DIAGNOSTIC CHECKLIST

FTD-ALS

FOR YOU: Changes in behavior, mood personality, muscle loss, or weakness

This checklist is designed to help you identify symptoms that should be discussed with your neurologist. Check the box next to each symptom that you or a loved one diagnosed with FTD or ALS has experienced. This form is not a substitute for a diagnosis by a medical professional.

If you are diagnosed with FTD, are you also experiencing any of the following?

GENERAL OBSERVED CHANGES

- [ ] Family history of genetic ALS
- [ ] End of day worsening in strength and speech
- [ ] Unexplained weight loss

LIMB AND MUSCLE PROBLEMS

- [ ] Weakness in legs leading to trips, stumbles, and falls
- [ ] Difficulty lifting arms above the head
- [ ] Clumsiness with hands or fingers that cause difficulties with fine motor skills (tying shoes, grasping a cup or pen, etc.)
- [ ] Changes in walking pattern
- [ ] Loss of muscle mass especially around thumbs
- [ ] General loss of muscle strength and/or neck weakness
- [ ] Episodes of spontaneous, uncontrolled muscle twitching
- [ ] Periodic uncontrollable muscle contractions, leading to tightness and stiffness

SWALLOWING AND SPEECH DIFFICULTIES

- [ ] Drooling
- [ ] Difficulty swallowing
- [ ] Choking
- [ ] Slowed speech
- [ ] Difficulty pronouncing words clearly
- [ ] Heavy tongue feeling or changes in gag reflex

If you are diagnosed with ALS, do you also have more than two of the symptoms below?

BEHAVIORAL CHANGES

- [ ] Making uncharacteristically rude or offensive comments
- [ ] Inappropriate behavior towards strangers, such as touching without permission
- [ ] Impulsive or reckless behavior, such as shoplifting or excessive spending
- [ ] Uncharacteristic aggression or frustration
- [ ] Lack of insight into diagnosis

APATHY AND LOSS OF EMPATHY

- [ ] Loss of interest in work or hobbies
- [ ] Indifference towards familial and/or personal relationships
- [ ] Neglect of personal hygiene
- [ ] Loss of initiative

TROUBLE WITH THINKING AND PLANNING

- [ ] Difficulty planning daily activities
- [ ] Uncharacteristic mistakes at work
- [ ] Challenges with managing finances
- [ ] Trouble with problem-solving

DIFFICULTIES WITH LANGUAGE

- [ ] Trouble recalling the names of objects or finding the right word
- [ ] Difficulty recalling the meanings of words
- [ ] Omitting words or making consistent word-usage errors
- [ ] Challenges understanding long sentences

If you want to learn more about FTD-ALS, scan the QR code with your smartphone or visit **theaftd.org/what-is-ftd/ftd-and-als-ftd-als**. #AskAboutFTD

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FTD-ALS

FOR YOUR HEATHCARE PROVIDER: Diagnosing FTD-ALS

The following chart contains diagnostic criteria developed by an international research workshop on FTD-ALS held in London, Canada. Referral to a neurologist specializing in cognition and behavior and/or a neuromuscular disease is recommended for a differential diagnosis. A diagnosis of FTD-ALS requires:

1. **Neuroimaging and a diagnosis of ALS**

2. **And the presence of** at lease 3 of the behavioral and cognitive symptoms or at least 2 of those behavioral/cognitive symptoms, together with loss of insight and/or psychotic symptoms

☐ **Early behavioral disinhibition** *(one of the three symptoms must be present)*	1. Socially inappropriate behavior 2. Loss of manners and recognition of decorum 3. Impulsive, rash, or careless actions
☐ **Early apathy or inertia** *(one symptom must be present)*	1. Apathy 2. Inertia
☐ **Early loss of sympathy or empathy** *(one symptom must be present)*	1. Diminished response to other people's needs and feelings 2. Diminished social interest, interrelatedness, or personal warmth
☐ **Early perseverative, stereotyped, or compulsive behavior** *(one of the three symptoms must be present)*	1. Simple repetitive movements 2. Complex, compulsive, or ritualistic behaviors 3. Stereotypy of speech
☐ **Hyperorality and dietary changes** *(one of the three symptoms must be present)*	1. Altered food preferences 2. Binge eating, increased consumption of alcohol or cigarettes 3. Oral exploration or consumption of inedible objects
☐ **Executive/generation deficits with relative sparing of memory of visuospatial functions** *(all the three symptoms must be present)*	1. Deficits in executive tasks 2. Relative sparing of episodic memory 3. Relative sparing of visuospatial skills

3. **Or the presence of** language impairment meeting criteria for semantic dementia/ semantic variant PPA or non-fluent variant PPA. This may co-exist with behavioural/ cognitive symptoms as outlined above.

Semantic variant PPA	☐ Impaired confrontation naming ☐ Impaired single-word comprehension ☐ Impaired object knowledge, especially for low-frequency or low-familiarity items ☐ Surface dyslexia or dysgraphia ☐ Spared repetition ☐ Spared speech production
Nonfluent/ Aggramatic PPA	☐ Aggramatism in language production ☐ Effortful and halting speech, inconsistent speech sound errors (verbal apraxia) ☐ Impaired comprehension of syntactically complex sentences ☐ Spared single-word comprehension ☐ Spared object knowledge

Strong, M. J., Abrahams, S., Goldstein, L. H., Woolley, S., Mclaughlin, P., Snowden, J., … Turner, M. R. (2017). Amyotrophic lateral sclerosis - frontotemporal spectrum disorder (ALS-FTSD): Revised diagnostic criteria. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 18(3–4), 153– 174. https://doi.org/10.1080/21678421.2016.1267768

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