

# Caregiver Education Program for ALS-FTD

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



**PennState Health**  
Milton S. Hershey Medical Center





# WELCOME!



- **1<sup>st</sup> 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.*

# AGENDA

Welcome & Introductions

Questionnaires

Educational Presentation: What is ALS/FTD?

Managing Difficult Behaviors

Problem Solving Techniques

Questionnaires

Refreshments & Socializing

# 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 Cognitive-Behavioral Change

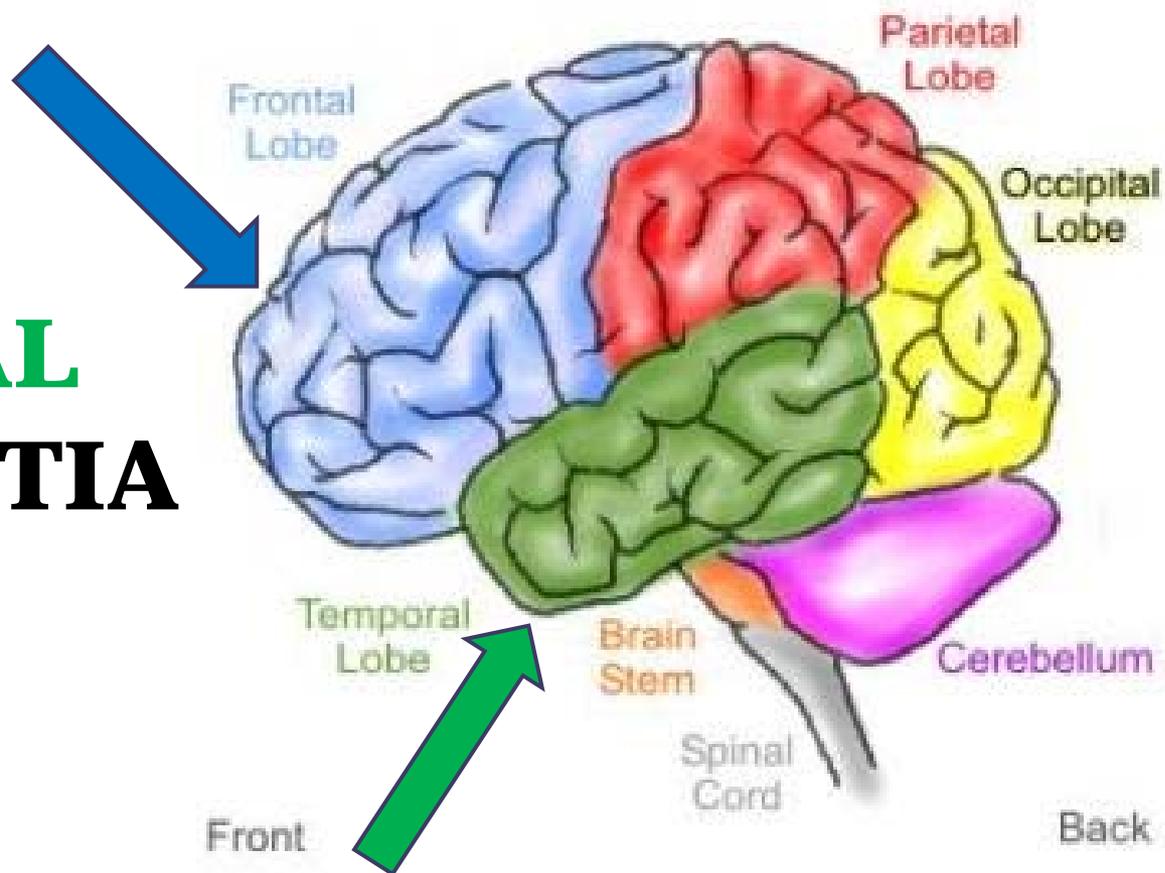
Frontotemporal Dementia

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

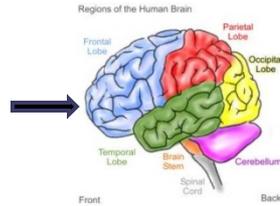
# What is FTD?

## **FRONTO TEMPORAL DEMENTIA**

Regions of the Human Brain



# The Frontal Lobes

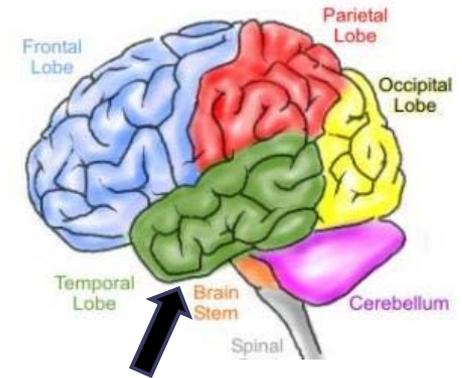


- Responsible for higher-order thinking  
[executive functions]
- Imagine what a CEO of a company does:
  - Planning, Organizing
  - Integrating information (example: ability to read body language and tone of voice to detect sarcasm)
  - Starting a task or a project
  - Following social rules
  - Adjusting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

Regions of the Human Brain



# '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

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## **Behavioral Variant FTD (bvFTD):**

Change in behavior and/or personality: inappropriate, rude, childish

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## **Progressive Non-fluent Aphasia (PNFA):**

Can understand what someone says, but can't put own thoughts into words. Speech slows or stops eventually. Difficulty with word-finding.

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## **Semantic Dementia (SD):**

Still speaks, but conveys very little. Familiar words lose meaning.

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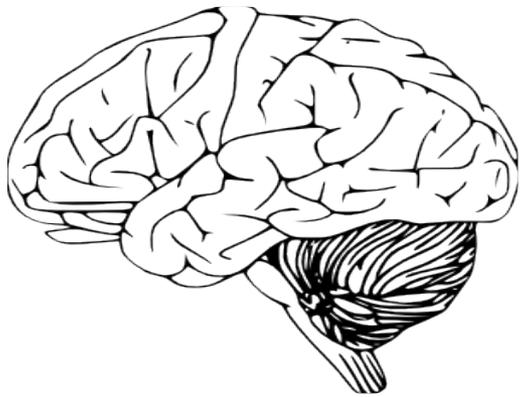
Q: Does everyone with FTD have the same symptoms?

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?

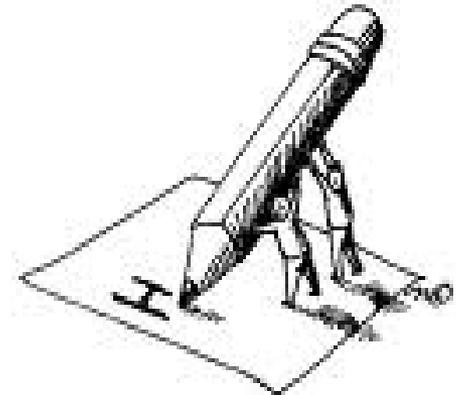
3 Basic Types of Symptoms to Manage:



**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'  
  
>>**OR**<<  
  
  - **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?

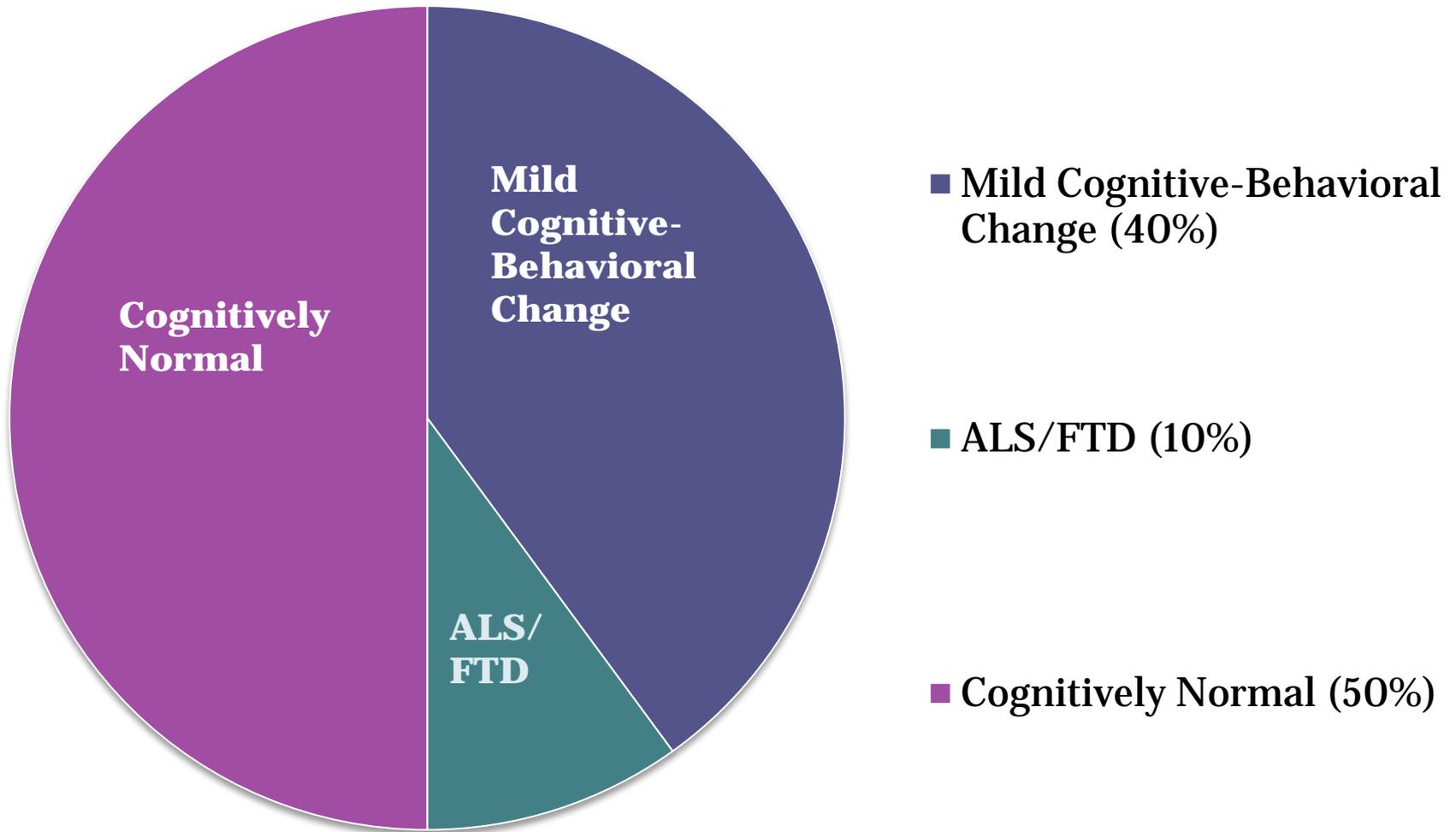
## Frontotemporal Dementia:

- Most common dementia in middle-aged adults (often begins **before age 65**)
- Memory is usually **not** affected

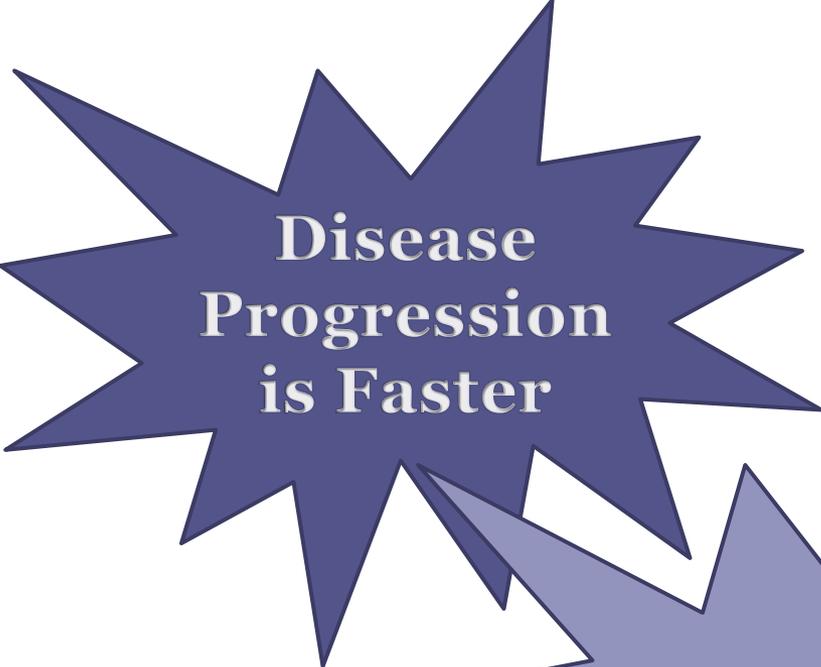
# How is FTD Diagnosed?

- **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**

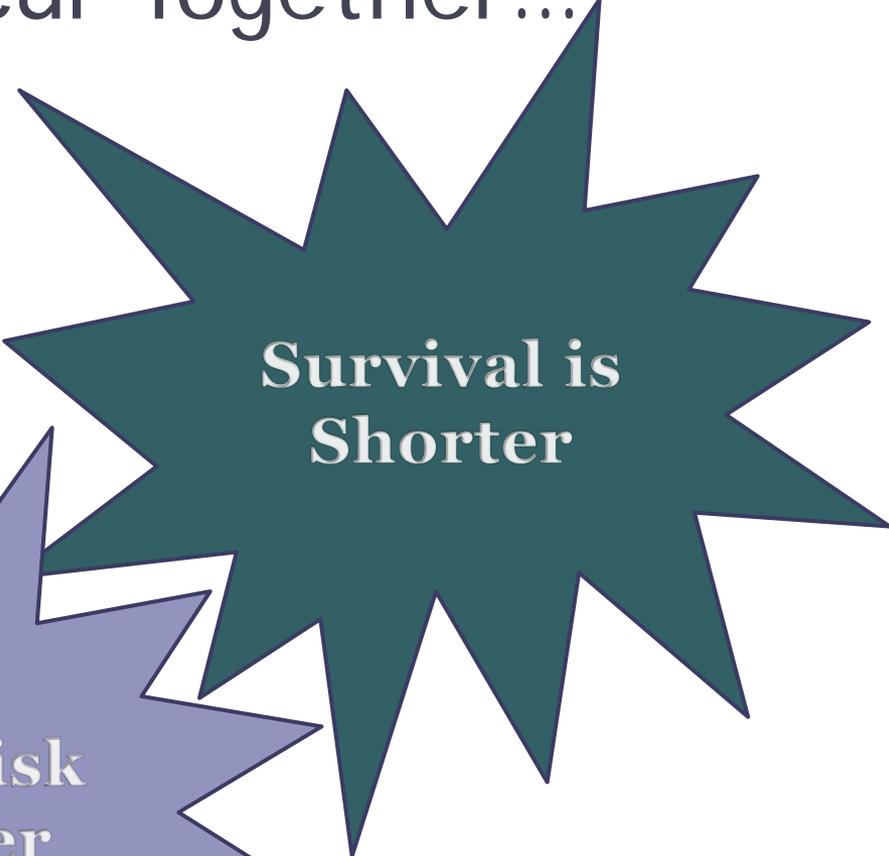
# How Common is Cognitive-Behavioral Change in ALS?



# 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

# 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](http://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

# 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”

# 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??? \_\_\_\_\_

## 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'

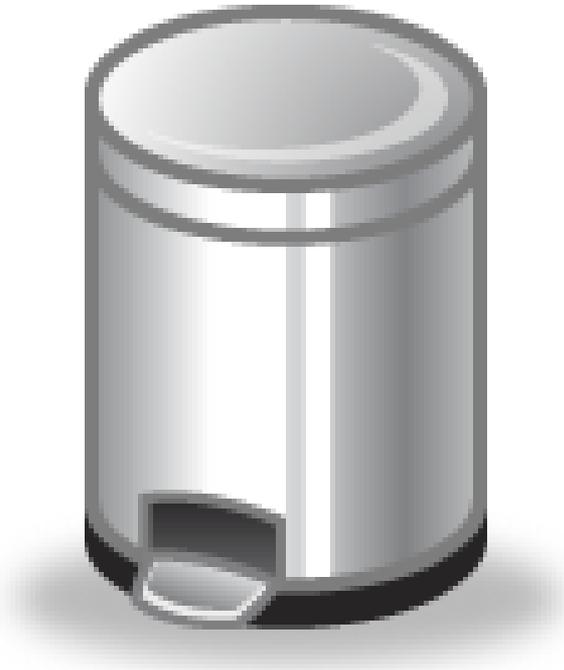


**John Mackey**  
Former Tight End, Baltimore Colts  
NFL Hall of Fame

# 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](http://www.theaftd.org)

- AFTD Helpline

- **Phone: 866-507-7222**

- **E-mail: [info@ftd-picks.org](mailto:info@ftd-picks.org)**



About AFTD | What is FTD? | Research | Support & Resources | Healthcare Professionals | Newsroom

## WELCOME

The Association for Frontotemporal Dementias is the place to turn for accurate information, compassion and hope when lives are touched by frontotemporal dementias. FTD, also called frontotemporal lobar degeneration (FTLD), is a cluster of progressive diseases that affect the regions of the brain that control personality, behavior, language, and decision-making.

*If you are new to AFTD, it is helpful to begin with the overview and pages for those facing a [new diagnosis](#).*

## FEATURES



### Las Vegas Area Support Group to Begin Meeting August 11

A caregiver support group that is forming in the Las Vegas area will begin meeting on Wednesday, August 11. The group will continue to meet on the second Wednesday of each month from 7 to 8:30 p.m. in the community room of Glazier's at the Desert Marketplace, 8525 West Warm Springs Road, Las Vegas. It is being led by Lisa Radin, a founding member of AFTD and co-editor with son Gary of *What if It's Not Alzheimer's? A Caregiver's Guide to Dementia*. Before attending, please email Lisa at [lradin@jalide.net](mailto:lradin@jalide.net) or call the Alzheimer's Association, Desert Southwest Chapter – Southern Nevada Region, at 702-248-2770.



### NPR Member Station Reports on *Dementia That's Neither Alzheimer's Nor Easy*

Howard Rosen, M.D., a member of the [AFTD Medical Advisory Council](#), was interviewed by Peter O'Dowd of NPR member station KJZZ in Phoenix for a report on frontotemporal dementias. The story, which aired July 6, 2010, included interviews with caregivers from a Phoenix-area support group. Dr. Rosen is a neurologist at University of California, San Francisco.



### Scientists Invited to Research FTD Biomarkers

The search for FTD specific biomarkers is the focus of the AFTD/ADDF 2010 Drug Discovery Request for Proposals. The grant process challenges scientists to advance the ability to identify the pathological differences among the FTD syndromes that are needed to select patients for clinical trials. Proposals are due September 9, 2010.

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- ▶ [More Ways to Contribute](#)

What's Happening

- ▶ [2010 AFTD Research RFP](#)
- ▶ [Dutch film supports AFTD](#)
- ▶ [NYT runs tribute by Elinor Lioman](#)
- ▶ [More in the newsroom](#)

Additional Resources

- ▶ [Contact Us](#)
- ▶ [Helpline](#)
- ▶ [Media](#)
- ▶ [Visit our Facebook page](#)
- ▶ [Regional resources: U.S. | Canada](#)

Get Involved

Advocacy

Newly Diagnosed

# Additional Resources

- University of California, San Francisco (UCSF)

<http://memory.ucsf.edu/ftd/>

UCSF University of California, San Francisco | About UCSF | Search UCSF | UCSF Medical Center 中文 | Español

Return to Memory and Aging Center

## Frontotemporal Dementia

Text Size T T [FTD Home](#) [FTD Matters](#) [News & Articles](#) [Staff Directory](#)

[Overview](#) [Living with FTD](#) [Community & Support](#) [Medical Information](#) [Research](#)

### What is FTD?

Types of FTD

Is it FTD?

Signs and Symptoms

Disease Progression

Treatments

FTD and the Creative Mind

The Basic Biology of FTD

★ Help us understand attention [Learn more ▶](#)

#### Before you worry that it's FTD

Your doctor's first mission is to rule out other possible illnesses that may look like FTD, such as Alzheimer's disease, Parkinson's disease or psychiatric problems. In most cases, meeting with an FTD expert is the best way to determine a correct diagnosis.

[Read more ▶](#)

#### Help us find a cure for frontotemporal dementia

UCSF's Memory and Aging Center (MAC) actively conducts research and clinical trials to improve the diagnosis and treatment of FTD – and even search for a cure. Your participation helps us reach these goals. Talk to your doctor or contact us to see if joining a research project is right for you.

[Read more ▶](#)

#### To discuss with your doctor

[Tests](#)

[Genetic Counseling](#)

[Clinical Trials & Research](#)

[Make a Clinic Appointment](#)

[Help Your Doctor Help You](#)

[Make a Gift](#) [Memory & Aging Center Staff](#) [Help Your Doctor Help You](#) [Events & Conferences](#)

# Additional Resources

- Family Caregiver Alliance  
[www.caregiver.org](http://www.caregiver.org)

**FCA FAMILY CAREGIVER ALLIANCE®**  
 National Center on Caregiving

Public Policy & Research | Caregiving Info & Advice | Fact Sheets & Publications | Newsletters | Groups | Press Room | About FCA

**HOT TOPICS**

- 2009 SAN FRANCISCO ALZHEIMER'S/DEMENTIA SUMMIT
- FACT SHEETS & HEALTH INFO
- NEW! FAMILY CARE NAVIGATOR: STATE-BY-STATE GUIDE
- WORK AND ELDERCARE
- ONLINE DISCUSSION GROUPS
- SF BAY AREA CAREGIVER SERVICES
- WORKSHOPS, CLASSES AND CONFERENCES
- CALIFORNIA'S CAREGIVER RESOURCE CENTERS
- RESEARCH & CLINICAL TRIALS
- CAREGIVING FAQS
- CAREGIVER TIPS
- PERSONAL STORIES AND PHOTOS
- CAREGIVER INFORMATION IN OTHER LANGUAGES
- OTHER WEB RESOURCES
- INTERVIEWS

Información en Español  
 Information in Chinese

**NATIONAL CENTER ON CAREGIVING**

- Health Care Reform and Family Caregivers
- NCC honors the 2009 Caregiving Legacy Award Recipients
- Making Our Voices Heard Session at Aging in America Conference 2010
- Latest issue, *Caregiving PolicyDigest*

**TECHNICAL ASSISTANCE CENTER**

**Technical Assistance Center for Caregiver Programs**

- LATEST ISSUE of the *Newsletter of the Technical Assistance*
- Give us your feedback
- Announcements
- Trainings

**INNOVATIONS CLEARINGHOUSE**

**Innovations Clearinghouse on Family Caregiving**

Programs, Public Policy and Technical Assistance for Professionals

Key Feature: Campaign for Better Care

**NEW TO CAREGIVING**

- Fact Sheet: Caregiving
- Where to Find My Important Papers
- Taking Care of YOU: Self-Care for Caregivers
- First Steps for New Caregivers
- Ask FCA: Find resources in your community

**FCA BLOGS**

Caregivers. Our pioneering programs-- services, research and advocacy-- important work of families nationwide chronic, disabling health conditions.

3, 2010

Family

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**FAMILY CARE NAVIGATOR**

**Family Care Navigator™**  
 State-by-State Help for Family Caregivers

CALIFORNIA CAREGIVERS

- Bay Area Services
- Statewide Services

# Additional Resources

- ALS Support Group
- FTD Support Group
- ALS Clinic Team
- Further Reading
  - 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](http://www.ftd-picks.org)

**Thank You for Attending!**