Caregiver Education Program for ALS-FTD

Funding provided by the ALS Association and Penn State Department of Neurology
WELCOME!

• 1st session of its kind

• Aim = interactive, relevant, hands-on

• Caregiving can be a rewarding experience – if you have the right tools and support

Your honest feedback at the end of the session will help shape this into a useful session for future caregivers
Announcement:
Creating a Network of Support

• We encourage you to build a supportive network of people

• Sign up in the back of the room if you would like to share your contact information with today’s attendees

**Reminder: ALSA professionals will not share your contact information due to privacy laws.**
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Learning Objectives

1. Recognize and understand the medical terms associated with cognitive-behavioral change in ALS, and be able to list the subtypes that commonly occur.

2. State the signs and symptoms of cognitive-behavioral change in ALS, and list 3 management strategies specific to your loved one’s needs.

3. Describe 5 strategies for self care and prevention of caregiver burnout.

4. Meet one other individual who provides care for someone with ALS/FTD.

5. List 3 different resources for obtaining information and/or support related to ALS/FTD.
Session Outline

- Part 1: The Basics of ALS-FTD
- Part 2: Managing Difficult Behaviors
- Part 3: Problem-Solving Techniques
Part 1: The Basics of ALS and Frontotemporal Dementia (FTD)
Most Common Cause of Cognitive-Behavioral Change in ALS:

**Frontotemporal Dementia (FTD)**

- Cognitive-Behavioral change in ALS happens on a spectrum:

  - Mild changes *may* progress into dementia, or they may not.
  - Term “FTD” in this presentation will refer to cognitive-behavioral change in ALS
What is FTD?

FRONTO
TEMPORAL
DEMENTIA
The Frontal Lobes

- Responsible for higher-order thinking [executive functions]
- Imagine what a CEO of a company does:
  - Planning, Organizing
  - Integrating information (example: ability to read body language and tone of voice to detect sarcasm)
  - Starting a task or a project
  - Following social rules
  - Adjusting behavior according to the situation
The Temporal Lobes

- Responsible for Language
  - Producing (speaking or writing) language
  - Understanding what words mean
  - Putting words together in a meaningful way
  - Spelling and writing words
  - Interpreting tone and volume of speech
‘Dementia’

• Dementia = “A loss of brain function that occurs with certain diseases. It can affect memory, thinking, language, judgment, and behavior.” [Definition from Google Health]

• Actual changes in the brain cause the symptoms of dementia

• Dementia is a **progressive** disease
  ▫ Gets continually worse with time
### Understanding the Medical Jargon: Sub-Types of FTD

<table>
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<th>Sub-Type</th>
<th>Description</th>
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<td><strong>Behavioral Variant FTD (bvFTD):</strong></td>
<td>Change in behavior and/or personality: inappropriate, rude, childish</td>
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<td><strong>Progressive Non-fluent Aphasia (PNFA):</strong></td>
<td>Can understand what someone says, but can’t put own thoughts into words. Speech slows or stops eventually. Difficulty with word-finding.</td>
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<td><strong>Semantic Dementia (SD):</strong></td>
<td>Still speaks, but conveys very little. Familiar words lose meaning.</td>
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Q: Does everyone with FTD have the same symptoms?
A: No

- Someone with FTD can present in a number of different ways
- Whichever brain regions are affected more (frontal or temporal, right or left) will impact which symptoms there are
- Three primary subtypes
- As the disease gets worse, more and more symptoms can develop
So What Does this Mean?
3 Basic Types of Symptoms to Manage:

- Cognitive
- Behavioral
- Language
Cognitive Symptoms of FTD

- May have difficulty:
  - Understanding complex ideas [Abstract Thinking]
  - Reasoning and making decisions
  - Organizing thoughts, activities
  - Recognizing that there is something wrong [Loss of Insight]
  - Ignoring distractions
  - Understanding someone else’s point of view [Empathy]
Language Symptoms of FTD

- Breakdown in communication:
  - Difficulty processing language
  - Common words don’t make sense anymore
  - Makes errors in speech [says ‘apple’ instead of ‘orange’]
  - Can’t think of the right word for an object
  - Speech is slower
  - Loss of ability to spell, use basic grammar
    - Spelling errors like ‘blevie’ instead of ‘believe’
    - Leaving out certain words like ‘a’ and ‘the’
Behavioral Symptoms (1 of 3)

• Change in Interactions with People
  ▫ Inappropriateness, loss of awareness of social rules
  ▫ Angry outbursts, unpredictable, sometimes aggressive and unsafe behavior [Irritability, Aggression]
  ▫ Loss of emotional connection to others [Decreased Empathy]
Behavioral Symptoms (2 of 3)

- **Change in activity level:**
  - *Increase* in undesired behaviors, more ‘acting out’
  - *Decrease* in activity; withdrawing from interests and loved ones; needing to be prompted *[Apathy]*
Behavioral Symptoms of FTD (3 of 3)

• **Change in Day-To-Day Behaviors**
  - Excessive spending, opening new accounts, giving money away, fixation on money
  - Becoming ‘stuck’ on ideas or actions [perseverating]
  - Change in eating behaviors (food fads, stuffing, not eating)
  - Neglecting personal hygiene
How does FTD Compare to Alzheimer’s Disease?

**Frontotemporal Dementia:**

- Most common dementia in middle-aged adults (often begins **before age 65**)

- Memory is usually **not** affected
How is FTD Diagnosed?

- Requires information from a variety of sources:
  - Caregiver interview
  - Cognitive (or Neuropsychological) Testing
  - Sometimes imaging is needed (MRI, CT, or PET)
- No ‘quick and easy’ test is available to diagnose FTD
How Common is Cognitive-Behavioral Change in ALS?

- **Mild Cognitive-Behavioral Change (40%)**
- **ALS/FTD (10%)**
- **Cognitively Normal (50%)**
When ALS and FTD Occur Together...

- Disease Progression is Faster
- Survival is Shorter
- Safety Risk is Higher
Implications for Care

People with ALS/FTD:
Are Less Likely to Follow Treatment Recommendations

- Caregiver should assume medication management
- Creative approaches to implementing changes in care
- Begin implementing changes before they are absolutely necessary (allow extra time)
Implications for Care

People with ALS/FTD:
Have Symptoms That Will Continue to Change Over Time

- Consider a combination of medication and behavior management interventions
- Seek outside sources of support and information
- Care for yourself in order to manage stress
Implications for Care

People with ALS/FTD: May Lose Reasoning and Decision-Making Abilities

- Assess driving ability
- Limit use of power tools, equipment, etc.
- Freeze financial accounts and run credit checks regularly
Addressing Legal Issues

Because FTD will eventually interfere with one’s ability to participate in treatment planning...

- Decision about feeding tube
- Decision about ventilator
- Other medical treatment decisions
Addressing Legal Issues

... The patient should:

- Appoint a healthcare Power of Attorney (POA)
- Complete an Advance Directive (Living Will)

*As EARLY in the disease process as possible*

**Bottom Line:**

The caregiver should develop an understanding of the patient’s goals for care while he/she can still verbalize them
Section 1: The Basics of ALS/FTD

Take-Home Points

- **Actual brain changes** are the cause of cognitive-behavioral symptoms
- Dementia symptoms will **continue to worsen** over time
- Caregiver will play an important role in **shared decision-making** with the patient
Part 2: Managing Difficult Behaviors
Create a Tool Kit for Difficult Behaviors

- Behavioral
- Environmental
- Physical
- Pharmacological (Medications)
- Caregiver Responses
Individualize Management Strategies

- Consider the whole picture
- Look for patterns in the person’s behavior or particular times of day
- Keep log or record (see hand-outs)
- Adjust strategies as the behaviors change

♦ Behavioral ♦ Environmental ♦ Physical ♦ Pharmacological ♦ Caregiver
Behavioral Strategies

• Use simple words, Yes/No questions
• Praise desired behaviors
• Find soothing rituals
  ▫ Hand massage
  ▫ Favorite music/movie
  ▫ Time with a pet
• Avoid arguing... change the subject
• Find a walking buddy for restless times during the day

◊ Behavioral ◊ Environmental ◊ Physical ◊ Pharmacological ◊ Caregiver ◊
Environmental Strategies (1 of 3)

• Create a structured, predictable daily routine
  ▫ Helps for apathy, disinhibition, sleep difficulty
  ▫ Takes the pressure of making decisions off of the patient
  ▫ Tips:
    • Match activities to ability level
    • Individualize routine to patient’s likes & interests

Example: www.ftd-picks.org
  ➔ Support & Resources
  ➔ Caregiving Challenges
Environmental Strategies (2 of 3)

- Monitor patient’s contacts with the outside world
  - Disconnect land line
  - Use 1 cell phone with password
  - Password protected internet
  - Child-controls for TV, websites
  - Consider alarm or bell on door
  - Freeze credit card accounts
Environmental Strategies (3 of 3)

• Keep out of Sight / Limit Access to:
  ▫ Car keys, car
  ▫ Power tools
  ▫ Guns & firearms
  ▫ Medications
  ▫ Unsafe foods (if choking, BINGING, is a concern)
Physical Interventions

• Create picture board for communication
• Use Hand massage to encourage eating
• Lock doors
• Avoid physical restraint
• Adjust sound, lighting to limit agitation

♦ Behavioral ♦ Environmental ♦ Physical ♦ Pharmacological ♦ Caregiver
Pharmacological (Medications)

• No medications will cure FTD
• Some medications may be effective to help with agitation, irritability
• Consider side effects
• Treat depression
• May be necessary for psychiatrist consultation
Caregiver Responses

- Remember that these changes are no one’s fault
- Work to accept the physical changes
- Seek out information about ALS/FTD
- Seek out support – emotional and social
- Take care of your own needs too...
Concerns for ALS/FTD Caregivers

- Highest risk group of all caregivers for stress!
  - Higher stress than Alzheimer’s Disease caregivers
  - Higher stress than ALS caregivers
- Depression, anxiety, anger, guilt, frustration, irritability, resentment
- Physical illness
- Impaired sleep
- Isolation
- Stigma
- “Caregiver burnout”

♦ Behavioral ♦ Environmental ♦ Physical ♦ Pharmacological ♦ Caregiver
Caregiver Self-Care Techniques

• **Regular Planned Breaks**
  ▫ Even if just a few moments at a time
  ▫ Have multiple friends/family members to help
  ▫ Use in-home care, respite care
  ▫ Adult day care
  ▫ Long-term care placement
  ▫ Hospice care

• Relaxation and breathing techniques
• Prayer, meditation, reading, journaling
• Regular eating times
Caregiver Self-Care Techniques

- Focus on improving your own sleep
  - Use of baby monitor, alarm for bed
- Regular exercise (DVD’s, videos, Wii, etc.)
- Regular visits to your doctor
- Treatment for depression
- Stay connected to your friends and family (phone, internet)
- Resource/support group
- Other???

♦ Behavioral ♦ Environmental ♦ Physical ♦ Pharmacological ♦ Caregiver
Section 2: Behavior Management

Take-Home Points

- Develop a ‘tool kit’ full of different approaches

- Medications may help with some behaviors, but won’t cure the ALS/FTD

- Remember to care for yourself during this challenging time
Part 3: Problem-Solving Techniques
The Problem-Solving Approach

The process of understanding the nature of our problems in life, and...

*attempting to change:*

- **The PROBLEM** situation
- **AND/OR**
- **Our REACTION** to the problem
Charting New Waters...
Why Problem-Solving?

• Help to find solutions for unique behaviors
• ALS + FTD = constantly changing circumstances
• ‘Writing the manual’ for how to deal with ALS/FTD
• You have the most knowledge about your own situation
• A tool to individualize approaches to your needs
The Problem Solving Approach

1. Identify the Problem
2. Brainstorm Options
3. Try the Best Option
4. Assess the Outcome
5. Try Another Option
Effective Solutions:

- Achieve the problem-solving goal
- Maximize positive outcomes
- Minimize negative outcomes
Real-Life Example #1:
New NFL ‘Gear’

John Mackey
Former Tight End, Baltimore Colts
NFL Hall of Fame
Real-Life Example #2: Out in Public
Real-Life Example #3: The Round, White Circle in the Bathroom
Individual Activity

• Pick your most challenging problem at the moment

• Work through the problem-solving process (worksheet provided)

• Share your results with the group (optional)

• Try your best solutions at home
Tips for Effective Problem-Solving

• The first option won’t always be the best
• What you originally thought was the problem might not have been the problem!
• Brainstorm all of the options, even if they don’t sound reasonable
• Seek options from other caregivers, family, friends, or ALS staff
• What worked today may not work tomorrow
• There’s always another option – persistence!
Section 3: Problem Solving Techniques

Take-Home Points

- You have control to change behaviors and/or change your reactions to behaviors
- Brainstorm, brainstorm, brainstorm
- Try solutions until you find the one that works best
Additional Resources

- Association for Frontotemporal Dementia (AFTD)
  www.theaftd.org

- AFTD Helpline
  - Phone: 866-507-7222
  - E-mail: info@ftd-picks.org
Additional Resources

- University of California, San Francisco (UCSF)

http://memory.ucsf.edu/ftd/
Additional Resources

- Family Caregiver Alliance
  www.caregiver.org
Additional Resources

- ALS Support Group
- FTD Support Group
- ALS Clinic Team
- FurtherReading
  - Book - *What if it’s Not Alzheimer’s? A Caregiver’s Guide to Dementia.* By Lisa Radin
- Bi-annual FTD Caregiver Conference, University of Pennsylvania (2011)
  - Recordings of previous conferences available at www.ftd-picks.org
Thank You for Attending!