



Comfort Care, Hospice and End-of-life Considerations

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Goals

- Provide an overview of hospice and comfort care principles for end-of-life.
- Review benefits hospice care and explore specific considerations for people living with FTD.
- Dispel common myths about hospice



No disclosures or conflicts of interest



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“If I have seen further, it is by standing on the shoulders of giants.”

Isaac Newton



Remembering Dr. Geri Hall

Long-time friend of AFTD & mentor

We are forever grateful for your contributions to FTD care that continue to ripple far and wide.



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“Cure sometimes, treat often, **comfort always.**”



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Progression over Time

FTD symptoms can progress in unpredictable ways and at unpredictable rates.

Mild	Moderate	Advanced	End of Life
		Profound continuation of previous symptoms	Bedfast or chair-bound
		Incontinence	Very limited or no verbal language
		Eating /swallowing difficulties	Recurrent infections
		Impaired movement & balance skills	Swallowing difficulties

Regardless of the initial FTD diagnosis, the differences between the disorders blur over time, and in the final stages, the person requires total care.

Most adults report they would not want aggressive medical interventions if they had advanced dementia.

Most proxy decision-makers report that *comfort* is the primary goal of care for their person with advanced dementia.

And yet...



People with end-stage dementia have

- Fewer completed advance directives
- More distressing symptoms amenable to treatment
(pain, eating problems, neuropsychiatric symptoms, infections)
- More costly and burdensome interventions offering little to no clinical benefit
- More avoidable transitions of care
 - Almost 2X ED visits and hospitalizations
 - 4X hospital stays
- Higher mortality after hospitalizations

Benner et al, 2018; CAPC, 2019; Sampson et al, 2018



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The critical question

How do we bridge the gap between the care people say they want and what they actually receive?



Advance care planning – It's never too early

“Advance care planning is critical in the management of persons with advanced dementia, and *it is the strongest and most consistent modifiable factor* associated with avoiding unwanted and unnecessary treatments.”

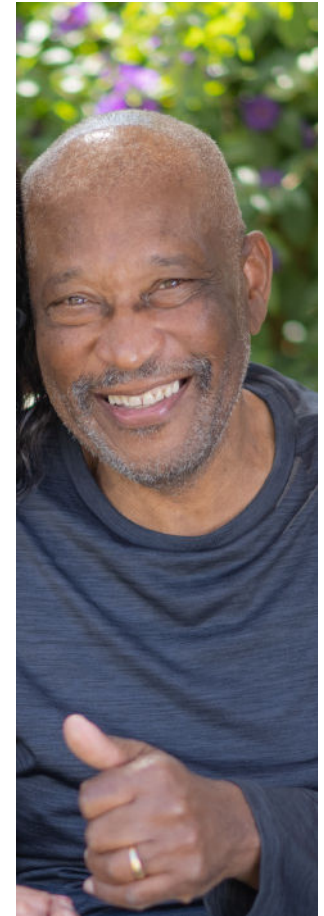
Mitchell, 2021

- **Advance care planning** involves discussing and preparing for future medical care decisions if you become seriously ill or unable to communicate your wishes.
 - It's a *process* rather than a single conversation
- **Advance directives** are legal documents expressing your medical care decisions that go into effect if you cannot communicate your own wishes.

nia.nih.gov

Meet Don

- Don was diagnosed with bvFTD at age 58 at a memory clinic.
- For the next 4 years, his wife Linda cared for Don in their home. As Don's symptoms worsened, he became increasingly dependent on Linda's help for his care needs & activities.
- When Linda developed health issues & could no longer care for Don in the home, he moved into a memory unit.
- Don's condition continued to decline over time in spite of the good care he received at the facility.



Don had signs of advance stage FTD

- Completely dependent on others for all his care
- Incontinent of bowel and bladder
- Increased difficulty swallowing w/ episodes of choking
- Eating less and losing weight
- Physically weaker
- Unstable gait & required assistance to stand or transfer
- Sleeping more
- Increased confusion
- Only spoke an occasional word & struggled to understand others
- In past year, Don had a UTI and a respiratory infection



What now?

Is it time to consider hospice care?

- Linda asked Don's physician to visit & perform a comprehensive evaluation to determine if there were any treatable conditions contributing to Don's decline
(e.g., dental problems, infections, negative reactions to medications & other common ailments Don couldn't self-report)
- The physician did not find any reversible conditions and concluded that Don's FTD had become very advanced
- She suggested Don and Linda would benefit from hospice care
- Linda agreed and Don was enrolled



What is Hospice Care?

- Care focused on the whole person with a serious illness that is approaching end of life (usually 6 months). Treatments focus on comfort rather than curative.
- Provided by specially-trained experts who focus on symptom management and quality of life
- Provided where the person resides
 - Hospice does not provide 24-hour direct caregiving services. It augments care currently being provided in a person's home or residential facility

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Palliative and Hospice Model

Hospice care is a *type* of palliative care focused on people *in the last 6 months of life* and their families.

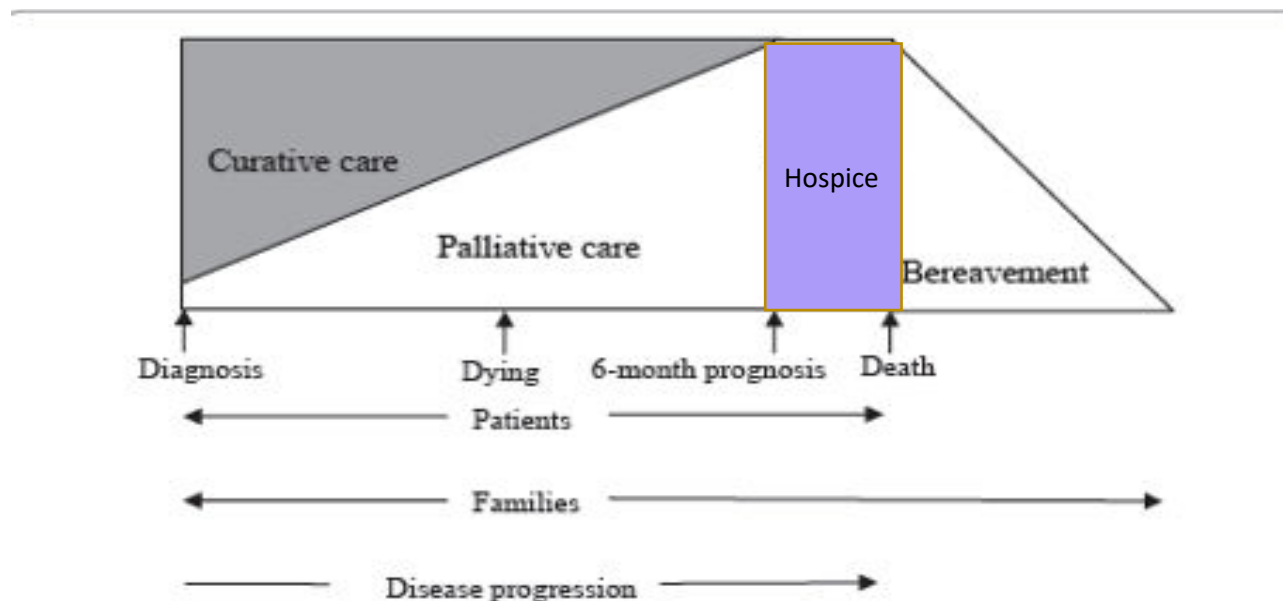
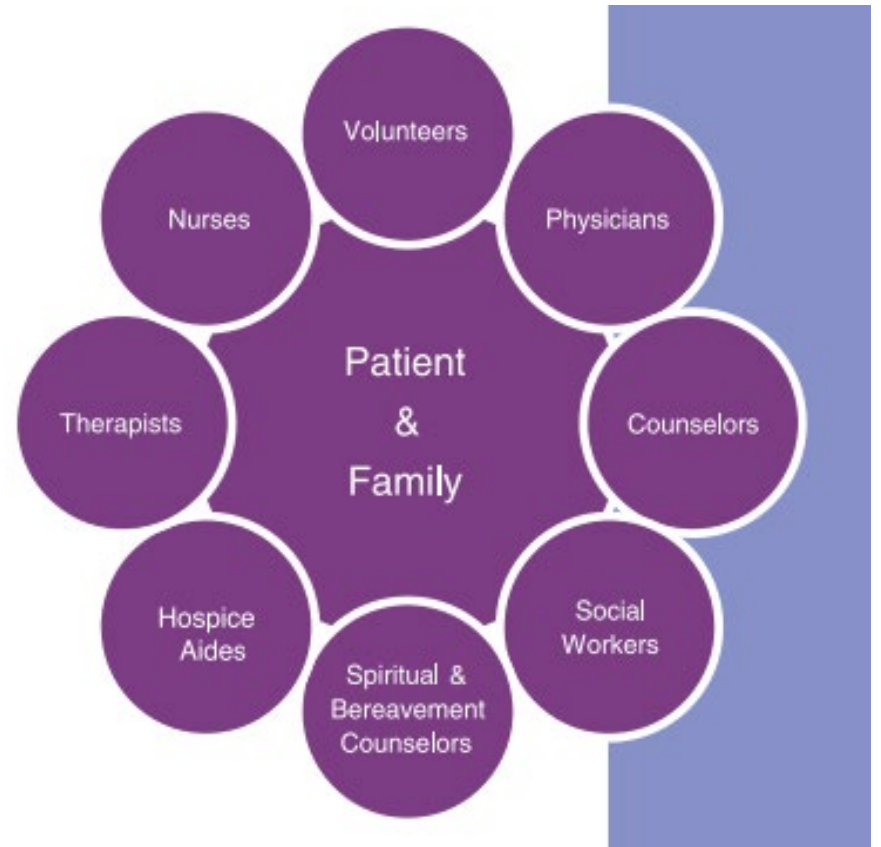


Figure 2: Model of palliative care in illness trajectory. Adapted from "the integrated model of care" proposed by World Health Organization (WHO), 1990 [58].

What does hospice provide?

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

- Interdisciplinary Team
- Medications
- Medical Equipment
- Supplies
- Respite
- Inpatient Units
- Volunteers
- Bereavement support



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When is it time for hospice?

- When the person meets eligibility criteria for the hospice diagnosis and a physician has provided a terminally ill diagnosis that anticipates a life expectancy of six months or less
- And when the person diagnosed or proxy–decision maker decides to elect the hospice benefit

You do not have to wait for the physician to initiate conversations about hospice. Let providers know that you want to discuss hospice in advance and be kept aware of when the time for hospice is approaching.



How much does hospice cost?

- Medicare, Medicaid and most private health insurances pay for hospice.
- Some hospice agencies provide needed care *regardless of one's ability to pay.*



“You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to *live* until you die.”

Dame Cicely Saunders, founder of the first modern hospice



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Best Practices in Dementia Comfort Care

- Provide decision-making education / support
 - Identify decision-maker & complete Advance Directives
- Educate & support all care partners
 - disease progression, common complications, causes of death
- Simplify medications & avoid unnecessary interventions (tests, tubes, needles...)
- Maximize comfort w/ effective symptom management
- Liberalize care plans– person-directed care – and customize sensory/spiritual experiences (e.g, food as pleasure / comfort)

CAPC, 2019; Mitchell, 2021

Clarifying Goals of Care - Advance Directives

Don appointed Linda as his Medical Power of Attorney (MPOA) and Mental Health Power of Attorney (MHPOA) soon after his FTD diagnosis.

The hospice team reviewed with Linda the details and *realistic* outcomes associated with the following choices:

- Resuscitation
- Hospitalizations
- Antibiotics
- Feeding tubes
- Falls with fracture: comfort care vs. surgery



Don's Advance Directives

Linda (MPOA) signed “Allow natural death” because she knew Don's wishes

- Don did not want resuscitation, hospitalizations, feeding tubes, antibiotics or any unnecessary interventions to prolong the terminal stage of FTD
- All care was to focus on maximizing comfort and optimizing quality of life.

We hold the key to the person's *quality of life*.



Customizing Care

There's a story behind every person

Don's hospice team & facility staff offered customized sensory and spiritual experiences to provide pleasure and celebrate Don as a whole person.

Dougherty et al, 2007



About Me[®]

This information will allow us to personalize care, bring comfort in its many forms, and honor what matters most to the individual. Please do not answer anything you feel would violate the person's privacy.

My name is: _____ I prefer to be called: _____

I was born and raised in: _____

Important people in my life are (include relationships): _____

My work in life includes (note military service): _____

My interests, hobbies and talents: _____

Spiritual and/or cultural preferences: _____

Favorite movies, TV shows, videos, books, photos: _____

Favorite types of music (include singing) and sounds (birds, water): _____

I like the smell of (flowers, perfume, spices): _____

Favorite foods and beverages: _____

Touch preferences or sensitivities (hands, feet, face): _____

Other things that make me happy (animals [type], children, sports [type], activities, stories): _____

Things I dislike or that upset me: _____

What comforts me most when I'm upset: _____

Vision and hearing abilities (hearing aids? glasses?): _____

Communication abilities (speech, gestures, writing): _____

Movement abilities (arms, legs, stand, walk, hand dexterity): _____

Personal care (bath or shower? AM or PM? Frequency? Oral care?): _____

Sleeping habits (wake, naps, bedtime, things that help sleep): _____

I like to be known for (e.g., personality traits, accomplishments, values, contributions, humor): _____

What matters most to me now is: _____

Patient Name _____ Patient ID _____

Pain in dementia

is often under-recognized and under-treated

- Increased risk for pain:
More prone to falls, accidents, injury
Inability to express pain/needs
- Commonly causes distressed behaviors, increased confusion, reduced function & QOL
- Be aware of the “NO” response.
- Teach PAINAD so all can observe for indicators of discomfort
- Scheduled vs prn analgesics

Pain Assessment In Advanced Dementia (PAINAD) Scale

	0	1	2	Score
Breathing Independent of Vocalization	Normal	Occasional labored breathing, short period of hyperventilation	Noisy labored breathing, long period of hyperventilation, Cheyne-Stokes respirations	
Negative Vocalization	None	Occasional moan or groan, low level of speech with a negative or disapproving quality	Repeated troubled calling out, loud moaning or groaning, crying	
Facial Expression	Smiling or inexpressive	Sad, frightened, frown	Facial grimacing	
Body Language	Relaxed	Tense, distressed pacing, fidgeting	Rigid, fists clenched, knees pulled up, pulling or pushing away, striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
			Total	

A score of 4 or greater should be reported to the RN for pain intervention.

Source: Warden V, Hurley A C, Volker L. (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale. *Journal of the American Medical Directors Association*, 4, 9-15.

<http://dementiapathways.ie/filecache/04a/ddd/98-painad.pdf> or <https://geriatricpain.org/painad>

Don's care plan was revised to honor his end-of-life wishes

- Medications were simplified to focus comfort
- Diet & routine liberalized - offered favorite snacks without pressure to accept
- Closely monitored for possible causes of distress
- Needs anticipated
- Offered opportunities for pleasure & meaningful engagement when awake
- Knowledge, skills and support were tailored to fit the needs of Don's family and facility caregivers



Examples

Hospice team approach for Don, Linda and facility

Education for Linda & facility on what to look for/ expect as Don declined

Frequent check-in communications & emotional support

24/7 collaboration on symptom management to maximize comfort

CNA visits for personal care using techniques to minimize distress

Team modeled approach /communication techniques for advanced dementia

Customized sensory & spiritual experiences for meaningful engagement

FTD caregiver support group & classes on ambiguous loss & mindfulness

Pet therapy volunteer

Chaplain provided spiritual support for Don & Linda

Supportive equipment (e.g., hospital bed) & supplies (e.g., incontinent briefs)



Most Common Causes of Death for Persons with Dementia

- Difficulties with eating and decreased nutrition
- Infectious episodes leading to sepsis
- Falls with fractures

Mitchell, 2021



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Synthesis of FTD experts' “red flags” that signal final decline

No formal criteria used to prognosticate the last 6 months of life in a person with FTD

The *severity* of dementia is the greatest predictor of the final stage of life.

- Requires total assistance for care
- Difficulties w/ swallowing, chewing and food pooling in mouth - can trigger coughing and choking episodes & increase risks for aspiration pneumonia
- Severe language impairment
- Immobility - poses risks of tissue breakdown & blood clots
- Incontinence of bowel & bladder - may lead to infections / sepsis
- Frequent falls - may lead to fractures and other serious injuries
- Significant weight loss and wasting
- Signs of motor neuron disease (e.g., ALS) causes more rapid decline

Don's final 6 months

- Napped more & slept longer
- Limited to being in bed or chair
- Stopped speaking
- Little interest in eating/drinking & lost more weight
- Had more coughing / choking episodes



Don's final days

Developed aspiration pneumonia

- Stopped eating / drinking, became non-responsive
- Hospice team offered 24/7 support and education to Linda & the facility during this emotionally difficult time
- They monitored Don very closely for any signs of distress in body, mind and spirit & treated as needed
- Don's room was peaceful so all could sense comfort & calm
 - Focused on individualized methods. Don's favorite music played, neroli aromatherapy infused the room, Linda gently stroked his hands. She moistened his lips when they seemed dry and softly expressed her love to Don.
- Don died comfortably with Linda at his bedside

Linda eventually participated in and benefited from 13 months bereavement support



Evidence-based outcomes

Benefits of Hospice Dementia Care

- Lower rates of restraints, feeding tubes, hospitalizations
- More effective symptom management
- Interdisciplinary support for patients and families
- 13 months of bereavement counseling
- Respite care
- Dying in place of choice
- Families perceived higher quality of care and dying
- Lower healthcare costs

CAPC, 2019; Harrison et al, 2022



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Hospice Eligibility Criteria 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 infections
 - Septicemia (serious blood infection)
 - Recurring fever after antibiotics
 - Pressure ulcers (bed sores)

<https://cms.gov>



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Special considerations

Barriers to Hospice Admission for Persons with FTD

- Many don't understand FTD is a terminal condition
- Accurately predicting end of life for a person with any type of dementia is difficult , but particularly FTD
- Hospice eligibility criteria were based upon the progression of Alzheimer's disease
- People with FTD generally do not match the established dementia criteria for hospice admission & still "look good"
 - Generally younger & more physically robust
 - Have fewer chronic illnesses, less severe memory impairments & may not look frail as they near end of life
 - May still walk



Use your voice

We must be fierce advocates for educating all who participate in health care to recognize signs of late-stage FTD so persons with FTD and their families have easier and more timely access to all the benefits of hospice services.

And advocate for FTD to be stated on the death certificate to improve data tracking and raise awareness

Spread the word...

Considerations for Choosing a Hospice for Persons with FTD

Do they have experience serving persons w/ FTD and their families?
What have they learned?

How do they determine eligibility for a person with FTD?

Is hospice staff available 24/7, including weekends & holidays?
How long does it take to respond to emergencies after hours?

Ask about specific services they will provide

- How much care and what type of care will the person receive? What's the visit schedule?
- Will care differ if it's in the home or facility?
- Will they train families and facilities how to give hospice care and medications?
- Will they teach what to expect as person approaches death and how to maximize comfort?
- How will hospice coordinate/collaborate with family and staff?
- If disagreements arise, how will they be resolved?
- Can family still opt to use their primary provider?
- What grief and bereavement services do they provide and for how long?

What to expect after death?
If needed, how will they facilitate brain donation or autopsy?
Will FTD (or sub-type) be written as cause of death?

Ask about all costs, insurance coverages, and out-of-pocket expenses. (Clarify if it affects LTC insurance or other coverages.)



Common Misconceptions About Hospice

- All hospices are the same. They are all part of one organization.
- It's where you go to die.
- It's "giving up" or "doing nothing".
- It's only for the last hours or days of life.
- It's only for cancer.
- It's only for the elderly.
- You can't keep your own doctor if you enter hospice.
- Once the choice is made, there's no turning back.
- It's the doctor's responsibility to bring up hospice.
- Hospice professionals hasten death.



Voices of people living with dementia

Ideal end-of-life care



- Keep me comfortable
 - Recognize, evaluate and treat pain and other symptoms
- Uphold my dignity
- Facilitate self-determination and informed decision-making
 - Be frank regarding realistic outcomes for chronic illnesses and acute events
 - I want my family present to advocate for my wishes
- Provide staff skilled in palliative dementia care

100% of participants did not wish resuscitation or “heroic” measures



There's always more we can do.
Comfort always

You don't have to do this alone.

Thank you.



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For more information on FTD, neuropalliative care and hospice...

Neuropalliative Care

- Webinar - The Role of Neuropalliative Care in FTD (2020)
By Dr. Christina Vaughan
- Partners in FTD Care (Winter 2020)

Comfort Care & Hospice in Advanced FTD

- Webinar - Hospice Care: Maximizing Comfort and Enhancing Quality of Life (2011)
By Hospice of the Valley, Phoenix. AZ
- Partners in FTD Care (Fall 2016)

<https://www.theaftd.org>

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