LONG TERM CARE
SOCIAL WORKERS OF IOWA

FALL CONFERENCE
2024

Northcrest Community ~ Ames, Iowa
Friday, November 8, 2024

Hospice or Palliative Care??: Understanding the Unique Power of a Multidisciplinary Team

Dr. Tom Mouser, MD, Chief Medical Officer, EveryStep

Frontotemporal Degeneration (FTD): Misdiagnosed and Misunderstood

Deb Scharper, Ambassador/Support Grp Leader, AFTD National Volunteer Network

Medicare Update for Social Workers

Cynthia Letsch, JD, Attorney, Letsch Law Firm

Financial Elder Exploitation

Crystal Doig, Director of Lifelong Links, Aging Resources of Iowa

AGENDA

Friday, November 8, 2024

8:30 a.m.	Announcements
8:30 - 10:00 a.m.	*Hospice or Palliative Care – Dr. Tom Mouser*
10:00 - 10:15 a.m.	Break
10:15 - 11:15 a.m.	*Hospice or Palliative Care – Cont.~*
11:15 - 11:30 a.m.	Break
11:30 - 12:30 p.m.	*Frontotemporal Degeneration – Deb Scharper*
12:30 - 1:15 p.m.	Lunch
1:15 - 2:45 p.m.	*Medicare Update – Cynthia Letsch*
2:45 - 3:00 p.m.	Break
3:00 - 4:00 p.m.	*Financial Elder Exploitation – Crystal Doig*

This program complies with the Iowa Board of Social Worker Examiners Rules for Continuing Education, meeting 6.0 general continuing education contact hours.

Long Term Care Social Workers of Iowa *1040 Market Street, Carlisle, IA 50047* *director@ltcswi.com* *www.ltcswi.com*

LTCSWI FALL CONFERENCE 2024

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WORKSHOP GOALS AND OBJECTIVES

Hospice or Palliative Care

- Understand the similarities and differences between hospice and palliative care services
- Understand key roles of the social worker on hospice and palliative care teams
- Learn how the Medicare hospice benefit works and how it benefits patients
- Understand the power and potential behind non-hospice palliative care services
- Learn key communication techniques that help in productive advance care planning
- Understand how the IPOST can be used in advance care planning

Frontotemporal Degeneration (FTD)

- List how FTD differs from other types of dementia
- Identify the common signs and symptoms of FTD
- Describe how FTD impacts families
- Identify how families and healthcare professionals can learn about current FTD research
- Describe supportive resources provided by The Association for Frontotemporal Degeneration

Medicare Update

Participants will be informed of newly passed final rules and initiatives that the Center for Medicare and Medicaid Services have implemented and the effect that these rules may have on persons on Medicare, whether residing in a residential care center or receiving skilled care services. Additionally, participants will be informed of the current standard that is required as qualification for continued skilled care services and the appropriate language to provide the resident that informs the resident of denial or discontinuation of skilled care services, depending on the reasoning for which the services are being denied or discontinued.

Financial Elder Exploitation

Financial exploitation costs Iowans thousands of dollars each year. Hear about Iowa cases and how you can protect yourself and others from scams from strangers or exploitation from friends and family.

About Our Presenters...

Tom Mouser, MD. After completing residency in Internal Medicine at University of Iowa: Des Moines, Dr. Mouser went on to fellowship training at Stanford University in Hospice and Palliative Medicine. Since returning to Des Moines, he has worked as the Chief Medical Officer of EveryStep for the past 13 years. During his time at EveryStep, Dr Mouser has worked with countless patients and families to aid in complex care navigation, symptom management, and advance care planning to help realize their identified goals of care.

Deb Scharper joined AFTD's National Volunteer Network in 2015. Throughout her volunteer tenure, she's raised critical awareness by sharing her family's story in the media and staffing AFTD information tables at community events, has brought others affected by FTD together through Meet & Greets, and raises funds through her annual Crusade for the Cure golf tournament. She's also led a Mason City-based support group for the past seven years. Prior to joining the inaugural Ambassador team in 2019, Deb served as the Midwest Regional Coordinator, AFTD's former volunteer leadership position. As an Ambassador, Deb continues to raise awareness and educate others in Iowa, southern Minnesota, and Wisconsin's La Crosse region while being an advocate and caregiver for her loved one with FTD.

Cynthia Letsch, JD, practices primarily in the areas of elder law, estate planning, special needs planning, guardianship and conservatorship, and post death. She is admitted to practice in the states of Iowa, Nebraska, and Missouri, and the Federal Districts of Nebraska and Southern Iowa. She is a member of the elder law and probate sections of numerous bar associations and the National Academy of Elder Law Attorneys, a Certified Medicaid Planner, and is a frequent speaker on topics related to Medicaid planning.

Crystal Doig has over thirty years of experience serving and empowering people in various roles throughout her career. She holds a B.A. in social work from the University of Montana and is certified in Aging/Geriatrics from Boston University. Additionally, Crystal is a certified Information Referral Specialist in Aging and Disability and a certified Options Counselor. She has dedicated 18 years to Aging Resources, where she has held multiple roles such as Case Manager, Lead Case Manager, Family Caregiver Specialist, and Elder Rights Specialist/Advocate. Prior to her tenure at Aging Resources, Crystal served as a home care supervisor and volunteer/mentoring director in the field of disabilities and aging at the Napa/Solano County Area Agency on Aging. Crystal's wealth of experience and expertise make her an invaluable asset in her field.

EveryStep

Care & Support Services | Home Care | Hospice
Interpretation | Community Health | Grief & Loss Services

Hospice or Palliative Care? Understanding the unique power of a multidisciplinary approach

Tom Mouse Jr. MD
Chief Medical Officer
EveryStep

Case #1

- 68 y/o female with recurrent breast cancer metastatic to the lung. Tumor burden responding to chemo with very minimal systemic toxicity. Functionally doing well and at routine f/u for CT staging. CT shows decreased tumor burden but also shows incidental finding of small free air under the diaphragm. Patient is asymptomatic but admitted for further evaluation.

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Case #1

- Hospital Day #1
  - Colorectal surgical subspecialist consulted
    - Conservative approach recommended given asymptomatic presentation
    - Working diagnosis diverticular microperforation vs metastatic disease vs ulcer perforation
    - Broad spectrum antibiotics recommended
    - Patient made NPO

Case #1

- Hospital Day # 5
  - Pulmonology consulted
    - New dyspnea and hypoxia
    - Differential: atelectasis, vs chemo toxicity vs PE
  - Duplex shows bilateral DVT's
  - Greenfield filter placed
  - Started on anticoagulation

Case #1

- Hospital Day #12
  - Noted to have GI bleed
  - Anticoagulation stopped and reversed
  - Still NPO and showing protein calorie malnutrition

Case #1

- Hospital Day #23
  - Anticoagulation restarted
  - Patient feeling good
  - NPO and on TPN

Case #1

- Hospital Day # 24
  - Patient with heavy GI bleed
  - Bleeding scan shows bleed at splenic flexure
  - GI consult—not an endoscopy candidate
  - Octreotide drip started
  - Colorectal surgery re-consulted

Case #1

- Hospital Day #27
  - Surgery does not recommend exploratory laparotomy
  - Comfort care recommended
  - Patient desiring transfer to SNF on TPN

Case #1

- Hospital Day #28
  - No post acute facility will take patient on TPN
  - Patient and family adamant TPN must be continued despite good PO intake for 5 days
  - Patient intent on getting out of hospital
  - Oncology recommending hospice but patient wanting to get her affairs in order first
  - Patient no longer wanting rehab—just wants to be close to home to get affairs in order
  - No d/c plan viable with patient goals

Case #1

- Hospital Day #29
  - Phone call from colorectal surgery asking if I could help by palliative care consult.

Case #2

- 65 y/o male who presented to the hospital with ARF of unknown etiology and SIRS. Further evaluation showing sepsis syndrome secondary to UTI. Source of UTI felt to be secondary to obstructive uropathy from enlarged prostate. Transferred to ICU for treatment.

Case #2

- Hospital Day #4
  - Hemodynamically stable but ARF progressing
  - Nephrology consulted and diagnosed ATN
  - PSA checked and elevated
  - Oncology consulted

Case #2

- Hospital Day #5
    - Oncology consults and orders prostate biopsy
    - Nephrology initiates hemodialysis
    - Pulmonology continues aggressive supportive care and infection treatment

Case #2

- Hospital Day #7
    - Hemodialysis continues—renal function not improving
    - Biopsy returns consistent with prostate cancer
    - Staging studies ordered

Case #2

- Hospital Day #10
    - Oncology meets with patient with good news—very treatable and localized cancer with prognosis of likely many years to live.
    - Pulmonology feels infection treated and talk of transfer to floor
    - Hemodialysis stopped early due to hemodynamic instability. Renal function worse
    - Nephrology with guarded prognosis

Case #2

- Hospital Day #12
  - Still on hemodialysis but patient and families spirits up due to good news from oncology. Looking forward to oncology clinic f/u once discharged from hospital.

Case #2

- Hospital Day #13
  - Nephrology tells patient he is not tolerating hemodialysis
  - CVVHD attempted

Case #2

- Hospital Day #14
  - Hospice consulted due to terminal prognosis
  - Patient elects for hospice with transfer to inpatient hospice house.

Case #2

- Hospice Day #1
  - Patient and family angry and distressed over hospice transfer and wanting to with hospice medical director about what is going on.

Your Preference?

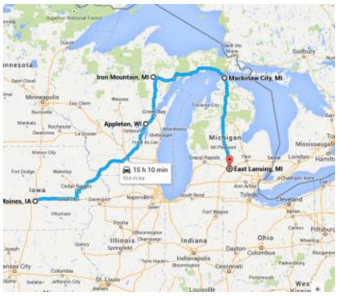
Your Preference?

Your Preference?

Your Preference?

Your Preference?

Scenic = 15 Hours



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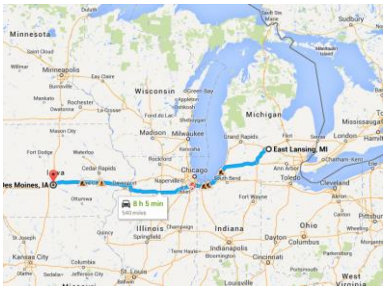
Not So Scenic = 8 Hours



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…If I only would have known…

Preferences – (Context+Values)=

Regret

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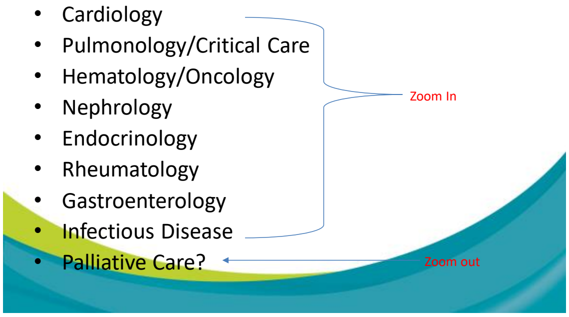
Subspecialist?

- Definition:
  - A doctor with a narrow area of expertise in a specialized area (www.medicarenewsgroup.com)
  - A person who devotes themselves to one subject or to one particular branch of a subject (www.dictionary.com)

Subspecialist?

- We often think about:
  - Focusing in—narrower focus
    - Organ based
    - Disease based
  - Area of unique expertise in a needed area of knowledge
  - Fund of knowledge the requires special training/skill

Subspecialist?



- Cardiology
- Pulmonology/Critical Care
- Hematology/Oncology
- Nephrology
- Endocrinology
- Rheumatology
- Gastroenterology
- Infectious Disease
- Palliative Care?

Subspecialist?

- Most subspecialties
  - How disease impacts a body system/organ
  - Focus on treatment of organ dysfunction
- Palliative Care
  - How all comorbidities affect the patient
  - Focus on burdens of disease
  - Focus on patient understanding/empowerment
  - Focus on shared decision making
  - Focus on patient and family understanding

Palliative Care?

- Focus on improving quality of life through
  - Relieving suffering from symptoms
  - Facilitating understanding of ones illness
  - Helping navigate complex medical decisions
  - Identifying ones goals of care and pairing with treatment choices
  - Coordinating care across healthcare settings
  - Identifying and treating psychosocial and spiritual suffering as well as physical suffering
  - Focus on patient and family

Palliative Care Expertise

- Well trained in how to facilitate and navigate complex discussions with patients and families
- Advanced training in pharmacology and treatment of physical suffering
  - Pain
  - Nausea/vomiting
  - Delirium
  - Dyspnea
  - Insomnia
  - Anxiety/Depression

A Case for Palliative Care

- 2000 IOM reports US healthcare is often poor quality, low value, fragmented and often results in harm.
- Much fragmentation within and outside health systems
  - EHR's don't synch
  - Numerous subspecialists and physicians across various settings of care for every patient
  - Post acute care facilities are disconnected from acute facilities
  - Reimbursement tied to high volume not high quality

A Case for Palliative Care

- Numerous studies have shown patients and families suffering from serious illness experience:
  - Inadequate symptom treatment
  - Unmet psychosocial needs
  - Fragmented care
  - Poor communication regarding illness and treatment choices
  - Escalating financial costs

Bharadwaj et al

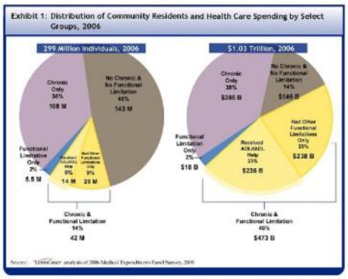
A Case for Palliative Care

- In 2025 it is projected that healthcare costs will account for 20% of GDP in US
- Roughly 5% of patients account for 2/3 of US healthcare costs
- Only half of the sickest 5% are near end of life
- The sickest 5% are comprised of those with multiple chronic conditions and functional impairment

(Teno et al.)

A Case for Palliative Care

Exhibit 1: Distribution of Community Residents and Health Care Spending by Select Groups, 2006

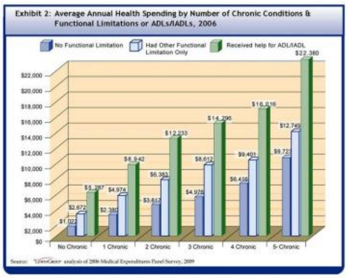


Source: "LewinGroup" analysis of 2006 Medical Expenditures Panel Survey, 2009

National Academies of Sciences Engineering, and Medicine

A Case for Palliative Care

Exhibit 2: Average Annual Health Spending by Number of Chronic Conditions & Functional Limitations or ADLs/IADLs, 2006

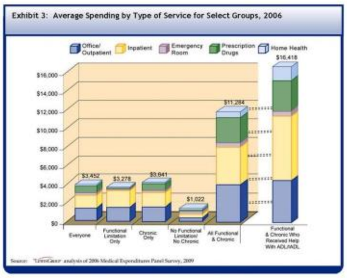


Source: "LewinGroup" analysis of 2006 Medical Expenditures Panel Survey, 2009

National Academies of Sciences Engineering, and Medicine

A Case for Palliative Care

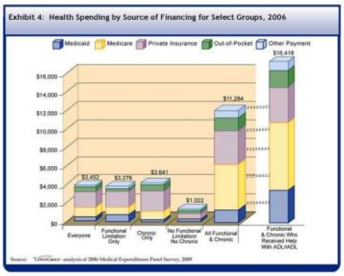
Exhibit 3: Average Spending by Type of Service for Select Groups, 2006



Source: "LewinGroup" analysis of 2006 Medical Expenditures Panel Survey, 2009

National Academies of Sciences Engineering, and Medicine

A Case for Palliative Care



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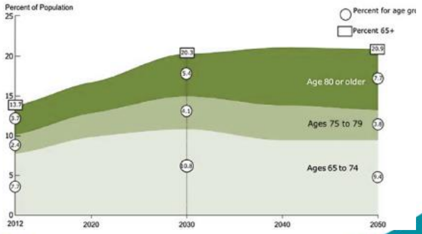

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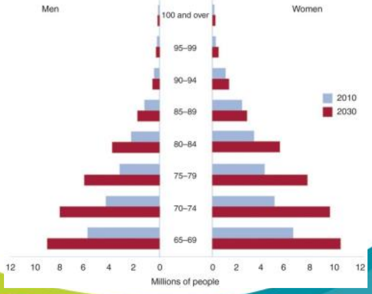
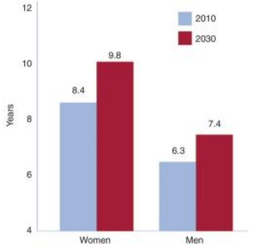


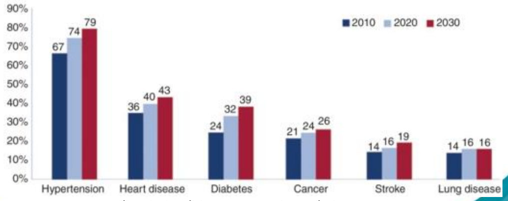
Gaudette et al. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4845680/



Medicare Beneficiary Expected Years of Life with a Disability at Age 65, 2010 and 2030.

Gaudette et al. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4845680/

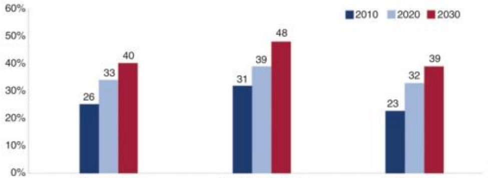
A Case for Palliative Care



Chronic Conditions among US Population Aged 65 and Older, 2010–2030.

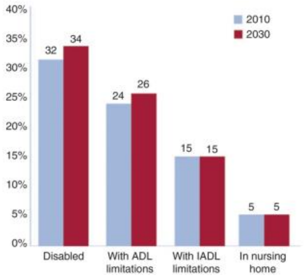
Gaudette et al. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4845680/

A Case for Palliative Care



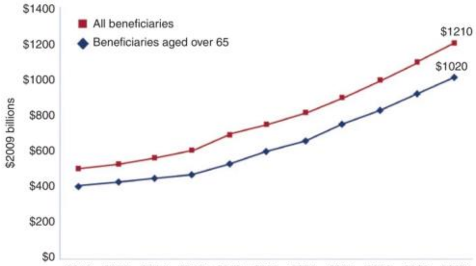
Chronic Conditions, by Race and Ethnicity, 2010–2030.

Gaudette et al. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4845680/



Functional Status of U.S. Population Aged 65 and Older, 2010 and 2030.

Gaudette et al. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4845680/



Gaudette et al. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4845680/

Family Impact

- In 2011 17.7 million individuals were caregivers to older adults
  - Only 15% provided care for <1 year
  - 70% provided care for 2-10 years
- Caregiving places major strain on finances and health of caregivers
  - Lost days at work/income
  - Anxiety/depression
  - Social isolation
  - Moral distress

(National Academies of Sciences Engineering, and Medicine)

Changing Caregiver Dynamics

- Caregiver workforce is shrinking/changing
  - More women in the workforce
  - Fewer children/small extended families
  - Increased diversity of caregivers
  - Families live further apart
  - Older age spouse as caregiver pushes more on children

(National Academies of Sciences Engineering, and Medicine)

Palliative Care

- End of Life Discussions
  - Associated with less aggressive medical care
    - Less ventilation
    - Lower ICU admissions
    - Increased hospice length of stay
      - Associated with better QOL
- Improved patient QOL
  - Associated with better QOL for caregiver post mortem
  - Associated with less depression in caregiver post mortem

(Wright et al.)

Early Palliative Care

- In patients diagnosed with non-small cell lung cancer (Temel et al.)
  - Better quality of life
  - Less depression
  - Less aggressive end of life care
  - Lived 2.8 months longer

Early Palliative Care

- In newly diagnosed lung cancer and GI malignancy (El-Jawahri et al.)
  - Decreased caregiver distress
  - Decreased caregiver depression

Palliative Care

- Reduced hospital costs for Medicaid
  - On average $6900 less per admission
    - $4098 savings per live discharge
    - $7563 savings per patient who died prior to discharge
  - Spent less time in the ICU
  - Less likely to die in the ICU
  - Estimates of up to $84-$252 million dollars savings possible if extrapolated to all hospitals in New York

(Morrison et al. 2010)

Palliative Care

- Associated with reduction in direct hospital cost
  - Approximately $1700 per admission ($174/day) per live discharge
  - Approximately $5000 per admission ($374/day) per patient who died

(Morrison et al. 2008)

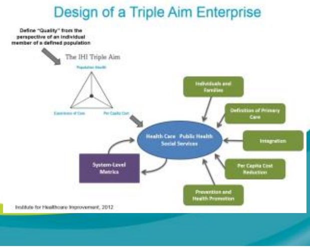
Early Palliative Care

- Facilitate significant hospital cost avoidance
  - Shorter length of stay (5.08 days)
  - Reduced Cost ($2362/day)
  - Decreased mortality
  - Decreased readmissions at 30, 60 and 90 days
  - Increased hospice referrals
  - Decreased ICU days
  - Cost avoidance on average of 1.5 times the cost of the Palliative Care Program

(Bharadwaj et al.)

Palliative Care

- Achieves the Triple Aim
  - Improving patient experience/satisfaction
  - Improving population health
  - Reducing Cost



Institute for Healthcare Improvement, 2012

State of Palliative Care

- 2014 WHO calls access to palliative care a human right but…
  - In US to date very difficult to access outside of large medical centers
  - Most healthcare providers lack training
    - Pain and symptom management
    - Communication techniques
    - Care coordination
  - Most of public are unaware
    - Only 8% of Americans report being knowledgeable about palliative care (Meier et al.)

State of Palliative Care

- Most healthcare providers have misconceptions
  - Feel it is end of life care/comfort care
  - Are not aware of the benefits
  - Feel it is redundant to what they already do
- Workforce shortages in tertiary providers
  - Fellowship programs need more federal funding
    - Only 141 programs with limited positions
    - In 2010 estimates of 6000-18000 more physicians to meet needs of current programs in 2011(Lupu)
  - Shortages in nurses, social work and chaplaincy (Meier et al.)

State of Palliative Care

- Palliative care providers are stretched thin
  - Reimbursement limits numbers
  - Busy with highly complex cases
  - Need more training in primary palliative care of all providers
- Patients in home setting don't have access to sustainable home medical services/personal care
- More dollars need to be devoted to research
  - 0.2% of annual NIH budget supported palliative care research (Meier et al.)
- Need better accreditation and regulatory requirements

The Work Is Worth It!

- Quality of life is worth any amount of work or money!!

The Work Is Worth It!

"We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being."--Atul Gawande

"Our ultimate goal, after all, is not a good death but a good life to the very end." --Atul Gawande

History of Hospice

- 1948 - Dame Cicely Saunders begins work with terminally ill
- 1963 - Saunders lectures at Yale
- School of Nursing Dean, Florence Wald takes interest
- 1967 - Saunders founds first hospice, St Christophers Hospice in London
- 1969 - Elisabeth Kubler-Ross book, "On Death and Dying" becomes an international best seller
- 1974 - Wald helps found Connecticut Hospice

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History of Hospice

- 1978 - Hospice movement noted to be a viable concept for care
- 1979 - 26 hospices included in demonstration project
- 1982 - Congress makes provision to start Medicare Hospice Benefit
- 1984 - JCAHO initiates hospice accreditation
- 1986 - Congress makes hospice benefit permanent and gives 10% increase in reimbursement

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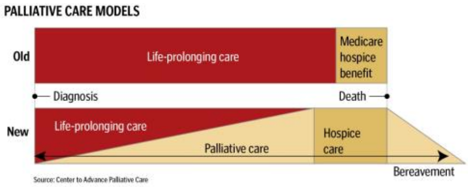
Focus of Hospice: *To amplify living for whatever amount of time one has to live*

- Patient-centered care plan
  - Built towards patient's "Goals of Care"
  - Aggressive/high tech care focused on QOL
  - Built towards evidence based management of all comorbidities
- Family is central to hospice focus of care during AND AFTER death
  - Study JAMA 2016 shows better family perceptions of care with hospice (Wright)
  - Hospice provides minimum of 12 months bereavement services after death

Focus of Hospice

- Work in interdisciplinary team
  - Hospice medical director, nurses, nurses aids, chaplains, social work, bereavement counselors, other healthcare professionals
  - By COP hospice must have 5% of total care provided by volunteers

The Continuum



Source: Center to Advance Palliative Care

Common Triggers for Referral

- Any patient with "Failure to Thrive"
  - BMI <20
  - 10% body weight loss in 6 months time
- Advanced Dementia
  - Chronic non-healing wounds
  - Recurrent serious infections
    - Sepsis
    - Pneumonia
  - Progressive weight loss
  - Large functional decline

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Common Triggers for Referral

- Any patient with advanced neurologic disease
  - Parkinson's
  - ALS
  - Acute CVA
  - Post CVA syndrome with progressive decline

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Hospice Benefit Design

- Covers all medical care
  - Care: Nursing, nurses aid, spiritual care counselor, **social worker**, hospice physician other healthcare professionals
  - All DME related to terminal illness's
  - All medications related to terminal illness's
  - Doctors visits related to terminal illness's
  - Any Medical procedures/studies related to terminal illness

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Hospice Benefit Design

- Certification/Benefit periods
  - 1st benefit period: 90 days
  - 2nd benefit period: 90 days
  - 3rd and subsequent benefit periods: 60 days each

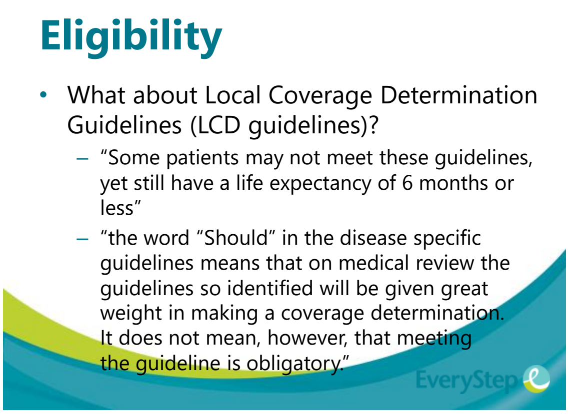
The Hospice Medical Director must agree recertification appropriate and must write recertification narrative.

Hospice Benefit Design:
Termination of hospice services

- Discharge for stability
  - Hospice alone to decide this
  - PCP input considered but only hospice can determine discharge for stability
- Discharge for cause

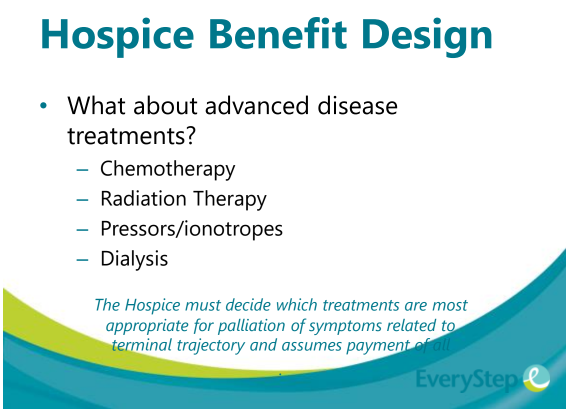
Hospice Benefit Design:
Termination of hospice services

- Revocation of benefit
  - **Patient decision to revoke**
    - Upon revocation Medicare A, B and D all reinstated immediately
    - Patient can re-elect benefit—if recertified--but restarts in next certification period



Eligibility

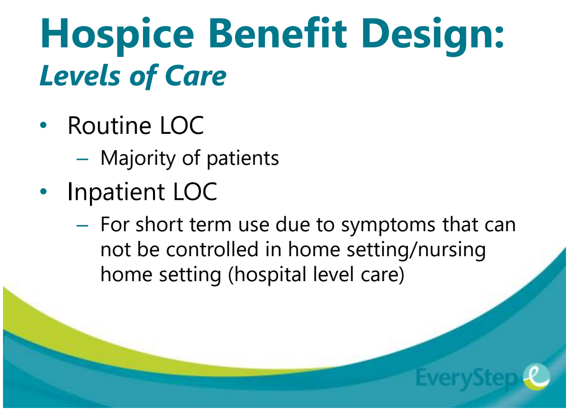
- What about Local Coverage Determination Guidelines (LCD guidelines)?
  - “Some patients may not meet these guidelines, yet still have a life expectancy of 6 months or less”
  - “the word “Should” in the disease specific guidelines means that on medical review the guidelines so identified will be given great weight in making a coverage determination. It does not mean, however, that meeting the guideline is obligatory.”



Hospice Benefit Design

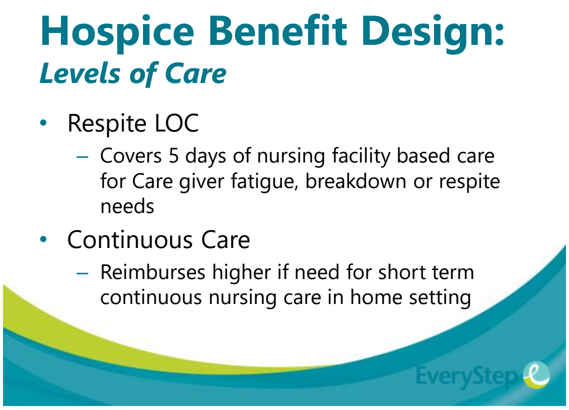
- What about advanced disease treatments?
  - Chemotherapy
  - Radiation Therapy
  - Pressors/ionotropes
  - Dialysis

The Hospice must decide which treatments are most appropriate for palliation of symptoms related to terminal trajectory and assumes payment of all



Hospice Benefit Design:
Levels of Care

- Routine LOC
  - Majority of patients
- Inpatient LOC
  - For short term use due to symptoms that can not be controlled in home setting/nursing home setting (hospital level care)

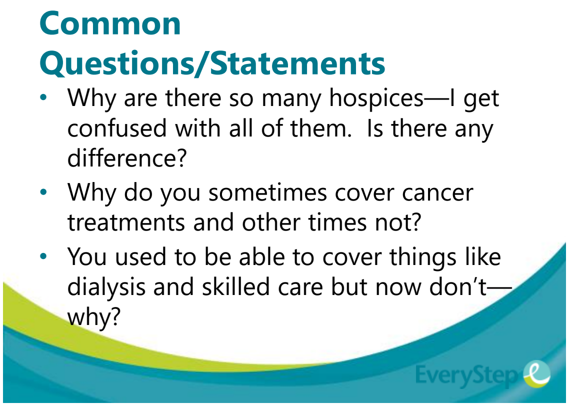


Hospice Benefit Design:

Levels of Care

- Respite LOC
  - Covers 5 days of nursing facility based care for Care giver fatigue, breakdown or respite needs
- Continuous Care
  - Reimburses higher if need for short term continuous nursing care in home setting

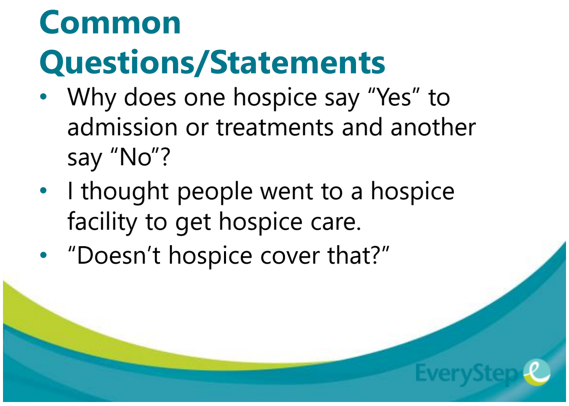
EveryStep



Common Questions/Statements

- Why are there so many hospices—I get confused with all of them. Is there any difference?
- Why do you sometimes cover cancer treatments and other times not?
- You used to be able to cover things like dialysis and skilled care but now don't—why?

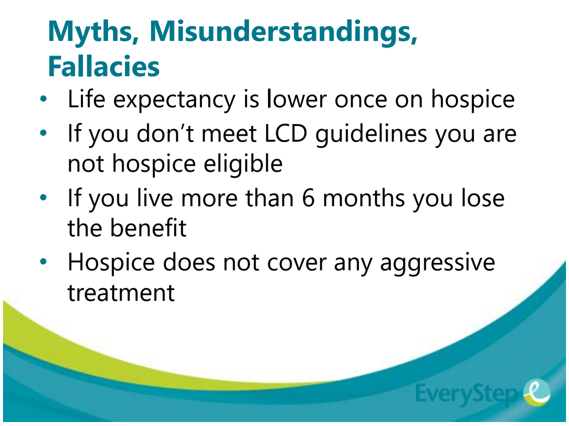
EveryStep



Common Questions/Statements

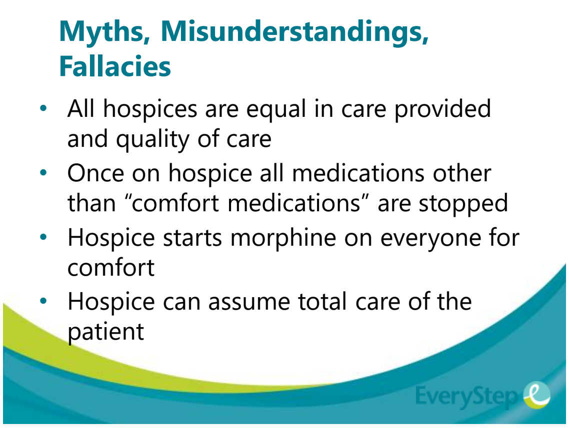
- Why does one hospice say "Yes" to admission or treatments and another say "No"?
- I thought people went to a hospice facility to get hospice care.
- "Doesn't hospice cover that?"

EveryStep



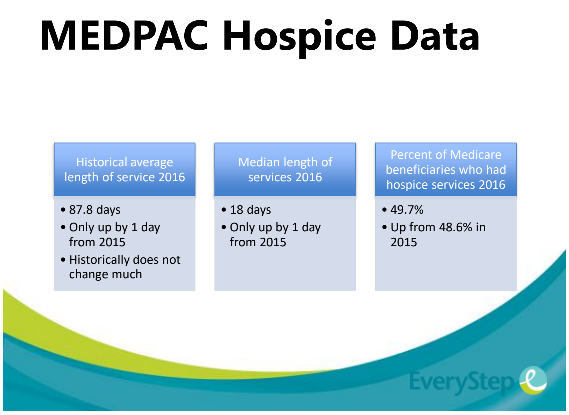
Myths, Misunderstandings, Fallacies

- Life expectancy is lower once on hospice
- If you don't meet LCD guidelines you are not hospice eligible
- If you live more than 6 months you lose the benefit
- Hospice does not cover any aggressive treatment



Myths, Misunderstandings, Fallacies

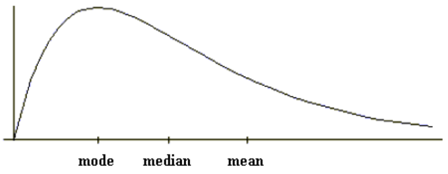
- All hospices are equal in care provided and quality of care
- Once on hospice all medications other than "comfort medications" are stopped
- Hospice starts morphine on everyone for comfort
- Hospice can assume total care of the patient



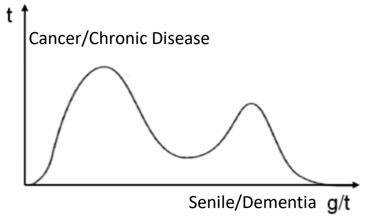
MEDPAC Hospice Data

Historical average length of service 2016	Median length of services 2016	Percent of Medicare beneficiaries who had hospice services 2016
• 87.8 days • Only up by 1 day from 2015 • Historically does not change much	• 18 days • Only up by 1 day from 2015	• 49.7% • Up from 48.6% in 2015

Skewed Distribution



Skewed Distribution



Bimodal Distribution

t

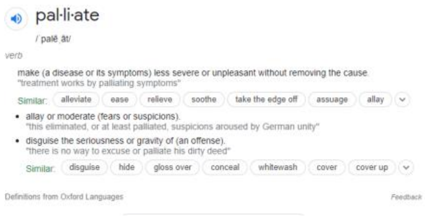
What Drives These Trends?

- Provider and system related issues
  - Care fragmentation
  - Fear of difficult conversations
  - Being too close to patient's/families to be objective
  - Failure to identify a terminal trajectory of decline
  - Hospices being too stingy and not understanding regulations/COP's
  - Failure to discuss goals and context of illness

What Drives These Trends?

- Patient and family related issues
  - Fear
    - That hospice and palliative care will take away options
    - That hospice and palliative care will shorten their life
    - That they have to leave there home and go to a hospice house
    - That they will loose their doctors
    - That they are choosing to stop medical care
  - Not informed
    - That they are near end of life
    - That Hospice can help them live better and many times live longer
    - That Hospice comes to them and creates an advanced evidence-based care plan that revolves around their goals
    - That their medical team and support will get bigger not smaller
    - That aggressive evidence based medical care is amplified
    - That options for better care grow and solutions for challenging gaps are found

Hospice/Palliative Care Scope



pal·li·ate

/ˈpalēˌāt/

verb

make (a disease or its symptoms) less severe or unpleasant without removing the cause.
"treatment works by palliating symptoms"

Similar: alleviate ease relieve soothe take the edge off assuage allay

- allay or moderate (fears or suspicions).
  "this eliminated, or at least palliated, suspicions aroused by German unity"
- disguise the seriousness or gravity of (an offense).
  "there is no way to excuse or palliate his dirty deed"

Similar: disguise hide gloss over conceal whitewash cover cover up

Definitions from Oxford Languages

Hospice/Palliative Care Scope

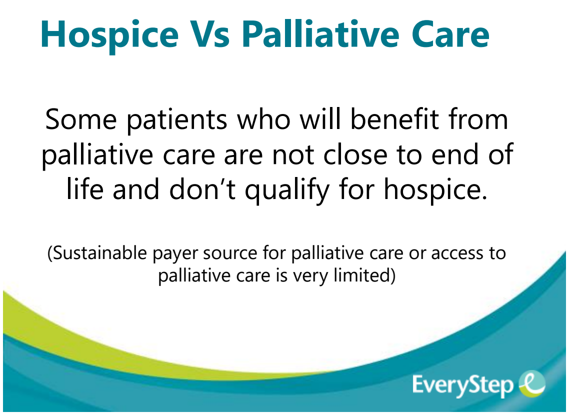
- Work in multidisciplinary teams
- Focus on…
  - Symptom relief
  - Relief of stress/burdens of illness
  - Improving QOL for patient and family
  - Patient and family NOT just the disease

Hospice and Palliative care

- When we encounter patients with serious illness they are often
  - Disenfranchised
  - Disengaged or disengaging
  - Feeling
    - Afraid
    - Alone
    - Hopeless
    - Helpless
    - Overlooked
    - Confused
    - Unheard
    - Abandoned
    - Angry

Hospice Vs Palliative Care

All patients with serious illness and chronic disease with high burdens of suffering benefit from palliative care services!



Hospice Vs Palliative Care

Some patients who will benefit from palliative care are not close to end of life and don’t qualify for hospice.

(Sustainable payer source for palliative care or access to palliative care is very limited)

Hospice Vs Palliative Care

All hospice patients receive palliative care services by the hospice team

(Hospice benefit=sustainable payer source for palliative care team for those with end stage/terminal disease)

Hospice Vs Palliative Care

Everyone who qualifies for the hospice benefit should be informed of the benefit and what it could provide for them.

Beyond Pain??

- Serious illness and chronic disease are like a tangled ball of yarn:

There is no easy path through,
and it takes patience,
persistence and
a team to unravel it all

Total Pain

- 5 domains of “Total Pain”
  - Physical
  - Material
  - Social
  - Emotional
  - Developmental

EveryStep

Case #1

56 y/o male with colon cancer who presents to the hospice house with refractory pain despite significant escalation of opioids in the home

- Taking over 1000 OME’s per day
- Estranged from family and has very little support system
- Pain reported as “Everywhere”
- Pain reports often not matching presentation
- Very high anxiety levels

EveryStep

Case #1

- Attempts made to up titrate opioids based on reporting using methadone and IV Dilaudid with dosing exceeding 10,000 OME per day.
- Extreme opioid tolerance caused concern and questions of prior substance abuse history

EveryStep

Case #1

- All concerns discussed at IDG meeting and social work aware of need to build relationship and trust

EveryStep

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Case #1

- Patient revealed he is estranged from his mother because he “hates her” due to her lifelong drug use problems.

EveryStep

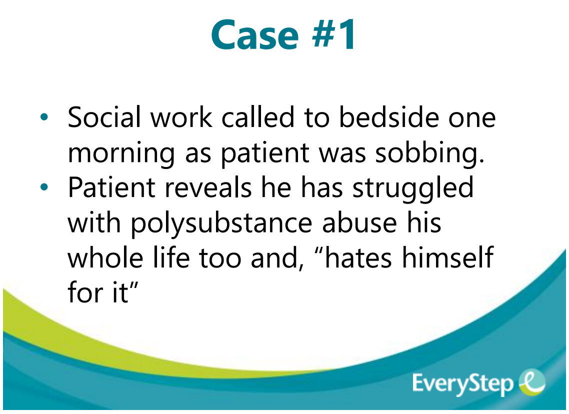
98

Case #1

- In subsequent days patient begins to discuss his own estrangement from his own children

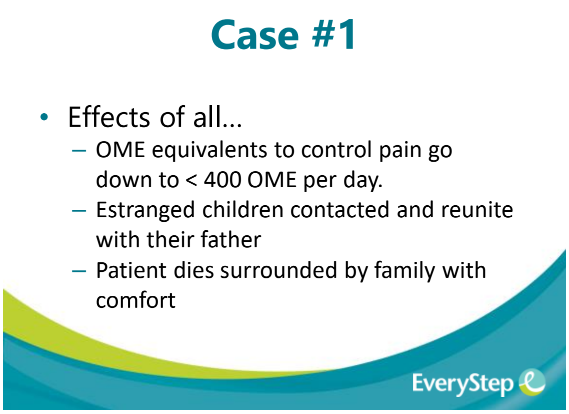
EveryStep

99



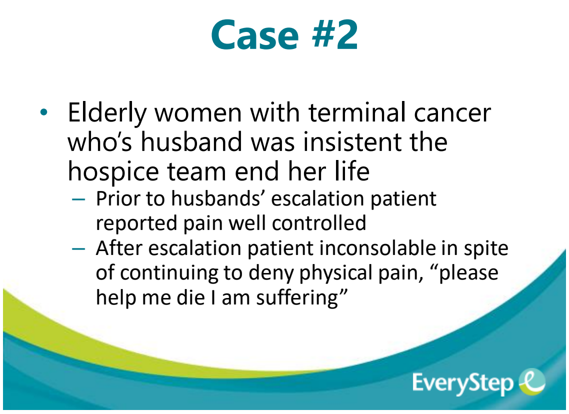
Case #1

- Social work called to bedside one morning as patient was sobbing.
- Patient reveals he has struggled with polysubstance abuse his whole life too and, “hates himself for it”



Case #1

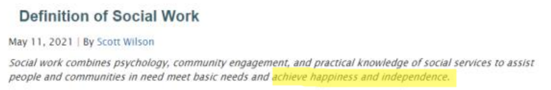
- Effects of all…
  - OME equivalents to control pain go down to < 400 OME per day.
  - Estranged children contacted and reunite with their father
  - Patient dies surrounded by family with comfort



Case #2

- Elderly women with terminal cancer who’s husband was insistent the hospice team end her life
  - Prior to husbands’ escalation patient reported pain well controlled
  - After escalation patient inconsolable in spite of continuing to deny physical pain, “please help me die I am suffering”

Role of a Social Worker



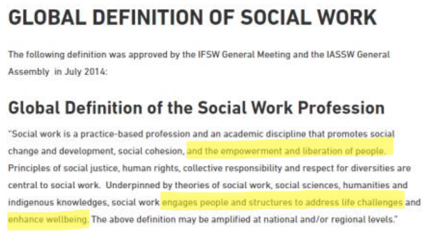
Definition of Social Work

May 11, 2021 | By Scott Wilson

Social work combines psychology, community engagement, and practical knowledge of social services to assist people and communities in need meet basic needs and achieve happiness and independence.

https://www.humanservicesedu.org/definition-social-work/

Role of a Social Worker



GLOBAL DEFINITION OF SOCIAL WORK

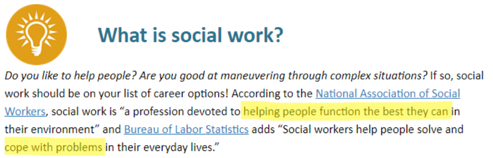
The following definition was approved by the IFSW General Meeting and the IASSW General Assembly in July 2014:

Global Definition of the Social Work Profession

"Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledges, social work engages people and structures to address life challenges and enhance wellbeing. The above definition may be amplified at national and/or regional levels."

https://www.ifsw.org/what-is-social-work/global-definition-of-social-work/

Role of a Social Worker



What is social work?

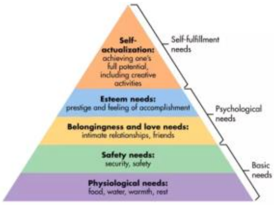
Do you like to help people? Are you good at maneuvering through complex situations? If so, social work should be on your list of career options! According to the National Association of Social Workers, social work is "a profession devoted to helping people function the best they can in their environment" and Bureau of Labor Statistics adds "Social workers help people solve and cope with problems in their everyday lives."

https://www.cswe.org/Students/Discover-Social-Work/What-is-social-work

Role of a Social Worker

- Summing up the job role
  - **Assist/help people**
    - Meet needs (basic and complex)
    - Achieve happiness
    - Solve problems
    - Cope with problems
  - **Empower people**
    - Toward independence
    - Functioning the best they can
  - **Engages with people**
    - Enhance wellbeing
    - Addresses life's challenges

Maslow's Hierarchy of Needs



https://www.simplypsychology.org/maslow.html

Case #3

- Elderly female who presents to PC clinic with extensive stage small cell lung cancer
  - Pain uncontrolled
  - Has severe fatigue
  - High anxiety
  - Expresses QOL very poor

Case #3

- All who know patient note she is likely to not follow through and/or return for f/u as has a "long history of non-compliance"

EveryStep

Case #3

- PC team social worker begins to dig into issues and barriers
  - Does not know how to use cell phone well
  - Does not have a car and walks to appt
  - Lives with a friend who has numerous children and is a concerning home situation

EveryStep

Case #3

- PC team social worker secures
  - An apartment
  - Transportation services
  - Meal services
  - Teaches how to use phone and programs in PC team numbers
  - Holds therapy sessions and has frequent follow-up by phone

EveryStep

Case #3

- Community pharmacist and PCP comment that patient seems like a “new person”
- Patient expresses joy and QOL is now expressed as really good!!

EveryStep

What hospice/PC social workers say

- Connecting with community resources
  - Respite placement support
  - Medicaid applications
  - DPOA and advanced directives
  - Life-line
  - Hired help
  - Veteran assistance and benefits
  - Financial resources
  - Legal resources

EveryStep

Case #4

- Young women with end stage Huntington’s disease.
  - High burden of suffering
    - Uncontrolled Chorea
    - Pain
    - Anxiety
    - Grief
    - Huge financial burdens

EveryStep

Case #4

- Team surrounding patient and family to meet needs
- Social work learns patient overlooked SSDI renewal and Iowa Medicaid renewal and was going to lose SSDI check and Medical insurance

EveryStep

What hospice social workers say

- Anticipatory grief services
  - Family readiness and understanding of what to expect
  - Exploration of goals
  - Education of how hospice can help achieve goals
  - End of life information and support

EveryStep

What hospice social workers say

- Addressing important needs
  - Fundamental needs
    - Food
    - Clothing
    - Utilities
    - Safe home environment/structural safety
    - Safe and sustainable caregiver setup/plan
  - Help with funeral planning/arrangements

EveryStep

Case #5

- 48 y/o female referred to PC clinic with numerous needs
  - Depression
  - Chronic pain
  - Frequently In ED (5 times in prior month)

EveryStep

Case #5

- PC team identifies
  - Almost histrionic presentation
  - Each clinic visit is overwhelmed by emotion and a litany of problems and odd stories/circumstances
  - Question undiagnosed intellectual disability

EveryStep

Case #5

- PC team identifies
  - Patient is going to lose apartment
  - Patient having significant problems with her mother
  - Patient has very challenged support system
  - Patient has very challenged coping strategies

EveryStep

Case #5

- PC social worker
  - Does home visit and helps coordinate clean up
  - Gets homecare involved with mother
  - Helps advocate for patient to landlord to secure apartment
  - Helps advocate for further mental health services

Case #5

- Result
  - Patient in safe housing helps stabilize emotionality
  - Psychiatric services help identify and treat diagnoses
  - PCP notes patient has not been to ED much and is coping better
  - Symptoms all endorsed as controlled and patient thriving

What hospice social workers say

- Addressing psychosocial needs/issues
  - Unfinished business
  - Family dynamics
    - Estranged relationships
    - Conflicts
    - Challenged relationships
    - Family communication and coping
  - Validating patients' life and accomplishments
  - Advocate for patient and family self determination
  - Provide emotional support
  - Assist with closure

Case #6

- 80 y/o male with End Stage Alzheimer's dementia who has serially declined over 1 year on hospice and was no longer showing interest in food and fluid
  - Wife and HCPOA noted numerous conversations historically with husband and knew he would not want artificial hydration and nutrition
  - Stepchildren upset and calling DHS indicating stepmom was abusing patient
  - DHS investigation unfounded but children continued to struggle and accuse and allegedly accost stepmother and allegedly force-feeding food and vitamins stepmom did not want patient to take.

EveryStep

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What hospice/PC social workers say

- Advocating for self-care in caregivers
  - Asking for and accepting help
  - Education on use of respite benefits
  - Assess willingness and ability to provide sustainable care

EveryStep

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Case #7

- 36 y/o patient with end stage ALS
  - Young family
  - Wife overwhelmed
  - Patient and wife not always in agreement
  - Wife trying to do too much with regards to caregiving and raising young children
  - Social work provided huge support and empowerment towards navigation to nursing home

EveryStep

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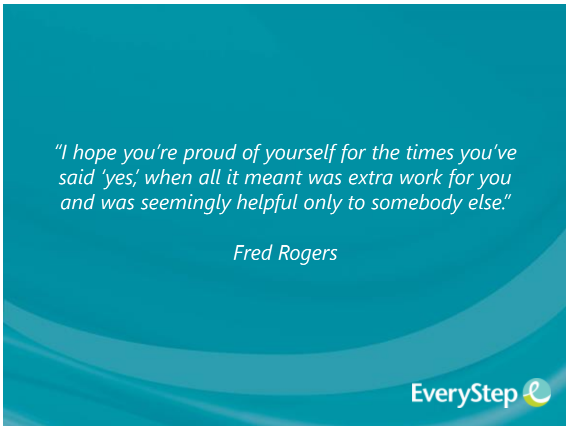
Working Together

PHOTO COURTESY DAIMLERCHRYSLER

https://auto.howstuffworks.com/car-engine-pictures.htm

EveryStep

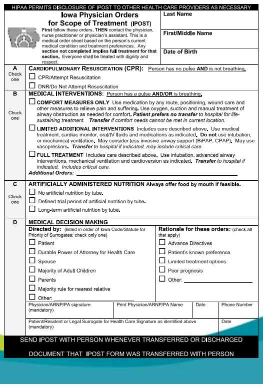


"I hope you're proud of yourself for the times you've said 'yes,' when all it meant was extra work for you and was seemingly helpful only to somebody else."

Fred Rogers

EveryStep

EveryStep



HIPAA PERMITS DISCLOSURE OF IPOST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Iowa Physician Orders for Scope of Treatment (IPOST)

First follow these orders, **THEN** contact the physician, nurse practitioner or physician's assistant. This is a medical order sheet based on the person's current medical condition and treatment preferences. Any **section not completed implies full treatment for that section.** Everyone shall be treated with dignity and respect.

Last Name

First/Middle Name

Date of Birth

A Check one — **CARDIOPULMONARY RESUSCITATION (CPR):** Person has no pulse **AND** is not breathing.

☐ CPR/Attempt Resuscitation

☐ DNR/Do Not Attempt Resuscitation

B Check one — **MEDICAL INTERVENTIONS:** Person has a pulse **AND/OR** is breathing.

☐ **COMFORT MEASURES ONLY** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. ***Patient prefers no transfer** to hospital for life-sustaining treatment.* ***Transfer** if comfort needs cannot be met in current location.*

☐ **LIMITED ADDITIONAL INTERVENTIONS** Includes care described above. Use medical treatment, cardiac monitor, oral/IV fluids and medications as indicated. **Do not** use intubation, or mechanical ventilation. May consider less invasive airway support (BiPAP, CPAP). May use vasopressors. ***Transfer** to hospital if indicated, may include critical care.*

☐ **FULL TREATMENT** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation and cardioversion as indicated. ***Transfer** to hospital if indicated. Includes critical care.*

Additional Orders: ______

C Check one — **ARTIFICIALLY ADMINISTERED NUTRITION Always offer food by mouth if feasible.**

☐ No artificial nutrition by tube.

☐ Defined trial period of artificial nutrition by tube.

☐ Long-term artificial nutrition by tube.

D — **MEDICAL DECISION MAKING**

Directed by: (listed in order of Iowa Code/Statute for Priority of Surrogates; check only one)

☐ Patient

☐ Durable Power of Attorney for Health Care

☐ Spouse

☐ Majority of Adult Children

☐ Parents

☐ Majority rule for nearest relative

☐ Other: ______

Rationale for these orders: (check all that apply)

☐ Advance Directives

☐ Patient's known preference

☐ Limited treatment options

☐ Poor prognosis

☐ Other: ______

Physician/ARNP/PA signature (mandatory)	Print Physician/ARNP/PA Name	Date	Phone Number
Patient/Resident or Legal Surrogate for Health Care Signature as identified above (mandatory)			Date

SEND IPOST WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

DOCUMENT THAT IPOST FORM WAS TRANSFERRED WITH PERSON

Preparing for the conversation

- Review records
- Talk to key players of healthcare team
- Prepare setting
- Eliminate distractions
- Identify key players
- Allow plenty of time

Tips for the conversation

- Introductions
- Establish goal/warning shot
- **Engage**
- Responding to the spoken and unspoken
- Use open ended questions
- **Avoid medical jargon**
- Clarify understanding

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Setting The Scene For Difficult Conversations

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Body Language

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Body Language

- Mary, given the serious nature of your illness I wanted to talk with you about your treatment preferences going forward.

Open ended vs Closed Questions

- Tell me what you understand about your illness
  - Vs…Do you understand what COPD is?
- Have you gotten the sense from your doctor what to expect going forward
  - Vs…Do you think you are going to get better?

Open ended Vs Closed questions

- Tell me what you understand about your illness?
  - Do you understand what COPD is?
- Do you think you are getting better or worse or about the same?
  - How do you think you are doing?
- Tell me what you most hope for, knowing your illness is not getting better?
  - What is it you want?
- Have you gotten a sense from your Doctor on what to expect going forward?
  - Do you think you are going to get better?

SPIKES or Ask/Tell/Ask

- **S**etup: Ensure surroundings appropriate
- **P**erception: Open ended questions to draw out patients perception
- **I**nvitation: What is patient comfortable knowing
- **K**nowledge: Share medical information
- **E**mpathy: Show empathy in responding to patient emotions
- **S**ummary: Check for understanding and discuss next steps

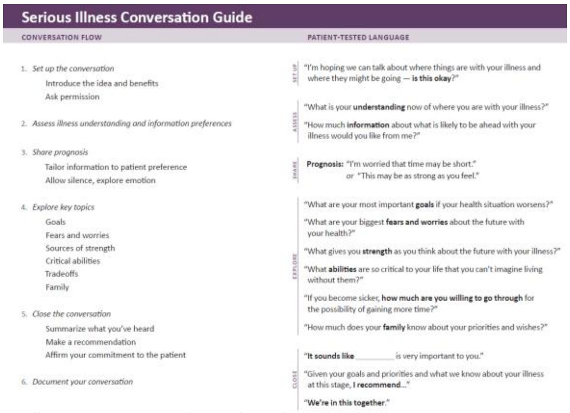
- ASK
- TELL
- ASK

Ask...Tell...Ask

- Ask: Tell me what you understand about your illness?
- Tell: Is it OK if I share my perspective as a doctor?
- Asking: Given all we have talked about what is the most important thing to you right now?

Advanced Questions To Ask

- Reflexive questions:
  - What do you think would happen if you were to stop…?
  - What benefits do you think might come from stopping…?
- Strategic question:
  - What change do you think might help indicate it is time to stop…?
  - What change would need to take place before you would be comfortable stopping...?



Serious Illness Conversation Guide

CONVERSATION FLOW		PATIENT-TESTED LANGUAGE
1. *Set up the conversation* Introduce the idea and benefits Ask permission	SET UP	"I'm hoping we can talk about where things are with your illness and where they might be going — **is this okay**?"
2. *Assess illness understanding and information preferences*	ASSESS	"What is your **understanding** now of where you are with your illness?" "How much **information** about what is likely to be ahead with your illness would you like from me?"
3. *Share prognosis* Tailor information to patient preference Allow silence, explore emotion	SHARE	**Prognosis:** "I'm worried that time may be short." or "This may be as strong as you feel."
4. *Explore key topics* Goals Fears and worries Sources of strength Critical abilities Tradeoffs Family	EXPLORE	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
5. *Close the conversation* Summarize what you've heard Make a recommendation Affirm your commitment to the patient 6. *Document your conversation*	CLOSE	"**It sounds like** ________ is very important to you." "Given your goals and priorities and what we know about your illness at this stage, **I recommend**..." "**We're in this together**."

http://www.instituteforhumancaring.org/documents/Providers/Serious-Illness-Guide-old.pdf

- "Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same: What is your understanding of the situation and its potential outcomes? What are your fears and what are your hopes? What are the trade-offs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?"
  - Atul Gawande, *Being Mortal: Medicine and What Matters in the End*.

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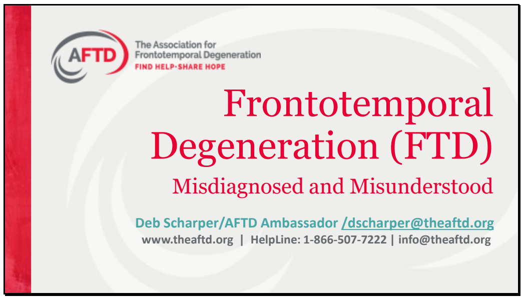
- Lupu D., 2010. Estimate of Current Hospice and Palliative Medicine Physicians Workforce Shortage; Journal of Pain and Symptom Management 40(6) 899-911

Slide 1



The Association for Frontotemporal Degeneration
FIND HELP·SHARE HOPE

Frontotemporal Degeneration (FTD)

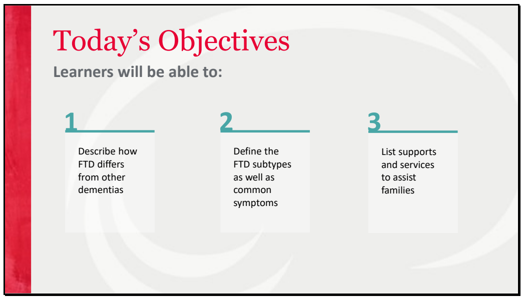
Misdiagnosed and Misunderstood

Deb Scharper/AFTD Ambassador /dscharper@theaftd.org
www.theaftd.org | HelpLine: 1-866-507-7222 | info@theaftd.org

Slide 2

My Story Is Personal, But I'm Not Alone

Slide 3



Today's Objectives

Learners will be able to:

1. Describe how FTD differs from other dementias
2. Define the FTD subtypes as well as common symptoms
3. List supports and services to assist families

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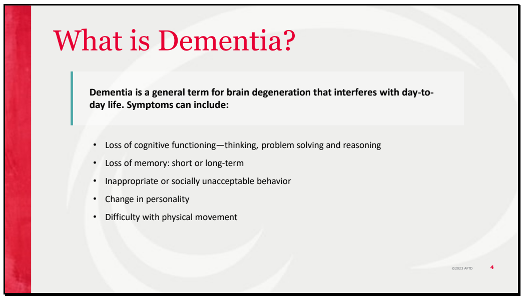
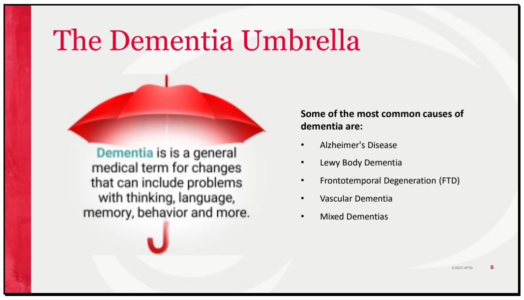


What is Dementia?

Dementia is a general term for brain degeneration that interferes with day-to-day life. Symptoms can include:

- Loss of cognitive functioning—thinking, problem solving and reasoning
- Loss of memory: short or long-term
- Inappropriate or socially unacceptable behavior
- Change in personality
- Difficulty with physical movement

Slide 5



The Dementia Umbrella

Dementia is is a general medical term for changes that can include problems with thinking, language, memory, behavior and more.

Some of the most common causes of dementia are:

- Alzheimer's Disease
- Lewy Body Dementia
- Frontotemporal Degeneration (FTD)
- Vascular Dementia
- Mixed Dementias

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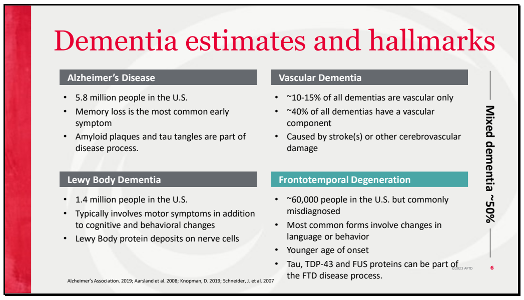

Dementia estimates and hallmarks

Alzheimer's Disease

- 5.8 million people in the U.S.
- Memory loss is the most common early symptom
- Amyloid plaques and tau tangles are part of disease process.

Lewy Body Dementia

- 1.4 million people in the U.S.
- Typically involves motor symptoms in addition to cognitive and behavioral changes
- Lewy Body protein deposits on nerve cells

Vascular Dementia

- ~10-15% of all dementias are vascular only
- ~40% of all dementias have a vascular component
- Caused by stroke(s) or other cerebrovascular damage

Frontotemporal Degeneration

- ~60,000 people in the U.S. but commonly misdiagnosed
- Most common forms involve changes in language or behavior
- Younger age of onset
- Tau, TDP-43 and FUS proteins can be part of the FTD disease process.

Mixed dementia ~50%

Alzheimer's Association. 2019; Aarsland et al. 2008; Knopman, D. 2019; Schneider, J. et al. 2007

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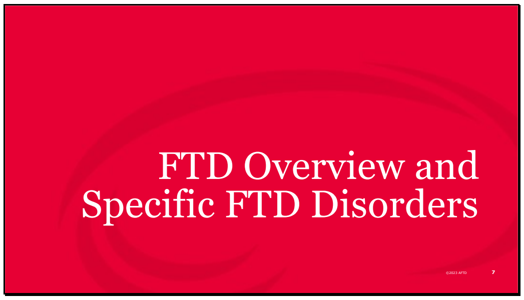
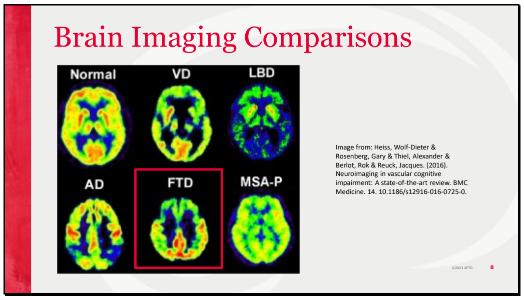


FTD Overview and Specific FTD Disorders

Slide 8



Brain Imaging Comparisons

Image from: Heiss, Wolf-Dieter & Rosenberg, Gary & Thiel, Alexander & Berlot, Rok & Reuck, Jacques. (2016). Neuroimaging in vascular cognitive impairment: A state-of-the-art review. BMC Medicine. 14. 10.1186/s12916-016-0725-0.

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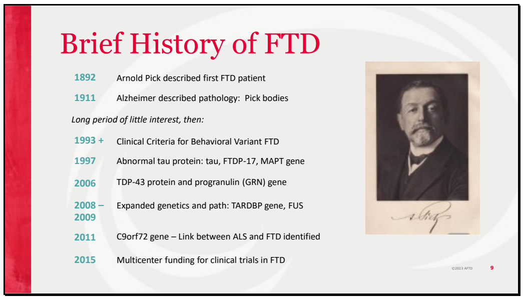

Brief History of FTD

1892	Arnold Pick described first FTD patient
1911	Alzheimer described pathology: Pick bodies

Long period of little interest, then:

1993 +	Clinical Criteria for Behavioral Variant FTD
1997	Abnormal tau protein: tau, FTDP-17, MAPT gene
2006	TDP-43 protein and progranulin (GRN) gene
2008 – 2009	Expanded genetics and path: TARDBP gene, FUS
2011	C9orf72 gene – Link between ALS and FTD identified
2015	Multicenter funding for clinical trials in FTD

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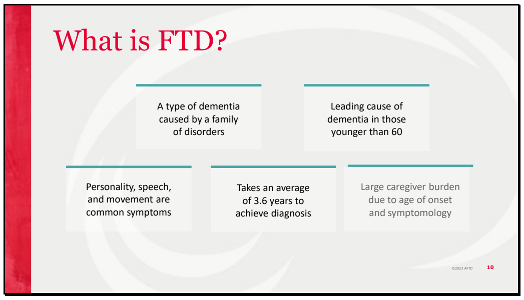


What is FTD?

A type of dementia caused by a family of disorders

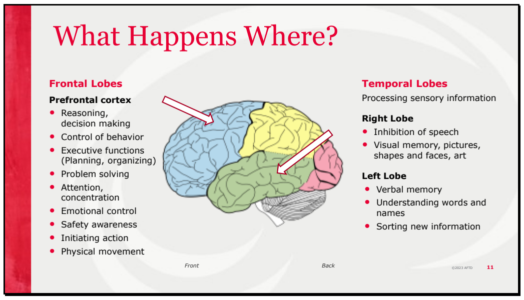
Leading cause of dementia in those younger than 60

Personality, speech, and movement are common symptoms

Takes an average of 3.6 years to achieve diagnosis

Large caregiver burden due to age of onset and symptomology

Slide 11



What Happens Where?

Frontal Lobes

Prefrontal cortex

- Reasoning, decision making
- Control of behavior
- Executive functions (Planning, organizing)
- Problem solving
- Attention, concentration
- Emotional control
- Safety awareness
- Initiating action
- Physical movement

Temporal Lobes

Processing sensory information

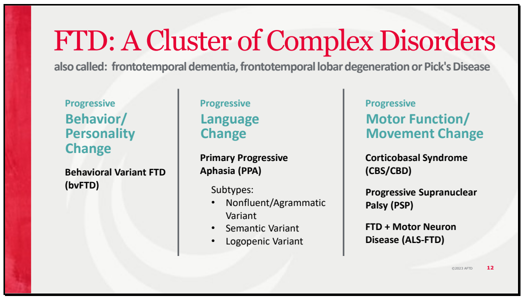
Right Lobe

- Inhibition of speech
- Visual memory, pictures, shapes and faces, art

Left Lobe

- Verbal memory
- Understanding words and names
- Sorting new information

Slide 12



FTD: A Cluster of Complex Disorders

also called: frontotemporal dementia, frontotemporal lobar degeneration or Pick's Disease

Progressive
Behavior/ Personality Change

Behavioral Variant FTD (bvFTD)

Progressive
Language Change

Primary Progressive Aphasia (PPA)

Subtypes:
- Nonfluent/Agrammatic Variant
- Semantic Variant
- Logopenic Variant

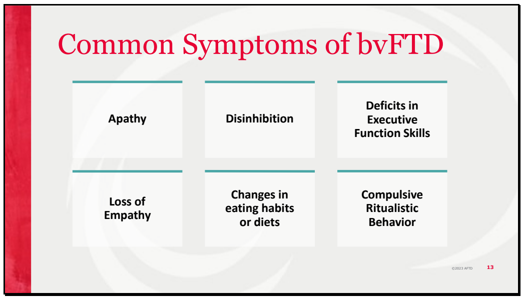
Progressive
Motor Function/ Movement Change

Corticobasal Syndrome (CBS/CBD)

Progressive Supranuclear Palsy (PSP)

FTD + Motor Neuron Disease (ALS-FTD)

Slide 13



Common Symptoms of bvFTD

- **Apathy**
- **Disinhibition**
- **Deficits in Executive Function Skills**
- **Loss of Empathy**
- **Changes in eating habits or diets**
- **Compulsive Ritualistic Behavior**

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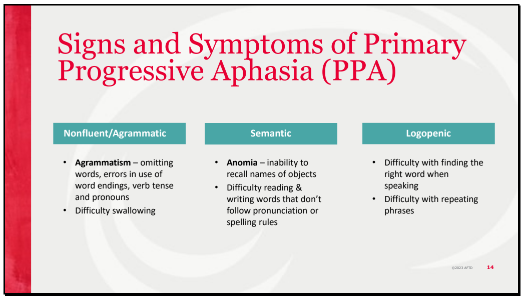

Signs and Symptoms of Primary Progressive Aphasia (PPA)

Nonfluent/Agrammatic

- **Agrammatism** – omitting words, errors in use of word endings, verb tense and pronouns
- Difficulty swallowing

Semantic

- **Anomia** – inability to recall names of objects
- Difficulty reading & writing words that don't follow pronunciation or spelling rules

Logopenic

- Difficulty with finding the right word when speaking
- Difficulty with repeating phrases

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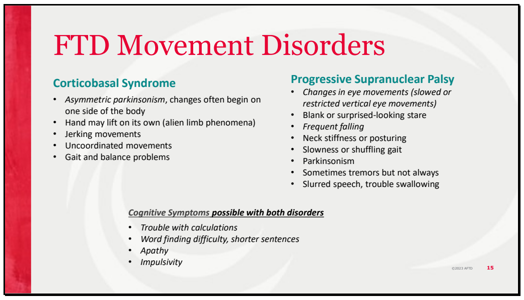

FTD Movement Disorders

Corticobasal Syndrome

- *Asymmetric parkinsonism*, changes often begin on one side of the body
- Hand may lift on its own (alien limb phenomena)
- Jerking movements
- Uncoordinated movements
- Gait and balance problems

Progressive Supranuclear Palsy

- *Changes in eye movements (slowed or restricted vertical eye movements)*
- Blank or surprised-looking stare
- *Frequent falling*
- Neck stiffness or posturing
- Slowness or shuffling gait
- Parkinsonism
- Sometimes tremors but not always
- Slurred speech, trouble swallowing

Cognitive Symptoms ***possible with both disorders***

- *Trouble with calculations*
- *Word finding difficulty, shorter sentences*
- *Apathy*
- *Impulsivity*

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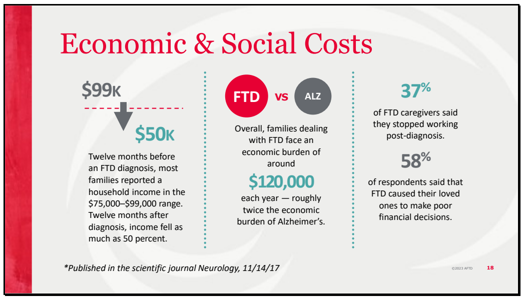
FTD-ALS

The discovery in 2011 that the *C9orf72* gene mutation can cause both FTD and amyotrophic lateral sclerosis (ALS) has transformed a long-held belief that ALS is 'purely' a movement disorder and that FTD Is 'purely' a cognitive or behavioral form of dementia.

Slide 17

Impact on Families

Slide 18



Economic & Social Costs

$99K

$50K

Twelve months before an FTD diagnosis, most families reported a household income in the $75,000–$99,000 range. Twelve months after diagnosis, income fell as much as 50 percent.

FTD vs ALZ

Overall, families dealing with FTD face an economic burden of around

$120,000

each year — roughly twice the economic burden of Alzheimer's.

37%

of FTD caregivers said they stopped working post-diagnosis.

58%

of respondents said that FTD caused their loved ones to make poor financial decisions.

**Published in the scientific journal Neurology, 11/14/17*

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Kids & Teens

- Young onset diagnosis very often means that kids or teens may be home
- Caregivers need to balance the needs of the children with the person living with FTD
- Children become part of the care team

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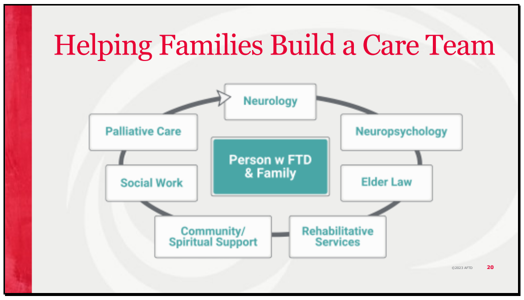


Helping Families Build a Care Team

Person w FTD & Family

Neurology

Neuropsychology

Elder Law

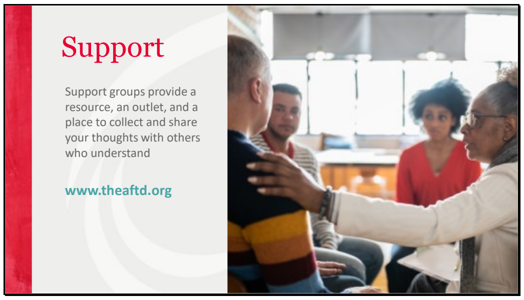
Rehabilitative Services

Community/ Spiritual Support

Social Work

Palliative Care

Slide 21



Support

Support groups provide a resource, an outlet, and a place to collect and share your thoughts with others who understand

www.theaftd.org

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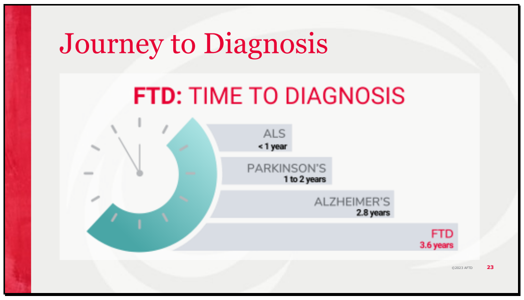
Diagnosis, Treatment and Research

Slide 23



Journey to Diagnosis

FTD: TIME TO DIAGNOSIS

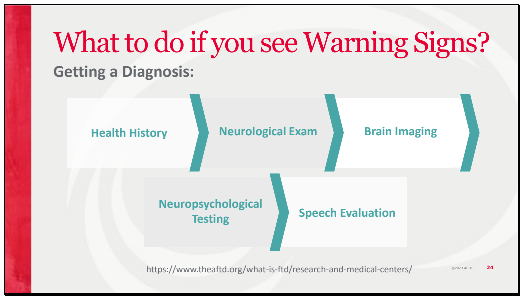
ALS
< 1 year

PARKINSON'S
1 to 2 years

ALZHEIMER'S
2.8 years

FTD
3.6 years

Slide 24



What to do if you see Warning Signs?

Getting a Diagnosis:

Health History

Neurological Exam

Brain Imaging

Neuropsychological Testing

Speech Evaluation

https://www.theaftd.org/what-is-ftd/research-and-medical-centers/

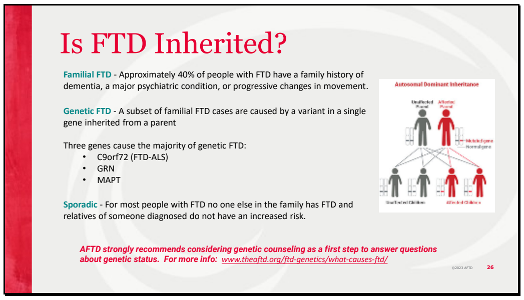
Slide 25

FTD Treatments & Therapeutic Interventions

There is hope with current research and research participation

- *Currently: No disease-altering treatment to stop or slow the disease*
- Active research is looking for treatments and effective therapies:
  - Learn more: www.theaftd.org/research-clinical-trials/featured-studies/
- There are effective treatments that can manage symptoms:
  - Off-label use of medications
  - Supportive therapies: Speech Therapy, Physical Therapy, Occupational Therapy, Support Groups, Palliative care, Dementia-friendly spaces

Slide 26



Is FTD Inherited?

Familial FTD - Approximately 40% of people with FTD have a family history of dementia, a major psychiatric condition, or progressive changes in movement.

Genetic FTD - A subset of familial FTD cases are caused by a variant in a single gene inherited from a parent

Three genes cause the majority of genetic FTD:
- C9orf72 (FTD-ALS)
- GRN
- MAPT

Sporadic - For most people with FTD no one else in the family has FTD and relatives of someone diagnosed do not have an increased risk.

AFTD strongly recommends considering genetic counseling as a first step to answer questions about genetic status. For more info: www.theaftd.org/ftd-genetics/what-causes-ftd/

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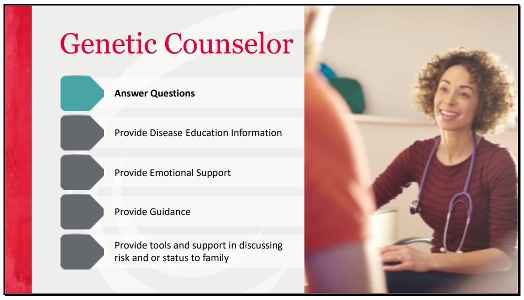

Genetic Counselor

- **Answer Questions**
- Provide Disease Education Information
- Provide Emotional Support
- Provide Guidance
- Provide tools and support in discussing risk and or status to family

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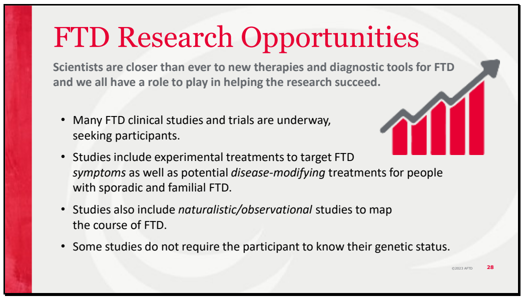

FTD Research Opportunities

Scientists are closer than ever to new therapies and diagnostic tools for FTD and we all have a role to play in helping the research succeed.

- Many FTD clinical studies and trials are underway, seeking participants.
- Studies include experimental treatments to target FTD *symptoms* as well as potential *disease-modifying* treatments for people with sporadic and familial FTD.
- Studies also include *naturalistic/observational* studies to map the course of FTD.
- Some studies do not require the participant to know their genetic status.

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Where to Learn More

Sign up for the FTD Disorders Registry: ftdregistry.org

- Co-founded by two non-profits, the Registry is a resource for persons diagnosed, families, and caregivers to participate in research.
- Healthcare providers and others may sign up to receive communications.
- The Registry provides one location to learn about research participation opportunities and share their stories to inform research design.
- Participants' personal information is NEVER shared.

Sign up for AFTD newsletters to stay informed about research opportunities and progress: theaftd.org

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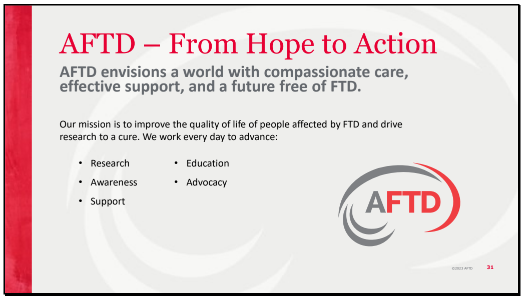
AFTD Resources

Slide 31



AFTD – From Hope to Action

AFTD envisions a world with compassionate care, effective support, and a future free of FTD.

Our mission is to improve the quality of life of people affected by FTD and drive research to a cure. We work every day to advance:

- Research
- Awareness
- Support
- Education
- Advocacy

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Resources from AFTD

HelpLine	info@theaftd.org 866-507-7222
Websites	www.theaftd.org www.aftdkidsandteens.org
Publications	*Help & Hope* *Partners in FTD Care* *The Doctor Thinks It's FTD. Now What?* *What About the Kids?* *Understanding the Genetics of FTD* *Walking with Grief: Loss and the FTD journey*
Grants	Respite, Travel, Quality of Life
Support	National and regional on-line and local in-person groups theaftd.org/living-with-ftd/aftd-support-groups

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AFTD Resources for Medical and Care Professionals

- Partners in Care quarterly publication focusing on a specific issue or topic
  - Partners in FTD Care | AFTD (theaftd.org)
- Clinical presentations of symptoms:
  - Clinical Presentations | AFTD (theaftd.org)
- Webinars and Annual Conference
- AFTD Helpline: 1-866-507-7222 or info@theaftd.org

For additional info, go to For Health Professionals | AFTD (theaftd.org) *or contact the AFTD Helpline.*

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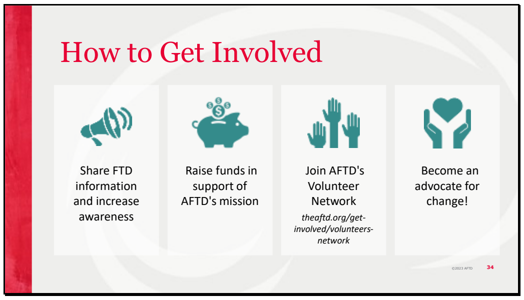

How to Get Involved

Share FTD information and increase awareness

Raise funds in support of AFTD's mission

Join AFTD's Volunteer Network
theaftd.org/get-involved/volunteers-network

Become an advocate for change!

Slide 35

Stay Connected with AFTD Resources

Scan to sign up for AFTD's newsletters

Contact AFTD's HelpLine
info@theaftd.org
866.507.7222

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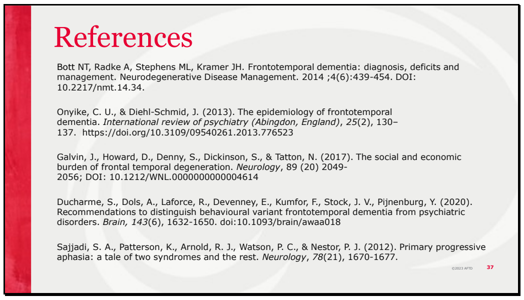
Questions?

Slide 37



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Sajjadi, S. A., Patterson, K., Arnold, R. J., Watson, P. C., & Nestor, P. J. (2012). Primary progressive aphasia: a tale of two syndromes and the rest. *Neurology*, *78*(21), 1670-1677.

MEDICARE UPDATE

MEDICARE AND MEDICAID PROGRAMS; MINIMUM STAFFING STANDARDS FOR LONG-TERM CARE FACILITIES AND MEDICAID INSTITUTIONAL PAYMENT TRANSPARENCY REPORTING

IMPLEMENTATION DEADLINES

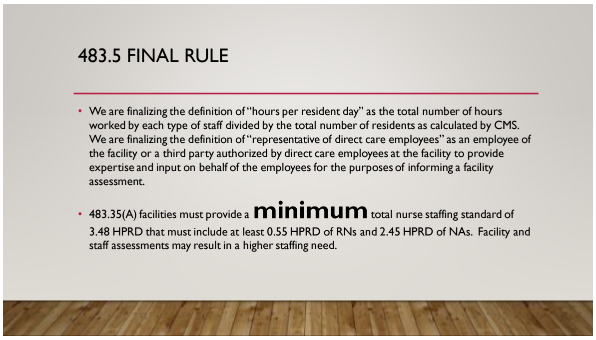
The regulations at § 483.71 must be implemented by August 8, 2024, for all facilities.

The regulations at § 483.35(b)(1) and (c)(1) must be implemented by May 11, 2026, for non-rural facilities and May 10, 2027, for rural facilities as defined by the Office of Management and Budget.

The regulations at § 483.35(b)(1)(i) and (ii) must be implemented by May 10, 2027, for non-rural facilities and May 10, 2029, for rural facilities.

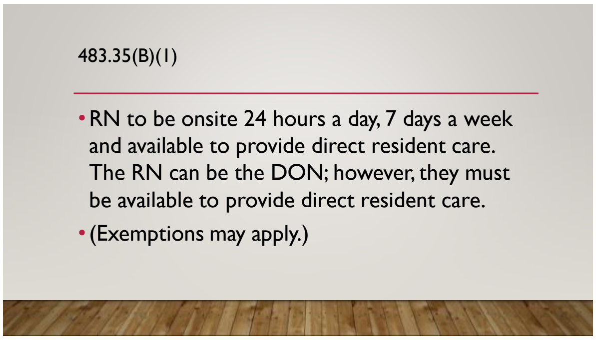
483.70(E) IS NOW ITS OWN NEW SECTION 483.17

- We are finalizing as proposed the addition of "behavioral health issues" to § 483.71(a)(1)(ii); the addition of "and skill sets" to § 483.71(a)(1)(iii); and the addition of "as required" in § 483.73(a)(1) through (3).
- Also, LTC facility actively require the participation of the nursing home leadership and management, including but not limited to, a member of the governing body, the medical director, an administrator, and the director of nursing; and, direct care staff, including but not limited to, RNs, LPNs/LVNs, NAs, and representatives of direct care staff, if applicable. The LTC facility must also solicit and consider input received from residents, resident representatives, family members, and representatives of direct care staff when conducting the facility and staff assessment used to determine the number of RN and staff hours that will be required.
- LTC facility must use the facility assessment, including making staffing decisions, developing and maintaining a plan to maximize recruitment and retention of direct care staff, to inform contingency planning for events that do not necessarily require activation of the facility's emergency plan.



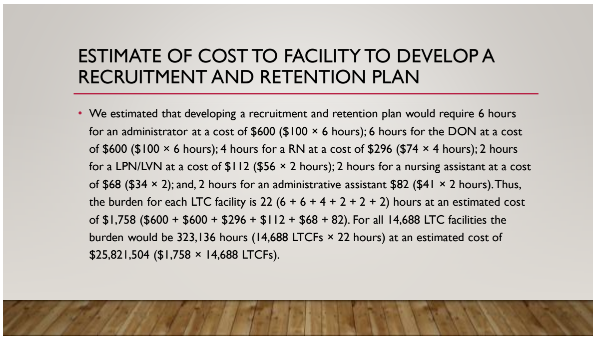
483.5 FINAL RULE

- We are finalizing the definition of "hours per resident day" as the total number of hours worked by each type of staff divided by the total number of residents as calculated by CMS. We are finalizing the definition of "representative of direct care employees" as an employee of the facility or a third party authorized by direct care employees at the facility to provide expertise and input on behalf of the employees for the purposes of informing a facility assessment.
- 483.35(A) facilities must provide a **minimum** total nurse staffing standard of 3.48 HPRD that must include at least 0.55 HPRD of RNs and 2.45 HPRD of NAs. Facility and staff assessments may result in a higher staffing need.



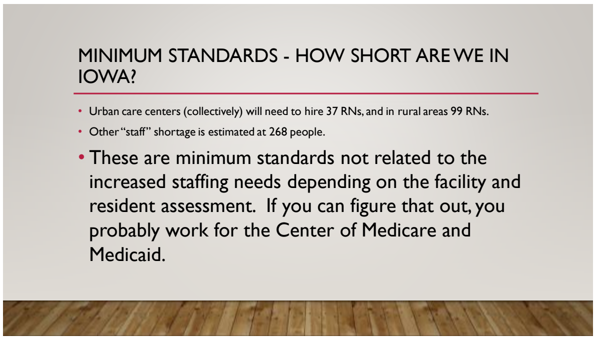
483.35(B)(1)

- RN to be onsite 24 hours a day, 7 days a week and available to provide direct resident care. The RN can be the DON; however, they must be available to provide direct resident care.
- (Exemptions may apply.)



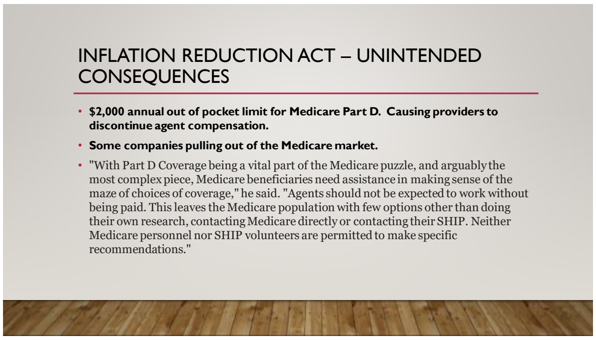
ESTIMATE OF COST TO FACILITY TO DEVELOP A RECRUITMENT AND RETENTION PLAN

- We estimated that developing a recruitment and retention plan would require 6 hours for an administrator at a cost of $600 ($100 × 6 hours); 6 hours for the DON at a cost of $600 ($100 × 6 hours); 4 hours for a RN at a cost of $296 ($74 × 4 hours); 2 hours for a LPN/LVN at a cost of $112 ($56 × 2 hours); 2 hours for a nursing assistant at a cost of $68 ($34 × 2); and, 2 hours for an administrative assistant $82 ($41 × 2 hours). Thus, the burden for each LTC facility is 22 (6 + 6 + 4 + 2 + 2 + 2) hours at an estimated cost of $1,758 ($600 + $600 + $296 + $112 + $68 + 82). For all 14,688 LTC facilities the burden would be 323,136 hours (14,688 LTCFs × 22 hours) at an estimated cost of $25,821,504 ($1,758 × 14,688 LTCFs).



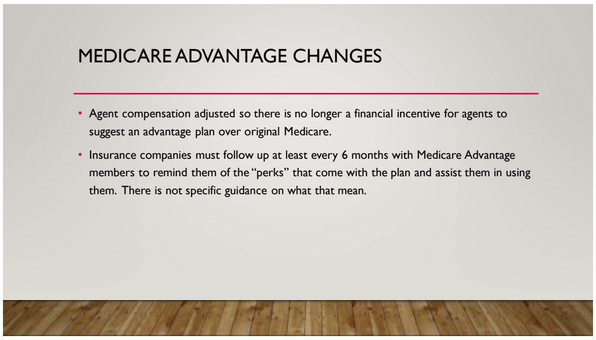
MINIMUM STANDARDS - HOW SHORT ARE WE IN IOWA?

- Urban care centers (collectively) will need to hire 37 RNs, and in rural areas 99 RNs.
- Other "staff" shortage is estimated at 268 people.
- These are minimum standards not related to the increased staffing needs depending on the facility and resident assessment. If you can figure that out, you probably work for the Center of Medicare and Medicaid.



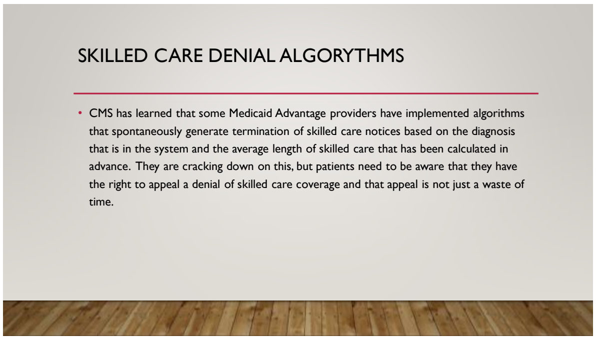
INFLATION REDUCTION ACT – UNINTENDED CONSEQUENCES

- **$2,000 annual out of pocket limit for Medicare Part D. Causing providers to discontinue agent compensation.**
- **Some companies pulling out of the Medicare market.**
- "With Part D Coverage being a vital part of the Medicare puzzle, and arguably the most complex piece, Medicare beneficiaries need assistance in making sense of the maze of choices of coverage," he said. "Agents should not be expected to work without being paid. This leaves the Medicare population with few options other than doing their own research, contacting Medicare directly or contacting their SHIP. Neither Medicare personnel nor SHIP volunteers are permitted to make specific recommendations."



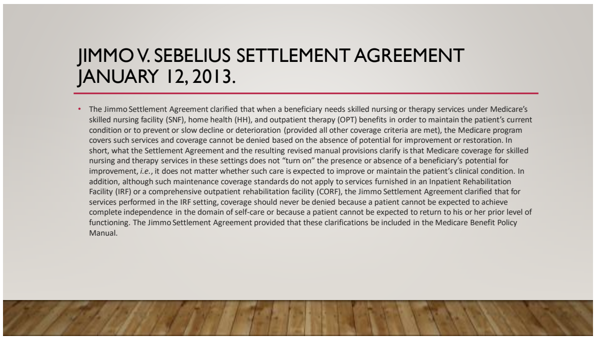
MEDICARE ADVANTAGE CHANGES

- Agent compensation adjusted so there is no longer a financial incentive for agents to suggest an advantage plan over original Medicare.
- Insurance companies must follow up at least every 6 months with Medicare Advantage members to remind them of the "perks" that come with the plan and assist them in using them. There is not specific guidance on what that mean.



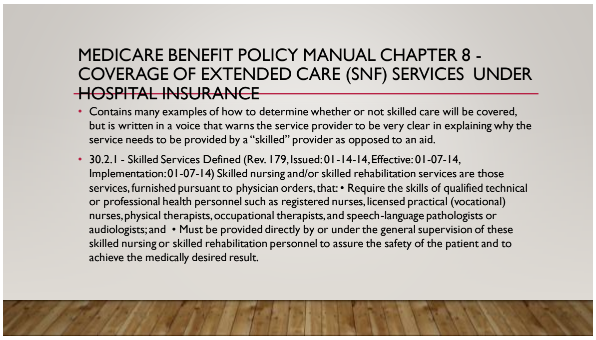
SKILLED CARE DENIAL ALGORYTHMS

- CMS has learned that some Medicaid Advantage providers have implemented algorithms that spontaneously generate termination of skilled care notices based on the diagnosis that is in the system and the average length of skilled care that has been calculated in advance. They are cracking down on this, but patients need to be aware that they have the right to appeal a denial of skilled care coverage and that appeal is not just a waste of time.



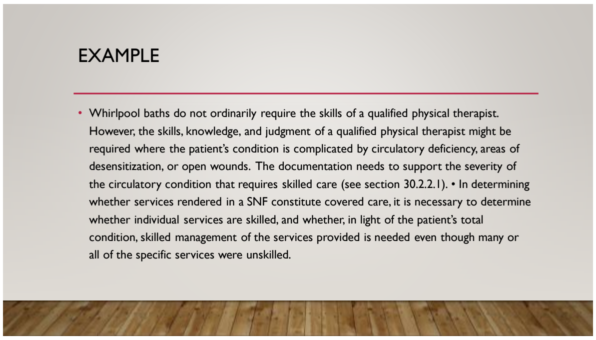
JIMMO V. SEBELIUS SETTLEMENT AGREEMENT JANUARY 12, 2013.

- The Jimmo Settlement Agreement clarified that when a beneficiary needs skilled nursing or therapy services under Medicare's skilled nursing facility (SNF), home health (HH), and outpatient therapy (OPT) benefits in order to maintain the patient's current condition or to prevent or slow decline or deterioration (provided all other coverage criteria are met), the Medicare program covers such services and coverage cannot be denied based on the absence of potential for improvement or restoration. In short, what the Settlement Agreement and the resulting revised manual provisions clarify is that Medicare coverage for skilled nursing and therapy services in these settings does not "turn on" the presence or absence of a beneficiary's potential for improvement, *i.e.*, it does not matter whether such care is expected to improve or maintain the patient's clinical condition. In addition, although such maintenance coverage standards do not apply to services furnished in an Inpatient Rehabilitation Facility (IRF) or a comprehensive outpatient rehabilitation facility (CORF), the Jimmo Settlement Agreement clarified that for services performed in the IRF setting, coverage should never be denied because a patient cannot be expected to achieve complete independence in the domain of self-care or because a patient cannot be expected to return to his or her prior level of functioning. The Jimmo Settlement Agreement provided that these clarifications be included in the Medicare Benefit Policy Manual.



MEDICARE BENEFIT POLICY MANUAL CHAPTER 8 - COVERAGE OF EXTENDED CARE (SNF) SERVICES UNDER HOSPITAL INSURANCE

- Contains many examples of how to determine whether or not skilled care will be covered, but is written in a voice that warns the service provider to be very clear in explaining why the service needs to be provided by a "skilled" provider as opposed to an aid.
- 30.2.1 - Skilled Services Defined (Rev. 179, Issued: 01-14-14, Effective: 01-07-14, Implementation: 01-07-14) Skilled nursing and/or skilled rehabilitation services are those services, furnished pursuant to physician orders, that: • Require the skills of qualified technical or professional health personnel such as registered nurses, licensed practical (vocational) nurses, physical therapists, occupational therapists, and speech-language pathologists or audiologists; and • Must be provided directly by or under the general supervision of these skilled nursing or skilled rehabilitation personnel to assure the safety of the patient and to achieve the medically desired result.



EXAMPLE

- Whirlpool baths do not ordinarily require the skills of a qualified physical therapist. However, the skills, knowledge, and judgment of a qualified physical therapist might be required where the patient's condition is complicated by circulatory deficiency, areas of desensitization, or open wounds. The documentation needs to support the severity of the circulatory condition that requires skilled care (see section 30.2.2.1). • In determining whether services rendered in a SNF constitute covered care, it is necessary to determine whether individual services are skilled, and whether, in light of the patient's total condition, skilled management of the services provided is needed even though many or all of the specific services were unskilled.

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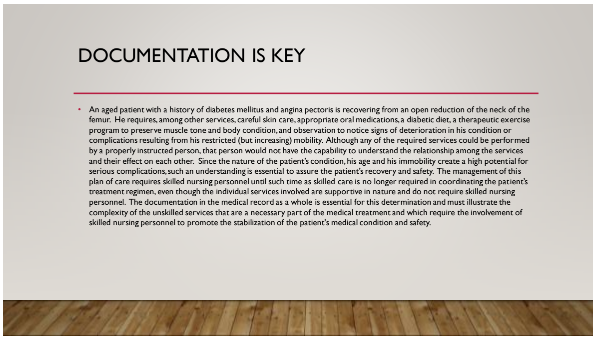

DOCUMENTATION IS KEY

- An aged patient with a history of diabetes mellitus and angina pectoris is recovering from an open reduction of the neck of the femur. He requires, among other services, careful skin care, appropriate oral medications, a diabetic diet, a therapeutic exercise program to preserve muscle tone and body condition, and observation to notice signs of deterioration in his condition or complications resulting from his restricted (but increasing) mobility. Although any of the required services could be performed by a properly instructed person, that person would not have the capability to understand the relationship among the services and their effect on each other. Since the nature of the patient's condition, his age and his immobility create a high potential for serious complications, such an understanding is essential to assure the patient's recovery and safety. The management of this plan of care requires skilled nursing personnel until such time as skilled care is no longer required in coordinating the patient's treatment regimen, even though the individual services involved are supportive in nature and do not require skilled nursing personnel. The documentation in the medical record as a whole is essential for this determination and must illustrate the complexity of the unskilled services that are a necessary part of the medical treatment and which require the involvement of skilled nursing personnel to promote the stabilization of the patient's medical condition and safety.

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Jimmo v. Sebelius **Settlement Agreement Program Manual Clarifications Fact Sheet**

Overview:

As explained in the previously-issued *Jimmo v. Sebelius* Settlement Agreement Fact Sheet (available online at http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/SNFPPS/Downloads/Jimmo-FactSheet.pdf), the Centers for Medicare & Medicaid Services (CMS) is issuing revised portions of the relevant program manuals used by Medicare contractors. Specifically, in accordance with the settlement agreement, the manual revisions clarify that coverage of skilled nursing and skilled therapy services in the skilled nursing facility (SNF), home health (HH), and outpatient therapy (OPT) settings "…does not turn on the presence or absence of a beneficiary's potential for improvement, but rather on the beneficiary's need for skilled care." Skilled care may be necessary to improve a patient's current condition, to maintain the patient's current condition, or to prevent or slow further deterioration of the patient's condition.

The Settlement Agreement:

The settlement agreement itself includes language specifying that "**Nothing in this Settlement Agreement modifies, contracts, or expands the existing eligibility requirements for receiving Medicare coverage**."

Rather, the intent is to clarify Medicare's longstanding policy that when skilled services are required in order to provide care that is reasonable and necessary to prevent or slow further deterioration, coverage cannot be denied based on the absence of potential for improvement or restoration. As such, the manual revisions contained in Change Request (CR) 8458 do not represent an *expansion* of coverage, but rather, provide clarifications that are intended to help ensure that claims are adjudicated accurately and appropriately in accordance with the *existing* Medicare policy. Similarly, these revisions do not alter or supersede any other applicable coverage requirements beyond those involving the need for skilled care, such as Medicare's overall requirement that covered services must to be reasonable and necessary to diagnose or treat the beneficiary's condition. The following are some significant aspects of the manual clarifications:

- **No "Improvement Standard" is to be applied in determining Medicare coverage for maintenance claims in which skilled care is required.** There are situations in which the patient's potential for improvement would be a reasonable criterion to consider, such as when the goal of treatment is to restore function. We note that this would always be the goal of treatment in the inpatient rehabilitation facility (IRF) setting, where skilled therapy must be reasonably expected to improve the patient's functional capacity or adaptation to impairments in order to be covered. However, Medicare has long recognized that there may be situations in the SNF, home health, and outpatient therapy settings where, even though no improvement is expected, skilled nursing and/or therapy services to prevent or slow a decline in condition are necessary because of the particular patient's special medical complications or the complexity of the needed services.

- The manual revisions clarify that a beneficiary's lack of restoration potential cannot, in itself, serve as the basis for denying coverage in this context, without regard to an individualized assessment of the beneficiary's medical condition and the reasonableness and necessity of the treatment, care, or services in question. Conversely, such coverage would not be available in a situation where the beneficiary's maintenance care needs can be addressed safely and effectively through the use of *nonskilled* personnel.

- Medicare has never supported the imposition of an "Improvement Standard" rule-of-thumb in determining whether skilled care is required to prevent or slow deterioration in a patient's condition. Thus, such coverage depends not on the beneficiary's restoration potential, but on *whether skilled care is required*, along with the underlying reasonableness and necessity of the services themselves. The manual revisions serve to reflect and articulate this basic principle more clearly. Therefore, denial notices for claims involving maintenance care in the SNF, HH, and OPT settings should contain an accurate summary of the reason for the determination, which should always be based on whether the beneficiary has a *need for skilled care* rather than on a lack of improvement.

Appropriate Documentation:

Portions of the revised manual provisions now include additional information on the role of appropriate documentation in facilitating accurate coverage determinations for claims involving skilled care. While the presence of appropriate documentation is not, in and of itself, an element of the definition of a "skilled" service, such documentation serves as the *means* by which a provider would be able to establish and a Medicare contractor would be able to confirm that skilled care is, in fact, needed and received in a given case. Thus, even though the terms of the settlement agreement do not include an explicit reference to documentation requirements as such, we have nevertheless decided to use this opportunity to introduce additional guidance in this area, both generally and as it relates to particular clinical scenarios.

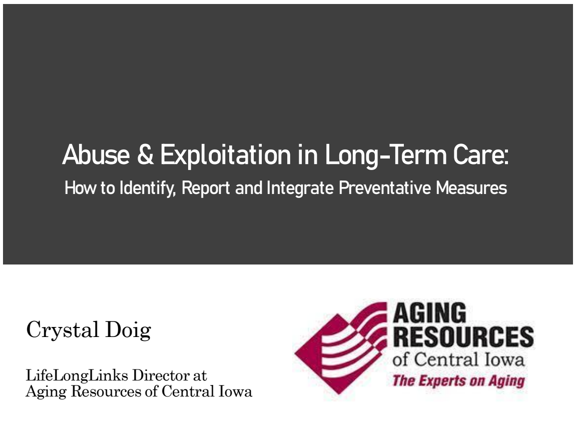
We note that this material on documentation does not serve to require the presence of any particular phraseology or verbal formulation as a prerequisite for coverage (although it does identify certain vague phrases like “patient tolerated treatment well,” “continue with POC,” and “patient remains stable” as being *insufficiently explanatory* to establish coverage). Rather, as indicated previously, coverage determinations must consider the *entirety* of the clinical evidence in the file, and our enhanced guidance on documentation is intended simply to assist providers in their efforts to identify and include the kind of clinical information that can most effectively serve to support a finding that skilled care is needed and received—which, in turn, will help to ensure more accurate and appropriate claims adjudication.

Care must be taken to assure that documentation justifies the necessity of the skilled services provided. Justification for treatment would include, for example, objective evidence or a clinically supportable statement of expectation that:

- In the case of rehabilitative therapy, the patient’s condition has the potential to improve or is improving in response to therapy; maximum improvement is yet to be attained; and, there is an expectation that the anticipated improvement is attainable in a reasonable and generally predictable period of time.
- In the case of maintenance therapy, the skills of a therapist are necessary to maintain, prevent, or slow further deterioration of the patient’s functional status, and the services cannot be safely and effectively carried out by the beneficiary personally, or with the assistance of non-therapists, including unskilled caregivers.

Forthcoming Activities:

As discussed in the previously-issued *Jimmo v. Sebelius* Settlement Agreement Fact Sheet, CMS is planning to conduct additional educational outreach and claims review activities in the near future pursuant to the settlement agreement.



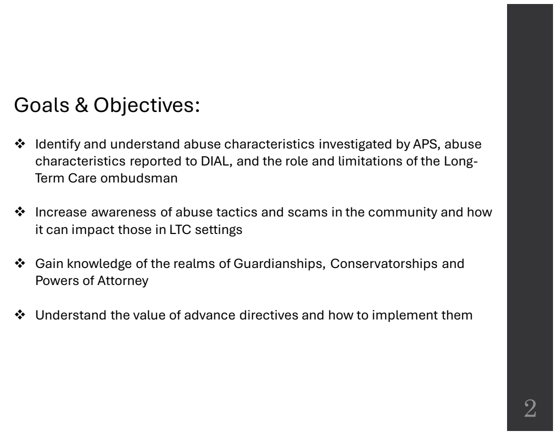
Abuse & Exploitation in Long-Term Care:

How to Identify, Report and Integrate Preventative Measures

Crystal Doig

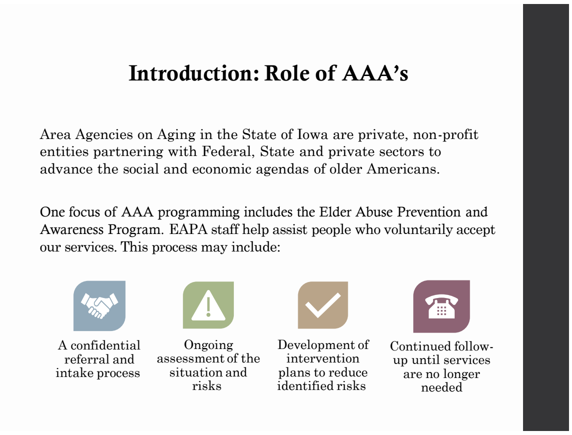
LifeLongLinks Director at
Aging Resources of Central Iowa

AGING RESOURCES of Central Iowa
The Experts on Aging



Goals & Objectives:

- Identify and understand abuse characteristics investigated by APS, abuse characteristics reported to DIAL, and the role and limitations of the Long-Term Care ombudsman
- Increase awareness of abuse tactics and scams in the community and how it can impact those in LTC settings
- Gain knowledge of the realms of Guardianships, Conservatorships and Powers of Attorney
- Understand the value of advance directives and how to implement them



Introduction: Role of AAA’s

Area Agencies on Aging in the State of Iowa are private, non-profit entities partnering with Federal, State and private sectors to advance the social and economic agendas of older Americans.

One focus of AAA programming includes the Elder Abuse Prevention and Awareness Program. EAPA staff help assist people who voluntarily accept our services. This process may include:

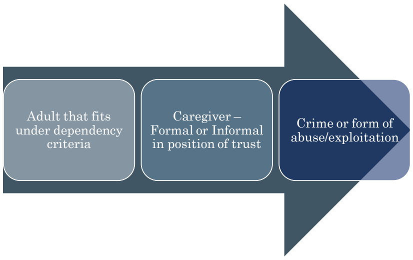
- A confidential referral and intake process
- Ongoing assessment of the situation and risks
- Development of intervention plans to reduce identified risks
- Continued follow-up until services are no longer needed

Iowa's Definition of Elder Abuse

Elder Abuse: term used to describe general abuse towards older adults, for those who are dependent and those who are **not** dependent.

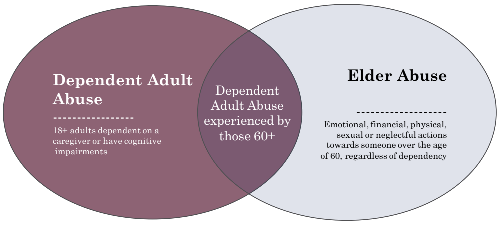
Vulnerable Adult: A person sixty years of age or older who is unable to protect himself or herself from elder abuse as a result of age or a mental or physical condition. Does NOT have to be dependent.

3 Key Factors for a Dependent Adult Abuse Report



- Adult that fits under dependency criteria
- Caregiver – Formal or Informal in position of trust
- Crime or form of abuse/exploitation

In Iowa, all Dependent Adult Abuse cases for those over 60 are considered **ELDER ABUSE**, but not all Elder Abuse cases rise to the level of **DEPENDENT ADULT ABUSE.**



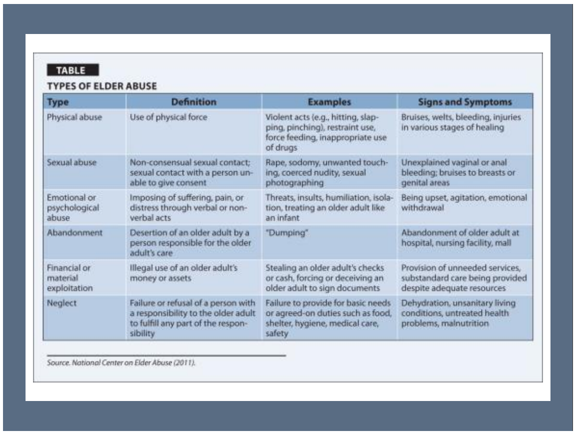
Dependent Adult Abuse

18+ adults dependent on a caregiver or have cognitive impairments

Dependent Adult Abuse experienced by those 60+

Elder Abuse

Emotional, financial, physical, sexual or neglectful actions towards someone over the age of 60, regardless of dependency

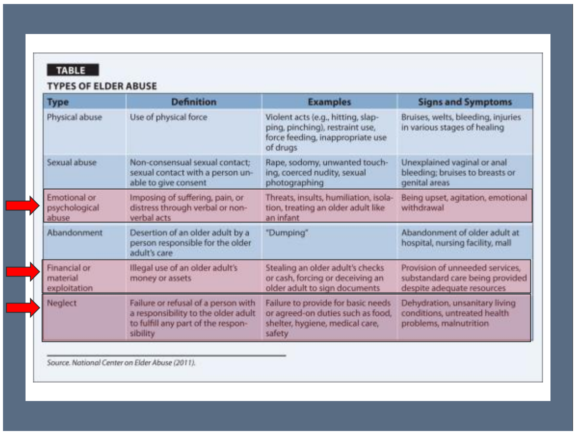


TABLE

TYPES OF ELDER ABUSE

Type	Definition	Examples	Signs and Symptoms
Physical abuse	Use of physical force	Violent acts (e.g., hitting, slapping, pinching), restraint use, force feeding, inappropriate use of drugs	Bruises, welts, bleeding, injuries in various stages of healing
Sexual abuse	Non-consensual sexual contact; sexual contact with a person unable to give consent	Rape, sodomy, unwanted touching, coerced nudity, sexual photographing	Unexplained vaginal or anal bleeding; bruises to breasts or genital areas
Emotional or psychological abuse	Imposing of suffering, pain, or distress through verbal or nonverbal acts	Threats, insults, humiliation, isolation, treating an older adult like an infant	Being upset, agitation, emotional withdrawal
Abandonment	Desertion of an older adult by a person responsible for the older adult's care	"Dumping"	Abandonment of older adult at hospital, nursing facility, mall
Financial or material exploitation	Illegal use of an older adult's money or assets	Stealing an older adult's checks or cash, forcing or deceiving an older adult to sign documents	Provision of unneeded services, substandard care being provided despite adequate resources
Neglect	Failure or refusal of a person with a responsibility to the older adult to fulfill any part of the responsibility	Failure to provide for basic needs or agreed-on duties such as food, shelter, hygiene, medical care, safety	Dehydration, unsanitary living conditions, untreated health problems, malnutrition

Source. National Center on Elder Abuse (2011).



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Source. National Center on Elder Abuse (2011).

Emotional/Psychological Abuse in LTC Facilities

One of the common forms of abuse in LTC facilities includes emotional abuse (also known as verbal or psychological abuse). This occurs when a resident experiences threats intended to control or intimidate them.

Examples of emotional abuse include:

- *Restricting a resident's activities against their will*
- *Degrading a resident (appearance, gender, race, intelligence, etc)*
- *Isolating them from family, friends, or other residents*

Residents who experience emotional or psychological abuse may often develop mental health issues such as anxiety, depression, and even PTSD.

Watching for Micro-Aggressions

- Microaggressions refer to 'commonplace behavioral indignities whether intentional or unintentional communicating hostile, derogatory or negative attitudes toward marginalized groups,'
- Microaggressions can be perpetrated by staff members and even family members who come to visit.
- The nursing home is responsible for protecting residents from abuse — **even when it's carried out by a family member.** Staff members must take note of interactions between family members and recognize possible signs of abuse.

Financial Exploitation in LTC Facilities

Nursing home financial abuse occurs when someone steals from an older person or uses manipulation to get money from them (including scams).

Examples of financial abuse include:

- Misusing power of attorney to change a resident's will
- Non-payment of NF bill
- Preventing the resident from accessing their own bank account
- Stealing cash, credit cards, or valuables from a resident

While there may not be physical harm involved, financial abuse can be just as damaging as the other types of abuse in nursing homes. Not only can it cause severe anxiety, but it can also rob residents of the money they need to pay for their long-term care.

Warning Signs of Financial Exploitation in Facilities

Sudden changes or newly added names on an elder's bank docs or advanced directives

Unpaid bills despite adequate funds or unexplained changes in a bank account or banking practices

The sudden appearance of previously uninvolved relatives claiming financial rights

Nursing staff paying an inordinate amount of attention to the elderly person's finances

An elderly person signing strange financial documents they don't understand

Unexplained transfers or the disappearance of funds or valuable possessions

Scams as Financial Exploitation

- Grandparent scams
- Debt collection scams
- Charity scams
- Blackmail scams
- Lottery or prize scams

Neglect in LTC Facilities

Being one of the more common forms of abuse in long-term care facilities, neglect occurs when staff members fail to provide proper care to residents, resulting in damage to a resident's physical and emotional well-being.

Neglect is often not perpetrated on purpose; however, it is amplified by understaffing and increased workload.

Examples of LTC neglect include:

- Failing to quickly report injuries/illnesses to doctors/family
- Ignoring a resident's complaints
- Leaving residents unattended for periods of time

Routes of Reporting

- If you are seeking to report dependent adult abuse in a nursing facility or hospital by a staff member, Monday through Friday, 8 a.m. to 4:30 p.m., contact the Department of Inspections and Appeals: 1-877-686-0027 or hfd_complaint@dia.iowa.gov.
- If you want to report any other abuse, neglect, exploitation, or self-neglect of a dependent adult, please call the HHS toll-free, hotline number, which is answered 24 hours a day, 7 days a week: 1-800-362-2178.
- To report suspected abuse in a long-term care facility, contact the Iowa Department of Inspections and Appeals Nursing Home and Home Health Complaint Hotline at 1-877-686-0027 or email **hfd_complaint@dia.iowa.gov**.
- If you have concerns about your quality of care, quality of life or rights as a resident/tenant, or if you have concerns on behalf of your loved one who is living in one of Iowa's long-term care facilities, contact the **Office of the State Long-Term Care Ombudsman** at 1-866-236-1430.
- For a coordinated entry point to Iowa's information and referral resources regarding long-term independent living, contact **Lifelong Links** online or call 1-866-468-7887.

What are your next steps?

- A family member is refusing to pay the facility bill
- Staff member is seen making derogatory comments about a female resident
- Another resident within the facility

Advance Directives:
Proactive approaches to minimizing abuse

Living Will	A written document that describes the medical treatments you want if you're seriously or terminally ill. It doesn't allow you to designate someone to make decisions for you.
Power of Attorney	A legal document that allows you to appoint someone to make financial decisions for you if you're unable to.
Durable Healthcare Power of Attorney	A signed, dated, and witnessed document that names someone to make medical decisions for you. **A doctor must *activate* this for it to take affect**

Court Actions

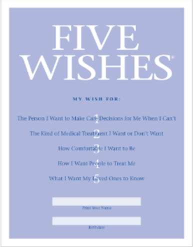
- Guardianship: A court-ordered arrangement that gives someone the legal authority to make decisions about a person's health, including where they live and whether they go to assisted living. A guardian can also be legally required to provide care for a person's property.
- Conservatorship: A court-ordered arrangement that gives someone the legal authority to make financial decisions for a person, such as paying bills, accessing bank accounts, and cashing checks.

These options may be pursued if an older adult continually falls for scams, is unable to manage their own affairs, cannot competently live or make decisions on their own behalf.

The 5 Wishes Booklet

A unique way to create your own living will

- This booklet is unique in that answers to end-of-life wishes are written and worded by the individual themselves
- Assists in "starting the conversation" of how loved ones want to be treated during end-of-life processes
- You can order through their website: https://www.fivewishes.org/



FIVE WISHES®

MY WISH FOR:

1 The Person I Want to Make Care Decisions for Me When I Can't

2 The Kind of Medical Treatment I Want or Don't Want

3 How Comfortable I Want to Be

4 How I Want People to Treat Me

5 What I Want My Loved Ones to Know

Print Your Name

Birthdate

Open for Questions & Discussion

Thank you for joining us!