The University of Arizona Health Sciences

The CARES Toolkit

End-of-Life **Ca**ses and **Res**ources:

An Interprofessional Toolkit for Health Science Students

Case Study

Interprofessional: 30-Year-Old White Man Living with ALS

Case Title

Case Summary

Encounter Setting

After hours call to group practice.
IP enhancement: The group practice includes physicians, nurse practitioners, nurses, medical assistants and administrator.

Ex. Community site, home, clinic, ED, hospital, assisted living, long-term care nursing home

Context / Reason for Encounter

You are taking after hours call for your group practice. You receive a call from Carol, who identifies herself as a nurse and girlfriend of Dr. Stephen Jones. She explains that she lives with and takes care of him. You know Stephen - he is a recent graduate from the family medicine program where you are a faculty member. You had heard he was diagnosed with ALS (Amyotrophic Lateral Sclerosis) shortly after finishing his residency program. Carol is crying - their usual doctor is out of the country, “His doc makes home visits and takes care of Stephen,” she explains. “We ran out of morphine for Stephen yesterday. Today he’s really, really in a lot of pain.” You decide to make a home visit; he lives a few blocks from you.

Reason for Encounter: Severe pain

Ex. Background/sets the stage; include cultural beliefs/perspectives, ADLs/IADLs,suicide ideation or risk of

Demographics

Gender

Male (he, him)

Age or Date of Birth

30-years-old

Ethnicity

White

Living Situation

Stephen lives with his partner, Carol; owns house.

Ex. Living in house/apartment/mobile home/homeless (unhoused), number of people in home, do they feel safe at home or in neighborhood, primary language/languages spoken at home

Patient Occupation

Family Physician, self-employed but unable to work now.

Stephen moonlighted during residency on free weekends providing substitute coverage (locum tenens) that paid $200 per hour but provided no health benefits. He continued this work after finishing his residency. At the time of his ALS diagnosis six months ago he was self-employed.

Insurance Coverage Status

Uninsured, Self-pay

Eligible for the following benefits/services

Family / Caregiver Issues

Stephen's partner, Carol, took family medical leave from her job as an ER nurse to take care of him.

One or more caregivers, family caregivers, paid caregiver, etc.

Social History

Social Economic Status

Social Determinants of Health

Ex. Food or housing or transportation insecurity; utility need; financial resources; childcare; education; employment instability; legal resources; social isolation; health literacy

Social / Mental Health Wellbeing

Religious / Spiritual Considerations

Cultural Beliefs / Perspectives

Patient Health Information

History of Present Illness

Dr. Jones is a 30-year-old male with severe (8 out of 10) pain increasing over the last 24 hours. He was diagnosed with Amyotrophic Lateral Sclerosis (ALS) six months ago, shortly after finishing his residency program. His course has been rapidly progressive, and he is now very emaciated and weak, limited to his bed. Steven says he is very anxious – partially because of the severe pain, but he also worries about his debts - his $250,000 in student loans and $300,000 house mortgage. He has no way to pay off his debt now. Carol says that over the past few weeks Stephen is not interested in food and is able to take only small sips of juice and water due to difficulty in swallowing. He is no longer able to carry on daily living activities – he cannot feed himself, ambulate or use his arms or legs.

Illness Course / Treatment Information

Physical Exam

Vital Signs: Ht: 6ft 2in; Wt: 135 lbs; Pulse: 92; BP: 90/64; Respiratory Rate 18

General: Emaciated male, lying immobile in a hospital bed in his living room. He immediately recognizes you and smiles. He answers questions in a barely audible whisper, and nods or shakes his head for yes/no answers. He winces in pain as you gently examine him.

Neurologic: Alert, oriented to person, place and time. His reflexes are brisk, with several beats of clonus in his upper extremities. He has a Babinski sign on the right foot, and a Hoffman's sign in his right thumb and index finger.

Musculoskeletal: Upper and lower extremity muscles are atrophied throughout. He has muscle fasciculations in his thighs and calves.

Skin: There are no decubitus ulcers nor evidence of skin breakdown.
Lungs: Shallow respirations

Heart: Tachycardia at 92, no murmurs

Abdomen: Bowel sounds are present. No masses.

Genital: Foley catheter in place, dark colored urine is trickling slowly into the bag.

Rectal: Declined. The stool in hemoccult negative.

Medications / Treatments

Morphine sulfate liquid 10mg/ml every 8 hours as needed for pain.

Allergies / Intolerances

No allergies.

Tobacco, Alcohol, or Substance Abuse

Tobacco: none; Alcohol: none.

Review of Systems

Include mobility, cognition, mood; do they need assistive devices? Does living environment impact mobility?

Past Medical History

No significant past medical history.

Include alternative medicine preferences; cultural perspectives

Family History

He has no children or siblings. No history of ALS in the family. His 58-year-old mother is healthy. His dad died of an acute myocardial infarction at age 62.

Health & Community Services

Is the Patient Currently Receiving or Will They Need Any New Home and/or Community-Based Services?

Healthcare Services:

Eligibility / Enrollment / Contact Information

Community Services:

Eligibility / Enrollment / Contact Information

Overall Assessment

Acute, severe pain in a patient with advanced ALS.

Advance Care Planning

- Comfort measures
- Do not hospitalize, intubate, or place feeding tube
- He wishes to die at home if possible

Please provide details/scenario about serious illness or end-of-life conversations with the patient, family and/or providers; and indicate if the patient has any Advance Directives on file

What Matters Most to the Patient Now?

He is in severe pain and wants relief as soon as possible.

What Do They Want Their Health For?

Comfort measures only; wishes to die at home.

“What matters most?”

Next Steps / Outcomes

What Happens Next?

1. What health services might Dr. Jones be eligible for that he can receive at home?
2. What can be done to better control his pain and anxiety?
3. What health insurance coverage might Dr. Jones be eligible for in his current condition?
4. What more do you need to know about his current directives, or if he wishes to modify them?
5. What can be done about his financial situation – affordable care, medications, respite care, accrued student loan debt, mortgage? Who will assume his obligations?
6. What policy issues need attention in terms of health professions education costs?

Details About Family Conversations

What Happens at, or Near, Death of Patient?

What Support Does Family Need Before and After Death of Patient?

Challenging Conversations

Best / Worst Case

Risk / Benefit of Intervention

Interprofessional Focus

What Role Do Other Disciplines Play in This Patient's End-of-Life Care?

Nursing - personal care guidance, symtpom assessment, support of caregiver
Pharmacy - medication management of pain and other symptoms
Public health - access to community support services

Who Can Help You Provide the Best Care and Honor the Patient's Wishes?

How Will You Approach Utilizing a Team Approach to Providing Care?

Beyond Referrals, How Will You Become Comfortable with Going Outside Your Comfort Zone?

Are there any Integrative, Traditional, or Complementary Therapies that will Help the Patient at this Stage or Later?

Questions to Consider

Can You Identify Any Overarching Bias?

Can You Identify Any Possible Assumptions One Might Make About This Patient?

What Information About This Patient Might Inform Public Policy or Regulatory Action?

Teaching Points

Indicate 3-5 Teaching Points in this Case

☑ **ADVANCE CARE DIRECTIVE**

Teaching point: Each health science student should be

- knowledgeable about advance care directives; and
- be able to communicate and engage patients/families in advance care planning across settings and across the lifespan.

☑ **PALLIATIVE CARE AND HOSPICE**

Teaching point: Each health science student should be

- knowledgeable about palliative care and hospice and
- be able to effectively communicate this information to patients/families.

☑ **CULTURAL HUMILITY**

Teaching point: Each health science student should be

- knowledgeable about knowledgeable about cultural considerations in the care of patients and families, and
- be able to effectively communicate with humility, curiosity, care, respect, & dignity.

☑ **COMMUNITY RESOURCES**

Teaching point: Each health science student should be

- knowledgeable about community resources to support serious illness and end of life care, and
- be able to effectively connect patients/families with these resources.

☑ **CHALLENGING CONVERSATIONS**

Teaching point: Each health science student should be

- knowledgeable about how to deliver “best case/worse case” and
- be able to effectively conduct challenging conversations with patients/families (including how to discuss risk/benefits of interventions).

☑ **INTERPROFESSIONAL CARE**

Teaching point: Each health science student should be

- knowledgeable about the role of team members & benefits of team-based care and
- be able to effectively work with team members in the care of patients/families with serious illness or at the end of life.

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