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.

Expected FTD Behavior or a Superimposed Medical Condition?

Significant changes in personality, behavior and language are hallmarks of the frontotemporal degeneration (FTD) disorders. These characteristic symptoms do not occur in predictable stages and can increase or decrease as the disease progresses. Assuming a new or changing behavior is due to FTD may cause families and providers to miss treatable medical conditions masked by the underlying neurological disorder.

FTD behavior or symptom		Possible medical considerations
Apathy, social withdrawal, reduced initiative	May not eat or drink properly if not monitored	Weight loss, dehydration, electrolyte disturbance
	Decreased personal hygiene	Altered skin condition, rashes, infections; urinary tract infection; tooth decay
	Inadequate physical activity	Constipation; weight loss, generalized deconditioning, failure to thrive; blood clots due to circulation problems
Emotional blunting, loss of empathy	Hallmark of FTD, also in depression	Possible manifestation of pain
Disinhibited behaviors	Compulsive eating , especially carbohydrates	Weight gain and increase in associated health risks; tooth decay
	Compulsive drinking of water	Electrolyte disturbance presenting as increased confusion
	Compulsive drinking of caffeinated beverages	Agitation; elevated blood pressure and pulse; electrolyte disturbance; urinary incontinence
	Stuffing food into mouth	Death from choking; aspiration pneumonia, lung infections
	Hands in pants; scratching at crotch	Skin irritation, rash; urinary tract or other infection , vaginal yeast infection, prolapse
	Disruptive vocalizations, yelling	Generalized pain
	Disrobing (woman)	Hot flashes, hormone changes from menopause
Repetitive or stereotyped behaviors	Constant walking or roaming	Foot blisters, infections of feet; muscle pain; trauma from tripping or falling; danger of elopement
	Picking or biting fingers	Hand infections, tearing of nail beds and bleeding
	Chewing behavior	Tooth or gum pain
Impaired language fluency	Decreased verbal output expected with progression of PPA	Possible sign of mouth or teeth pain
Comprehension impairment	Inability to understand word meaning and concepts, recognize faces and objects	Vision changes requiring eye exam, updated glasses
	Unlikely to understand common scales used to evaluate pain	Close behavioral observation, non-verbal assessments
	May not recognize or conceptualize painful sensations	Monitor cooking activity, exposure to fire, heat, cold other hazards; evaluate after exposure
Movement or motor skills impairment	Abnormal limb posture(ie: CBD)	May indicate painful contractures, frozen shoulder from lack of use, fracture
	Unsteady gait and balance predisposes to falls	May indicate blisters, poorly fitting shoes
	Sudden cessation of walking and mobility	Assess for pain
Changes in mood	Agitation	Assess for pain; overstimulation or changes in environment; fatigue; excess caffeine
	Sadness or depression	Clinical depression (especially in PPA); may be sign of pain
Emotional incontinence common in PSP	Forced laughing or crying out of context	May indicate bodily sensation that needs investigation