



# Welcome

## Coffee Chat: End of Life Considerations

June 7, 2017

We will begin promptly at 2:30 p.m. EDT.

**Event Host**  
National Health  
Care for the  
Homeless Council



# Coffee Chat: End of Life Considerations

June 7, 2017



Health Care and Housing are Human Rights





# Panelists



## **Mark Fox, MD, PhD, MPH**

- Associate Dean and Director and Professor of Medicine and Pediatrics, Indiana University School of Medicine – South Bend
- Distinguished Adjunct Professor of Theology, University of Notre Dame



## **Annette Mendola, PhD**

- Director of Clinical Ethics, University of Tennessee Medical Center



# Overview

- Getting to know the audience
- Learning objectives
- Case Study #1 and discussion
- Case Study #2 and discussion
- Advance directives
- Q&A



# Audience Professional Positions





# Audience Work Environment





# Audience Age





# Learning Objectives

- Explore approaches and challenges related to caring for people who are homeless at end of life
- Engage in discussion of about relevant case studies
- Highlight strategies and resources for responding to challenging situations





# Case 1: Deborah



- “Deborah” is a 58 y/o Caucasian woman, anorexic, chronic inebriate, with virtually no social support. Medical diagnoses are spotty due to lack of follow through. Most notable for cirrhosis, esophageal varices, thrombocytopenia. Averages a dozen emergency room/hospitalizations each month. Highly suspicious of cancer, never fully evaluated. BH conditions include severe alcohol use disorder, borderline personality disorder, generalized anxiety disorder and severe depression.
- Grew up in foster care, multiple traumas. Extremely difficult to place in housing due to numerous evictions. High suspicion for Korsakov’s syndrome which profoundly inhibits her ability to follow through and be available for planned apartment searches. Client is reluctant to consider assisted living because of loss of income, and assistant living providers are reluctant to consider chronic inebriates.
- Focus 5 years ago was on behavioral health needs, particularly alcohol use disorder. Ct was successfully “sober” for 9 months which revealed agoraphobia. Loneliness complicated her recovery and she slowly decompensated back to severe use. There was a cascade of incidents with her landlord after 9 months incident-free. She was evicted and placed 2 times in subsequent months. The end result has been homelessness in spite of continued interest in housing her. Everyone who serves her has expected her to pass away at any time.



# Questions



- What decisions need to be made? Who should make the necessary decisions?
- What are possible courses of action?



## Case 2: Sam



- “Sam” is a 54 y/o gentleman who was admitted due to abdominal pain. He has multiple medical problems, including stage IV colon cancer and schizoaffective disorder. His prognosis is poor, but cannot be predicted with much certainty; likely weeks to months.
- He is divorced and has no children. He is estranged from most of his family, but has a sister who has remained involved in his life. She is willing to help with care planning and decision making, but is not willing to take him into her home.
- He has been intermittently homeless, sometimes staying in a hotel. Reportedly, when he stays in the hotel sometimes friends come to visit; they use his pain medication recreationally together, which leaves his pain untreated later.
- Sam is also a registered sex offender, which has complicated placement; many facilities will not take a patient with such a history, and some cannot due to proximity to schools and daycares.



# Questions



- What are the relevant facts?
  - Are any missing? If so, what?
  - What could we learn that would change the landscape?
- Who are the stakeholders? What is at stake for each?
  - [Who is vulnerable, and to what?]
- What decisions need to be made? Who should make the necessary decisions?
- What are possible courses of action?



# Potential Barriers



- Diminished and episodic decision making capacity
- Limited ability to provide history
  - Paper charts and EMR may be from multiple sources
- Increased risk for morbidity/mortality due to violence, poor nutrition, exposure, substance abuse, inadequate social support
  - Homelessness exacerbates mental illness



# Potential Barriers



- Difficulties with insurance/payment systems
- Transience
  - Limited/fractured relationships with family
  - Poor coordination of care
  - Multiple case managers
  - Inability to track records or find Advance Directives if they do exist



# EOL: Special Concerns in the Context of Homelessness



- Loss of dignity [especially the indignity and lack of compassion of being labeled]
- Dying alone [some want reconciliation with family, but more just wanted a compassionate presence at EOL]
- Disposition of their body [e.g. dying in public and not being found; buried or cremated in a mass grave, being treated in a culturally inappropriate manner]
- Not being remembered by anyone



# EOL: Special Concerns in the Context of Homelessness



- Fear of having doctors “pull the plug” on them
  - &/or looking for someone to give them permission to terminate lifesaving treatment
- Fear of being “experimented on”
- Loss of control, loss of privacy
- Inadequate pain management





# Preferences for Surrogates



- Most people who are homeless would like to have family make decisions for them if they are incapacitated
- Those who don't have family or don't want family to make their decisions may prefer physician surrogates over court appointed guardians
- Providers should seek an additional perspective
  - Ethics committees
  - Second physician



# What are Advance Directives?



- Take effect IF/when a patient loses decision making capacity
- Living Wills
- Surrogate decision makers
  - Patient-designated, physician-designated
  - Decision making standards
    - Substituted judgment
    - Best interests
    - “Synthetic” judgment



# Value of Advance Directives in Context of Homelessness



- Some research suggests that people who are homeless highly value the opportunity to complete ADs
- Lack of a consistent surrogate
- Loss of control in daily life
- Experiences with end of life
- Experiences in/with institutions
  - Fragmented care
  - Treated with varying degrees of compassion and dignity



# Advance Directives and Homelessness: Challenges



- Health care providers need to know whether an AD has been prepared and how to access it
- ADs are not always clear guides to a person's wishes
- People who are homeless may need special help to complete ADs
  - Literacy, health literacy
  - Fear, lack of trust



# Advance Directives



- SELPH AD is an Advance Care Planning form that was designed for use by people who are homeless
  - for health care planning only; not about money or property
- Help the person think about acceptable treatment outcomes in specific, functional terms
  - What is important for you to be able to *do* and *experience* in order for your life to be worthwhile?



# Forthcoming Resources on End-of-Life Care



- Caring for People Experiencing Homelessness Facing End of Life
  - Learning Lab at National Health Care for the Homeless Conference, Saturday, June 24, 2017: 8:30 AM-12:30 PM, Washington DC
  - Register here: <https://nhhc.confex.com/nhhc/2017/registration/call.cgi>
- Adapting Your Practice: Recommendations for End-of-Life Care for People Experiencing Homelessness (*Document to be published Summer 2017*)



# Questions & Answers



## **Mark Fox, MD, PhD, MPH**

- Associate Dean and Director and Professor of Medicine and Pediatrics, Indiana University School of Medicine – South Bend
- Distinguished Adjunct Professor of Theology, University of Notre Dame



## **Annette Mendola, PhD**

- Director of Clinical Ethics, University of Tennessee Medical Center

# Thank you for your participation.

Upon exiting you will be prompted to complete a short online survey. Please take a minute to complete the survey to evaluate this webinar production.

