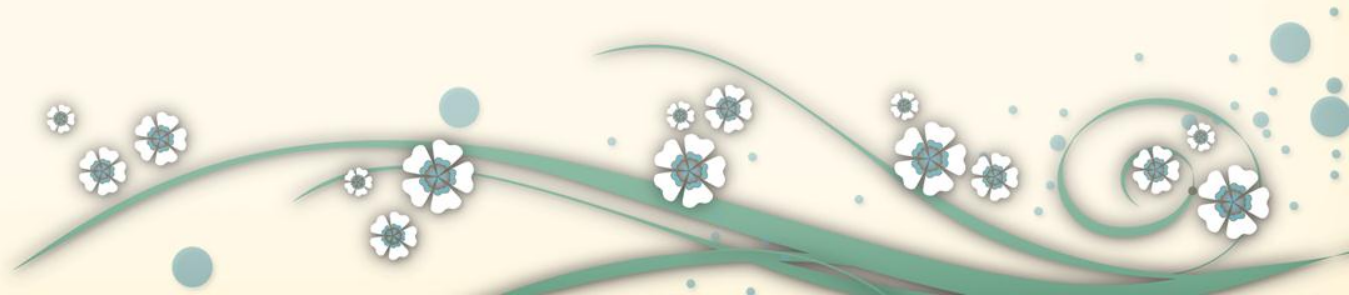


# Hospice Care: Maximizing Comfort and Enhancing Quality of Life for Persons with FTD and their Families

Hospice of the Valley Dementia Team



# The Facts

- Although a large majority of Americans say they would like to die at home...a majority of deaths still occur in hospitals.
- Studies suggest that prior to a person's death in the hospital...
  - › Distress occurs in people of all age groups
  - › There is high use of non-beneficial technologies
  - › Distress and burden increase for caregivers
  - › Communication often fails between patients, families and physicians about goals and decisions regarding care

# What is hospice?

A philosophy of care that provides comfort as life nears its end, rather than heroic lifesaving measures when they no longer offer any promising outcomes.



# Hospice Care

- Goal is comfort at the end of life for those with a terminal illness for whom there is little to no curative alternatives
- Care is typically provided where the person resides (e.g., private home, long-term care facility)
- Specializes in holistic care – physical, spiritual, emotional, social – provided by an Interdisciplinary Team

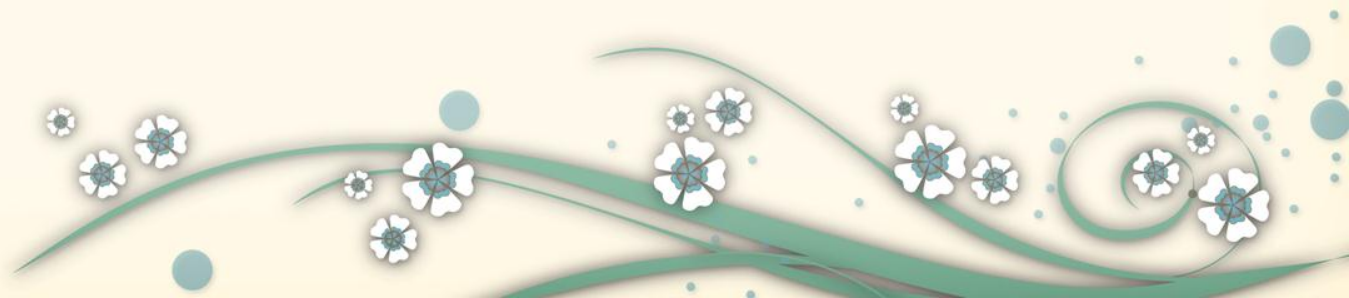
Though services may vary by region and depending on the hospice organization, these are the core services provided by hospice:



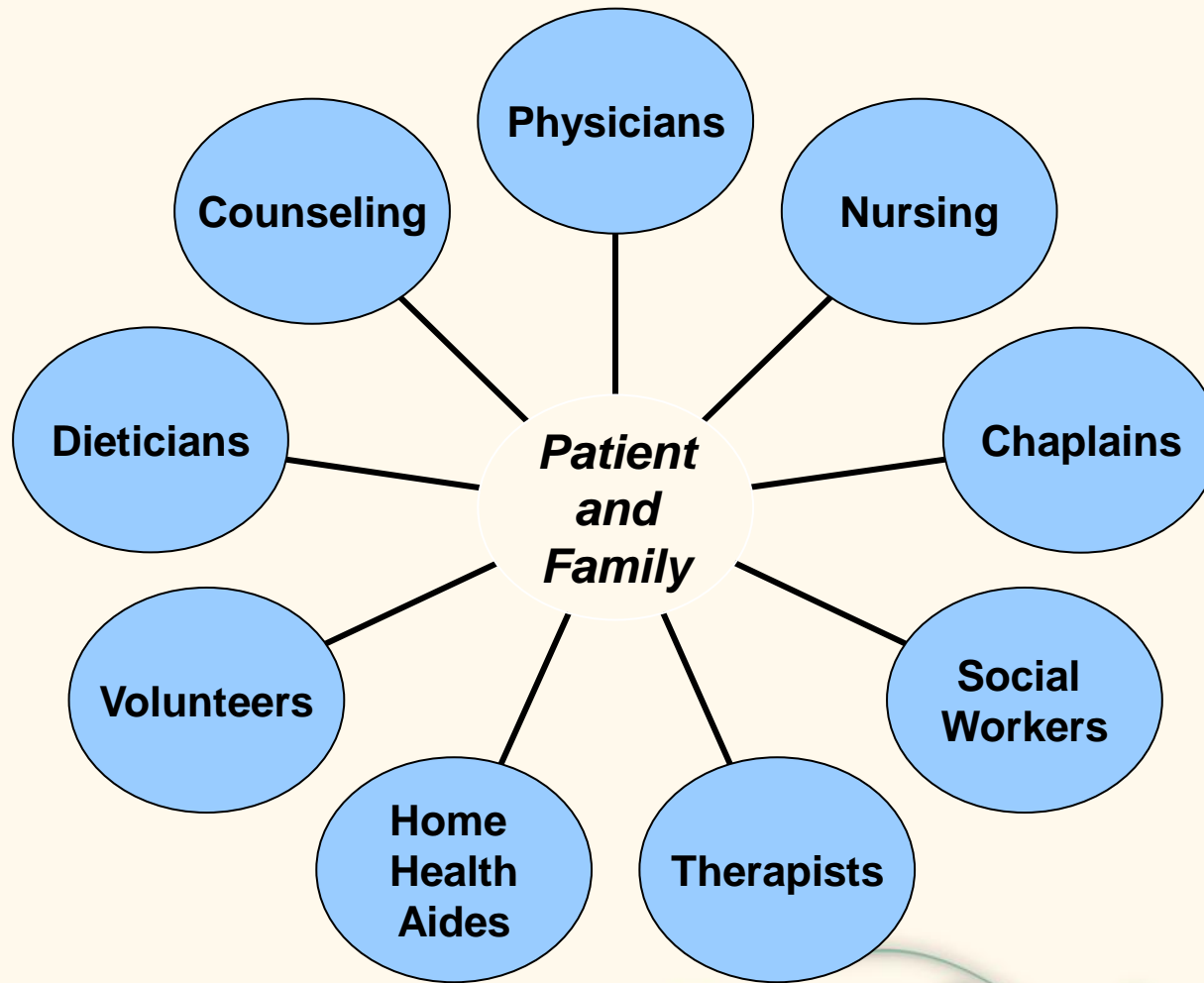
- › Interdisciplinary Team  
(see next slide)
- › Medications
- › Medical Equipment
  - › Supplies
  - › Respite
- › Inpatient Units

# Hospice care today...

- Over 4,000 different hospices across the U.S.
- They are NOT all part of one organization
  - › (For example, there are 40 separate hospice organizations in the Phoenix Area)



# The Hospice Team



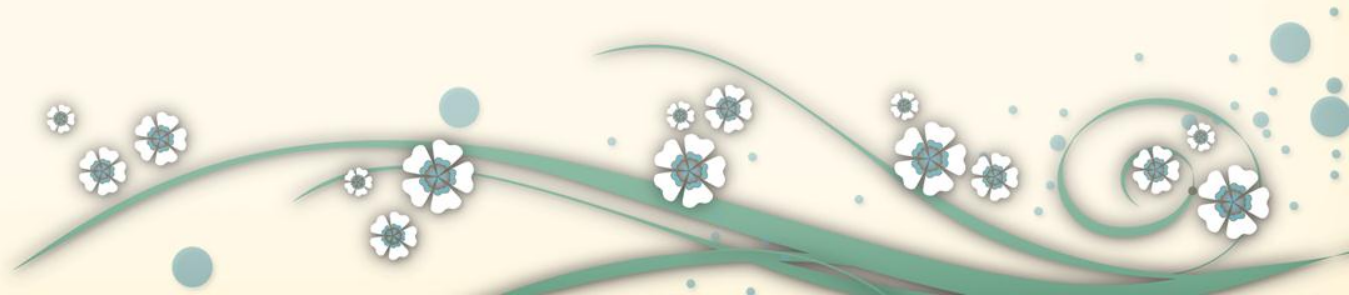
# How much does hospice cost?

- Hospice is paid for by Medicare and commercial health insurance
- Some hospice agencies may provide needed care regardless of ability to pay



# When is it time for hospice?

- When a physician has provided a terminally ill diagnosis and anticipates a life expectancy of six months or less
- And when the patient & family decide to elect the hospice benefit



# Hospice Eligibility for Dementia

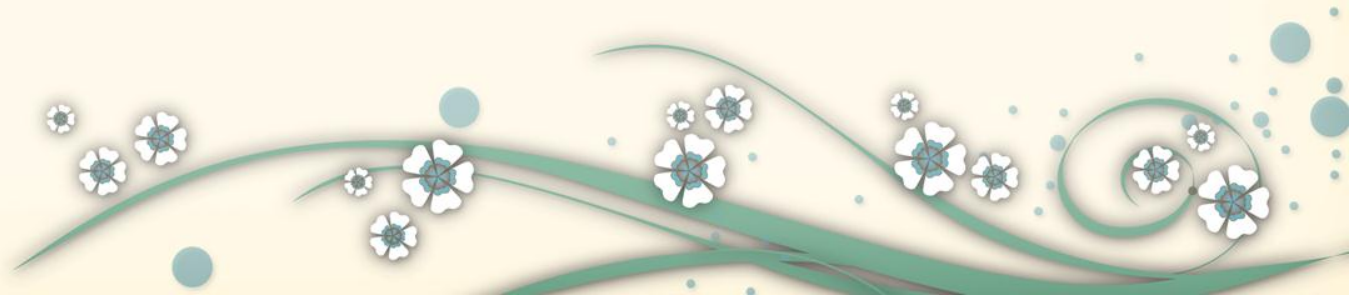
- The person is unable to walk, bathe, and dress independently.
- The person speaks few intelligible words.
- The person is incontinent of bowel and bladder.
- The person is steadily losing weight.
- One or more of the following has occurred in the past year:
  - › Aspiration pneumonia
  - › Kidney/urinary tract infection
  - › Recurring fever after antibiotics
  - › Pressure ulcers (bed sores)

# Barriers to Admission with FTD

- Patients are often younger & healthier
- FTD may not be recognized as a terminal condition
- Hospice criteria are based on the progression of Alzheimer's disease
- It is difficult prognosticating end of life for all types of dementia

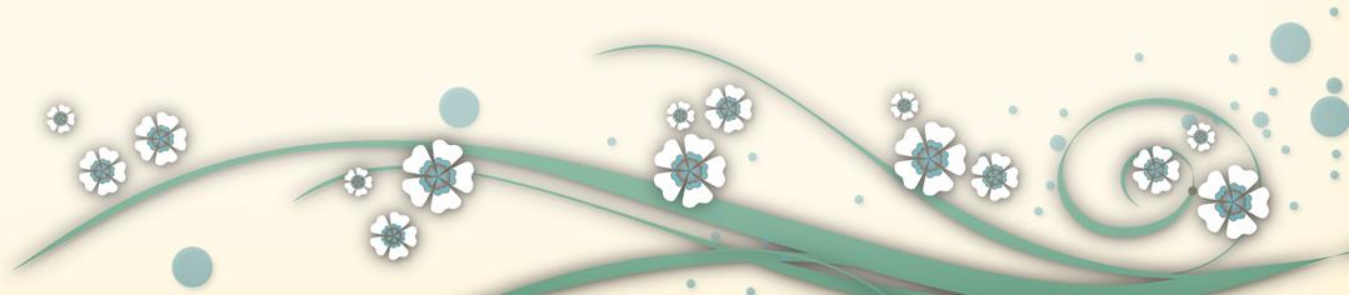
# Synthesis of Expert Opinions

- Although there are no formal criteria used to prognosticate the last 6 months of life in a person with FTD, clinical experts agree that certain signs and symptoms may serve as “red flags” to signal a final decline towards death.
- The following slides identify the “red flags”.



# Severity of Dementia

- A consensus of expert opinions suggests severity of dementia is the greatest predictor of the final stage of life.
- At this stage, the person with FTD requires assistance with all activities of daily living (ADL).



# Chewing/ Swallowing Difficulties

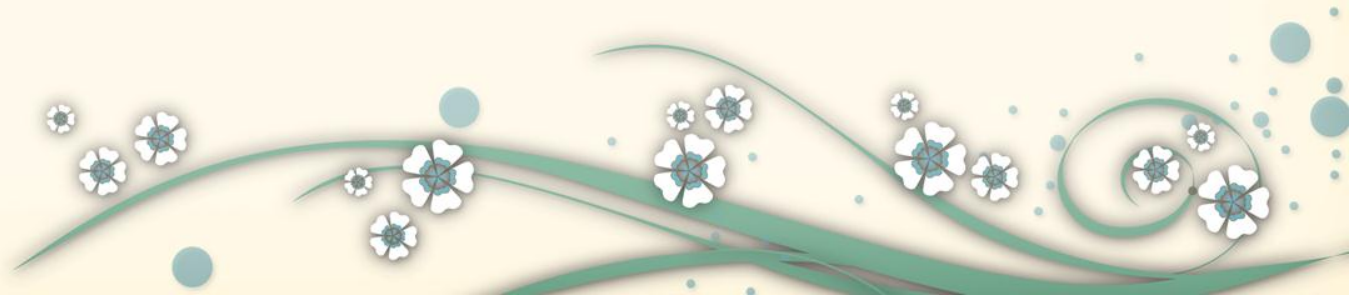
- Difficulties with effective swallowing (dysphagia)
- Changes in ability to chew
- Pooling of food or saliva in the mouth

May trigger more coughing / choking episodes & ultimately result in aspiration pneumonia.

# Incontinence

- Urinary incontinence and / or retention
- Bowel incontinence

These factors may lead to recurrent urinary tract infections (UTI) and ultimately sepsis (an infection throughout the body).



# Immobility

- Abulia (lack of initiative)
- Sedentary existence
- Bedfast patients

May increase the risk of death from complications related to blood clots

- Deep vein thrombosis (DVT)
- Pulmonary embolism (PE) (a blood clot that blocks a major blood vessel in the lung)



# Severe Language Impairments

- Dysarthria (difficulty in articulating) and Anarthria (loss of motor ability to produce speech)
- Aphasia (a partial or total inability to produce and understand speech due to neurological injury or disease)
- Spontaneous repetitive vocalizations were demonstrated in some persons with FTD approximately one year before death

# Significant Weight loss

- Difficulties with eating and swallowing
- Lack of desire to eat
- Abulia (lack of initiative)
- Apraxia (loss of the ability to perform activities that a person is physically able & willing to do)

May indicate significant disease progression and result in progressive weight loss and wasting.

# Falls

- Muscle weakness
- Gait instability
- Impulsivity
- Lack of focus on one's surroundings

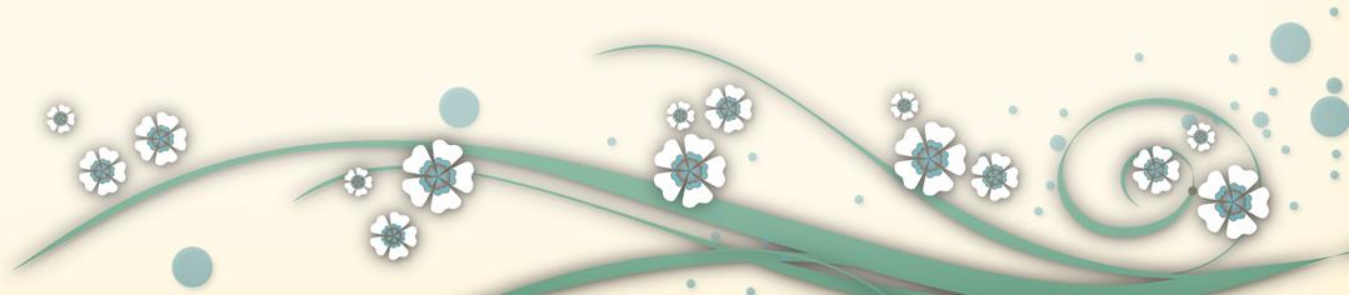
May result in increased risks for serious falls, fractures, and head injuries.

# Signs & Symptoms of Motor Neuron Disease

- Widespread fasciculations (involuntary muscle twitches)
- Muscle atrophy (a decrease in size or wasting)
- Muscle weakness
- Tremor
- Apraxia (loss of the ability to perform activities that a person is physically able and willing to do)
- Gait instability, frequent falls, loss of ambulation
- Flexion / extension contractures

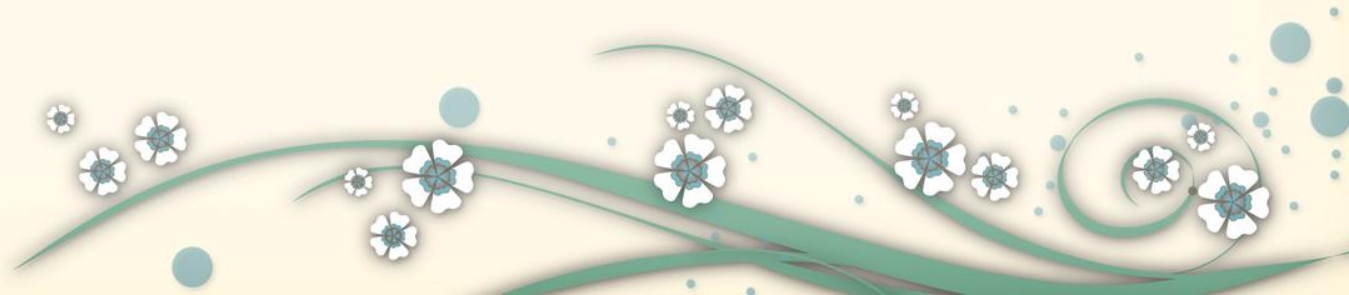
# FTD *and* ALS (Lou Gehrig's Disease)

- People with FTD *and* ALS usually decline more rapidly, with death resulting from ALS complications associated with swallowing difficulties (pneumonia) and respiratory weakness.



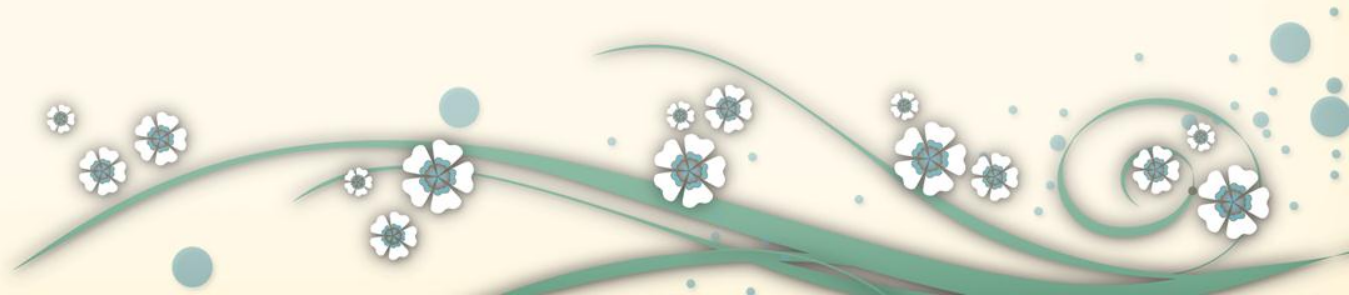
- Corticobasal degeneration (CBD) usually progresses slowly over 6 to 8 years. Death in CBD is generally caused by pneumonia, sepsis, or pulmonary embolism.
- Progressive Supranuclear Palsy (PSP) predisposes patients to serious complications from choking (pneumonia) and falls (head injury and fractures).
- Primary Progressive Non-fluent Aphasia end-of-life indicators typically involve swallowing difficulties and anarthria leading to high risk for developing aspiration pneumonia.

- Semantic Dementia typically progresses very slowly (8-10 years) and end-of-life is heralded by complications related to swallowing difficulties and a Parkinson-like immobility.
- Behavioral Variant (bvFTD) indicators include severe global cognitive and functional decline. Due to poor judgment and impulsivity, risk of accidental death may be higher than in other forms of dementia, and occur at relatively milder stages of impairment.



# Take Away Points

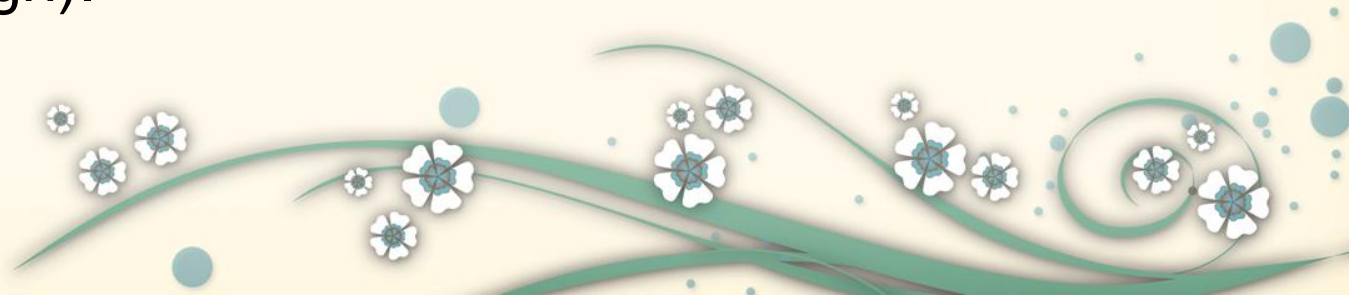
- Hospice criteria for dementia eligibility were created based upon the Alzheimer's model of disease progression, and pose significant challenges for persons with FTD in obtaining hospice services.





# Persons with FTD may not appear like Alzheimer's patients in their last 6 months of life

- Persons with FTD are generally younger, healthier, and typically do not have multiple co-existing chronic illnesses.
- Memory impairments may not be as severe in some forms of FTD, which may lead clinicians to misinterpret this fact as evidence that the patient is not in an advanced stage of the disease because they still “look good”.
- Persons with FTD may still ambulate (although the fall risk is very high).



# FTD Expert Consensus on Warning Signs

Use this information to help advocate for hospice services

- Severity of dementia
- Difficulties with swallowing
- Severe language impairments
- Immobility
- Incontinence & recurrent infections
- Frequent falls

# Remember...

You do not have to do this alone.

Hospice services have been shown beneficial for those with dementia & their loved ones.

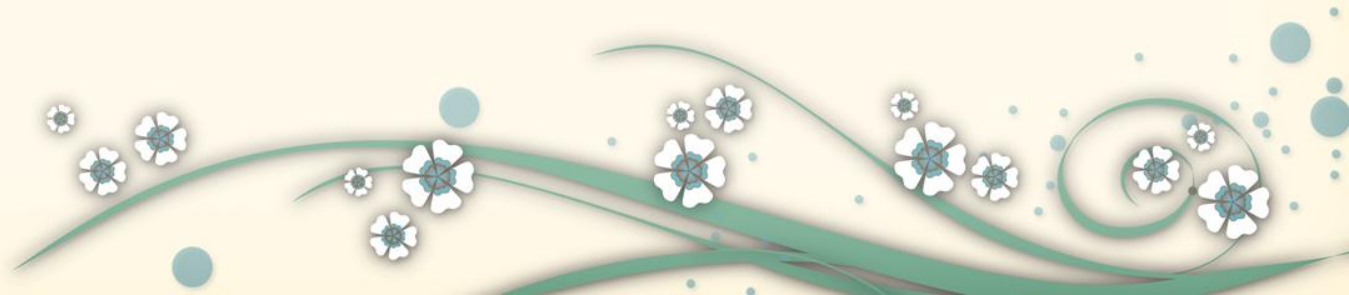
- Increase comfort, QOL and dignity
- Decrease hospitalization & use of unhelpful services

( Mitchell et al., 2007, Teno et al., 2011)

# Spread the Word

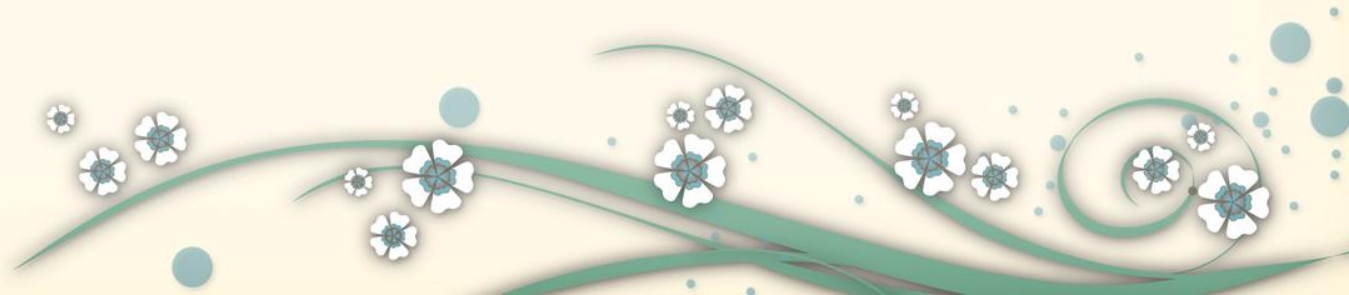
FTD caregivers and clinicians must assume the leadership role for educating health care and hospice providers on signs and symptoms associated with end-of-life in persons with FTD in order to establish easier access to palliative and hospice supportive services for patients and their families.

# Feedback from families of patients with FTD who received hospice care...

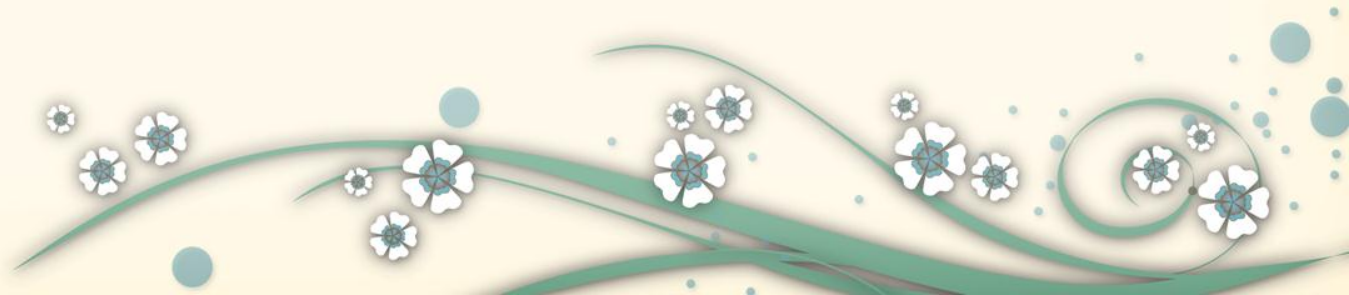


“One thing I was most impressed with was somebody from Hospice would come, and they would say, “You know, we need to get him a ‘whatever’ . The next day it was there! That was unbelievable. When I was doing stuff on my own I was very frustrated with how long things took and getting to the right people. Hospice seemed to be able to get things...you had the right phone numbers and you knew what to call and who to call. The next day the equipment would be there. That was terrific. Hospice always had a smile. Everybody that helped him always approached him with a smile.”

“The night my husband died, during the day Hospice said to me... “We’ re going to move his bed into the middle of the room.” They wanted the family to be able to gather around the bed. Sure enough, when the time came all of us were around that bed, on all four sides. They were right.”



“Hospice knew what I needed obviously before I knew I needed it. They were able to supply the help for my husband that I couldn't do. Hard as I tried, I couldn't do ten percent of what they knew he needed. Things for the wheelchair, things for the bed, to shower him, and people to shower him. Hospice did for my husband a great job. I can't imagine what that last six months would have been like without Hospice. They were a resource that is a one-of-a-kind.”





“What does hospice mean to me? It has meant my sanity. My husband’s illness is following a long, slow, downward spiral. The doctors would no longer treat him and so to speak “sent him home”, and I was at my wits' end trying to decide what to do. When we began hospice care, it gave me a much needed “sense of control”. Knowing I would receive continuous visits, caring and professional advice and emotional support has removed such an enormous level of stress – more than I realized I was experiencing.” (continued on next slide)

(Continued from previous slide)

“The hospice professionals that care for my husband are wonderful. They are his main social contact with the outside world and are always upbeat, smiling, and take the time to talk directly to him. The hospice volunteers we have used have also been more than helpful and positive. Hospice care has made all the difference in our life. I don't know how I would have been able to handle everything without this dedicated team. Thank you!!!”

“Hospice means I am not in this journey of dementia all by myself. As a full time caregiver with no family or outside help it can feel daunting at times. The unknown is scary and the staff at hospice has been through all this many times. Our hospice nurse gives me tons of info and things to think about. I know I have caring people to bounce off my ideas, thoughts and fears. If I start to have doubts about my abilities, they come up with solutions to get us by till the next change. Hospice can not save our loved ones from going through FTD, but they can save the caregiver from going down with them.”

“It is the ability to fulfill our wishes to keep him at home where he wants to be...enjoying the little things that he can still do as the phases of dementia pass. Keeping him safe at all times and knowing that help is truly just a phone call away. I don't think I worry near as much as I used to when I had no one to lean on. I am not sure I could get through this on my own.”

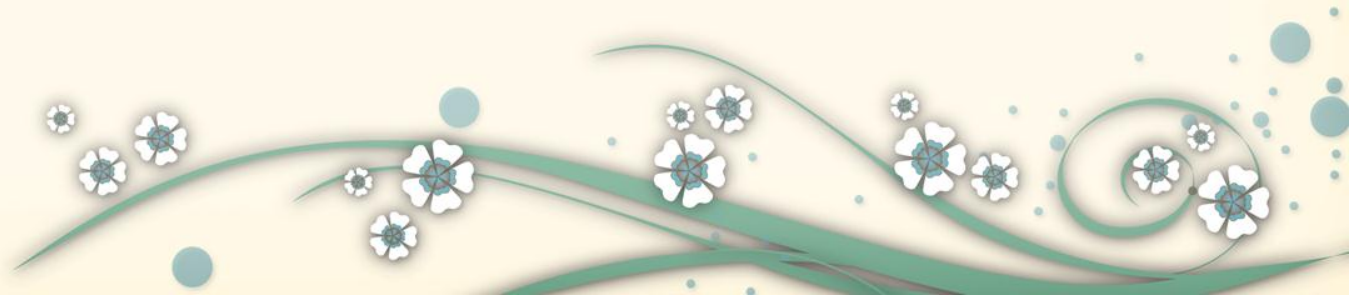
“At home hospice has just made the journey easier. Staff that cares and is there if you need them night or day. Social workers to help find tools that make caregiving in the home safer and more manageable. Supplies to help our loved ones stay clean and healthy. Nurses that are on top of his healthcare every week, ready at a moments notice to get the medicine we need without carting him off to doctors offices or long visits in the ER. Hospice staff helps me stay strong to do the job I need to do for him.”

# Our Goal

To ensure that all persons with FTD and their families receive the same expert end-of-life care afforded those with more common forms of dementia such as Alzheimer's disease.

# Thank You.

- We hope you have found this information to be of value.
- We invite you to share your own observations and experiences regarding FTD and end-of-life care.



# Hospice of the Valley Dementia Program

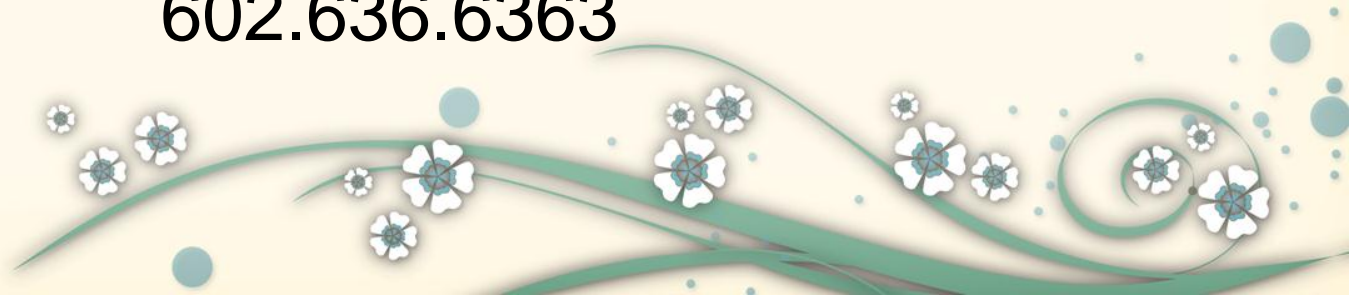
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# Resources

- Center for the Advancement of Palliative Care  
[www.capc.org](http://www.capc.org)
- Hospice and Palliative Nurse Association  
[www.hpna.org](http://www.hpna.org)
- National Consensus Project  
[www.nationalconsensusproject.org](http://www.nationalconsensusproject.org)
- American Academy of Hospice and Palliative Medicine  
[www.aahpm.org](http://www.aahpm.org)
- National Hospice and Palliative Care Organization  
[www.nhpco.org](http://www.nhpco.org)

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