Partners in FTD Care

a quarterly newsletter for facility caregivers

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Sexual Behavior in FTD

Introduction:
As humans, we are all sexual beings, aware of our gender at a very young age. Sexuality is our capacity for sexual feelings. Sexual behavior is how sexual feelings are experienced and expressed. Throughout our lives, society has taught us how and when to channel sexual drives: what is appropriate and what is not. When a person develops frontotemporal degeneration (FTD), especially behavioral variant FTD (bvFTD), the disease can cause changes in sexual behavior. Several types of changes are possible that are distressing to caregivers and others: a loss of interest in sexual intimacy, inappropriate remarks or actions associated with cognitive disinhibition, and an increase in sexual drive, and behavior (hypersexuality).

When FTD affects the social filters we use to navigate in our environment, the person has decreased abilities to inhibit sexual needs and desires. Examples of disinhibited sexual behavior include: the person may make suggestive statements, try to observe other residents in various states of undress, relieve their sexual urges in inappropriate settings or engage in unwanted touching. Hypersexual behaviors are seen in a minority of FTD cases (8-18%)[1] where individuals seek an increase in sexual stimulation over pre-disease levels, and became sexually aroused with pictures or individuals previously unattractive to them.

Loss of sexual interest seems to be most prevalent and impacts life at home. Issues with disinhibition and hypersexuality, while problematic while living at home, are magnified in long-term care settings where people live their private lives in a public setting. In a residential setting, normal behavior, such as masturbation, can be viewed as a "behavioral problem." Long-term care staff may find sexual expression in the residential setting startling, troubling, disgusting, and/or invasive. This is especially true when direct care providers are young or hold specific religious beliefs regarding expression of sexuality. The following are actual case vignettes that illustrate issues of sexuality in FTD and promote discussion and development of effective interventions.

Case 1-a: Sexual Remarks
John Smith, a 55-year-old former executive, had bvFTD for 3 years when his family placed him in an assisted living facility (ALF). At home he had been increasingly disinhibited around women, making suggestive, racy comments, and insisting he should touch them or have relations. Unable to stop this behavior with medications, John's wife opted for placement thinking that highly trained staff would know techniques to manage the problem. She felt that John would never approach "older" women.

John adapted quickly to the facility and became a favorite dinner escort of several ladies. However, his suggestive remarks continued with residents, staff, and visitors. Fearing for other residents, the activity director banned John from activities. He was limited to a specific table in the dining room where he ate alone. The facility staff confined John to his room and sought additional mood-controlling medication to curb his behavior. The

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Do you have questions about how to serve individuals with FTD? Partners in FTD Care can help. The collaboration of clinical experts and experienced caregivers produces case-based studies and practical interventions you can use. Sign up today!

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National FTD Awareness Week

is the first full week of October. AFTD's Food for Thought campaign October 5-12, 2014 is a chance to take part in a nationwide effort to raise awareness of FTD, and it can be done creatively within your own program or facility. Supporters all across the country will host individual awareness-raising and fundraising events involving two things: food and/or drink and some basic FTD education.

Food for Thought is a great way to help the people with FTD you serve and their families feel empowered for positive change. AFTD wants to get as many of these events going in, as many states as possible, so that we can draw national attention from the press and increase awareness. For more info visit: http://www.theaftd.org/get-involved/host-an-event/aftdsfood-for-thought

Serve some Food. Share your Story. Spread the Word

Partners Yahoo Group

The Partners in FTD Care Yahoo Group is an on-line space to ask questions about care and share practical interventions that work. The group is moderated by experienced clinicians and long-term care professionals who develop Partners in FTD Care materials. Join the conversation and learn from the pros. Sign up at http://groups.yahoo.com/neo/groups/PartnersInFTDcare/

primary care provider prescribed lorazepam 2 mgs twice a day to "calm him." This medication increased John's sexual behaviors and he touched a staff member's breast. An antipsychotic was added, making him slow and very drowsy. He still made a suggestive remark to a nursing assistant who screamed at him and threatened to sue John, his family, and the ALF for sexual harassment. John was sent to an acute care psychiatric unit for evaluation.

When the acute care unit determined John was ready for discharge, they reviewed his care notes, medications, and assessments with the psychiatrist, attending physician, his family, and ALF staff. The administrator determined that the facility could not safely care for a person with these behaviors. John was referred to a long-term care behavioral memory unit.

Case 1-b: The Marriage

John Smith was subsequently admitted to a LTC memory care unit specializing in behavioral issues. The staffing ratios were higher and training was provided to the family and staff. The first few weeks after admission John was weaned from many of the mood-altering medications and remaining doses were minimized. A meeting was held with staff to explain that John's sexual behaviors were symptoms of his FTD and that there was no immediate danger. The administrator contacted AFTD and obtained training materials on FTD. She used these materials to train staff, the Board, and the family support group.

Family of other residents became aware of John's behavior and expressed concerns that their loved one might be molested. One family demanded that John be discharged to "protect our mother from becoming molested." These statements/concerns were directed to the administrator who met with families individually to reassure them that their loved one was safe and John was being carefully supervised. She asked families what they would have wanted if their loved one exhibited these sexual symptoms. This led to discussions that were thoughtful and less outraged.

Troubles and Tips

Q: We have a female resident who takes off her clothes in activities, during meals, and in the living room. During a care planning meeting, staff suggested the following interventions: modified clothing, such as a jumpsuit and mittens, have her eat alone, and ban her from activities. Are these appropriate/permissible interventions?

A: When a resident exhibits disinhibited sexual behavior or is sexually aggressive, e.g., following or touching others, it is important to evaluate and manage the behaviors as symptoms of the disease. Training in both signs and symptoms of FTD and state regulations regarding management of behavior, coupled with coordinated care planning will enable staff to respond effectively to the needs of all residents.

Focusing on positive interventions, such as redirection to personalized activities, discussion topics, and food, will assist the resident while remaining compliant with regulations.

Regulations regarding management of behaviors and use of physical restraints address banning from activities, limiting to one table where a resident eats alone, and confining to a resident room as a violation of resident rights and should not be permitted. Modified clothing including jumpsuits, mittens, and modified furniture placement such as tray tables (based on position) may be considered physical/mechanical restraints and violation of resident rights. Educating staff regarding state-specific regulations involving restraints and resident rights will assist them in understanding what interventions are prohibited or permitted. It is important to involve the resident's physicians and request a gero-psychiatry examination. Never try to conceal behavior or an incident; families of other residents approached must be informed by an administrator who has a plan for management.

Additionally, the facility staff should be aware of their state regulations concerning what constitutes sexual behavior and abuse; reporting/documentation procedures; and appropriate interventions. Scheduling staff in-services with a representative from the state regulatory agency and/or the Area Agency on Aging who will provide education and support to staff on these subjects is beneficial.

In Case #1, the aide threatening to sue for sexual harassment was counseled about FTD. She was also offered individualized counseling. Ongoing support was provided to help the whole staff understand that John's behavior and remarks are symptoms of the FTD and not aimed specifically/socially at them.

The facility may, also, want to contact legal advice regarding specific incidents, e.g., communication, interventions, documentation, and potential liability.

John continued to make sexually suggestive remarks until one day he was seated next to a woman, Mary Jones, at dinner. After dinner, he followed the staff as they escorted Mary, who had moderate Alzheimer's disease, to her room. After that John and Mary, who was also married, would seek each other out in activities and during meals. In between scheduled events John and Mary would roam the halls holding hands. Once the staff observed John pull Mary into his lap and kiss her. They separated the couple, distracting Mary with activities.

John, however, was not to be distracted and continued to seek Mary out. Mary began to cry when John was not around. Both appeared to be comfortable being with each other. Last month the couple was found together in Mary's bed, snuggling. John was fondling Mary's breasts. There was no resistance or distress, but the staff felt they had to intervene. The facility contacted the state regulatory agency for guidance regarding reportable incidents and recommended interventions.

The staff met with both Mary's and John's families. John's wife felt he should be left to walk hand in hand, perhaps share a few kisses, and cuddle with clothing on. Mary's husband was outraged that Mary would violate her marriage vows and insisted the couple be separated. He threatened to charge John with attempted rape; however, relented after several meetings with the social worker. Mary was moved to another unit. Within a day, John had a new partner. Because John was a Veteran who served in Vietnam, his family opted to place him in a Veteran's care home where the behavior ceased.

Case 2: Masturbation

Molly Rose is a 45-year-old disabled unmarried pharmacist who suffers from moderate non-fluent type primary progressive aphasia (nfPPA). She has been essentially mute for the past year and is now developing disinhibited and compulsive behaviors. She is wheelchair dependent and resides in the memory care wing of the Happy Cactus ALF. Over the past four months Molly started to rub her genital area. The staff felt that she was masturbating and provided her with privacy. Instead of limiting the behavior to the confines of her room, Molly began to rub herself continuously in public areas of the facility. The staff tried to limit her access to her genital area using a jumpsuit, mittens, lap activities, and even trying using a tray table. She was put into jumpsuits so she was not able to expose herself. This only caused increased agitation and spontaneous yelling. An antidepressant and an antipsychotic were tried but failed to stop the masturbation.

A new nurse practitioner (NP) was assigned to oversee Molly's care. Upon completing a physical examination the NP discovered Molly's genital area to be excoriated and she noted vaginal discharge. The NP treated Molly for a urinary tract infection and vaginal yeast infection. Staff was retrained in providing feminine hygiene for Molly and the term "masturbation" was replaced with the word "itching." Within a week Molly was asymptomatic and her rubbing had stopped.

Case 3: The Exhibitionist

Sally is a 50-year-old single woman with PPA. She is mute and now exhibits disinhibited behavior. Whenever she sees a particular male resident in the hallway she spontaneously undresses. Staff moved her to another unit where Sally found another male resident and continued the behavior. The staff met and decided they could manage this behavior with jumpsuits. Whenever Sally approaches a male resident the staff divert her attention by giving her a Twinkie. They then divert her attention to her favorite video. This has proven effective.

Conclusions

It's complicated! When dealing with sexual behaviors in a long-term care residential setting, there are numerous considerations. Sexual behaviors in FTD need to be treated seriously with input from the range of people involved: the resident (if appropriate) staff, family, physician, social worker, nurse, and perhaps a psychiatrist. Also involve the state regulatory agency, Area Agency on Aging, and/or Ombudsman as required. Incidents, assessments, physical assessments, family meetings, physician interventions, care plans, and outcomes of interventions must be carefully documented.

Most sexual acting out is time-limited, decreasing as the FTD progresses. Successful interventions are the result of careful planning, open discussion with staff, attention to needs of all families and residents, and teamwork.

Questions:

1. What are some of the behavioral and environmental interventions tried to manage inappropriate sexual behaviors?

If the behavior is not aggressive, staff should understand that sexual behaviors in FTD are generally time-limited. As with all behaviors, remaining calm and patient are keys. Scolding, talking down to or correcting the resident are not effective behavioral interventions. Strategies such as removing visual triggers, using modified clothing and diversional activities (music, bird watching, rhythm activities, eating, videos, etc.) are often as effective as medication use and transfers. Modified clothing may be a positive intervention but the facility

should be aware of state regulations. Jumpsuits, mittens, etc. could be considered a restraint/resident rights issue if they prohibit movement, etc. Several facilities have had success with physical exercise, i.e. stationary bike, vigorous walking, and basketball. Additional considerations include arranging private opportunities for resident to masturbate and resident to engage in sexual activity with spouse/partner.

2. How do staff and family attitudes toward sexuality influence the reactions and interventions toward behaviors in the case examples?

Some staff feared John's remarks and felt they were sexual harassment. Staff members may object to John's sexual behaviors for several reasons including strongly held religious beliefs or may have been the victims of sexual abuse. Administrators need to provide information on sexual behaviors during orientation and provide on-going sessions that include open discussion. Staff frequently do not know what are acceptable and not acceptable sexual behaviors, and with whom. This contributes to feeling embarrassed to discuss or report behaviors and to difficulty documenting issues objectively and professionally. Understanding and articulating behavior is critical for developing effective interventions.

3. What role did medications play in managing the sexual symptoms discussed in the case examples?

It is important to understand that medications have not been shown to be effective in dampening libido. There are anecdotal reports suggesting some benefit from oral estrogen; however this has not been confirmed by research. Other clinical reports suggest citalopram or escitalopram may help to dampen libido; again, there is no research. Use of antipsychotics simply tends to slow the person therefore helping with supervision. Benzodiazepines for anxiety may actually worsen the problem as they decrease inhibitions further.

4. In what ways might physical health contribute to some sexual behaviors?

FTD impairs a person's ability to communicate their needs or report physical health issues. It is critically important that residents who appear to be masturbating – especially women – be evaluated first for conditions such as UTIs, yeast infections, vaginal or rectal prolapse, or vulvar cancer before dismissing the cause as sexual. Observation of the perineum does not necessarily occur when showering a resident.

Reference:

1. Mendez and Shapira (2013): Hypersexual Behavior in Frontotemporal Dementia: A Comparison with Early-Onset Alzheimer's Disease. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3596488/

Questions for Care Planning

FTD can cause several different types of changes in a person's sexual behavior. When considering what you might do about these behaviors think about the following questions, and remember that with all things sexual, it's complicated:

- What is the effect on the resident? What are the resident's rights to sexual expression?
- How does this behavior compare with family reports of lifelong sexual expression?
- Has a thorough physical assessment been done recently to rule out physical conditions that might cause the behavior?
- How does the resident's behavior affect other residents?
- How does it affect the staff? It is helpful if the most mature and experienced staff who will not overreact are assigned to the resident with sexual behaviors.
- How does it affect the resident's family and other visitors?
- Are there regulations regarding the management of the behavior in our state?
- Are there legal or regulatory issues to consider, such as accusations of molestation, rape, or sexual harassment?
- What is the goal of treatment? In intervening do we want to modify the behavior or to stop it?
- Can staff identify patterns or visual triggers that can be modified in positive interventions?

Sexual Behaviors in Facility Care

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. FTD alters specific areas of the brain that may lead to three types of changes in sexual behavior: decreased sexual desire, disinhibited remarks and actions, and increased sexual desire. Disinhibition and hypersexuality pose particular challenges in facility care.

Interventions strategies

- If approached, remain calm; do not take the remarks personally. Do not raise voice or reprimand.
- Redirect to another preferred activity, treat their suggestions with humor, distract, and walk away.
- Do not make fun of the resident. Address in a professional manner.
- Correcting or trying to "punish" the person will not be effective and might be construed as abusive.
- Track remarks for triggers. Avoid clichés, such as "Let's go to your room" or "It is time to go to bed," or statements that could be misunderstood; "Take off your clothes." The resident may take these phrases literally.
- Report remarks to the supervisor immediately. Understanding the manifestation of symptoms is necessary for effective management. The longer one waits to report and intervene with behaviors, the worse they will become.
- A support person should always accompany the individual in public.
- Positive behavioral and environmental interventions are most effective. If behaviors are determined to be disinhibited or compulsive, SSRI antidepressant medications may be tried.

When physical touching is involved

- While persons with FTD are unable to stop themselves from doing socially inappropriate actions, they may respond to the structure of someone telling them to stop.
- Ask the resident to remove their hand, etc. If they refuse or do not understand, remove their hand gently.
- If the resident has previously touched inappropriately, provide adequate personal space.
- It may be necessary to have a private duty caregiver with the resident, a caregiver of the same sex and/or two staff provide care.
- Provide the resident with something to carry, e.g., newspaper and/or a hands-on activity, such as a craft.
- Modest staff apparel is recommended, e.g., no low cut top, shorts.
- Track incidents of touching for triggers, positive interventions.
- Report all incidents of inappropriate touching of other residents, staff, and visitors to the supervisor immediately. If another resident is involved, nursing should conduct a full body assessment immediately.
- Assign 1:1 to be with the resident if constant supervision is necessary.

Approaches to personal care

- Follow resident's usual routine, and schedule when they are most agreeable rather than for the facilities schedule; break up tasks if needed, e.g., bathe arms on Mon., legs on Tues. to reduce time.
- Assign same gender staff to help bathe, if possible.
- Tell the resident what you are going to do before proceeding.
- Modest staff apparel is recommended; women wearing a smock that conceals breasts to reduce visual triggers.
- Ensure privacy, e.g., close shower curtain, cover with a towel, provide a robe.
- Go slowly, explain each step.
- Provide eye contact, keep level voice tone, and use simplified language.
- Be aware of personal and intimate space. Allot at least arm's distance when providing care.

- Give the resident something to hold, e.g., wash cloth, back scrubber, bath sponge.
- Report any inappropriate behaviors to the supervisor immediately.

Remember: These behaviors are part of a disease process AND staff may have individual reactions that interfere with care. Provide ample education and support, and allow opportunities for staff to discuss their feelings about resident sexual behaviors.