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

Darby Morhardt, MSW, LCSW
Cognitive Neurology and Alzheimer’s Disease Center
Northwestern University Feinberg School of Medicine
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

- 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

Younger Onset Dementia

Alzheimer’s Disease (AD)

Frontotemporal degeneration (FTLD)

Posterior Cortical Atrophy (PCA)

Primary Progressive Aphasia (PPA)

Primary Progressive Aphasia (PPA)

Behavioral Variant Frontotemporal degeneration (bvFTD)

Progressive Supranuclear Palsy (PSP)

Corticobasal Degeneration (CBD)

FTD – Motor Neuron Disease (MND)
**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
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

<table>
<thead>
<tr>
<th><strong>Language Type</strong></th>
<th><strong>Behavioral Type</strong></th>
<th><strong>Motor Type</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Progressive Aphasia (PPA)</td>
<td>Behavioral Variant Frontotemporal Dementia (BVFTD)</td>
<td>Corticobasal Syndrome</td>
</tr>
<tr>
<td>Early Onset (&lt;65)</td>
<td>Early Onset (&lt;65)</td>
<td>Progressive Supranuclear Palsy</td>
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<td>FTD-MND</td>
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**THREE TYPES OF DEMENTIA**

1. **Primary Progressive Aphasia (PPA)**
   - Early Onset (<65)

2. **Behavioral Variant Frontotemporal Dementia (BVFTD)**
   - Early Onset (<65)

3. **Corticobasal Syndrome**
   - Progressive Supranuclear Palsy
   - FTD-MND
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.ffaconnection.org](http://www.ffaconnection.org))
Behaviors Type
behavioral variant Frontotemporal Degeneration – bvFTD
Rascovksy 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
<table>
<thead>
<tr>
<th>MOTOR TYPE</th>
<th>PROGRESSIVE SUPRANUCLEAR PALSY - PSP</th>
<th>CORTICOBASAL DEGENERATION – CBD</th>
<th>FTD-MND</th>
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<tr>
<td>• Balance, vision, speech and swallowing problems.</td>
<td>• Similar to PSP (balance, vision, speech &amp; swallowing problems)</td>
<td>• A combination of FTD and ALS (Lou Gehrig’s disease)</td>
<td></td>
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<tr>
<td>• Worsened memory and mood</td>
<td>• Stiffness, jerkiness, slowness and clumsiness</td>
<td>• Changes in behavior and/or language</td>
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<tr>
<td>• Central body stiffness</td>
<td>• Memory or behavior problems</td>
<td>• Muscle weakness, shrinkage, jerking</td>
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<tr>
<td>• Personality changes</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>• Cannot look down voluntarily</td>
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</table>
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; devVugt et al., 2006)
- Behavioral symptoms of disinhibition and apathy were experienced more frequently and intensely

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

• Balancing care with maintaining a life of their own

• Managing their expectations of others

• Coping with emotions
  – Sadness, Anger, Grief, Stress, Guilt, Depression, Anxiety

• Planning for future care
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

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
Northwestern CNADC 2012 conference booklet
http://www.brain.northwestern.edu/

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

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

THE CNADC WOULD LIKE TO THANK THE
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www.nhn.northwestern.edu
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
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Younger Onset Dementia: Detection and Diagnosis

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<td>Northwestern University</td>
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<td>None</td>
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<tr>
<td>Stockholder in:</td>
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</table>
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?

Treatable Diseases
- Vascular
- Toxic/Metabolic
- Infection
- Epilepsy
- Tumor

Currently Uncurable Diseases
- Neurodegenerative Brain Diseases Destroy Brain Cells

Non Alzheimer Neuropathologies
- Diffuse Lewy Body
- FUS-opathies
- Tauopathies
- Prion

Alzheimer Disease Neuropathology

Neuropathology = abnormal brain cells, molecules/proteins

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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)

- TDP-43
- FUS
- Tauopathy-Pick’s
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

Cortical Lewy Body Disease

NORMAL BRAIN TISSUE

Courtesy Eileen Bigio MD, CNADC

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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

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

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

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<tr>
<td>Behavior worsens</td>
<td>Language worsens</td>
<td>Memory worsens and long term memories are also lost.</td>
</tr>
<tr>
<td>Increased lack of motivation</td>
<td>May develop behavior symptoms</td>
<td>Behavioral symptoms may develop</td>
</tr>
<tr>
<td>May develop aphasia</td>
<td>May develop motor symptoms</td>
<td>Become sedentary</td>
</tr>
<tr>
<td>May develop motor symptoms</td>
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</tbody>
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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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<td>Lei Wang</td>
<td>“FROM CELLS TO SOCIAL WORK”</td>
<td>Kristen Whitney</td>
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NIA & ACL WEBINAR #4
YOUNGER ONSET DEMENTIA

SPECIALIZED RESOURCES

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
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

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/Alz_Grants/index.aspx