Palliating the Complexity of Care in ALS

- Supports Healthy Muscle Function
- Promotes Mobility & Comfort
- Supports Heart & Overall Health
Where does Palliative Care fit in?

Before...

After...
If I lead with my brain, I won’t stumble and fall...

But when we engage without emotion, our hearts get rusty...
If I only had a brain...
If I only had a heart...
If I only had the nerve...
OK, SO WHERE'S THE COURAGE KEPT?
“You, my friend, are confusing courage with wisdom”

– the Wizard
Look closely at what you see...
Ask about what you don’t see…
and explore what you understand lies ahead...
“It’s not about death, it’s really about living with a disease that’s going to kill you; about good living on the way to death”

Joanne Lynn, MD
TIME Magazine, 2000
Why talk about care at the end of life?

✓ You WILL die successfully.
   ...but will you die comfortably?

❖ SUPPORT Study:

Joanne Lynn, MD and Joan Teno, MD

✓ Preferences at the end of life
✓ Medically futile care
✓ Symptom management
The Surprise Question

“Would you be surprised if this patient died within the next year?” within the next 6 months?”
Hospice and Palliative Care Referrals

• **Why?**
  – Advance care planning
  – Symptom management
  – Care coordination
  – Bereavement support

• **When?**
  – Life expectancy of 6 months or less
  – Uncontrolled symptoms
  – Caregiver breakdown/burden

• **How?**
  – Palliative Care Consult through CPRS
  – Community Hospice Programs
Case Study:

Randy, a 35 year old male Veteran seen by his PCP in the private sector for ongoing leg weakness that is unexplainable only when he plays football with his twin 12 year old sons, Joseph and Jared. His wife, Martha, has also noticed that she’s having a difficult time understanding Randy’s speech at the end of the day, when they take time to check-in with each other after the boys are in bed. Upon physical exam, his PCP notes symptoms in both the UMN(bulbar) and LMN (limb) regions which starts him thinking about ALS...

The mean time from the onset of symptoms to confirmation of the diagnosis of ALS is 10-18 months – Experience suggests that pursuing an early diagnosis of ALS outweighs the potential increase in risk of misdiagnosis (EFNS, 2011)

What else do we know about making the diagnosis of ALS?

✓ There’s no single investigation specific for ALS
✓ No single sensitive and specific disease biomarker
✓ Diagnosis is based on symptoms, clinical examination findings and the results of electodiagnostic, neuroimaging and laboratory studies
Case Study:

Fortunately, Randy’s PCP also knows these things to be true, and decides to refer Randy to the local neurologist sooner rather than later...

In line with Chaplain Bernie Jorn’s presentation on Tuesday regarding the patient’s cultural immersion into our arena of health care arena, from the patient’s perspective, what would be important for Randy and his wife to understand about the PCP’s referral to the Neurologist?

✓ Reason for the referral – for assistance in making a diagnosis
✓ Additional testing to be expected – not likely to be a single visit
✓ Diagnosis of ALS requires the absence of several other illnesses – diagnosis is made by exclusion
✓ Time period within which you anticipate Randy should be seen by the specialist, with instructions to call if scheduled otherwise (end visit with same – communicates interest and desire to stay connected as primary provider, empowers patient/caregiver by introducing care as an ongoing collaborative partnership
Case Study:

Upon examination, 3 months later, the Neurologist confirms progression of generalized neuromuscular symptoms in the bulbar and limb regions. He orders a comprehensive work-up, suspecting ALS, but hoping to rule it out by virtue of finding another reason for Randy’s symptoms. One month later, the Neurologist schedules a follow-up visit with Randy and Martha. He reports the findings, explaining that Randy has ALS and that there is no cure for this condition.

1. **Randy and Martha’s immediate response might include**...
2. **In your own practice, where are you when the diagnosis is being given?**
3. **How can we help them cope with this information?**

More than half of surveyed patients and caregivers state that they are dissatisfied by the manner in which the diagnosis has been communicated – Patients/caregivers are more satisfied if effective communication strategies are used, and more time is spent discussing the diagnosis – Callous delivery of the diagnosis may affect the family’s/carers’ psychological adjustment to bereavement later (EFNS, 2011)
Case Study:

Two months later, Randy asks for 2 weeks off from his fulltime job as a reporter with the local newspaper. His legs are getting weaker, and he had a fall at work earlier that same week. Fortunately, he was able to avert too much attention, but was getting more concerned about the increasing weakness. He calls Blue Cross to find out if he can get a second opinion – it’s a covered benefit, but he’s instructed to call his PCP to request the referral… Another month later, he learns that his 2nd opinion, unfortunately, confirms ALS with bulbar involvement and a poor prognosis. Martha persuades Randy to explore natural remedies for ALS that she’s been reading about on the internet. They make arrangements to leave the boys with Randy’s aunt and uncle, telling the twins that they ‘re going on a ‘second honeymoon’. They fly South to participate in a homeopathic treatment for ALS. Randy was started on high dose vitamins and herbal treatments including IV therapy. After 3 weeks, his condition worsened, and they made plans to return home. Checking-in at home, Randy’s uncle tells him he heard a story on NPR about the VA treating Veterans diagnosed with ALS. Randy says, “I’m not a Veteran, I was only on active duty for 2 years – I don’t qualify.”

What’s happening, or not, in this picture?
Case Study:

What’s happening, or not, in this picture?

✓ What happened after his diagnosis?
✓ Was he offered a 2nd opinion?
✓ Was riluzole prescribed?
✓ What’s the f/u, if any, with Neurology and/or his PCP?
✓ How was the information about the diagnosis delivered?
✓ What was the patient/family experience of same?
✓ What about a referral to the ALS Association? (on-line resource and/or nearest ALS Certified Center/local support group)
✓ Who is supporting Randy and Martha?
✓ Who else needs supporting?
✓ Anything else?

Where’s Waldo/ Palliative Care? Is it too early for Palliative Care?
Case Study:

What is Palliative Care?

✓ **Specialized medical care** for people with **serious illnesses**
✓ Care focused on providing **relief from the symptoms**, pain, and stress of a serious illness – whatever the diagnosis
✓ **Goal is to improve quality of life** – for both **patient and family**
✓ **Provided by a team** of doctors, nurses, and other specialists
✓ Work **together with** the patient’s **other providers/team members** to provide an **extra layer of support**
✓ Appropriate at **any age** and at **any stage** in a serious illness
✓ Can be provided along with **curative treatment**

So, is it too early for Palliative Care?
Case Study:

You’re the intake nurse in the VA PCP clinic who gets a call from Martha asking you how soon Randy can be seen by a doctor for evaluation and treatment of ALS. There’s no record in the system indicating he’s enrolled or eligible for VA benefits.

COMPARE NOTES:

✓ What do you tell Martha? What’s the process to get a Veteran patient enrolled at your facility? Is there an expedited process?
✓ How much time does it take for someone to get enrolled at your facility?
✓ Do you know where to transfer Martha’s call?
✓ Remembering the cultural integration challenges, how might you support Martha and Randy as they ‘meet’ the VA?

You tell Martha that once her husband is enrolled, he can expect to be seen within a month’s time. There’s silence on the phone, and, then, in the quiet, you hear Martha crying...
Case Study:

Your sister is one of Martha’s closest friends, and calls you to see if you’ll help Martha get her husband ‘into the system.’ Randy’s 2 week break from work was followed by his boss’s recommendation that he give serious consideration to going out on short term disability. Martha and Randy have exhausted their personal savings, trying to make up the difference between Randy’s salary and his short term disability payment. It’s getting harder and harder for Martha to leave Randy to go to work herself, because he’s falling at least once a week, and insists on continuing to try to do things for himself. Martha is close to depleting her own personal leave, and worries about the twins being at home alone with Randy if he falls.
Case Study:

When you get in touch with Martha, you take particular note as she’s describing Randy’s restlessness at night. On several nights, Martha reports awakening to find her husband sitting on the side of the bed, breathing deep, “like he’s trying to catch his breath.” He tells me he’s fine, and I usually fall back to sleep... He’s eating, but not much, and she worries about him getting dehydrated, especially because he’s coughing more often than not when he drinks, especially water. You’re resourcefulness serves them well, and you’re able to schedule Randy for ALS Clinic that same week. Checking him in for clinic, 2 days later, you see alarm on Martha’s face when she realizes her husband has lost 30 lbs. since he was last weighed, approximately 5 months ago.

As members of the ALS Team, you’ve each read and cosigned the ALS pre-clinic note in CPRS – a note written by the ALS Coordinator highlighting symptoms, changes, and concerns, and entered into CPRS with ALS Team members copied as additional signers. What are the top 3 issues that will be important to address during Randy’s visit?
Case Study:

The clinic visit goes well, with deliberate discussion about the rapid progression of his disease, multiple changes in roles and life patterns, and acknowledging the grief associated with multiple losses.

Watching his twin sons play ball is one of Randy’s greatest pleasures in life, especially because he’s covered all the local high school and Boys and Girls Club activities for the past 7 years. He even talked about how the Army helped prepare him, assigning him as unit photographer and unofficial historian.
Case Study:

You talk several times a week with Martha by phone. Randy’s speech has become too difficult to understand over the phone, but he’s enrolled in My HealtheVet, and you’ve invited him to be in contact with you via e-mail, but he’s slow to engage. What other concerns do you have, and what do you consider most important moving forward... What do Randy and Martha think is most important moving forward...
Case Study:

You arrive at work Monday to a distressed voice mail message from Martha telling you that Randy’s in ICU. She mentions him having a bad cough “maybe the flu” – you log on to CPRS and see that he presented to the ED and was admitted to ICU in respiratory distress. The following activities need to be addressed:
Case Study:

Randy has a PEG tube placed and a trach to help him mobilize his secretions. He will require nocturnal mechanical ventilation and is wheelchair dependent. The following conversations and arrangements need to be happening in order to prepare him for discharge home:

Anticipated psychosocial, emotional, and spiritual challenges might include – who will address them and when...
Case Study:

Randy’s medical condition progresses and he’s now requiring 24 hour skilled care. The day time caregiver assistance and student nurse assistance in the home, provided at 4-6 hours a day, is insufficient, especially given Martha’s need to continue working to maintain their income and health insurance coverage for the rest of the family. Randy’s care is becoming burdensome and he wrestles with the impact his care is having on his family. He’s thinking about what decisions will be in the best interest of his family. He has mixed feelings about his future and the health care decisions that will help determine his future. What options should be discussed to help him make informed choices, and how might he approach these same issues and discussion with Martha and the twins?
Negotiating the Journey

“A process of negotiation between accepting the inevitability of ALS and maintaining quality of life has been identified among ALS service users. Living with ALS may involve ‘abruption’ and ‘disruption’ but it also involves coping with loss through finding new meaning in life and exerting control. The adaptive response is characterized by a cyclical decision making process that seeks to preserve a sense of self and well-being in the face of adversity... ALS care is complex because service users exert control and independence as they negotiate between acceptance of ALS and desire to maintain quality of life. This poses many challenges for service providers as they must remain cognizant of the required negotiation between acceptance and independence while participating in the decision-making process about care. “ (Foley, ALS, 2011, p. 160)
What Helps Patients Disclose Concerns?

Promote Disclosure
- open-ended questions
- focus on psychological aspects
- empathic statements

Inhibit Disclosure
- leading questions
- focus on physical aspects
- advice and reassurance

- James Tulsky, Duke
Emotion Handling Skills (NURSE)

Name
“Some people would be angry...”

Understand
“It must be hard going through this alone”

Respect
“I am so impressed by your commitment to your mother”

Support
“I’ll be with you throughout all of this”

Explore
“Tell me more...”

Adapted from Family Meeting Guide, © 2010 Robert Arnold & Judith Nelson
Self Care:

AGREE or DISAGREE:

“‘I’m only as good as I feel’”

“Taking care of others is more important than taking care of myself”

“Taking care of myself takes time that I don’t have”

“I can take care of others well, even if I don’t take very good care of myself”

Self care involves taking time for anything that brings you pleasure, enjoyment, relaxation or replenishing.

“You can’t draw water from an empty well”
“remind yourself, affirm yourself, be kind to yourself”

Veterans with ALS and their caregivers need your partnership and your example...