

Changes in Sexual Behavior in the Home/Community

Humans possess an innate capacity for sexual feelings. Social guidelines teach us appropriate ways to express these sexual feelings in public settings, while intimate partners mutually agree upon acceptable behaviors in their private relationship. Issues surrounding changes in sexual conduct associated with frontotemporal degeneration (FTD) are especially challenging for family members, including spouses, significant others, children and parents.

FTD alters specific areas of the brain that may lead to three types of changes in sexual behavior: decreased sexual desire, disinhibited acts, and increased sexual desire.

Decreased sexual desire

The individual does not mean to hurt your feelings or discount the relationship you once shared. This is a symptom of the disease.

- The loss of physical and emotional intimacy may cause partners to feel angry, alone and lonely. Your feelings are understandable and valid, but may be difficult to express.
- It is often helpful to discuss these private issues with trusted friends, counselors, support groups, religious groups and health care providers.
- Partners who wish to maintain a sexual relationship with the person affected by FTD might initiate the encounters and take more of a lead in these activities.
- Find other ways to maintain an emotional connection by organizing activities both of you enjoy.
- Some partners find intimacy with other individuals while continuing to care for the person with FTD.

Disinhibited sexual behavior

These behaviors are not deliberate. The parts of the brain enabling self-control are damaged which prevent the person from adjusting their actions to fit the setting.

- Share information about FTD and the issues you are facing with family and friends. This can help others to be more understanding and give emotional support to reduce social isolation.
- Identify and avoid possible triggers. Disinhibited sexual remarks and actions generally occur in response to visual and environmental cues, e.g., touching a woman's breasts on the beach, kissing strangers in a waiting room, and masturbating whenever using a bathroom even in public spaces.
- Investigate ways to arrange a different activity for the person with FTD if a situation is a trigger and will cause embarrassment, e.g., a trip to the beach or to a party. A friend, relative or caregiver may be able to help arrange an option so the caregiver gets a break.
- Monitor access to alcohol; alcohol will increase disinhibition further.
- Avoid clichés, such as "it is time to go to bed" that may be understood literally.
- Give the person something to hold during personal care, e.g., wash cloth, back scrubber, bath sponge.
- Never leave vulnerable individuals (including children or frail elderly) alone with persons with disinhibited or hypersexual behavior.
- Have a support person accompany the individual in public and during medical procedures, e.g., teeth cleaning, getting blood or urine specimens.
- Remain calm when actions occur; do not take the remarks/actions personally. Do not raise voice or reprimand.
- Tell the person firmly to stop. While unable to stop themselves from socially inappropriate actions, people with FTD may respond to the structure of someone telling them to stop.
- Ask the person to remove their hand, etc. If they do not respond, remove their hand gently.

- Redirect to another preferred activity, treat their suggestions with humor, distract, and walk away. Ask for assistance in an activity, e.g., “Can you help me move this?” “Look what we got in the mail today?” “I was just going to have some cookies, would you like some?”
- Provide the person with something to hold or carry to distract them, e.g., newspaper, and/or a hands-on activity, such as a hand-held game or puzzle.
- Carry AFTD Awareness Cards to reduce need for explanation.
<http://www.theaftd.org/life-with-ftd/resources/awareness-cards>

Increased sexual desire or hypersexuality

Hypersexuality or an increase in sexual drive affects a smaller number of people with FTD. Because FTD alters a person’s empathy and leads to a lack of understanding of what a partner desires in a sexual relationship, behaviors can be distressing for partners and pose risks in the community. People may seek sexual encounters with neighbors, paid sex workers, or become sexually aroused with pictures or individuals previously unattractive to them, e.g., children or the frail elderly. There may be risk of criminal complaint and legal action if the behavior is unmonitored.

- Discuss with a healthcare provider a sudden onset of masturbation or increased frequency of touching genitalia which may indicate an infection.
- Many caregivers develop a schedule by circling a day on the calendar when they plan to have relations. When the relations occur, the patient marks it with an “X.” Then a new circle is placed on the calendar and the patient knows he/she has to wait.
- These scheduled activities are often a good way to schedule personal hygiene by stressing that relations are unappealing when the person needs personal care.
- When possible, direct the person to a private room for activities that bother others, for example, masturbating or watching sexually provocative television and internet programs.
- Monitor individual closely when in the community, particularly when others provide services requiring close contact, e.g., beauty salon or dental office.
- Be aware of the impact on children or teens in the home who observe a parent’s disinhibited or hypersexual behavior. Encourage children to talk to you or another trusted adult about questions and reactions.
- Consider facility placement. A supervised and structured setting is often most effective for managing behaviors that require constant vigilance to contain. Having children in the home or an older parent caring for an adult child with FTD may prompt earlier facility placement.

Remember: These behaviors are part of a disease process AND you have the right to feel angry and sad for the changed relationship.