Ability to adapt impaired



## **EMOTIONAL CHANGES**

- Depression
- Anxiety
- Excessive tearfulness
- Suicidal thoughts
- Delusions
- Hypochondriasis
- Bizarre somatic preoccupation (focus on own body)
- Emotional unconcern (indifference, remoteness, lack of empathy, apathy, blank facial expressions)
- Inappropriate emotional expressions:
  - Laugh instead of cry
  - Exaggerated expression
  - Switch quickly (lability)

## **BEHAVIORAL CHANGES**

- Mood and behavior changes early in the course:
  - Personal awareness impaired (poor personal hygiene and grooming)
  - Social awareness impaired (lack of social tact, petty crimes)
  - Disinhibition (inappropriate sexual behavior, physical aggression, inappropriate laughter and joking, restless pacing)
  - Lethargy
  - Family and work ignored or get less attention
  - Incontinence
- Changes vary with individuals
  - Some quiet and withdrawn; Some disinhibited and disruptive
  - Some lethargic; Some hyperactive
- Repetitive behaviors (e.g., wandering, clapping, singing, dancing)
- Ritualistic behaviors (e.g., hoarding, cleaning)
- Fixations and obsessions
- Impulsivity
- Hyperorality (e.g., overeating, food cravings, excessive smoking, excessive alcohol consumption, putting objects in mouth)
- Exploring and handling objects in environment excessively or inappropriately
- Sleep increase in time and increased drowsiness
- Movement rigid in later part of course, sometimes



## **INTERVENTIONS: Non-medicinal**

- Assess individual for abilities and functions (do not generalize FTD symptoms)
- Acknowledge that comprehension is usually better than expression of language:
  - Talk to person directly
  - Don't talk about person in front of her/him
- Avoid giving unintended cues or information
- Orient to time
- Structure person's time with activities and events
- Emphasize consistency; and predictability in:
  - Schedule of events and daily routines (in time, duration, and order)
  - Who is providing care (same caregiver each time)
  - The way a task is done (e.g., order of task steps, same task objects)
  - Where events and activities take place
  - Environment (e.g., avoid changing rooms or furniture)
  - Methods of communication
- When communicating:
  - Increase nonverbal forms of communication
  - Get and keep the person's attention
  - Give time to start action
  - Keep information and requests concrete
  - Use few words, short words and phrases
  - Use most important words first
  - Use music, singing, rhythm to help person move and to shift attention
  - Be clear and respectful with requests; minimize emotional energy and content of request
- Use speech therapy that relies on intact parietal lobe functions rather than impaired frontal lobe functions (e.g., use nonverbal stimuli and methods of communications, music, rhythm, fewer lengthy explanations or questions)
  - shift from one thought or activity to another slowly; give time
- Address social behaviors of person:
  - distress of caregiver regarding behaviors (embarrassment, concern)
  - impact on children and coworkers
  - community awareness, support, law enforcement



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Support family and caregiver

Address anger

Educate/remind caregiver FTD is a brain disorder

Prepare for employment and financial implications

Prepare for future care

Tell caregiver and family:

Explain course of FTD

Expectations must match individual abilities

Comprehension is usually less impaired than speech

Be predictable: minimize change, do the things the same way each time

### MEDICAL TREATMENTS

Cure unknown

Increase serotonin for repetitive and obsessive behaviors

Cholinesterase inhibitors do not help, since Acetylcholine is not reduced

### COMMENTS

In 1994 consensus criteria for clinical and pathologic diagnosis first created and have since been updated.

Pick bodies were first described in a patient by Arnold Pick in 1906.

Often misdiagnosed as AD

May be associated with Lou Gehrig's Disease (Amyotrophic Lateral Sclerosis)

### RESOURCES

<http://www.ninds.nih.gov/disorders/picks/picks.htm> (National Institute of Neurological Disorders and Stroke NINDS)

<http://www.FTD-Picks.org> (Association for Frontotemporal Dementias (AFTD))

<http://www.alzheimers.org> (Alzheimer's Disease Education and Referral Center ADEAR)

<http://www.alz.org> (Alzheimer's Association)

<http://www.med.umich.edu/madrc/> (Michigan Alzheimer's Disease Research Center MADRC)

Radin, L. & Radin, G. (editors) What if it's Not Alzheimer's? Prometheus Books, Amherst, New York 2003 (More info: phone 716-691-0133, ext. 207).



This caring sheet focuses on Frontotemporal Dementia (FTD). More details about the brain changes and resulting cognitive changes in dementia are in caring sheet #2.

Though these changes in behavior and cognition result from brain damage, they are often mistakenly viewed as intentional or manipulative.

In FTD the neuropathological changes to the brain are more varied than they are in Alzheimer's Disease (AD) or Dementia with Lewy Bodies (DLB). This is because the name (Frontotemporal) refers to the location rather than to the name of the neuropathology. Pick bodies (the neuropathology found in Pick's disease) are found in Pick's Disease which is one kind of FTD. AD and DLB are both named after the neurologists who discovered the neuropathology (abnormalities) found in the brain. There are various dementing disorders that affect primarily the frontal and temporal lobes of the brain. Someday the names of these disorders may replace the term "FTD".

## **Other Dementias**

See caring sheet #11 for more information about Alzheimer's Disease (AD) and caring sheet #12 for more information about Dementia with Lewy Bodies (DLB). At the end of caring sheet #11, there is a brief description of vascular dementia, another common cause of dementia.

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All Caring Sheets are available online at the following two websites: <http://www.lcc.edu/mhap> (Mental Health and Aging Project (MHAP) at Lansing Community College in Lansing, Michigan) and <http://www.dementiacoalition.org> (Michigan Dementia Coalition).

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