Welcome!
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Thinking and Behavior in ALS: Who, What, Why & How?
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Hosted by:
The ALS Association
National Office-Care Services
Thinking and Behavior in ALS: Who, What, Why & How?

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ALS Association Care Services Webinar
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Objectives

• Learn more about changes in thinking/behavior

• Know signs that challenges may exist

• Describe why it is important to know

• Know who can be challenged

• Address challenges for people with ALS, family members, and care providers
when i type i type often (sometimes) an 'e' instead of an ‘o' or opposite.
sometimes i spell my name as neerten, don't you think i know it is ‘noorten'
sometimes i can't recall people's name's or words like 'door', and an minute or hour later i know it again... i never experienced that before i was diagnosed.
sometimes i can not move my feet, before it was my right feed now i have it on and off with my left feet. when i had the 'excident' in the shower i tried to move my left feet forward and it went backward...weird...
sometimes when bonnie asks 'do you want coffee' i shake my head, try to shake up and down and it shakes left and right...also weird. when i am on the webcam with mom & dad, i answer 'no' i try to shake my head so they can see it, i can also see myself on the webcam, and i don't even see my head shake.
When I eat I must often put one of my fingers in my mouth to make sure the food doesn’t fall out my mouth. Occasionally I bite my finger, in my mind my finger is already out of my mouth, but it is not.
When Bonnie put my night ‘retainer’ in my mouth, or I do, I bite sometimes the fingers, I have no clue why?
Who

Thinking and/or behavior changes can come on before or after motor symptoms

50% of people with ALS will never have such change

50% with some change of behavior or thought

Symptoms highly variable & difficult to predict
When is it dementia?

**Impairment:** difference in thought/behavior but can still act for his/herself

**Dementia:** difference in thought/behavior  
**AND** can no longer act for his/herself

Different diseases cause dementia

When dementia is present – family/caregivers must make decisions
Who is affected by thinking/behavior change?

People with MND/ALS

Family members of people with MND/ALS

Care providers of people with MND/ALS
What does it look like?

Childlike, inappropriate behavior
Lost “filter” in conversation
Lost judgment/manners
Lack of empathy/concern for others
Inability to concentrate
Gets “stuck” on one idea or activity
Yes/No answers no longer reliable
Write/speaks words in wrong order

Forgets intended action
Difficulty with instructions
Sentences convey no meaning
Spelling declines
“Tip of tongue” phenomena
Trouble expressing thoughts
Cry/laugh too much
Why?

Proteinopathy through the neuro-axis

Genetic factors (i.e., C9ORF72)

Comorbid disease process to ALS/MND

Psychological adjustment – impact depression
Why look for it?

People with ALS/MND want to know

Caregivers want to know

Family members want to know

We are still learning about ALS

Knowing helps us learn **WHERE** to place expectations
A word about EXPECTATIONS

Expectations for people with ALS/MND, caregivers, care providers

Ideal for expectations to be “just right” and reflective of reality.

Challenges emerge when expectations do not reflect reality
HOW
Helping the Person with ALS/MND

Lack of awareness, anticipation, presence of agitation, apathy/indifference, withdrawal, frustration

- AAC (expression)
- Counseling to address anticipatory fear if FMH+ dementia/MND
- Functional communication boards (picture pointing)
- Simplify communication (two word phrases – noun verb, use nonverbals)
- Use of routine and schedule (less demand on memory)
- Audio books (when cannot hold books)
- Limit unfamiliar people/unfamiliar settings
- Physically “flank” person with disinhibition
- Distraction (touch, something the person loves)
- Simple cognitive task (i.e., counting) – counteract PBA
- Acceptance of change (patient’s adjustment is a reality)
- Medication (severe agitation, PBA)
- **Set realistic expectations**
Awareness predicts intervention with patient

Critical to evaluate awareness in the person with ALS/MND

Present awareness: Advanced Directives, care decisions, making intentions known, directing team

Absent awareness: Expectations for the person with ALS need to match his/her current ability

Interventions must be directed at family/care team when person with ALS does not have awareness or has restricted awareness.
Helping Family Members

Help is needed when there is:
Irritation, resentment, exhaustion, anxiety, physical problems, grief

Anger and anxiety = Responses to threat

Life with ALS is threatening
Helping Family Members

What does help look like?

• Neuropsychological assessment or cognitive screening of patient
• Durable medical equipment
• Communication devices
• Behavioral management
• ALS Clinic participation
• Education about ALS/MND and different stages of disease
• In-home help (housekeeper >>>>>>>> home health aide)
• Grief counseling
• Counseling to address anticipatory fear if FMH+ dementia/MND
• Respite time away from the person with ALS
• Giving up perfectionism
• Working with other family members
• Do not wait for a crisis – Advanced Directives, Legal Issues
• Educate providers working with the person with ALS
• Self-care (we are not done here 😊)
• **Set realistic expectations for the person with ALS and YOURSELF**
Self-care for caregivers

- Regularly schedule time for yourself
- Tell others specifically what you need
- Schedule and attend YOUR appointments
- Do not aggravate old injuries
- You have feelings!!!! Be honest.
- Faith counseling
- When you feel anger & frustration, it’s a sign!!!
- When you feel avoidant or despondent, it’s a sign!!!

You cannot provide care to others when you have nothing left to give.
Common Questions from Family

Anxiety over making decisions with or for the person with ALS/MND

1. How do I know that’s it is not just psychological?

2. How much do I let her/him do alone vs. assist?

3. When do you invoke advanced directives?
Helping the Provider of a Person with ALS

• Education
• Choose providers that know the disease and symptoms
• Do not assume all ALS providers know about thinking and behavior change in ALS.
• Share your concerns about yourself and your family
• Make sure your wishes are known
• Do not wait for a crisis to address advance directives.
• Remind providers to recognize “signs” that his/her expectations of the person with ALS or family members may need to change or may warrant additional diagnostic features of ALS presentation
Caregiving challenges offer opportunity to center/modify expectations.
Let’s Discuss a Case

62 year-old woman, retired receptionist
Married 40 years

**PBP:** symptoms began 1 year ago after URI but virus improved and symptoms progressed

Dysphagia, Sialorrhea, Cognitive Change, PBA, LMN changes arm/leg

**FMH:** Mother became functionally mute in her 50s, had memory problems and did not recognize people in last few years of life.

**NPSY evaluation:** MCI-Non-Amnestic
Let’s Discuss a Person and Her Husband

One year later -- Husband is frustrated and reactive. All symptoms progressed in patient. Pt is functionally mute. PEG tube just placed. Pt falling and refuses to use walker. He does not want to project anger/resentment onto patient but does not know what to do. He does all of the transfers. He has no help coming into the home.

Husband has not requested any assistance. Not connected with ALSA.

“'It’s not me.’”

We discuss emotional/physical fatigue and self-care.

“Getting help means she’s slipping away.”
Let’s Discuss a Person and Her Husband

Husband grapples with how much to let her try walking without walker versus insisting she use a walker and providing 24 hour supervision.

Husband waiting for her to tell him that she’s ready for help in the home.
Let’s Discuss a Person and Her Husband

Treatment plan:

1. Address safety issues and “signs” to implement interventions
2. Give permission to Husband to act on her behalf.
3. PCP physician referral for counseling
4. Connect with ALSA for resources/respite
5. Regularly scheduled respite time (i.e., craft beer brewing)
6. Acknowledge limitations of Patient and Self.
7. Live life well.
Questions & Discussion