The FrontoTemporal Dementia Symptoms and Staging Tool — FTD-SST

FrontoTemporal Dementia Stages & Symptoms	Behavioral Personality FTD		Communication & Language FTD			Motor & Movement Disorder FTD			
FrontoTemporal Dementia (FTD) is named because it primarily affects the frontal and temporal lobes. It is the most common dementia between the ages of 40-60. Sometimes referred to as Fronto-Temporal Lobar Degeneration, the term FTLD is the post mortem name.	bvFTD — Behavioral Variant FTD**	Pick's Disease**	PPA — Primary Progressive Aphasia	Semantic Dementia**	Logopengic Variant PSP**	ProSupra Nuclear Palsy PSP**	Corticobasal Ganglionic Degeneration	FTD with Motor Neuron Disease	ALS with Dementia
Stage 1 — Normal Aging									
Stage 2 — Typical First Signs and Early Depression Symptoms*									
Alterations in alertness									
Apathy									
Slow withdrawal of emotional responses									
Agitation									
Bursts of anger									
* Signs of disinterest									
* Apathy not related to being sad									
* Little insight into being sad									
* No self awareness of changes in mood									
* Increased irritability									
* Poor concentration									
* Lack of attention during interaction									
* Sadness or negative mood									
* Poor appetite or increased over eating									
* Insomnia or hypersomnia									
*** *If sleeping more than 14 hours/day, increased risk for infections and atrophied muscles*									
Stage 3 — Early Stage Symptoms									
Sudden interest in drinking	x								
Gradual loss of empathic response	x	x							
Decreased insight into behavior	x	x							
Shoplifting	x	x							
Increase in weight — 40lbs in 6 months	x	x							
Self-centered behavior	x	x							

Tam Cumings, PhD - Dementia Association

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Stage 3 — Early Stage Symptoms									
Uncaring behavior	x	x							
Withdrawal from people and activities	x	x							
Increase in spontaneous behavior, such as inappropriate friendliness, speaking candidly, revealing personal information to strangers, becoming angry during routine tasks at job or at home, may appear restless or irritable	x	x	x						
Unusual eating habits, such as food fixation (eating too much of a specific food), great craving for sweets, sucking and chewing on objects (pens, combs, spoons, etc.), hyper oral, shovel food	x	x	x						
Ignores social etiquette and boundaries, such as getting too close when speaking to others, tendency to hug, touch, talk in inappropriate or intimate ways (new behaviors for this person)	x	x	x						
Displays poor judgment	x	x	x	x					
Loss of facial empathy — masked face	x	x				x			
Decreased interest in spouse, children, family	x	x	x	x	x	x	x	x	x
Very mild short-term memory loss	x	x	x	x	x	x	x	x	x
Personal hygiene changes	x	x	x	x	x	x	x	x	x
Math skills good	x	x	x	x	x	x	x	x	x
Visual ability good	x	x	x	x	x	x		x	x
Mild word-finding difficulty (anomia)			x	x	x				

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Apathetic appearance in whole body			x	x	x			x	
Difficulty moving whole body or parts of body						x	x	x	x
Struggles to form words (dysarthia)			x	x	x	x			
Trembling limbs						x			
Balance problems						x			
Tipsy walking gait						x			
Exhibits doll's eyes — an inability to coordinate eye movements or aim the eye quickly up and down						x			
Acalculia — difficulty with math						x	x		
Stiff muscles in motion or when still							x		
Clumsy with one side of body (asymmetrical decline)							x		
Stiffness in one arm, followed by stiffness in one leg (paratonia)							x		
Alien hand movements — hand pushes away other objects or other hand							x		
Magnetic hand — hand seems drawn to other hand or other people's hands							x		
Fasciculations (muscle twitches or flutters)								x	
Muscle jerks								x	
Muscle cramps								x	
Loss of muscle tone								x	x

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Increase in falls and falls with injury						x	x	x	x
Difficulty doing skilled hand movements with one or both hands or arms (apraxia), which may result in difficulty buttoning shirt, turning book pages, shaving, applying makeup, eating, writing, etc.						x	x	x	x
Stage 4 — Early Middle Stage									
Judgement	x	x							
Rational thought	x	x							
Personality changes	x	x							
Impulse control	x	x							
Little concern about losses	x	x							
Rapid Eye Movement Disorder (REMD) — sleep disturbances	x	x							
Thrashing, kicking, punching, striking out while sleeping	x	x							
Can read and write accurately	x	x		x	x				
Loss or changes in executive function, such as time management, attention management, switch focus, plan and problem solve, integrate past experience with present	x	x				x			
Difficulty expressing words — nonfluent asphasia			x						
Incorrect grammar			x	x					

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Difficulty naming objects or recognizing familiar words or faces			x	x					
Performs ADLs			x	x	x				
Slow response to conversation			x	x	x				
Slow, weak, slurred, breathy, nasal speech (dysarthia)			x					x	
Speaks at a normal rate — fluent aphasia, but may be difficult to understand				x					
Difficulty understanding speech of others				x					
Expresses appropriate emotions				x					
Slow rate of speech					x				
Can repeat short, single words					x				
Outbursts of laughing or crying						x			
Akinesia — absence or slowed movement						x	x		
Bradykinesia — lack of spontaneous movement							x		
Shortness of breath due to weak muscles								x	x
Stage 5 — Late Middle Stage									
Loss of insight									
Repetition of behaviors									
Memory problems	x	x							
Severe cognitive deficits	x	x							
Language skills function late	x	x							

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Visuospatial skills still functional	x	x							
Great loss of affect — mask face	x	x	x	x	x	x	x	x	x
Increased sleep for day and night	x	x	x	x	x	x	x	x	x
Difficulty swallowing	x	x	x	x	x	x	x	x	x
Urinary incontinence	x	x	x	x	x	x	x	x	x
Severe loss of empathy	x	x	x	x	x	x	x	x	x
Difficulty adjusting mood to situation	x	x				x	x	x	
Emotional ups and downs	x	x					x		
Hesitance and slowed speech			x	x	x	x	x		
Loss of language fluidity			x	x	x				
Mutism			x	x	x				
Decreased motor movement skills						x	x	x	x
Short-term memory loss						x	x	x	x
Muscle atrophy						x	x	x	x
Struggles to form words (dysarthia)						x	x		
Abnormal posturing or frozen movements							x	x	
Unaware of one side of body							x		
Inability to balance — sitting or walking							x		
Reflexes are overactive								x	
Stage 6 — Late Stage Symptoms									
Short-term/long-term memory affected									
May stay in constant motion, walks or moves for hours									

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Disheveled appearance									
Beginning of severe weight loss									
Bowel incontinence begins									
Can feed self at times									
Great loss of language/mutism									
Difficult to engage									
Appears lost in own world									
Loss of total facial affect — masked									
Gait is greatly affected									
Combative or aggressive behavior									
Difficult to rehab									
Disregards eyeglasses, hearing aids, dentures									
Stage 7 — End Stage Symptoms									
Unable to sit erect									
Unable to walk									
Speech is lost									
Unable to hold head erect									
Extreme risk for falls									
Extreme risk for skin breakdown									
Semi-alert or asleep most of day									
Loss of ability to chew and swallow food properly									

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Disinterest in food or drink									
Extreme weight loss									
Total care for all ADLs									
Loss of ability to smile — indicative that death is near									

** Some of the FTDs are recognized as tauopathy disease. Tau is a protein found in the brain's cellular structure. Once tau begins to fold incorrectly in the cells, it disrupts and destroys the brain's ability to function. Alzheimer's Disease is also a tauopathy. This probably h elps explain why persons with FTD eventually begin to have many of the same late symptoms as persons with Alzheimer's Disease.