

# Care Partner Guide to Changes in Eating, Hyperorality, or Oral Behaviors in FTD



## Help & Support

Changes in dietary preferences or oral (mouth) behavior are among the criteria for the diagnosis of **behavioral variant frontotemporal degeneration (bvFTD)**, but they can occur in any type of FTD. Oral behaviors change as FTD progresses, and are magnified by other symptoms such as disinhibition, impulsivity, and lack of social awareness.

### Common Oral Behaviors in FTD

- Changes in eating habits
  - Unusual food preferences or “food fads”
  - Food-seeking or opportunistic behavior
  - Binge eating
  - Eating non-food items
  - Cravings for sweets and/or carbohydrates
- Increased or first-time use of tobacco or other smoking/vaping products
- Excessive water or alcohol consumption
- Grinding teeth
- Making repetitive sounds with the mouth, such as clicking sounds
- Compulsive need to have something in the mouth
- Chewing clothing or placing inedible objects in the mouth
- Biting, including body parts

### Approaches to Reduce the Frequency of Oral Behaviors

Care partners can discuss potential approaches and concerns with the person’s physician and care team. Taking notes or using **AFTD’s Behavior Tracker** can help identify any potential triggers or patterns in the person’s routine related to the symptom and communicate these concerns with the care team. Make sure to include:

#### Is intervention needed?

Not all behaviors will need intervention, and some can be noted simply as unusual or mildly annoying. However, if the symptom causes significant stress for the care partner or poses an immediate risk of harm to anyone (such as choking), interventions should be considered.

#### Is the behavior caused by FTD or is it related to another medical condition?

A medical evaluation by a primary care provider or neurologist can rule out any other medical issues or pain contributing to the behavior, and is especially important if the person cannot share their needs with you. Doctors may suggest pain medications or SSRI antidepressants (after reviewing their benefits and risks).

When starting a new medication, use a calendar or log to monitor side effects, positive or negative. Your healthcare team can also provide advice if alcohol or another addictive substance is the focus of the oral behavior.

Additionally, a dental consultation can identify any oral issues that can be contributing to the symptom. Watch for signs such as sensitivity to hot or cold when eating, refusal to eat, mouth odor, or signs of infection such as fever.

**The Association for Frontotemporal Degeneration**

[theaftd.org](http://theaftd.org) | HelpLine: 1.866.507.7222 | [info@theaftd.org](mailto:info@theaftd.org)

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### Practical Approaches

Since oral behaviors caused by FTD are caused by changes in the brain that the person can't control, talking and logic won't stop the behavior. Instead, look for ways to interrupt, redirect, or replace the behavior. Some approaches may work some of the time, or may only work for a short time. Having a "toolkit" of multiple options can help you find approaches that work in your situation. Try to keep your goals realistic: aim for reducing the frequency and the risk of the behavior, rather than stopping it completely.

Here are some approaches you can try:

- Whenever possible, include more physical activity in the routine, such as taking short walks, dancing, using a hand pedal exercise machine, or stretching.
- Provide frequent supervision and checks.
- Use white lies or "fiblets" to avoid unnecessary confrontations. For example, if the person becomes fixated on chocolate cake, tell them, "We are out of chocolate cake, but we have Jell-O for dessert."
- Consider offering healthier food or beverage replacements that are similar to the person's favorites.
- Switch out the packaging or containers of food items that are particularly triggering. Remove half of the items in the package to help limit overeating.
- Store food out of sight or in unusual places, such as the linen closet, to limit access.
- Provide food or other alternatives that the person can safely consume to occupy them for a time. These items may include gum, lollipops, or products available online for other oral motor conditions. Always use them as directed by the manufacturer, and with supervision. A speech-language pathologist can provide individualized recommendations and suggestions.
- If the person compulsively chews their clothes, consider different styles or designs that the person cannot place in their mouth. Remove buttons from clothing.
- Remove access to unsafe items such as chemicals or cleaning products.

Other health professionals can help. Ask for help from your extended care team, which may include a speech therapist, occupational therapist, dietician, or nutritionist.

### Care Partner Support

Connecting with other FTD care partners who may have experience with similar issues can be a valuable source of emotional support and identifying additional approaches. Find a support group by visiting [theaftd.org/living-with-ftd/aftd-support-groups](https://theaftd.org/living-with-ftd/aftd-support-groups)

Find opportunities for respite to care for your own health needs, connect with others, and do things you enjoy. Learn more about AFTD's Comstock Respite Grants by visiting [theaftd.org/living-with-ftd/resources/comstock-grants](https://theaftd.org/living-with-ftd/resources/comstock-grants)

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