



# Younger Onset Dementia

2013 NIH/ACL Alzheimer's Webinar Series

August 20, 2013



# Welcome

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# U.S. Alzheimer's Disease Centers

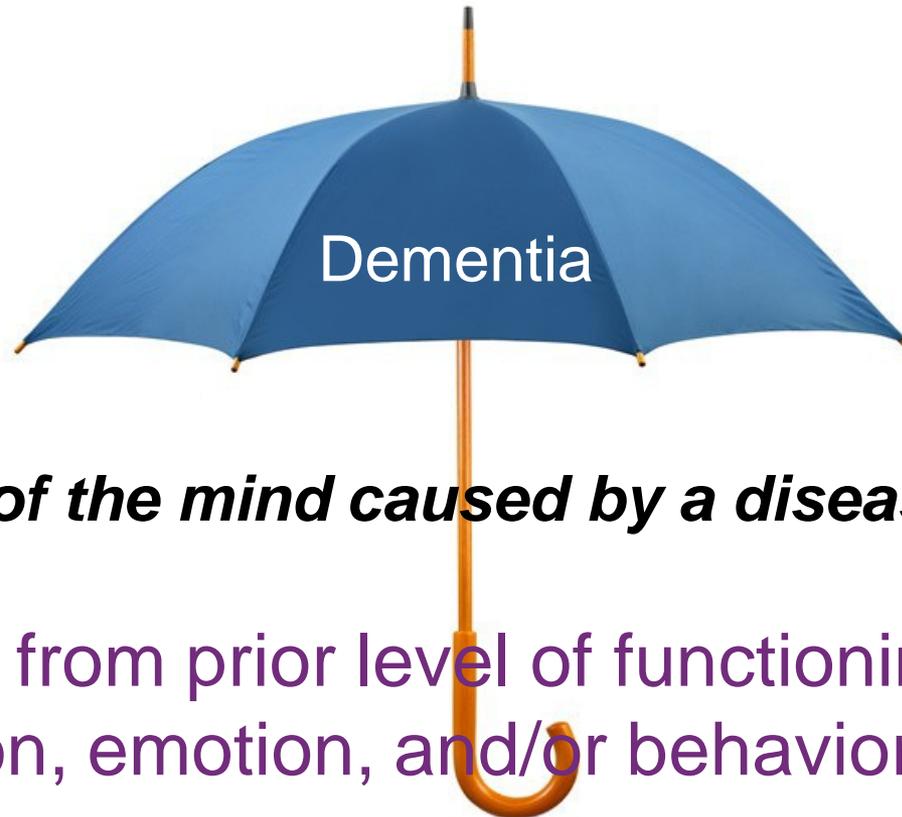


- Each AD center has:
  - Administrative Core
  - Education Core
  - Clinical Core
  - Data Core
  - Neuropathology Core
- Most also conduct clinical trials

# Younger Onset Dementia

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***A condition of the mind caused by a disease of the brain:***

- Decline from prior level of functioning in cognition, emotion, and/or behavior.
- Progressive worsening over time.
- Interferes with independence and daily activities.

## What is Younger Onset Dementia?

- Symptoms first occur <65 years of age
- Broad differential diagnosis
- Higher prevalence of rarer dementias
- Burden of inherited dementia is higher
- Presentation of Alzheimer's disease can be different <60

## What is Younger Onset Dementia?

- Persons with YOD are less likely to have co-existing major illness and sensory changes; therefore, healthier and fitter
- Younger Onset vs. Early Stage
  - Younger Onset <65
  - Early Stage – refers to the mild illness stage / newly diagnosed

# Prevalence of Younger Onset Dementia

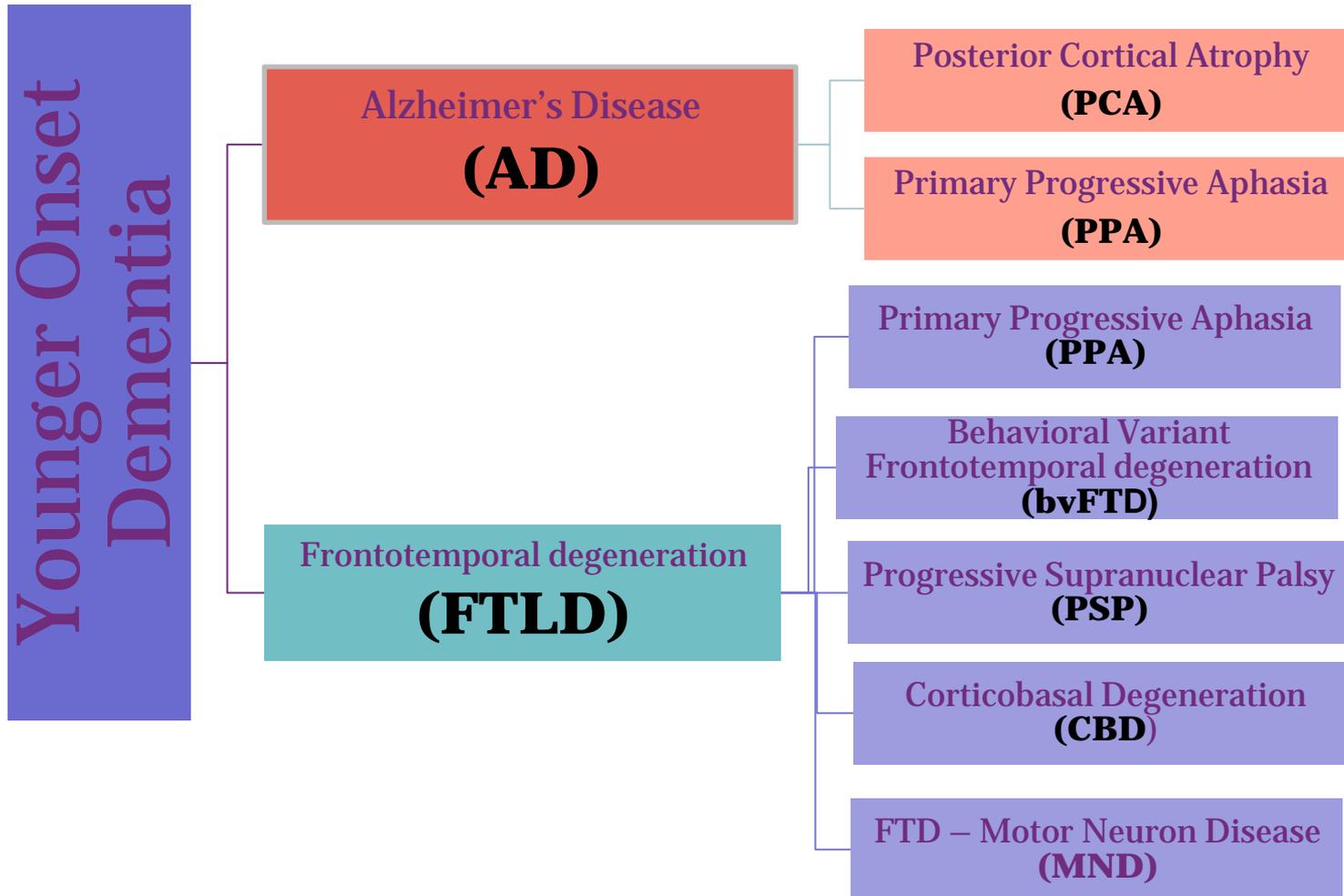
EARLY ONSET DEMENTIA  
A NATIONAL CHALLENGE, A FUTURE CRISIS

June 2006



- Approximately 220,000 individuals living with younger onset dementia (Alzheimer's Association, 2006)
- FTD disorders affect approximately 50,000-60,000 people in the U.S. (Knopman, 2011; AFTD, 2013)

# Neuropathology and Syndromes of Younger Onset Dementia

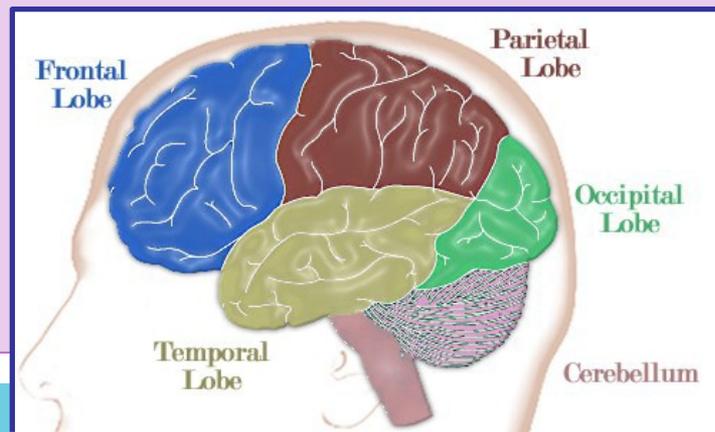


## Alzheimer's Disease

- A progressive illness that begins in the area of the brain responsible for memory
- Major symptom: inability to learn and retain new information
  - Forget current/personal events, conversations
  - Repetitive questions, commands
  - Misplace objects, get lost (spatial disorientation)
  - Age of onset > 65 years

# Posterior Cortical Atrophy

- Benson's syndrome – visual variant of Alzheimer's Disease
  - Decline in visual processing skills
  - Relatively intact memory and language in early stages
- Onset - typically between 50 and 65 years
- 5-15% of people diagnosed with AD have PCA



# What is Frontotemporal Degeneration? THREE TYPES OF DEMENTIA

## Language Type

Primary Progressive  
Aphasia (PPA)

Early Onset (<65)

## Behavioral Type

Behavioral Variant  
Frontotemporal  
Dementia (BVFTD)

Early Onset (<65)

## Motor Type

Corticobasal  
Syndrome

Progressive  
Supranuclear Palsy  
FTD-MND

## Language Type Primary Progressive Aphasia

- A clinical syndrome that is diagnosed when the following features are present:
  - A disorder of spoken or written language (aphasia)
  - The aphasia is caused by a degenerative brain disease (progressive)
  - The aphasia is initially the most salient feature and the chief cause of daily living limitations (primary)(IMPPACT, 2013 <http://www.ppaconnection.org>)

## Behavioral Type

### behavioral variant Frontotemporal Degeneration – bvFTD

Rascovsky et al (2011)

- Progressive deterioration of behavior &/or cognition
  - Early behavioral disinhibition
  - Early apathy or inertia
  - Early loss of sympathy or empathy
  - Early perseverative, stereotyped or compulsive/ritualistic behavior
  - Hyperorality and dietary changes
  - Sparing of memory and visuospatial symptoms

## MOTOR TYPE

### PROGRESSIVE SUPRANUCLEAR PALSY - PSP

- Balance, vision, speech and swallowing problems.
- Worsened memory and mood
- Central body stiffness
- Personality changes
- Cannot look down voluntarily

### CORTICOBASAL DEGENERATION – CBD

- Similar to PSP (balance, vision, speech & swallowing problems)
- Stiffness, jerkiness, slowness and clumsiness
- Memory or behavior problems

### FTD-MND

- A combination of FTD and ALS (Lou Gehrig's disease)
- Changes in behavior and/or language
- Muscle weakness, shrinkage, jerking

# Young Onset Dementia

Impact on the Person with  
Dementia and Family

# DIAGNOSIS

## The Difficulty Obtaining One

- Symptoms misinterpreted as psychiatric or attributed to normal aging
- Diagnosis often delayed after several attempts.

*“We went for two years without a diagnosis. It was difficult watching a family member changing and not knowing what to do for them. This is a stressful illness, but not knowing is worse.”*

*Spouse of person with YOD*

## Complex Family Dynamics

- Different life stage
- Shifts in family roles
- Young children caring for a parent
- Young adult children 'leaving home'
- Older parent caring for a middle aged child



## **Loss of Employment and Job-Related Income**

- More likely to be working at diagnosis
- Height of career
- Heavy financial commitments
  - Unable to perform job tasks
  - Misunderstanding by employers, co-workers
  - Loss of self-esteem, feeling of productivity
  - Change in career and retirement plans
  - May be terminated before illness understood

## Loss of Employment and Job-Related Income

*“We have a different look on how life will be. Retirement has changed. We thought we could go sit on a beach and watch the sunset, but that is changed and we can’t do anything about it.”*



*“We’re in our 50’s and all our plans for retirement, our plans to move to a second home, extensive travel plans, just went away.”*

## Social Security Disability and the Medicare 2-Year Wait

- Financial burdens for young families transitioning out of the work force early
- Social Security Disability Insurance (SSDI)
  - PPA on list of Compassionate Allowances Conditions
- Medicare two-year wait
- Long-term care costs

*“Our big issue is health insurance. We are currently on COBRA which expires soon. I’m trying to figure out how to extend COBRA beyond the normal 18 months in order to overlap with Medicare. We are currently facing a six month gap in coverage between the two.”*

## Caregiver Outcomes

- Caregivers of younger persons with dementia have significantly higher levels of burden (Freyne et al, 1999)
  - Longer duration of caring (average 3.4 years)
- Caregivers of persons with FTD have higher burden compared to AD (Boutoleau-Bretonniere et al., 2008; deVugt et al., 2006)
- Behavioral symptoms of disinhibition and apathy were experienced more frequently and intensely

Svanberg et al. (2011) The impact of young onset dementia on the family: a literature review. *International Psychogeriatrics*, 23, 256-371.

## Community Services

- There is a general lack of understanding of YOD, particularly the non-Alzheimer dementias of FTD and PPA among healthcare providers and social service agencies
- Many have never heard of FTD or PPA – more familiar with AD and the older demographic
- Fewer home and community based services options appropriate to patient needs
- Lack of safety net because of qualifying age restrictions

## Community Services

*“Trying to find adult day care facilities or respite care for physically active patients is next to impossible or too costly to use. We found that adult day care staff do not have training to deal with younger dementia patients. They are better prepared to deal with the needs of older individuals.”*

*“Many nursing homes would not consider him because he is too young and would not fit in. One nursing home indicated he would be a risk to employees just because he was a young male patient.”*

# Impact on the Person with Younger Onset Dementia

- Insight
  - Differing levels based on brain areas affected
    - AD – early to moderate stage - *“I’m still here”*
    - PPA (language type) – Increased depression
    - FTD (behavior type) – often impaired
- Relationship / Role Changes
  - Social
  - Family

## Impact on Children

- Robbed of parent at key developmental time
- Younger children may feel responsible for the disease
- May have school difficulties
- May feel angry and behave in aggressive way to ill parent
- May become the “caregiver of the caregiver”
- Impact on social relationships with others
- Genetic concerns

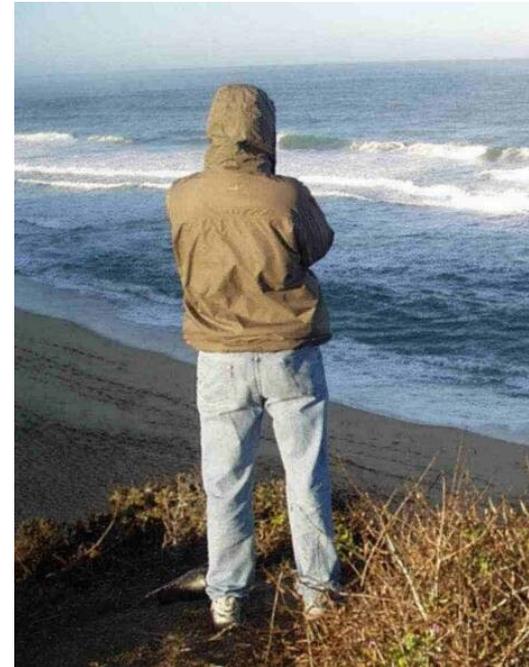
*“Our five year-old daughter has lost her father. The other day she came home and said, ‘I’m the only one at daycare who doesn’t have a dad at home.’”*

## Impact on Partner/Spouse

- Loss of a companion
  - Feeling “robbed of the future”
  - Role changes in the relationship
  - Reciprocity in relationship diminishes
  - Changes in feelings towards the person with dementia
  - Loss of a parenting partner
- Planning for future care
- Balancing care with maintaining a life of their own
- Managing their expectations of others
- Coping with emotions
  - Sadness, Anger, Grief, Stress, Guilt, Depression, Anxiety

## Impact on Partner/Spouse

*“He was my companion and I’ve lost him. When he left in April (to live in the nursing home) it was like he died. I really miss his friendship and companionship.”*



*“I lost my partner, I can no longer plan for the future”.*

# Resources

Education

Care & Support

## Legal / Financial Planning

- Power of Attorney
  - Health/Person and Finances/Property
  - National Association of Elder Law Attorneys  
<http://www.naela.org>
- Long-term care insurance
- Social Security Disability Insurance
- Medicare

## Care & Support

- Counseling
  - Individual
  - Family
  - Group
- Creative Arts Therapies
  - Music
  - Art
  - Dance/Movement



## Care & Support

- Long Term Care Services
  - In-Home and Adult Day Services
    - <http://www.homecareaoa.org>
    - <http://www.nadsa.org>
  - Respite
  - Assisted Living
  - Nursing Home
- Palliative Care / Hospice

## Care & Support

- Long Term Care Services
  - Funding sources may include:
    - Private Pay
    - Private Long Term Care Insurance
    - Public Funding, such as:
      - Medicaid
      - Older Americans Act (National Family Caregiver Support Program serves caregivers who are caring for individuals of any age with Alzheimer's disease or a related disorder), or
      - Other state/local sources

What is available may vary. Go to <http://www.eldercare.gov/> for your local Area Agency on Aging / Aging & Disability Resource Center.

## Where to learn more

- Association for Frontotemporal Degeneration (AFTD)
  - <http://www.theaftd.org/>
- CurePSP: Foundation for PSP CBD and related Brain Diseases
  - <http://www.psp.org/>
- National Aphasia Association (NAA)
  - <http://www.aphasia.org/>
- Alzheimer's Association
  - <http://www.alz.org>
- ADEAR - Alzheimer Disease Education and Research Center - National Institute on Aging
  - <http://www.nia.nih.gov/alzheimers>

FTD/PPA Caregiver & Professional Education and Support Conference  
November 4, 2013 - Chicago  
<http://www.brain.northwestern.edu/>

- PLENARY SESSION
  - State of Research and Treatment in PPA
  - Interventions for Language Changes
  - Coping with Relationship and Behavior Changes



- BREAKOUT GROUPS
  - Building a care team
  - Understand symptom based interventions
  - Strategies for communication
  - Navigating family conflict
  - Partners in care

2012 Conference Stats  
236 Family Caregivers  
88 Professionals  
26 Vendors

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**FRONTOTEMPORAL DEGENERATION (FTD)  
and  
PRIMARY PROGRESSIVE APHASIA (PPA)  
CAREGIVER AND PROFESSIONAL  
EDUCATION & SUPPORT CONFERENCE**



**SAVE THE DATE**  
**MONDAY, NOVEMBER 4, 2013**

For questions or information about sponsorship opportunities, please  
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# Northwestern CNADC 2012 conference booklet

<http://www.brain.northwestern.edu/>

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COGNITIVE NEUROLOGY AND ALZHEIMER'S DISEASE CENTER  
*of the Northwestern University Feinberg School of Medicine presents the*

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**FRONTOTEMPORAL DEGENERATION  
*and* PRIMARY PROGRESSIVE APHASIA**  
**FAMILY CAREGIVER AND PROFESSIONAL  
EDUCATION AND SUPPORT CONFERENCE**  
SATURDAY, MARCH 24, 2012

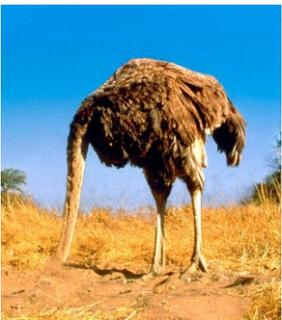
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THE CNADC WOULD LIKE TO THANK THE  
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FOR THEIR GENEROUS SUPPORT OF THIS EVENT

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# Lack of Public Awareness

*“If you say someone has cancer there is an immediate concern. When you say a young person has dementia often people don’t believe it or think you are exaggerating. Because their appearance is of a younger person and they don’t generally have physical disabilities, society does not expect odd behavior and reacts differently than they would of someone who is in their 80’s.”*

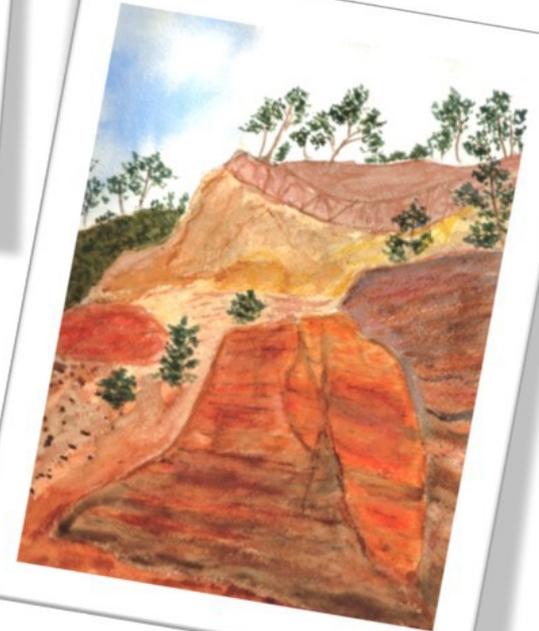


*“Many people just don’t believe me when I tell them what is wrong with him. Many people believe that this (dementia) is an old person’s disease. Society needs to be educated more about this illness.”*

## Conclusion

- The differential diagnosis of younger onset dementia is much broader
- Many may have a non-Alzheimer dementia
- Early diagnosis and early information lead to earlier treatment and planning
- Persons with YOD and families have different needs for services and support

# Images



## Thank you

### Acknowledgements:

Sandra Weintraub, PhD  
M.-Marsel Mesulam, MD  
Mary O'Hara, AM, LCSW  
Tamar Gefen, MS

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# Younger Onset Dementia: Detection and Diagnosis

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# Presenter Disclosure Information

**Employee of:** Northwestern University

**Consultant for:** None

**Stockholder in:** None

**Research support:** NIA, NIDCD, NINDS

**Honoraria from:** None

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# Definitions

Dementia is a “clinical syndrome” defined as:

*Gradual onset and progressive decline in thinking abilities and/or behavior; can affect motor function*

Interferes with daily activities, with need for assistance/supervision

Shortens life expectancy

Most common cause: brain degeneration



## Definitions

**Older onset dementia (most common)**

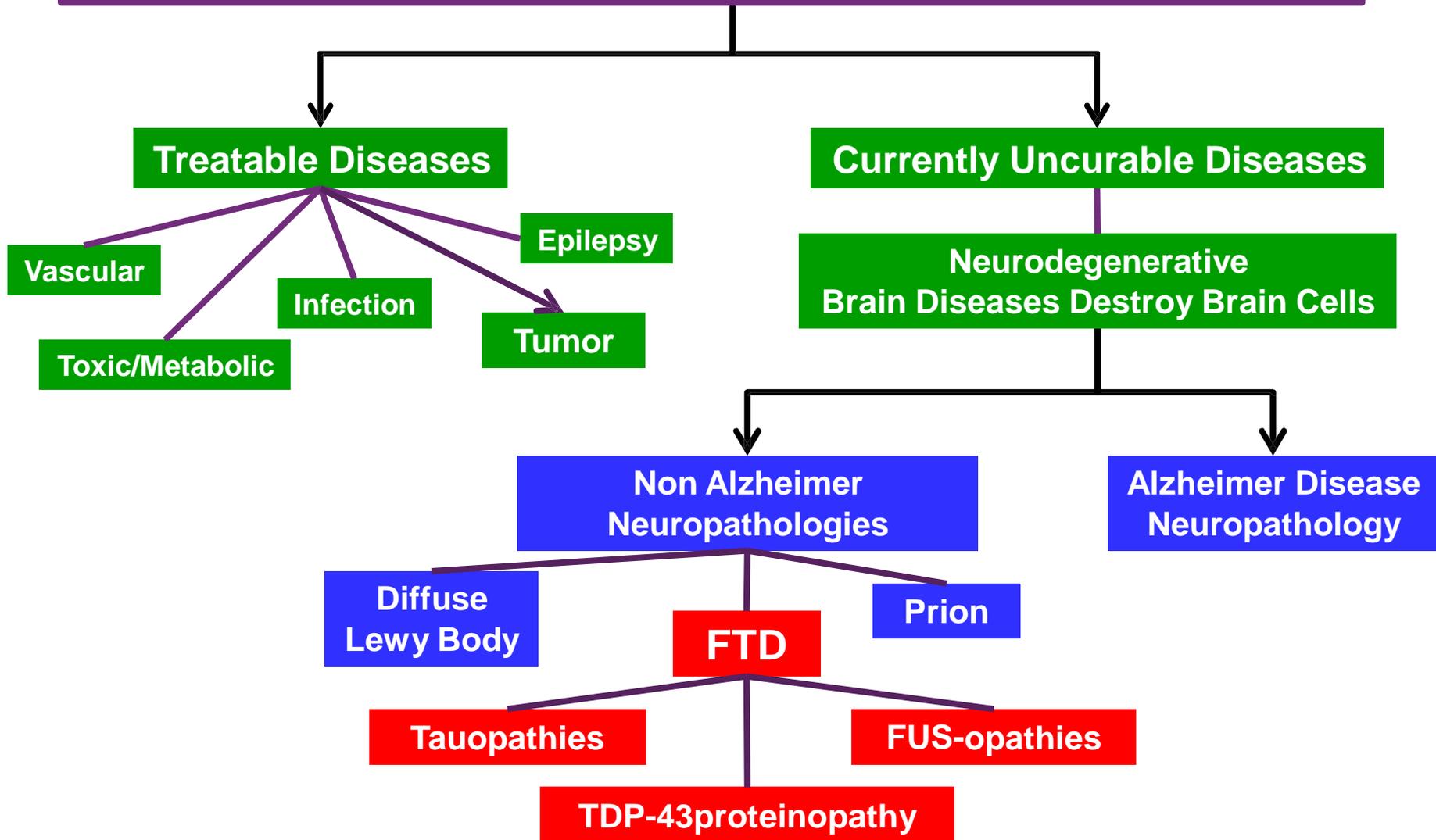
**Onset of symptoms is *65 years or older***

**Younger onset dementia:**

**Onset of symptoms is *under age 65;*  
*20's to early 60's***



# What Causes Younger Onset Dementia?



Neuropathology= abnormal brain cells, molecules/proteins



# Frontotemporal Degeneration Disorders (the symptoms experienced by the patient)

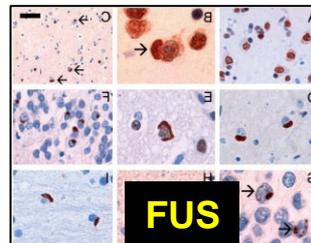
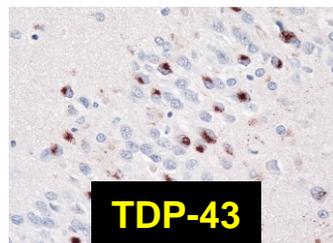
**Behavior Personality  
Decline  
aka  
Behavioral Variant  
FTD (bvFTD)**

**Language Decline  
aka  
Primary Progressive  
Aphasia (PPA)**

**Motor Symptoms and  
Movement Disorders  
  
Progressive  
Supranuclear Palsy  
Corticobasal  
Degeneration  
Motor Neuron Disease  
(ALS)**

## CAUSED BY

**Frontotemporal Degeneration Neuropathologies  
(the abnormalities in cells under the microscope)**





# Dementia Syndromes Due to Alzheimer's Disease (the symptoms the patient experiences)

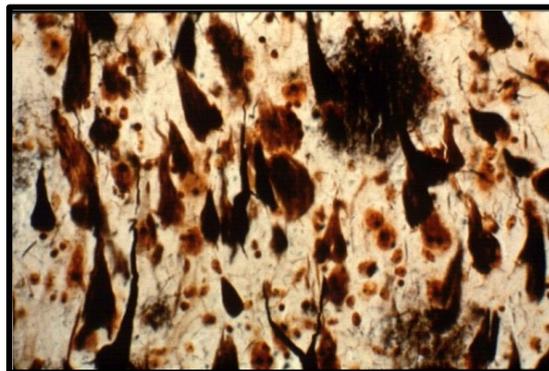
Language Decline  
(Less common)  
aka  
Primary Progressive  
Aphasia (PPA)

Memory Loss  
(most common)  
aka  
Dementia due to AD  
neuropathology

Visuospatial  
Dysfunction  
(least common)  
aka  
Posterior Cortical  
Atrophy

## CAUSED BY

**Alzheimer's Disease Neuropathology**  
(the abnormalities in cells under the microscope)





# Diagnosis of PPA: Language Dementia

Earliest symptoms: **Word-searching in speech; wrong words used, errors in words**

**Difficulty understanding the meaning of spoken and/or written words**

**Spelling and writing errors**

**Grammatical omissions/errors**

**Memory for events and behavior is normal**



# Diagnosis of BVFTD: Personality/Behavior Dementia

Earliest symptoms: **Loss of sympathy/empathy**

**Change in usual personality/character**

**Inappropriate judgment, social interaction**

**Loss of initiative, motivation**

**Mood disorders (anxiety)**

**Delusions (false beliefs)**

**Repetitive (obsessive) behaviors**

**Memory for events and language normal**



# Diagnosis of Dementia Due to Alzheimer Neuropathology (Memory Loss Dementia)

Earliest Symptoms: **Short term memory loss for recent events, conversations**

**Spatial disorientation- getting lost**

**Language and behavior normal**

**Occasionally “atypical” symptoms of PPA or visuoperceptual abnormalities**



# Younger Onset Symptoms of Movement Disorders

Tremor, rigidity (Parkinson-like)

Fasciculations (twitches) (ALS)

Gait/balance disorders

Eye movement abnormalities (on examination only)

Accompanied by dementia symptoms



# MOTOR TYPE

## PROGRESSIVE SUPRANUCLEAR PALSY - PSP

- Rare – 5-6 per 100,000
- Problems with falls
- Worsened memory and mood
- Personality changes
- Progressive central body stiffness
- Speech and swallowing problems
- Supranuclear gaze palsy (cannot look down voluntarily)
- Bulbar palsy (trouble with throat) affecting speech and swallowing

## CORTICOBASAL DEGENERATION – CBD

- Similar to PSP (balance, vision, speech & swallowing)
- Rare – 2000-3000 in US
- Difficulty generating & articulating speech
- Stiffness, jerkiness, slowness and clumsiness either in the upper or lower extremities
- Asymmetric onset of symptom
- Memory or behavior problems

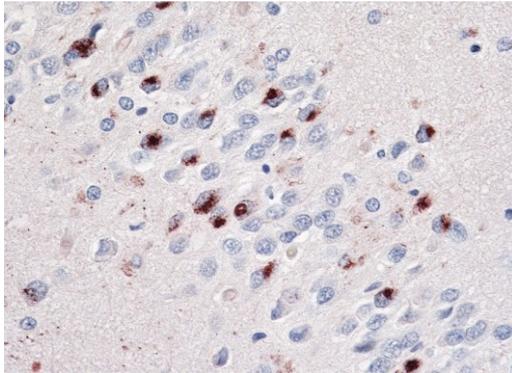
## FTD-MND

- A combination of FTD and ALS (Lou Gehrig's disease)
- Changes in behavior and/or language
- Muscle weakness, shrinkage, jerking

# Neurodegenerative Diseases That Cause Dementia Final Diagnosis Under The Microscope *After Death*

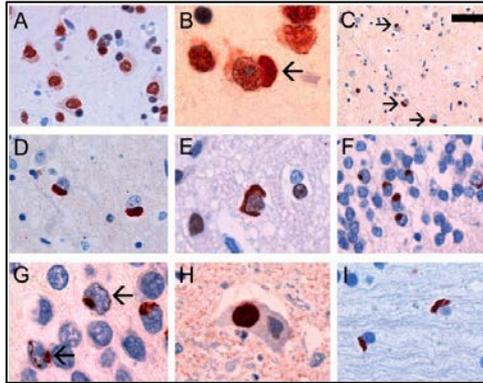
## FTD

### With TDP-43 Inclusions



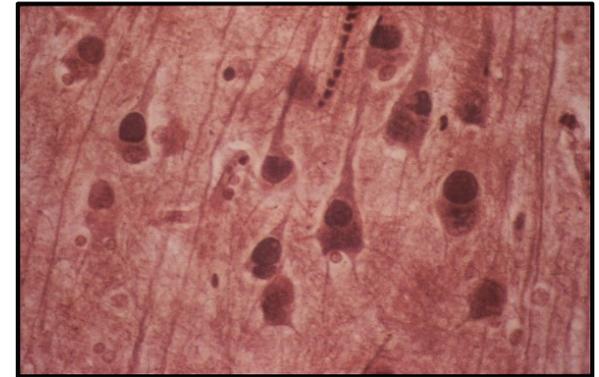
## FTD

### With FUS inclusions



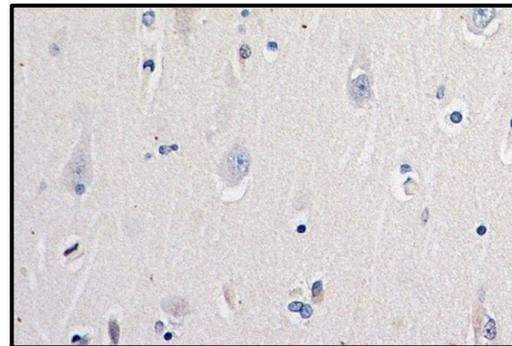
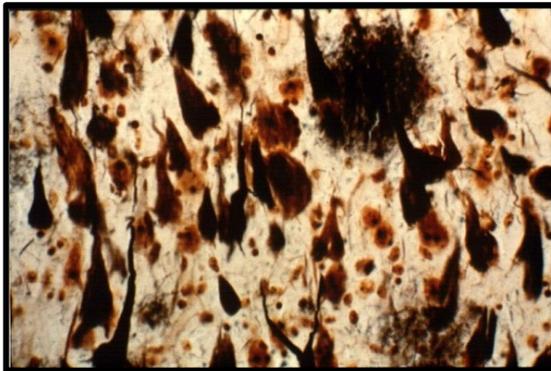
## FTD

### Tau Inclusions - e.g. Pick's disease



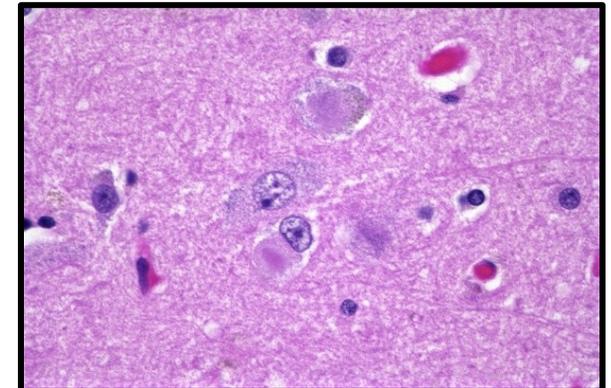
## FTD= Frontotemporal Degeneration

### Plaques and Tangles- Alzheimer's Disease



NORMAL BRAIN TISSUE

### Cortical Lewy Body Disease



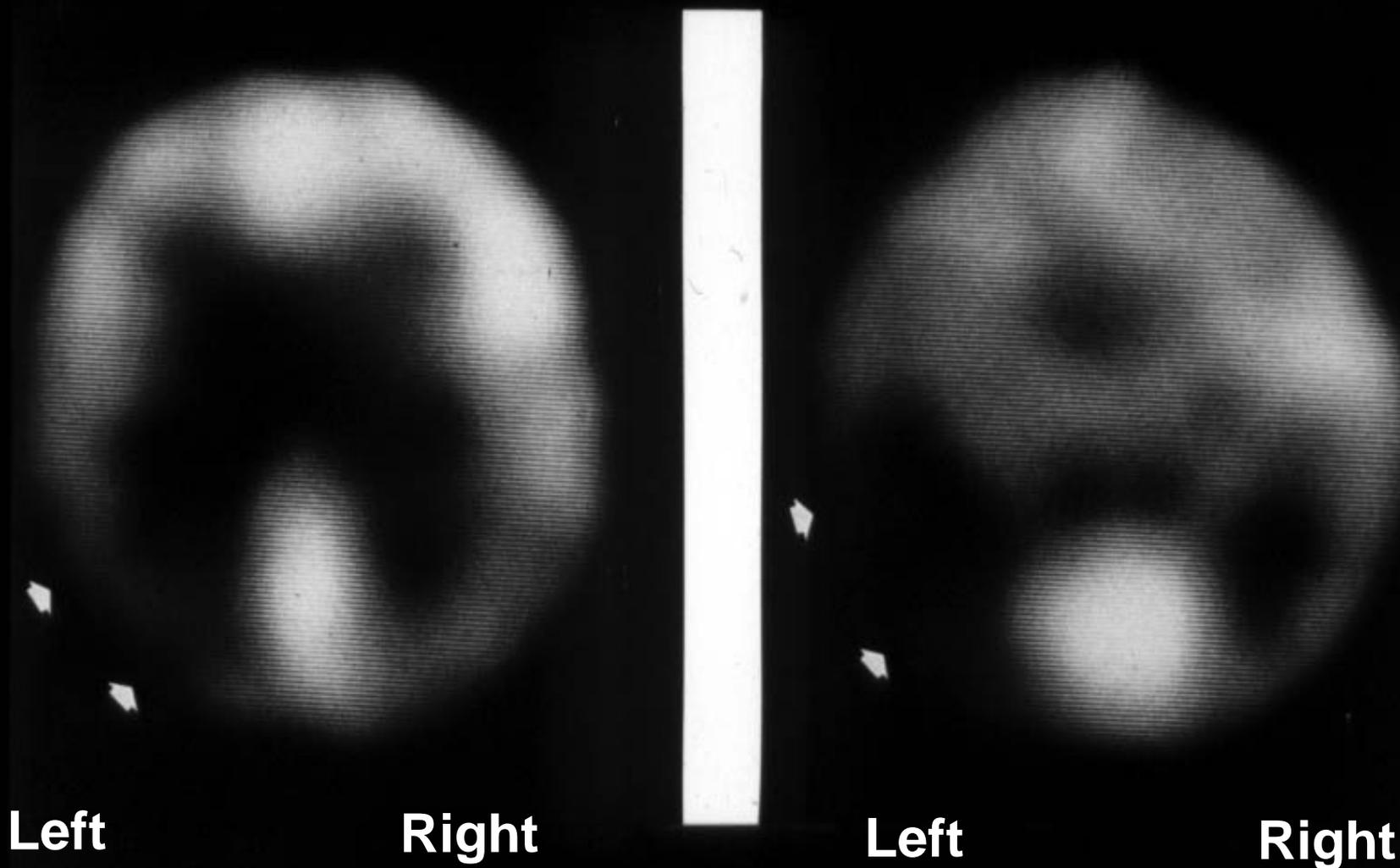
Courtesy Eileen Bigio MD, CNADC



**What causes some people to have memory loss, others to have language loss and others to have changes in personality?**

**Symptoms depend on *which part of the brain is initially attacked by the disease.***

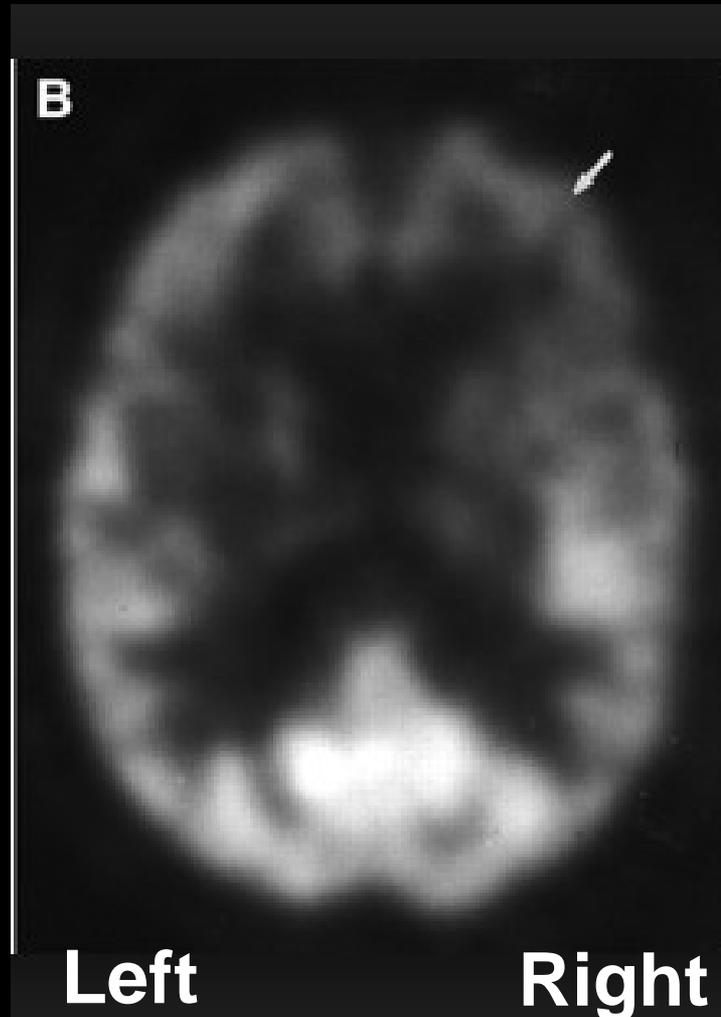
# FGD PET HYPOMETABOLISM IN LEFT BRAIN IN PPA



Chawluck , Mesulam , Hurtig, Kushner, Weintraub, Saykin,  
Rubin , Alavi , Reivich, *Annals of Neurology*, 1986



# PET HYPOMETABOLISM IN BOTH FRONTAL LOBES IN BVFTD





## Facts

Older onset dementia: most common cause is Alzheimer's neurodegenerative disease.

Younger onset dementia can be caused by *many diseases*: frontotemporal degeneration, stroke, brain tumor, traumatic brain injury, autoimmune disorders, Alzheimer neuropathology.

SO thorough evaluation could turn up a treatable cause!



## FACTS

2-5% young onset Alzheimer's is caused by genetic mutations that run in families

10-20% young onset bvFTD is caused by genetic mutations that run in families



# Known Genetic Mutations That Cause Young Onset Frontotemporal Degeneration

1. MAPT gene (chromosome 17, tau protein)
2. GRN gene (chromosome 17, progranulin protein)
3. TARDBP gene [chromosome 1, trans-active response DNA-binding protein 43-kDa (TDP-43)]
4. C9ORF72 gene (chromosome 9, unique TDP-43 proteinopathy)
5. VCP gene (chromosome 9, valosin-containing protein)
6. CHMP2B (chromosome 3, charged multivesicular body protein 2B)



# Known Genetic Mutations That Cause YOUNG ONSET Alzheimer's Disease

1. Presenilin 1 (PSEN 1) gene
2. Presenilin 2 (PSEN 2) gene
3. Amyloid precursor protein (APP) gene



# STATE-OF-THE-ART EVALUATION

## *Avoids Misdiagnosis and Lost Time*

**Neuropsychological Assessment:** Objective evidence of cognitive/behavioral deficits; normal or not?

**Behavioral Neurology Evaluation:** Unusual motor symptoms; *other possibly curable medical causes?*

**Psychiatric Evaluation:** Are symptoms psychiatric? *identify treatable symptoms*

**Laboratory Tests:** MRI, PET, Cerebrospinal fluid, Blood

- a) detect known features of neurodegenerative diseases (e.g., brain atrophy, AD, prion)
- b) rule out tumor, stroke, metabolic disorders



# Social Work Psychosocial Evaluation

Younger onset patients and families have unique needs for resources, management techniques, emotional support, financial security/planning

Affected persons may be in good health otherwise and will need adequate long term care and meaningful activities

Quality of life issues for affected persons, their spouses, and children (often teen-aged)



## ADVISE THOSE YOU SERVE TO:

TALK TO THEIR DOCTORS but be equipped with information since most general practitioners lack information about young onset dementia.

Request neuropsychological evaluation, preferably at a specialty center. If none is available, contact AFTD for guidance.

Request a PET scan, especially if all other tests have been negative or “normal.”

Request repeat exam in 6-12 months: Dementia progresses. Other causes of cognitive and behavioral change don't.



**WHAT HAPPENS WITH TIME?  
WHAT DOES THE FUTURE HOLD?**

# EARLY STAGE SYMPTOMS IN EARLY ONSET DEMENTIA

| <b>Behavioral Variant Frontotemporal Degeneration (bvFTD)</b>   | <b>Primary Progressive Aphasia (PPA)</b>  | <b>Dementia of the Alzheimer Type (DAT)</b>  |
|---|---|--|
| <p>Poor organizational skills</p> <p>Loss of initiative</p> <p>Personality change-uncharacteristic for former self</p> <p>Socially inappropriate</p> <p>Loss of “usual” emotional responses to people and events</p> <p><b>RETENTIVE MEMORY AND LANGUAGE NORMAL</b></p> | <p>Word finding difficulty while speaking</p> <p>Pronunciation or word choice errors</p> <p>Difficulty understanding conversation and words</p> <p>Difficulty reading and writing</p> <p><b>RETENTIVE MEMORY AND PERSONALITY NORMAL</b></p> | <p>Short-term retentive memory impaired (hours, days)</p> <p>Long term memory initially normal (distant past)</p> <p>Spatial disorientation (getting lost)</p> <p><b>PERSONALITY AND LANGUAGE NORMAL</b></p> |

It is hard to predict how long the disease will last and the rate at which symptoms will worsen

# LATE STAGE SYMPTOMS IN EARLY ONSET DEMENTIA

| <b>Behavioral Variant Frontotemporal Degeneration (bvFTD)</b>  | <b>Primary Progressive Aphasia (PPA)</b>  | <b>Dementia of the Alzheimer Type (DAT)</b>   |
|--|---|---|
| <p><b>Behavior worsens</b></p> <p><b>Increased lack of motivation</b></p> <p><b>May develop aphasia</b></p> <p><b>May develop motor symptoms</b></p> | <p><b>Language worsens</b></p> <p><b>May develop behavior symptoms</b></p> <p><b>May develop motor symptoms</b></p> | <p><b>Memory worsens and long term memories are also lost.</b></p> <p><b>Behavioral symptoms may develop</b></p> <p><b>Become sedentary</b></p> |

IN ALL TYPES OF DEMENTIA THE END STAGE IS SIMILAR  
it is hard to predict how long the disease will last and the rate  
at which symptoms will worsen



The early stages can last for many years.  
Symptoms may be confined to one or two  
functions (language, or behavior).

**BUT**

over time, as disease progresses in the brain,  
symptoms will increase eventually leading to  
more disability, requiring supervision and full  
care

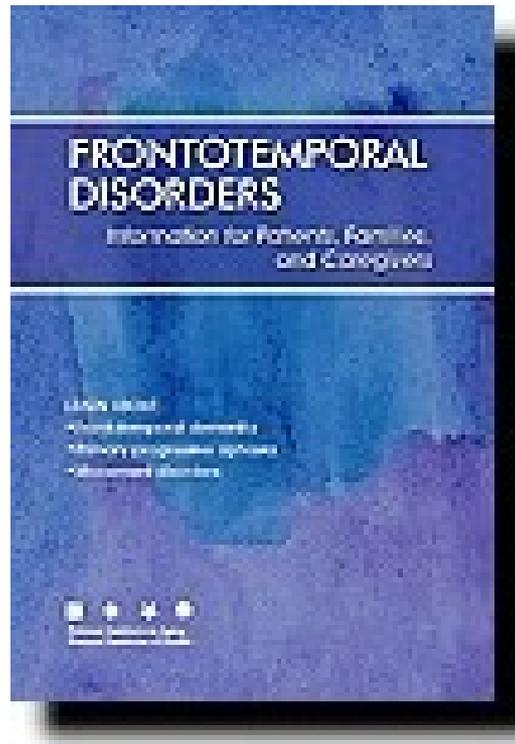


# RESEARCH NEEDS FOR YOUNGER ONSET DEMENTIA

1. Epidemiology/Public Health: We don't know prevalence/incidence, risk factors
2. Pathophysiology of non AD dementia- what causes it?
3. What should we target for drug development?
4. Behavioral interventions- coping with change
5. Public Policy Changes- Disability; SSA  
Compassionate Allowance



# Frontotemporal Disorders Booklet



<http://www.nia.nih.gov/Alzheimers/Publications/FTLD/>

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**The National Institute on Aging at NIH thanks the following people for their contributions to the vision and creation of this booklet:**

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**Susan Dickinson, MS, CGC**  
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# NORTHWESTERN PPA & FTD PROGRAM

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**“FROM CELLS TO SOCIAL WORK”**

NIA & ACL WEBINAR #4  
YOUNGER ONSET DEMENTIA

# SPECIALIZED RESOURCES

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Sharon S. Denny, MA  
Program Director  
The Association for Frontotemporal Degeneration

# A Focus on FTD Care and Cure

Driven by experience of family caregivers

Advance research and care together

Inclusive of all FTD clinical syndromes:

PPA, bvFTD, and movement disorders

Collaboration is critical for success



The Association for  
Frontotemporal Degeneration  
Opening the gateway to help and a cure

# AFTD is Mission Driven

Promote and fund research

Provide information, education and support

Educate physicians and health professionals

Increase public awareness

Advocate for LTC and social services

Facilitate the international exchange of ideas

*We envision a world where frontotemporal degeneration is understood, effectively diagnosed, treated, cured and ultimately prevented.*

# Information Empowers Families

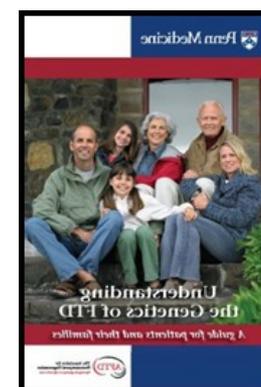
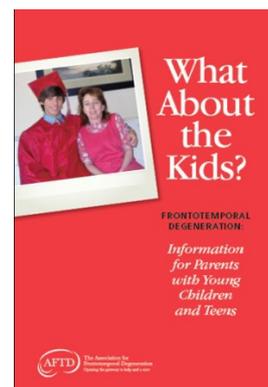
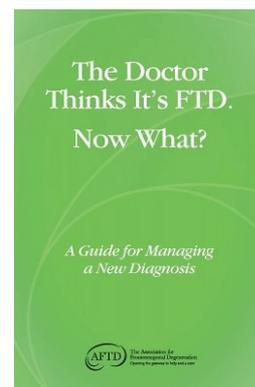
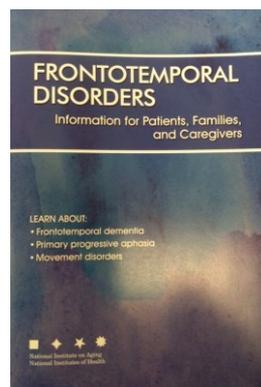
Accurate, current and specific to FTD

Guidance for managing care

Resources with experience in FTD

Connection to experts and emerging research

Website  
Newsletters  
Publications



# Support Encourages Strength

Higher burden of care

Tremendous risk of isolation

HelpLine- individual, responsive

AFTD phone groups (parents, PwFTD)

FTD support groups

Caregiver Connections

FTD Education Conferences

Respite and travel grants



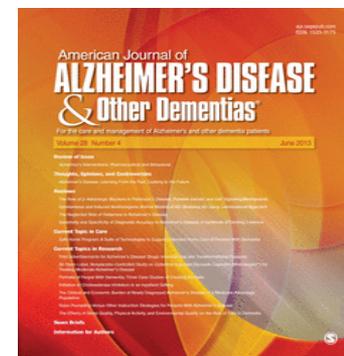
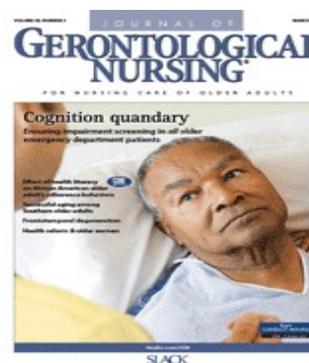
# Education Expands Understanding

Education for physicians

Outreach to professional groups

- ie: nurses, speech-language pathologists, day services, hospice

Healthcare professional section of website



# Partners in FTD Care

## Education for community healthcare professionals

- Introductory training materials
- Quarterly newsletter - case study, interventions and practical tips (“What to do About...”)
- Interactive on-line forum



# Research Drives Progress



Raise money for FTD research (pilot grants, drug discovery)

Stimulate partnerships – ADDF, FTSG

Educate and empower families (longitudinal studies, brain donation, clinical trials)

# A Focus on FTD Care and Cure

Unique needs require specialized resources

AFTD creates:

- A community of and for those affected
- A hub for cross-disciplinary collaboration
- Opportunities to get involved
- *Change*

<http://www.theaftd.org>

HelpLine: 866-507-7222

[info@theaftd.org](mailto:info@theaftd.org)

## Questions?

Registration for Webinar #5:  
***Advanced Stage Dementia & Palliative Care***  
Tuesday, September 24, 1:30-3pm ET  
Now Open:  
<http://goo.gl/w03Or1>

Slides, audio and transcript for 2013 webinar series will be available under Resources and Useful Links at:  
[http://www.aoa.gov/AoARoot/AoA\\_Programs/HPW/AIz\\_Grants/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HPW/AIz_Grants/index.aspx)