

Evaluating and Managing Pain

Evaluating pain in people with frontotemporal degeneration (FTD) can be challenging. Behavioral changes are often attributed to the disease rather than triggering an evaluation for pain or discomfort. When you understand FTD symptoms and adopt an observant approach, multi-disciplinary interventions can make a real difference in compassionate care.

Tips for identifying and managing pain include:

- Anticipate pain from concomitant conditions such as arthritis, back pain, peripheral neuropathy and other medical conditions. Treat.
- Use AFTD's Daily Care Snapshot Tool (<http://www.theaftd.org/wp-content/uploads/2011/09/Packet-Daily-care-snapshot.pdf>) to communicate a person's medical issues and past treatment to care providers.
- Don't discount the ability of the person with FTD to give an appropriate response to questions, but confirm with additional evaluation.
- Avoid "Yes/No" questions when asking about pain. People with FTD may answer indiscriminately; the first response is usually "No."
- Ask specific questions, e.g., "Where is your stomach?" or "Press where it hurts." Include gestures to provide non-verbal cues, e.g., point to stomach, etc.
- Automatically check for range of motion. For example, during personal care such as dressing, routinely check feet and shoes of people who roam or pace extensively.
- Non-verbal pain scales that use numbers or faces may be helpful, but don't stop after a single assessment. People with FTD may not recognize emotion from faces use in the facial pain scale.
- Don't discount general or vague reports from family or care providers that something is different or not right. Ask them to look back in time; incremental changes may not be noticed day to day.
- Treat with routine acetaminophen to assess vague reports of something being different; if the behavior subsides, it may confirm the presence of pain.
- Non-verbal behavior is more difficult to read in FTD than Alzheimer's disease (AD). In AD, behavior is generally consistent. Someone with a sore foot may stop walking which triggers evaluation. A person with FTD and compulsive behavior may keep walking even if it hurts.
- Increased chewing behavior or decreased appetite and eating may indicate pain in the teeth/gums and should be evaluated.
- Watch for resistance to dressing or personal care which may indicate pain; evaluate. If reaction is in the shoulder, switch from a pullover to shirt with buttons.
- Grabbing behavior (a person's wrist, arm, etc.) may be common in FTD as related to a frontal lobe reflex. If it intensifies, it may be a reaction to pain.
- Someone scratching at his or her crotch may have pain or itch in that area rather than disinhibited behavior. Skin evaluation (especially of the peri area) should be done each bath day.
- Develop a pain management plan and communicate it to all staff and the family for input and to provide consistent care.
- Include PT, OT and speech therapies in pain evaluation and management, i.e., exercises, heat/cold, massage, positioning, transfer techniques, mobility beds/devices and adaptive clothing/devices.
- Provide recreational interventions, such as soothing music, pet visits, aromatherapy and massages.
- Use common sense and careful observation on a continuing basis.