

Adapting Your Practice

Recommendations for End-of-Life Care for People Experiencing Homelessness

Health Care for the Homeless

Clinicians' Network

2018

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Preface

Clinicians experienced in caring for individuals who are homeless routinely adapt their practice to foster better outcomes for these patients. This document was written for health-care professionals, program administrators, other staff, and students serving patients facing end of life who are homeless or at risk of homelessness. Its purpose is to enhance understanding of end-of-life care among experienced homeless services providers and among primary care providers who are less experienced in the care of homeless and other marginalized people.

Standard clinical guidelines often fail to take into consideration the unique challenges presented by homelessness that may limit access to needed services or the ability to adhere to a plan of care. To address this oversight, the Health Care for the Homeless (HCH) Clinicians' Network has made the development of recommended clinical practice adaptations for the care of impoverished people experiencing homelessness one of its top priorities. Since 2002, the Network has developed and revised recommendations for the management of health problems that are common among homeless people and are particularly challenging for their caregivers. These recommendations are available at www.nhchc.org.

End-of-life care for people experiencing homelessness was identified as a Network priority in 2015. In October 2016, the Clinicians' Network Steering Committee met with leaders of the Respite Care Providers' Network (RCPN) and the National Consumer Advisory Board (NCAB) to define the guidelines' major content areas. In January 2017, an advisory committee comprising health and social service providers experienced in end-of-life care for underserved populations was convened to develop recommendations for end-of-life care for people experiencing homelessness. These recommended practice adaptations reflect their collective judgment about end-of-life care for this population.

The recommendations in this document specify what experienced clinicians know works best for patients experiencing homelessness, with the realistic understanding that limited resource availability in local areas, fragmented health care delivery systems, and lack of follow-up often compromise adherence to optimal clinical practices. We hope that these recommendations provide helpful guidance to health care professionals serving individuals facing end of life who are homeless or at risk of homelessness and that they will contribute to improvements in both quality of care and quality of life for these patients.

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INTRODUCTION

Homeless populations have diverse and complex end-of-life needs (McNeil, Guirguis-Younger, & Dilley, 2014). Chronic diseases and mortality rates are high in the United States, especially in homeless and underserved populations. The number of older adults without homes will rise to 95,000 by 2015. This is evident already in Health Care for the Homeless programs that have seen a 51% increase in the number of persons over the age of 50 between 2004 and 2008 (Knopf-Amelung, 2013).

Some people living in homelessness experience sudden deaths on the streets from exposure or violence, but most deaths are the result of illness or chronic health conditions. In a study of deaths among homeless adults in Boston, investigators found that death most often occurred in a hospital or residential dwelling; exposure to cold caused only 4 of 606 deaths (Rousseau, 1998). There are high mortality rates among people experiencing homelessness, who often die of conditions that are more easily treated in people with stable housing, such as pneumonia, influenza, HIV/AIDS, liver disease, renal disease, cold-related injuries, and cardiac arrhythmias (Hwang et al., 2001). Because they lack access to health care for chronic health conditions, many people living in homelessness also die as a result of heart disease, cancer, lung disease, and other chronic illnesses.

This publication will present recommendations for providing end-of-life care for people experiencing homelessness in a variety of settings. First, it will present information relevant for diagnosis and evaluation, followed by recommendations on establishing a plan of care and options for models of care. This guideline is intended to be used in cases where individuals have already been diagnosed with a life-limiting illness.

Clinical practice guidelines for people who are homeless employ the same standards of care as for people with stable housing. Nevertheless, primary care providers who routinely serve homeless individuals recognize an increased need to consider living situations and co-occurring disorders when

working with these patients to develop a plan of care. The practice adaptations recommended in this document are based on a comprehensive review of published reports and consensus opinion of clinicians with expertise in homeless health care, palliative care, and end-of-life care. These recommendations are intended to be consistent with the standard clinical guidelines listed below. Their purpose is to facilitate adherence to these standards in the care of impoverished, displaced persons with multiple medical and psychosocial problems.

Summary of Recommended Practice Adaptations for End-of-Life Care for People Experiencing Homelessness

These recommendations of the HCH Clinicians' Network were created by the Advisory Committee on End-of-Life Care for People Experiencing Homelessness, whose members have expertise in homeless health care and end-of-life care.

Patient Assessment and Evaluation

1. Focus primarily on assessing the social, emotional, mental, and environmental needs that affect the delivery of care for the terminally ill patient experiencing homelessness.
2. Focus the initial physical exam on the patient's area of concern or areas most likely to be affected given the diagnosis or chief complaint. Perform serial focused exams as tolerated (if needed). Attempt to evaluate the stage of the patient's condition. Look for evidence of occult alcoholism or addiction.
3. Practice trauma-informed care during the physical examination and in all patient encounters, recognizing that individuals who are homeless are likely to have experienced some form of previous trauma.
4. Many screening tools are available to evaluate a patient's functional status, mental health, and pain. As completing multiple assessments can be overwhelming, evaluate which assessments are necessary at each visit and limit the number performed according to the patient's verbal and nonverbal cues.

Goals of Care

1. Providing the best in care at the end of life requires that providers assist their patients in clarifying their priorities for making treatment decisions and establishing goals of care. Terminally ill patients should be allowed to maintain a sense of control by taking an active part in their own treatment.
2. Goals of care are individual choices that may be different from those of the health care team but should be respected and honored.

3. Recognize that both Western medicine and integrative, complementary, and alternative medicine (ICAM) are options in end-of-life care to ensure optimal comfort for some patients.
4. Employ a harm-reduction philosophy regarding addiction, placement (patients may choose to stay outside), and medication adherence (both mental health and medical treatment).
5. Providers should work with teams and ensure that self-care and mutual support are an integral component of all programs.

Advance Care Planning

1. Identify opportunities throughout the spectrum of health care for implementing processes to assist patients experiencing homelessness in end-of-life planning and completion of advance directives.
2. Assess cultural influences that might affect end-of-life care decision making.
3. Allow the terminally ill patient to maintain a sense of control by taking an active part in his or her own treatment.
4. Offer assistance in completion of advanced directives, including medical power of attorney, living will, and DNR.
5. Consider the necessity of executing financial and mental health care powers of attorney and drawing up a last will and testament for the proper disposal of the patient's possessions and financial resources.
6. Develop educational materials for use by members of the health care team in assisting patients in completing advance directives.
7. Distribute easily executed advanced directive forms that do not overwhelm or confuse the patient with unnecessary information.
8. Identify and facilitate the optimal means for personal storage and access to the advanced directives for the patient experiencing homelessness.

9. Use state registries to both file and access a patient's advanced directive to ensure that a patient's end-of-life health care wishes are honored in the event of a medical emergency that may require hospitalization.

Pain and Symptom Management

1. Encourage local shelters to permit adaptations in routine for patients with serious or life-limiting illness who may require daytime rest, oxygen concentrators, secure locations to store controlled medications, and other special accommodations.
2. Investigate options for assisting patients who require opioid therapy and choose to remain in street environments, such as providing storage for personal belongings.
3. Patients with legitimate needs for opioids to control their pain and who are at risk for opioid abuse, diversion, or theft may need modifications in opioid prescribing such as smaller quantities at more frequent intervals, a lockbox to store medication if in a shelter environment, and/or dosage adjustments for high levels of pain tolerance with attention to the potential for undertreatment resulting from "pseudoaddiction."
4. Recognize that patients who obtain their food from congregate dining rooms or from discarded or inexpensive sources may have difficulty modifying their diets to manage GI symptoms. They may need education as well as extra support in identifying resources for obtaining, purchasing, and storing food.
5. Providers should be aware that patients near end of life who reside in a respite center where they expect to spend their final days may need to be transferred to an inpatient hospice unit for severe symptom management to ensure their comfort and safety.
6. Anticipate the impact of the dying process on other residents of a respite or group living environment who may witness events such as seizures, bleeding, or the death itself. Preparations

should be made to provide emergent management and supportive care when needed. If a hospice agency is involved, it may be able to assist in the process and also provide emotional and psychological support to affected residents and staff if such an event occurs.

Substance Use and Mental Health

1. Adopt nonexclusionary practices that facilitate engagement in care. This could include eliminating policies that require sobriety as a precondition for admission, as is the case in many shelter-based programs.
2. Consider a harm-reduction framework in the provision of hospice and palliative care. Examples might include interventions such as having needle exchange services readily available and prescribing medications that address opioid withdrawal such as methadone and suboxone.
3. Provide medications that reduce alcohol cravings and implementation of managed alcohol programs for individuals who desire to continue alcohol consumption at the end of life.
4. Prioritize therapeutic alliance and flexible treatment approaches over rigid treatment adherence. (This includes supporting a patient's decision to discontinue psychotropic medication.)
5. Ensure parity in the availability of mental health treatment and medical care.

Social Supports

1. Engage the terminally ill patient in a conversation regarding life review.
2. Access community, government, and societal resources necessary to ensure that the terminally ill patient experiencing homelessness receives the care necessary to ensure a good death.
3. Discuss family dynamics: who needs to be contacted? Who should NOT be contacted?
4. Shelter pets may need placement during hospice or after death.
5. Inventory personal belongings; do not forget storage units and secret hiding places.
6. Discuss funeral arrangements and care of remains after death occurs.

7. Explain bereavement services, provided free of charge, to family and loved ones after the patient's death.

Benefits and Entitlements

1. Multiple types of benefits are available through Social Security, Medicaid, the Veterans Administration, and Health Care for the Homeless Services.
2. Connect the person to the local Health Care for the Homeless grantee for homeless specific resources and care.
3. Working with a benefits-and-entitlements case manager or specialist to assist in evaluating and applying for entitlement benefits at end-of-life can help to maximize supports.

Spiritual Components

1. Allow for expression of spirituality as defined by the patient.
2. Engage patient in the life review process, keeping mindfully aware of grief-related issues that may emerge because of the patient's medical condition, housing status, and comorbidities.
3. Identify friends and loved ones of the patient to assess for anticipatory grief and grief responses to the death of the patient, and make necessary referrals to community resources for aftercare.

Models of Care

1. Evaluate the continuum of existing local services to identify gaps in end-of-life care for those experiencing homelessness.
2. Determine how the HCH organization can build relationships with existing community resources and create programs designed to fill in the gaps identified.

Patient Assessment and Evaluation

Major Recommendations:

1. Focus primarily on assessing the social, emotional, mental, and environmental needs that affect the delivery of care for the terminally ill patient experiencing homelessness.
2. Focus the initial physical exam on the patient's area of concern or areas most likely to be affected given the diagnosis or chief complaint. Perform serial focused exams as tolerated (if needed). Attempt to evaluate the stage of the patient's condition. Look for evidence of occult alcoholism or addiction.
3. Practice trauma-informed care during the physical examination and in all patient encounters, recognizing that individuals who are homeless are likely to have experienced some form of previous trauma.
4. Many screening tools are available for evaluating a patient's functional status, mental health, and pain. As completing multiple assessments can be overwhelming, evaluate which assessments are necessary at each visit and limit the number performed according to the patient's verbal and non-verbal cues.

Rationale: Complex medical and psychosocial issues associated with homelessness often warrant a limited physical exam or deferral of the physical exam or other evaluations until a therapeutic relationship is better established. A history of trauma, common among homeless people, may present psychological barriers to a comprehensive examination, which can be reduced through an approach to care that makes the patient feel safe and in control.

Evidence: Recommendations are based on expert consensus of practitioners experienced in homeless health care with expertise in end-of-life care and behavioral health care.

Sources: Hopper et al., 2010; Hwang et al., 2008; Morrison, 2007; Waldmann in O'Connell, 2004

The assessment process represents an opportunity for a care provider to foster a therapeutic alliance with a patient. This section will present detailed guidelines for taking a patient's history, conducting a physical exam, and using appropriate assessment and diagnostic tools. As underlying guidelines for the assessment and evaluation process, it is recommended that care providers seek to

1. Explain your medical or service background, what you can offer, and any limitations relevant to the service provision setting.
2. Acknowledge the power and importance of giving the patient the opportunity to tell his or her story.
3. Operate on the basis that people have the right to be heard without judgment.

History

Initial history. The most important goals of history taking are to allow patients to tell their stories and feel heard nonjudgmentally and to build confidence that, as their provider, you have their best interests in mind while obtaining important medical information. Many people experiencing homelessness have negative associations with medical settings and providers, so gaining the patient's trust may take extra effort. Providers may ask different questions, depending on the setting and pathway to engagement for those facing end of life; for example, history taking in outpatient/clinic or outreach settings will differ greatly from that conducted in inpatient settings.

1. ***Introductory questions:*** Initiate conversation with a few open-ended, general background questions that demonstrate interest in the patient and allow for the establishment of rapport. For example: “*How old are you? Where are you from originally? How long have you been in this city/town? How are you feeling today?*” These questions are relevant to the patient’s well-being, self-image, and goals and can help confirm your interest in his or her health.
2. ***Provider’s experience and limits of clinical setting:*** Briefly explain your medical background and what your facility might have to offer the patient; for example: “*I am a physician, and I have been doing health care for the homeless work for 20 years. I specialize in internal medicine and also addiction medicine. This clinic is equipped to provide comprehensive health care.*”
3. ***Information to be requested:*** Explain that you are going to ask about the patient’s physical health, mental health, and history with substances. At the first visit, ask about substance use or not, based on the level of engagement, what the patient has reported so far, and estimation of whether or not the patient will be able to respond truthfully. Recognize that a shorter interval between visits can facilitate follow-up and help establish necessary rapport.

The clinician will often have current relevant diagnostic information in the inpatient setting that will bring the conversation to the course of the illness. In the outpatient setting, many patients are presenting with functional impairments and physical presentations of cachexia, pain, and fear and are often brought in by friends who are concerned about rapid decline. The patient may or may not have diagnostics, imaging, or lab results from outpatient or emergency department admits revealing potentially life-limiting conditions that did not receive follow-up.

Course of illness. Ask the patient to describe the course of his or her primary illness, including when it was diagnosed, who has been treating him or her, what treatment(s) he or she has received, and how he or she has responded to treatment. The course of illness requires that the clinician attend closely to the patient's mood and his or her own emotional reactions to the patient. Inquire about prior treatment, which may entail gathering records from multiple past episodic events. In some cases, patients who are facing end-of-life or life-limiting illness have had partial workups or even partial courses of treatment that were abandoned. Even fairly routine workups may have been complicated by the patient's homeless status.

It is also important to assess whether a long-term therapeutic alliance is being established or if it is a one-time visit. If there is any suspicion or confirmation that the patient is facing a life-limiting illness, and if the attending clinician is not going to be able to form a long-term alliance, then it is key to ensure a "warm hand-off" and a commitment from care team providers, such as specialists, social workers, community-based resources, or peer specialists.

Symptoms. Ask about current symptoms associated with the patient's primary diagnosis, how problematic they are for the patient, and what the patient is doing to manage his or her symptoms. Focus on functionality; for example, if the patient is in end-stage COPD, has he or she been able to use his or her oxygen as needed while homeless? If the patient has urogenital or colorectal disease, is increasing fecal or urinary incontinence affecting him or her? (If the patient uses alcohol, he or she may not be attuned to the changes in bowel habits that herald malignancy.) What pain is presenting? Is the patient able to describe differences between his or her past and current pain levels to help you understand whether you are dealing with malignant pain or chronic pain?

- Look for a plausible origin for symptoms.

- Identify factors that intensify or alleviate symptoms, with special attention to factors related to homelessness; this is a good place to focus on the possibility of substance use as alleviating or aggravating symptoms.
- Specific assessment tools for pain assessment may be found in the Assessment section.

Medical history. Obtain history of other medical illnesses, surgical history, or mental health problems. If the patient has had positive engagement with other care providers, including mental health providers, those connections can be regenerated; where current engagement exists, care coordination may be offered. Patients should be helped to understand that the life-limiting condition does not preclude care for other nonmalignant problems (e.g., dental care, vision care, foot care, etc.).

Medications. Review any prescriptions, over-the-counter medications, herbs, teas, ointments, and supplements that the patient takes.

Allergies. Ask whether the patient has any allergies that should be accounted for.

Family history. Ask questions about the patient's family history of illnesses, with special attention to whether there is a family history of the patient's presenting illness.

Social history. Determine current living situation, especially as this relates to functional impairments and access to medical care for inpatient encounters. Ask patients about their living situations to assess residential stability and the possibility that they are homeless.¹ (*Where do you live? Who lives there with*

¹ A homeless person, as defined by the Bureau of Primary Health Care, is “. . . an individual without permanent housing who may live on the streets; stay in a shelter, mission, single room occupancy facility, abandoned building or vehicle; or in any other unstable or non-permanent situation. An individual may be considered to be homeless if that person is ‘doubled up,’ a term that refers to a situation where individuals are unable to maintain their housing situation and are forced to stay with a series of friends and/or extended family members. In addition, previously homeless individuals who are to be released from a prison or a hospital may be considered homeless if they do not have a stable housing situation to which they can return. A recognition of the instability of an individual's living arrangement is critical to the definition of homelessness.” (*Principles of Practice: A Clinical Resource Guide for Health Care for the Homeless Programs*, Bureau of Primary Health Care/HRSA/HHS, 3/1/99; PAL 99-12)

you? How long have you lived there? Where did you sleep last night? Where will you sleep tonight?") Ask where they sleep and spend time during the day and how they can be contacted. Ask explicitly about access to food, water, shelter, restrooms, and a place to store medications. Assess environmental factors that may threaten health and safety. If the patient is staying in a shelter/vehicle on the street or in any other unstable living situation, ask if this is the first time “without a home,” recognizing that some people are reluctant to admit that they are homeless or don’t consider themselves homeless if staying with a relative or friend. Try to determine whether residential instability is chronic or episodic. Try to understand the circumstances that precipitated homelessness and explore available housing options, recognizing that chronic pain management is especially difficult without stable housing ([HCH Clinicians' Network, 2010](#)). Ask about the patient’s gender identity and sexual orientation. Ask about travel history, which may help with the diagnosis of primary and secondary conditions.

Other questions relevant for end-of-life care may include the following:

- How will this person get to follow-up appointments?
- Are there transportation programs available in the state to transport unsheltered patients to medical appointments?
- Are resources available for caloric supplements, food, or nutrition?
- Does the patient have access to bathrooms and hygiene supplies?
- How might literacy and primary language affect access to follow-up care?
- What types of social support exist, such as family, friends, or agencies, that the patient would want contacted in case of emergency or a decline in his or her condition? This is often a time when folks who are estranged from family members may become willing to discuss reconnection with siblings, parents, or children, although this conversation can be particularly sensitive.

- Is there past or ongoing substance use? In some cases, patients with life-limiting illnesses may be using substances that mask their malignant pain.
- What financial resources exist for the patient, including income from employment, other sources of income, or health insurance?

Assess patient perception of prognosis. Determine what the patient has been told to expect and/or what course he or she expects his or her illness to follow in the future. Some patients may have a perception that “short and sweet” is preferable to “endless suffering,” which may be related to inequalities in care and poor allocation of resources in impoverished communities. This may also be an appropriate time to initiate discussion of advance directives and whether or not the patient has identified a surrogate decision maker or durable power of attorney for health care. Because advance directives vary by state, it is important that clinicians know local procedures in this regard. Clinicians should be aware that, particularly in this population, a patient’s prognosis may change after implementation of the care plan. Patients in poor living conditions may appear to be very close to the end of life; however, if they are able to reside in a supportive environment with consistent meals, adequate sleep, and availability of necessary medications, they may stabilize and improve clinically. This presents unique challenges for providers, who may have to help patients transition from one model of care to another over the course of time.

Physical Examination

Physical exam. For many patients who are homeless, a full-body, unclothed, comprehensive exam is not possible until a therapeutic relationship has been established between the provider and the patient.

It is important to practice trauma-informed care² during all patient visits, as many people experiencing homelessness have experienced previous trauma. At the initial visit, perform a focused physical exam pertinent to the patient's chief complaint and diagnosis, if known. Pay attention to the patient's comfort level as well as verbal and nonverbal cues. Always describe each step of the exam and why it is necessary if that is not clear from the patient's understanding of his or her condition before it is performed and make sure that you have the patient's permission for each part of the exam before proceeding. As you evaluate an area, describe your findings. Be prepared to find other signs of possibly unrelated conditions common among people experiencing homelessness, including infections, infestations, or signs of current or past alcoholism or addiction. As patients experiencing homelessness may experience delays in accessing health care, they may have a more advanced initial physical exam than patients who present earlier in course of the illness.

Some elements of a regular physical examination may not be possible depending upon the environment where patients are encountered, and care providers need to develop the flexibility to adapt to their surroundings, but whenever possible, these components should be part of the physical exam:

- a. Vital signs, including blood pressure, pulse, pulse oximetry, temperature, respiratory rate, height, weight, and BMI at each visit as the patient permits. If possible, identify the patient's baseline weight before the start of the illness.
- b. In addition to the physical exam pertinent to the patient's chief complaint or diagnosis, at the first visit and then as indicated going forward on or serial focused exams at subsequent visits, the head and neck, chest, heart, lungs, abdomen, lower extremities,

² Trauma-informed care is “a strengths-based framework that is grounded in an understanding of and responsiveness to the impact of trauma that emphasizes physical, psychological, and emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment” (Hopper, et al., 2010, p.82).

upper extremities, skin, lymph nodes, and neurologic system should be examined to assess the extent of disease. If a genital exam is indicated, assess if the patient has a history of sexual trauma and make sure that he or she feels comfortable with this exam. If possible, offer patients the option to have an examiner of the gender with which he or she feels most comfortable. Identify whether the patient has any implanted or inserted medical devices, such as a pacemaker, AICD, port, drains, or PICC line or whether he or she is using oxygen, and confirm that there are no signs of infection, poor wound healing, or other abnormal findings.

- c. Functional exam: As the patient walks, assess his or her gait, stability and risk for falls, ability to sit and stand, general strength, and nutritional status. Assess if the patient needs assistive devices, such as a cane, walker, or wheelchair. Perform focused exams as indicated. Consider the use of validated exams to evaluate strength or risk of falls, such as
 - i. Get Up and Go Test: https://www.ons.org/sites/default/files/TUG_Test-a.pdf
 - ii. Physical Performance Test (9 items): <http://www.brightonrehab.com/wp-content/uploads/2012/02/Physical-Performance-Test-PPT.pdf>
- d. General appearance and mental status. Assess the patient's general appearance, including assessment of weight, build-up of fluid, signs of muscle wasting or cachexia, grooming, and skin color (looking for pallor, jaundice, or other changes). Assessing a patient's mental status and capacity for medical decision-making at baseline and at each visit is also important, as this can change as a patient's illness progresses or as a side effect of medications. A patient's mental status can be assessed by his or her responses during conversation and through different tools, such as those listed below.

- i. Mini Mental Status Exam—A screening tool for assessing cognitive impairment:
<https://www.mountsinai.on.ca/care/psych/on-call-resources/on-call-resources/mmse.pdf>
 - ii. A common, simple assessment is to assess whether a patient is awake, alert, and oriented to person, place, and time (AAOx3)
- e. Clinical signs of impending death: Patients in the last 12–72 hours of life may exhibit clinical signs that death is imminent, including episodes of apnea, Cheyne-Stokes breathing, the death rattle, cyanosis of peripheral extremities, decreased or lack of radial artery pulse, decreased urine output, respiration with mandible movement, dysphagia with liquids, or decreased level of consciousness. (Hui et al., 2014)
- i. If the patient has requested comfort care, as opposed to aggressive life-prolonging care, the physical exam is often even more abbreviated, focusing on observation, palpation of pulses and extremities, and limited auscultation.
- **A note about trauma survivors:** Be aware that a high percentage of people experiencing homelessness have experienced physical, sexual, and/or emotional abuse. Homeless women and transgendered persons are among those at highest risk for sexual and physical assault ([Kushel et al., 2003](#)). Practice trauma-informed care ([HCH Clinicians' Network, 2010 Dec](#)), which means being sensitive to the patient's comfort level and paying attention to nonverbal cues; do whatever she or he can tolerate at the time. Schedule a return visit within a short period of time and plan frequent follow-up encounters to complete the examination. If a history of sexual abuse is suspected, a necessary genital examination could be deferred until the patient is ready. Whenever possible, offer patients the option of being examined by a health care provider of the gender with which he or she

is most comfortable. To decrease anxiety, explain the purpose of each visit and what the patient can expect to happen. Always explain what you are going to do before touching the patient; describe what you are looking at or palpating while you perform the procedure; and if it is normal, say so. Stress what is healthy about the person during the examination.

Assessment, Screening, and Diagnostic Testing

Specific assessment, screening, and diagnostic testing depends on the individual patient's diagnosis, previous work-up and treatment, and prognosis. Assess what the patient knows about his or her diagnosis and treatment plan. If the patient plans to continue care with you, ask the patient's permission to request past records, including imaging tests, blood work, pathology reports, progress notes, treatment records, and contact information for the specialists treating the patient, as indicated. You may need to have the patient sign a release of information form to request records and can also look on health information exchanges or regional health information organizations (RHIOs).

If obtaining prior records is not possible, depending on the diagnosis, baseline labs, including a CBC, CMP (including albumin to assess nutritional status), PT/INR, PTT, urinalysis, A1C, HIV test, hepatitis serologies, or tumor markers could be helpful. Consider a urine drug screen to identify substance abuse that could affect a patient's care. Imaging and other diagnostic testing depends on the specific illness. Before ordering any test, explain to the patient why each test is necessary and obtain permission, as patients may not want certain tests performed. Some patients may decline, defer, or want to space out diagnostic testing. If a patient's vital signs or clinical condition suggest that he or she is unstable, consider sending the patient to the hospital for emergency care.

Depending on the underlying end-of-life condition, palliative options may be available that can extend life and/or decrease symptoms of the condition, such as palliative radiation or chemotherapy

for some cancers. If a patient has not been referred to a specialist who could provide palliative treatments, discuss risks and benefits of potential options. If the patient is interested in palliative therapies, on the referral describe past workups and explain any situations unique to your patient that would help the specialist in treating the patient. Depending on the situation, particularly if a patient has difficulty describing his or her medical history or navigating the health care system, or you can foresee other barriers to care, contacting the specialist ahead of time or after the visit can be helpful to coordinate care and ensure that the patient receives the care that he or she needs. If the patient permits and it is logistically feasible, it can help to bring a friend, family member, social worker, member of the homeless care team, or someone else that the patient trusts to the appointment who can help with providing collateral history, offering clarifications if the patient does not understand, or assisting with the next steps of follow-up from the appointment.

For all life-limiting conditions, assessing a patient's physical, psychological, and functional status is important for identifying appropriate support services, along with a plan for obtaining them. However, performing multiple assessments or answering too many questions at one visit can be overwhelming for a patient. Evaluate which assessments are necessary at each visit and limit the number performed according to the patient's verbal and non-verbal cues. Evidence-based, validated, commonly used tools are listed below, but depending on the patient's willingness to participate in these assessments, conversation with the patient to assess his or her pain, functional status, and mental health can also be effective. (All descriptions and the definition of functional status are from the National Palliative Care Research Center: <http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx>.)

1. Functional status is defined as “an individual's ability to perform normal daily activities required to meet basic needs, fulfill usual roles, and maintain health and well-being” (National Palliative Care Center, 2013). As a patient's condition changes, he or she may experience a

decline in functional status and ability to care for him- or herself. Validated tools to assess functional status include the following.

- a. Karnofsky Performance Scale: commonly used for assessing terminally ill cancer patients, often used to determine appropriateness of hospice referral.
http://www.npcrc.org/files/news/karnofsky_performance_scale.pdf
- b. ECOG Performance Status: a tool for doctors and researchers to assess how a patient's cancer is progressing, how the disease affects the daily living abilities of the patient, and how to determine appropriate treatment and prognosis.
http://www.npcrc.org/files/news/ECOG_performance_status.pdf
- c. Palliative Performance Scale: measures the functional status of a patient and assigns a Palliative Performance Value; serves as a communication tool for quickly describing a patient's current functional level.
http://www.npcrc.org/files/content/pps_for_distribution_2015_-_with_watermark_sample.pdf
- d. Katz Index of Independence in Activities of Daily Living: assesses the ability of patients to conduct activities of daily living.
http://www.npcrc.org/files/news/katz_index_of_independence_in_activities_of_daily_living.pdf
- e. Edmonton Functional Assessment Tool (EFAT): a tool to evaluate functional performance of patients with advanced cancer over time and to document the degrees of functional performance of patients throughout the terminal phase.
http://www.npcrc.org/files/news/edmonton_functional_assessment_tool_EFAT.pdf

2. A patient's mental health can also change over the course of a chronic illness. For example, as Dr. Elisabeth Kübler-Ross described, over the course of a terminal illness, a patient can experience five stages of grief, including denial, anger, bargaining, depression, and acceptance (1969). If social workers are members of a health care team, they often have additional training and experience in performing mental health assessments. Validated screening tools to assess patients' and caregivers' psychological needs include the following:
 - a. PHQ2 & PHQ9: validated screening tool for depression in general populations
<https://www.uspreventiveservicestaskforce.org/Home/GetFileByID/218>
 - b. Geriatric Depression Scale (GDS) Short Form: a 15-item screening tool for symptoms of depression in the elderly. <http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx>
 - c. Geriatric Depression Scale (GDS) Long Form: a 30-item screening tool for symptoms of depression in the elderly.
http://www.npcrc.org/files/news/geriatric_depression_scale_long_form.pdf
 - d. Hamilton Depression Rating Scale: provides an indication of depression and, over time, provides a guide to progress.
http://www.npcrc.org/files/news/hamilton_depression_scale.pdf
 - e. Caregiver Strain Index: a tool that measures strain related to care provision. Used to assess individuals who have assumed the role of caregiver for an older adult.
http://www.npcrc.org/files/news/caregiver_strain_index.pdf
3. A psychosocial assessment should account for the following:
 - a. Relevant past and current health situation (including the impact of problems such as pain, depression, anxiety, delirium, and decreased mobility)

- b. Family structure and roles
- c. Patterns/style of communication and decision making in the family
- d. Stage in the life cycle, relevant developmental issues
- e. Spirituality/faith
- f. Cultural values and beliefs
- g. Patient's/family's language preference and available interpreter services
- h. Patient's/family's goals of care, including preferences for end-of-life care
- i. Social supports, including support systems, informal and formal caregivers involved, and identified surrogate decision-maker(s)
- j. Resources available, and barriers to access
- k. Past experience with illness, disability, death, and loss
- l. Mental health functioning, including history, coping style, capacity, literacy, crisis management skills, and risk of suicide/homicide
- m. Unique needs and issues relevant to special populations such as refugees and immigrants, children, and individuals with severe and persistent mental illness
- n. Communicating the patient's/family's psychosocial needs to the interdisciplinary team
- o. Pre-bereavement assessment for patient's support network and/or family

4. Pain and Other Symptoms Assessment: It is important to assess and address a patient's pain and other symptoms of terminal illness and its treatments, including fatigue, nausea, constipation, weakness, excess secretions, and confusion. Validated tools include the following:

- a. Wong-Baker FACES Pain Rating Scale: a visual analog scale

http://www.npcrc.org/files/news/wong_baker_FACES_pain_rating_scale.pdf

- b. 0-10 Pain Rating Scale:

https://healthy.kaiserpermanente.org/static/health/pdfs/pain/nat_painscale_english.pdf

- c. Brief Pain Inventory Short Form & Long Form: a pain assessment tool for use with cancer patients. Provides information on the intensity of pain (the sensory dimension) as well as the degree to which pain interferes with function (the reactive dimension).

http://www.npcrc.org/files/news/briefpain_short.pdf

and http://www.npcrc.org/files/news/briefpain_long.pdf

- d. Brief Fatigue Inventory: a tool to rapidly assess the severity and impact of cancer-related fatigue. http://www.npcrc.org/files/news/brief_fatigue_inventory.pdf

- e. McGill Pain Inventory Short Form: a questionnaire incorporating a series of adjectives to describe the characteristics and intensity of pain.

http://www.npcrc.org/files/news/mcgill_pain_inventory.pdf

- f. Needs at the End-of-life Screening Tool (NEST): a comprehensive assessment and outcome measures instrument.

http://www.npcrc.org/files/news/needs_end_of_life_screening_NEST.pdf

- g. Edmonton Symptom Assessment Scale (ESAS): a brief screen to determine if certain common symptoms are present, and their severity.

http://www.palliative.org/NewPC/_pdfs/tools/ESAS-r.pdf

5. Assessment of Physical and Cognitive Function: The following indices may be useful in providing a snapshot of the physical and cognitive functioning of patients:

- o Mini Mental Status: <http://www.dementiatoday.com/wp-content/uploads/2012/06/MiniMentalStateExamination.pdf>

- Montreal Cognitive Assessment (MOCA): <http://www.mocatest.org/>
- Mental Residual Functional Capacity: <http://ssaconnect.com/tfiles/SSA-4734-F4-SUP.pdf>
- Physical, Occupational therapy evaluations for safety in self-care such as fall risk, etc.:
<http://www.aafp.org/afp/2001/0715/afp20010715p299-f2.pdf>
- Physical Functional Residual Capacity, an SSI form:
<https://secure.ssa.gov/apps10/poms/images/SSA4/G-SSA-4734-U8-1.pdf>

Plan and Management

When developing an end-of-life plan of care, patient-centered care and advocacy are key. Care plans can be designed to alleviate suffering and enhance self-determination, although the specific approach will vary depending on whether the patient is sheltered or unsheltered. Care plans should account for the patient's own goals by asking questions such as:

- What does the patient want? What are his/her hopes?
- What end-of-life options are available?
- Which end-of-life treatment options are accessible to the patient?
- Are there cultural influences to consider as barriers to end-of-life care?
- What are some of the barriers to end-of-life and palliative care for this patient?
- What are my own beliefs that may affect my influence on the plan?

This section contains information on developing care plans and advance care planning while accounting for personal autonomy, pain and symptom management, substance use and mental health, social supports, benefits and entitlements, and spiritual components of end-of-life care.

Goals of Care

Major Recommendations:

1. Providing the best in care at the end-of-life requires that providers assist their patients in clarifying patients' priorities for making treatment decisions and establishing goals of care. Terminally ill

- patients should be allowed to maintain a sense of control by taking an active part in their own treatment.
2. Goals of care are individual choices that may differ from those of the health care team but should be respected and honored.
 3. Recognize that not only Western medicine but also integrative, complementary, and alternative medicine (ICAM) are options in end-of-life care to ensure optimal comfort for some patients.
 4. Employ a harm-reduction philosophy regarding addiction, placement (patients may choose to stay outside), and medication adherence (both mental health and medical treatment).
 5. Providers should work with teams and ensure that self-care and mutual support are integral to all programs.

Rationale. Recommendations are based on expert consensus of practitioners experienced in homeless health care with expertise in end-of-life care.

Patients facing end of life often have decisions to make about various treatment options, especially when to stop attempts at curative treatment and elect comfort care only. It is incumbent on care providers to avoid making assumptions and decisions without clarifying what is most important to the patient. Some patients may want aggressive treatment with a goal of prolonging life to the greatest extent possible, while others may choose to place greater priority on goals such as comfort, independence, and avoiding hospitalization. Gaining an understanding of the patient's priorities will enable the health care team to provide care that is appropriate and consistent with the patient's wishes.

One of the main tenets of end-of-life and palliative care is to ensure that the terminally ill patient achieves a good death. Research has shown that a good death has certain themes; the top three are a specific dying process, pain-free status, and emotional well-being. However, in reality, a good death can

be defined only by the one experiencing it. Therefore, open communication about goals and values must take place. Fostering a therapeutic alliance is essential to the process.

One of the most important aspects of end-of-life or palliative care has been the ability to discuss death openly with the patient. End-of-life conversations are often difficult for providers and patients. These conversations are often intense and can be emotional. As difficult as they may be, they are necessary. Certain aspects of care must be discussed. However, providers must recognize and be aware

ICAM

Many patients are interested ICAM, either for belief in cure or for management of terminal illness. There is evidence that a variety of ICAM modalities can be helpful as an adjunct in terminal illness, including but not limited to Traditional Chinese Medicine, acupuncture, massage, meditation, prayer, guided imagery, laughter therapy, yoga, healing touch, Reiki, aromatherapy, nutrition, and supplements. These modalities can serve as useful adjuncts for alleviating symptoms. Many patients are using ICAM and not discussing it with providers. It can be helpful to identify if your patients are using or interested in any ICAM modalities and helping with referral if needed. There are often free or low cost resources that may be located and accessed in many communities.

If your patient is using ICAM modalities in belief of cure for a terminal illness, particularly instead of Western modalities, it is important to avoid alienating them or endorsing a cure that doesn't have evidence, while also avoiding instilling false hope for treatments whose efficacy is not substantiated by available evidence. For example, one could say that while these modalities may be curative for some individuals, some treatments may not be evidence-based. (See Estores & Frye, 2016; Leong, 2015; National Health Care for the Homeless Council, 2008.)

of cultural considerations when undertaking this task. It may not be possible for some individuals in many cultures to talk about these important issues. Patients and families from Native American, Asian, and other cultures may be reluctant to discuss the prospect of death openly. In the United States, there is more openness and emphasis on patient autonomy and the right to make decisions. For more information on cultural influences on end-of-life decision making and death-related issues, see Appendices.

Terminally ill patients who have mental capacity must be involved in decision making about the type of care

they receive, regardless of their prognosis. Patients may seek curative or comfort care, and open communication about options available to the patient is an ethical responsibility of medical providers caring for them. Patients experiencing homelessness, much like the frail elderly (<http://medical-dictionary.thefreedictionary.com>), are a vulnerable population and can be susceptible to exploitation. Respect for the dignity and value of the individual person should be the basis for all conversations about end-of-life and palliative care options.

Some terminally ill patients find their suffering to be intolerable and seek ways to hasten their death. For these patients, every attempt should be made to provide optimal symptom management, provide comfort care, and attend to their existential suffering. They may be given the option to withdraw further aggressive or life-sustaining treatments such as chemotherapy, dialysis, ventilator support, or pacemaker support of cardiac activity. Patients may also choose voluntary cessation of food and fluid intake. In some circumstances, a more aggressive intervention such as palliative sedation may be considered. "Death with Dignity," also referred to as physician-assisted death, is currently legal in seven states. This option is available to patients who reside in a state that has enacted statutes to permit this practice and respects the right of both patients and providers to act according to their own ethical principles. Further information about "Death with Dignity" and state-by-state information is available at www.deathwithdignity.org/learn/access.

While the choice to stop life-saving medications is within the rights of each individual, it can be challenging for the practitioner. All clinicians and service providers are encouraged to work with teams and talk openly with their colleagues about any difficulties they are having with patient choices.

Another sometimes-challenging conversation for practitioners to have with patients is a discussion about integrative, complementary, and alternative medicine (ICAM). Not all patients, including patients experiencing homelessness, want allopathic/Western medicine.

Advance Care Planning

Major Recommendations:

1. Identify opportunities throughout the spectrum of health care for implementing processes to assist patients experiencing homelessness in end-of-life planning and completion of advance directives.
2. Assess cultural influences that might impact end-of-life care decision making.
3. Allow the terminally ill patient to maintain a sense of control by taking an active part in his or her own treatment.
4. Offer assistance in completion of advanced directives including the medical power of attorney, living will, and DNR.
5. Consider the necessity of executing a financial power of attorney, drawing up a last will and testament for the proper disposal of the patient's possessions and financial resources, and a mental health care power of attorney.
6. Develop educational materials for members of the health care team to use in assisting patients in completing advance directives.
7. Distribute easily executed advanced directive forms that do not overwhelm or confuse the patient with unnecessary information.
8. Identify and facilitate the optimal means for personal storage and access to the advanced directives for the patient experiencing homelessness.
9. Use state registries to both file and access a patient's advanced directive to ensure that a patient's end-of-life healthcare wishes are honored in the event of a medical emergency that may require hospitalization.

Rationale. Research shows that homeless adults are interested in and able to document advance care plans and worry about what will happen to them if they lose capacity for medical decision making. Patients in homeless circumstances have increased morbidity and mortality in comparison with their housed peers, may not be in close contact with their health care proxy when an emergency occurs, and may have difficulty storing advance care documents and ensuring that they are accessible in the event of an emergency. For these reasons, providing opportunities for discussion, documentation, and accessibility of advance care planning documents is critical. Homeless adults often have different comorbidities, experiences with the health care system, barriers to care, and views about health care in comparison with their housed peers, which health care providers must consider when assisting with advance care planning.

Terminally ill patients have the right to make decisions about the type of care they receive. Research shows that homeless adults are interested in and able to document advance care plans, including appointing a health care proxy and discussing code status and care they would want in different situations, but rarely have the opportunity (Leung et al., 2015; Song et al., 2010; Song et al., 2007; Norris et al., 2005). In comparison with their housed peers, people experiencing homelessness often have contrasting realities with the health care system, including barriers to care and views about health care in general. In addition, they suffer vastly different comorbidities (Culhane et al., 2013). It is important to discuss and document advance care planning wishes with homeless patients, as with all patients, while they have capacity for medical decision making (Farrell et al., 2016). (See Patient Assessment and Evaluation Section above: Assessment of Physical and Cognitive Function scales.)

Other key barriers to end-of-life care services for people experiencing homelessness include:

- 1) Insufficient availability for palliative and end-of-life service sites for the completion of legal advance care directives and the DNR.

2) Operating procedures that link advanced directive documents to one centralized depository that stores all legal documents for all health-care providers to use.

Patients coping with homelessness may be less able to appoint a health care proxy, which complicates care if they lose capacity for medical decision making and become “unbefriended.” The size of the surrogateless and unbefriended homeless populations in the United States, both domiciled and undomiciled, are unclear; the unbefriended rate is estimated to be between 3–4% in nursing homes (Williamson et al., 2016; Karp & Wood, 2003). The United States lacks a systematic societal approach to address surrogatelessness and unbefriendedness. Different states use different approaches, including public guardianship, volunteer advocate programs, “external committees of trained volunteers,” partnering nursing home staff with patients to serve as advocates if they lose capacity for medical decisions, and nonprofits building relationships with patients and then acting as “conservators” in the future (Bandy et al., 2014; Connor et al., 2016). Allowing people experiencing homelessness to understand and sign advanced directives will improve their quality of life and peace of mind, and they will be empowered to know that they are in control of their end-of-life decisions with a sense of grace and dignity.

End-of-life education offers providers an opportunity to address other concerns and/or issues about death and dying with patients, which may include:

- Fear that they will be anonymous, unacknowledged, and unmemorialized after death
- Fear of providers not delivering appropriate care, including stopping life support or withdrawing pain and/or supportive measures
- Fear of what happens to their bodies after death (i.e., cremation, body given to medical research)

- Fear of sudden, violent death or a painful, prolonged death

If a patient's condition is incurable, it is important to discuss with the patient what to expect as the illness progresses. It is important to discuss cardiopulmonary resuscitation and invasive procedures, such as feeding tubes, drains, or catheters, any of which may be required if the patient's condition deteriorates, and what he or she can expect if these procedures are performed, depending on the severity of his or her condition.

Another important issue health care providers should not overlook when assisting patients experiencing homelessness with advanced planning is the need to ensure that the patient's personal effects are distributed at the time of death in accordance with his or her wishes. Often, patients experiencing homelessness have certain items that are meaningful to them that they wish to have given to either family or friends. Either the health care proxy or someone on the health care team may take care of the task after the patient's death. A simple will and testament is easily completed. (See the Appendix section of this document for an example.) Forms for each state can be found at

<https://www.lawdepot.com/contracts/last-will-and-testament-usa/#.WTHVZjOZPPA>

This process of completing a last will and testament can be an empowering experience for the patient, taking pride in knowing that what little he or she may have will have meaning and live on after he or she is gone. Other considerations in this category include the following:

- Recording the patient's oral history
- Compiling photographs and mementos into a scrapbook
- Writing letters to loved ones and friends
- Finding safe homes for pets once the patient can no longer care for them

The purpose of advance directives is to provide information about an individual's wishes with regard to end-of-life treatment that will serve to guide medical decision making in the event that the individual no longer has the capacity. The extent to which advance directives are useful depends on a

POLST, MOLST, and DNR

- ✓ POLST (Practitioner Orders for Life-Sustaining Treatment) or MOLST (Medical Orders for Life-Sustaining Treatment) are synonymous terms for actionable medical orders that specify which treatments a patient is to receive near the end of life. Patients complete them with their health care providers when they are expected to have one year or less to live. The name of the document used and items included on the orders are state-specific. Some states have registries for these documents and/or make them accessible electronically throughout the spectrum of health care. (See reference list for links to the forms for different states; see Appendices for a sample POLST document).
- ✓ Do Not Resuscitate (DNR) documents are not medical orders and specify only whether CPR and aggressive resuscitation should be attempted in the event of cardiopulmonary arrest. They are still used in many locales; however, unlike a POLST or MOLST document, DNRs do not give specific direction about care near the end of life. If POLST or MOLST documents are not available in a given state, then patients should complete DNR forms when they no longer wish to have cardiopulmonary resuscitation attempted.

variety of factors, including how clear and specific they are, how accurately they reflect an individual's desires when the time comes that serious illness necessitates their use, and whether or not surrogate decision makers and the medical team caring for the patient have access to the document. Research shows that homeless adults are interested in and able to document advanced care plans, including appointing a health care proxy and delineating preferences for end-of-life care, but they rarely have the opportunity. They are more likely to complete advance directives when they receive assistance from trained counselors (Sumalinog et al.,

2016). The importance of end-of-life education and advance care planning becomes particularly acute for those patients with a terminal illness and should be accomplished while they still have capacity for medical decision-making.

Barriers to completion of advance directives for those patients experiencing homelessness include the following:

- lack of trust in health care providers
- poor continuity of care
- not having a family member or friend whom they would want as a surrogate decision maker
- inadequate supportive services

Going where people experiencing homelessness congregate means that advance directives may need to be completed in health care institutions, drop-in centers, soup kitchens, shelters, and medical service sites. Allowing patients experiencing homelessness to understand and sign advance directives will improve their quality of life and peace of mind, and they will be empowered to know that they are in control of their end-of-life decisions, maintaining their grace and dignity.

For advance directives to be useful, they must be accessible to the medical team and surrogate decision makers. To this end, some states and organizations have developed advance care registries, wallet-sized cards, and mobile phone apps, as described below. For each locale, determine and use the optimal means of storing and accessing the advance directives. Encourage patients who have already completed advance directives to provide a copy to their health care provider(s) as well as any named health care proxies and to use one of the storage options available in their community.

In particular, when working with people experiencing homelessness, it is important to use systems set up in each state to increase the likelihood that a treating hospital can access a patient's advance directives in an emergency. The poor transfer of health care information across the health care system may significantly affect patients experiencing homelessness who lack a health care proxy with whom they are in close contact or a place to store documents (Morrison et al, 1995). To address these

problems, some states, including Arizona, California, and Montana, have developed advance care registries; others, including Idaho, New York, and West Virginia, have registries for MOLST/POLST documents (see Advance Directives section for more information). Some states and organizations, including the American Bar Association and the Healthcare Association of New York State (HANYs), have developed portable, wallet-sized cards and mobile phone apps documenting health-care proxy information that a hospital could access directly from an unresponsive patient in case of emergency.

For excellent information and resources for advanced directive information readily available for the public, see this document's appendices as well as the following websites:

- <https://www.compassionandchoices.org/eolc-tools/>
- <http://www.pbs.org/newshour/updates/decisions-future-documents-need-2/>

Pain and Symptom Management

Major Recommendations:

1. Encourage local shelters to permit adaptations in routine for patients with serious or life-limiting illness who may require daytime rest, oxygen concentrators, secure locations to store controlled medications, and other special accommodations.
2. Investigate options for assisting patients who require opioid therapy and choose to remain in street environments, such as providing storage for personal belongings.
3. Patients who have legitimate needs for opioids to control their pain and who are at risk for opioid abuse, diversion, or theft may need modifications in opioid prescribing such as smaller quantities at more frequent intervals, a lockbox to store medication if in a shelter environment, and/or dosage adjustments for high levels of pain tolerance with attention to the potential for undertreatment because of “pseudoaddiction.”

4. Recognize that patients who obtain their food from congregate dining rooms or from discarded or inexpensive sources may have difficulty modifying their diets to manage GI symptoms. They may need education as well as extra support in identifying resources for obtaining, purchasing, and storing food.
5. Providers should be aware that patients near end of life who reside in a respite center where they expect to spend their final days may require transferral to an inpatient hospice unit for severe symptom management to ensure their comfort and safety.
6. Anticipate the impact of the dying process on other residents of a respite or group living environment who may witness events such as seizures, bleeding, or the death itself. Make preparations to provide emergent management and supportive care when needed. If a hospice agency is involved, it may be able to assist in the process and to provide emotional and psychological support to affected residents and staff if such an event occurs.

Symptom management is one of the main ways to provide comfort and dignity to patients at end of life. Anticipating the symptoms that are likely to occur for a given diagnosis will facilitate the implementation of individualized care plans. The primary focus should be on prevention, when possible, and then treatment as symptoms occur.

Regardless of whether a patient resides in supportive housing or a respite center or with family or friends, he or she may have increasing difficulty in going to an outpatient setting to see a provider for symptom management. Using the services of palliative care or hospice teams is encouraged for patients nearing end of life. Those who are eligible and willing to sign up for hospice services will benefit from regular nursing visits, assistance with personal care, and provision of necessary medication, as well as support from chaplaincy and social work. If acute symptoms require more intensive interventions, the

patient may be transferred to an inpatient hospice unit. An additional advantage of hospice enrollment is that it may help the patient avoid unnecessary and burdensome hospital visits.

Social isolation is problematic for many patients experiencing homelessness. Assess the support network available to each patient to determine whether willing, reliable, and competent individuals are available to provide assistance. Educate potential caregivers regarding management of expected symptoms, and make them aware of the potential requirement for increasing care as the patient nears death.

Terminally ill patients often present with multiple symptoms that require assessment and treatment. The following validated tools may be useful in making an initial assessment:

- The revised Edmonton Symptom Assessment Scale
- Memorial Symptom Assessment Scale-Short (MSAS) Form and Condensed MSAS
- MD Anderson Brief Symptom Inventory
- Rotterdam Symptom Checklist
- Symptom Distress Scale
- Memorial Delirium Assessment Scale
- Confusion Assessment Method (CAM)

For more information on symptom management in the context of serious illness, the Medical College of Wisconsin curates a library of short “Fast Facts” that provides recommendations regarding symptom assessment and management: <https://www.mypcnow.org/fast-facts>.

Pain. Pain control is one of the most challenging and important tasks for caregivers of patients who are at end of life and who need palliative care. Multiple studies have documented that pain is often untreated or undertreated despite a wide variety of available pharmacologic and nonpharmacologic

treatment options. Medical providers treating patients with life-limiting illness should use every means possible to achieve optimal pain control while avoiding excessive unwanted side effects. The context of homelessness, especially in combination with substance use and mental illness, presents additional challenges to medical providers. The following are general guidelines and recommendations helpful to medical providers caring for people who are homeless or marginally housed at end of life.

Accurate pain assessment is crucial to developing a plan for pain control. Perform an initial complete assessment that takes into account the type, severity, duration, and characteristics of the patient's pain as well as the pain's effect on the patient's ability to function. Although many standardized tools exist and may be used for this assessment (see the National Palliative Care Research Site at <http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx>), many providers prefer to use simpler tools to gather the information and follow the patient's pain through course of treatment. Standard pain rating scales of 1–10 are commonly used and widely understood. Always encourage patients to describe their pain in their own words. A patient's description of pain intensity should always be considered accurate, and the medical team should also be alert to assess the patient's emotional response to the pain he or she is experiencing.

In 1990, the World Health Organization outlined a stepwise ladder for choice of pharmacological agents in the treatment of pain. While this stepwise approach has been widely used for many years and may be helpful for some patients, clinicians recognize that many patients with terminal illness require opioids for effective analgesia and that stepwise approaches to care should not be a cause for delaying adequate pain treatment.

Three general types of pain have been described and comprise broad categories that may guide additional choices of pharmacological agents for treatment. Cancer pain crosses through all three of these categories.

- **Visceral pain** is poorly localized and frequently described as cramping or squeezing. It is common in cancer patients who have abdominal metastases (e.g., biliary or colonic obstruction). Adjuvant therapy aimed at the etiology of the pain should be added to opioids. This may mean mechanical means of reducing gastric peristalsis and secretions, such as a drain or catheter. Sometimes corticosteroids are used (for example, to reduce edema surrounding tumors).
- **Neuropathic pain** is often described as burning or tingling and has a radiating character. It may be constant or intermittent. SSRIs, SNRIs, tricyclic antidepressants, or anticonvulsants are commonly used as adjuvant agents, and multiple medications may be required.
- **Somatic pain** is usually well localized and may be pressure-like or aching. Its source is skin or musculoskeletal, and it usually responds to nonsteroidal anti-inflammatory agents and corticosteroids. Frequently, narcotics alone cannot control bone pain, requiring the addition of one of these agents, bisphosphonates, or, possibly, palliative radiotherapy.

Opioids are a mainstay treatment for pain at end of life. Tables are available to determine equianalgesic doses of commonly used opioid medications. Providers should be comfortable using these tables to assist with dosage conversions when switching from one opioid to another or when treating a patient with hepatic or renal dysfunction. Patients requiring multiple doses per day of a short-acting agent should be started on a long-acting agent, with continuation of the short acting agent for anticipated breakthrough pain. Different dosage forms (e.g., concentrated elixirs, skin patches and gels, or rectal suppositories) may also be used in individual situations in which standard oral dosing is challenging. Dosages should be adequate to control pain but as low as possible to avoid adverse reactions. Opioids may require rotation because of organ dysfunction or clinical changes such as

impaired swallowing. If opioids are rotated, providers must be comfortable with making dosage reductions to accommodate incomplete cross-tolerance.

Patients experiencing homelessness with serious illness and a legitimate need for opioids to control pain present special challenges because of heightened concerns regarding potential medication abuse, diversion, or theft. Some patients resist leaving the street environment to receive care in a respite center or shelter because of their ongoing illicit substance use, inability to tolerate a congregate setting, or unwillingness to leave partners or pets. Even healthy homeless persons with prescription pain medications become targets for medication theft; when seriously ill, they become more vulnerable. To provide safe pain control for these types of patients, seeking innovative solutions may be necessary, such as providing secure storage of belongings in “low-demand” or family shelters. Concerns regarding possible drug diversion may be addressed in cooperation with a hospice provider who may choose to prescribe smaller quantities of narcotics more frequently or be able to provide secure storage.

Terminally ill patients with addiction disorders may require higher-than-expected doses of opioids because of pre-existing tolerance. For providers, distinguishing between patients who exhibit inappropriate behaviors to obtain more narcotics due to inadequately treated pain (sometimes called “pseudoaddiction”) and patients who are seeking narcotics purely for the euphoric effects becomes more important. Inadequate pain treatment should be assumed until patterns emerge to suggest otherwise. It is particularly helpful for these patients to receive care in a respite center with medical capabilities or an inpatient hospice unit if possible to be able to better assess narcotic requirements for pain control. Pseudoaddiction symptoms will resolve with adequate pain treatment. Drug-seeking behavior is likely to persist regardless of treatment.

For a complete and thorough explanation of pain management in patients with substance-use disorders, access the following resources for up-to-date guidance and recommendations.

- <https://www.asam.org/public-resources/pain-and-addiction>
- <https://www.accp.com/docs/bookstore/psap/p7b05.sample03.pdf>
- <http://www.pharmaceutical-journal.com/learning/pain-management-in-patients-with-a-substance-use-disorder/20069490.article>

Respiratory symptoms. One of the most common symptoms near the end-of-life is dyspnea—difficulty breathing or shortness of breath. Although providers may anticipate dyspnea with lung cancer, COPD, or CHF, it is seen in most diseases at end of life. Nonpharmacologic measures to relieve dyspnea may be available through the hospice team, including respiratory therapies such as breathing training, portable oxygen, and chest physiotherapy. Durable medical equipment may include oxygen concentrators or equipment to minimize exertional dyspnea, such as a hospital bed, walker, wheelchair, overbed table, or bathroom aids. Additional items such as small fans and extra pillows are good options. Adapting the patient’s living environment by arranging items to minimize exertion is also quite helpful. In cases that require medication, use the following:

- Systemic opioids are the most effective pharmacologic agents and are the treatment of choice for symptomatic control of dyspnea. Studies have shown that judicious use of opioids for dyspnea does not hasten death.
- Patients with low oxygen saturations may benefit from oxygen supplementation. Providers may need to work with local shelters to make special arrangements for patients who require oxygen. Importantly, remind patients and caregivers that oxygen is a fire hazard and can cause fires that result in severe burns and even death. To prevent loss of services due to nonpayment of bills, it is imperative that local electric and gas companies have the necessary documentation on file indicating that one of their customers is using oxygen.

Neurologic Symptoms. Agitation and delirium are the most common neuropsychiatric complications seen in patients nearing the end of life and can result in distress for patients, caregivers, and health care providers. Delirium is an alteration in consciousness with impaired ability to maintain focus or shift attention. It is a change in cognition or the new onset of a disturbance in perception that differs from evolving dementia, and it has a variable course. Several causes have been identified, some of which are reversible:

- Narcotics
- Benzodiazepines
- Brain tumor/metastases
- Cancer treatments
- Psychotropic medications
- Metabolic factors including electrolyte imbalances, dehydration, organ failure (especially liver and renal failure)
- Infections

A balanced approach begins with identifying and treating the underlying cause of the agitation and delirium, if possible. If symptoms are severe and the patient is on hospice, he or she may need transferral to an inpatient hospice unit for care. The hyperactivity may take several hours to resolve after the underlying cause is corrected. If a reversible cause cannot be found and pharmacologic treatment is necessary, haloperidol or another neuroleptic agent such as olanzapine, risperidone, or aripiprazole would be the treatment of choice and, if swallowing is impaired, may be available in orally-dissolving tablets for easier administration. Benzodiazepines should be used with caution because they may worsen the delirium.

Agitation and anxiety may be confused with delirium, and a careful assessment is advised prior to treatment. Agitation and anxiety can usually be managed with short-acting benzodiazepines if pharmacologic treatment is necessary. Restlessness and agitation may be part of a terminal delirium or arise from other psychological or physical distress. For practical purposes, determining the exact cause may not be possible. However, if a patient has been treated for delirium and is still agitated and distressed, the addition of a benzodiazepine may be helpful.

Seizures may be caused by metastasis to the brain, electrolyte imbalances, or other neurologic injury. For patients with a known seizure disorder, the current effective anticonvulsant medication should be continued if the patient can swallow. Provide non-oral anticonvulsant medications for those who cannot swallow or who are expected to lose the ability to swallow when death is imminent. Benzodiazepines are commonly used to treat active seizures, and providers may choose an agent with a long half-life to prevent future seizures. Some benzodiazepines can be given sublingually (e.g., lorazepam) or rectally (e.g., compounded diazepam), if the oral route is unavailable. For a person with new onset seizure, the goals of care, location of the patient, and type of level of care available will guide evaluation and treatment.

Bleeding. Obvious or occult bleeding occurs in 10–20% of persons with advanced cancer. Multiple potential sources of bleeding include fungating malignant tumors, tumors that invade large vessels, variceal hemorrhage in end-stage liver disease, and bleeding as a consequence of a coagulopathy. When a risk of catastrophic bleeding is present, it is important to plan ahead and advise the patient, family, or caregiver whom to call, depending on established goals of care and directives given by the patient or the patient's surrogate with regard to hospitalization and resuscitation. Hospice patients who do not wish to have aggressive interventions should call the hospice rather than 911.

To minimize the traumatic impact of bleeding for patients and caregivers, education and practical preparations are helpful. This may include providing dark-colored towels, disposable gloves, plastic-lined waste containers, and a benzodiazepine for sedation. Hemostatic interventions such as application of direct pressure may be attempted when feasible. If the patient has a massive hemorrhage and is actively dying, support and nonpharmacological interventions may be more important than trying to give sedative medication. The patient will usually lose consciousness rapidly and may be frightened if left alone.

Gastrointestinal symptoms. Management of gastrointestinal symptoms frequently requires dietary modifications, which can be difficult for patients who eat food from community dining rooms or from discarded or inexpensive sources. Some respite centers may be able to accommodate special dietary needs, but this may be more difficult in a shelter or for a patient living on the street. Use social service resources to assist patients in obtaining food stamps whenever possible. Patients may need assistance in purchasing and storing food that is palatable and that aids in controlling their gastrointestinal symptoms.

Nausea can occur with or without vomiting and in general has one or more identifiable causes. These include but are not limited to the following:

- Medications
- Organ failure
- Electrolyte imbalances
- Obstruction
- Severe constipation
- Gastroparesis
- Inflammation or irritation of the gastrointestinal tract

- Tumors
- Ascites
- Central nervous system causes

First, address underlying causes, such as constipation, that have been identified. Non-pharmacologic interventions for symptom control may include preventing sights, sounds, and smells associated with nausea. Avoidance of fatty, spicy, and highly salted foods is frequently recommended. Complementary measures such as acupuncture, acupressure, massage, and ginger may reduce symptoms. Because many medications can cause nausea, review the patient's medication list and discontinue unnecessary medications, or ensure that medications known to cause gastrointestinal upset are taken with food.

Pharmacologic management should target the suspected pathway involved and may be more effective if given as scheduled, rather than as needed. Medication(s) should target nausea from each of the four basic etiologies of nausea and vomiting as follows:

1. Anticipatory or anxiety-related nausea (cerebral cortex): benzodiazepines, cannabinoids, and steroids
2. Nausea associated with dizziness or vertigo (vestibular): anticholinergics and H1 histamine antagonists
3. Toxic or metabolic causes of nausea (chemoreceptor trigger zone): 5HT₃ antagonists, D₂ antagonist, or NK1 antagonist
4. Gastrointestinal causes of nausea, such as partial bowel obstruction, ileus, or infection/inflammation (peripheral mechanoreceptors): steroids, prokinetic agents, D₂ antagonists, and anticholinergic agents

Constipation is a common complaint; persons at risk are older and those who have advanced disease, decreased physical activity, and cognitive impairment and who take multiple medications. Constipation is an enduring, dose-related side effect of opioids that must be expected and managed proactively. Assessment with plain radiographs may be indicated if the following are suspected: bowel ischemia, bowel obstruction, megacolon, or megarectum. For patients complaining of infrequent stools, consider stimulant medications such as senna or Bisacodyl. For patients complaining of hard stools, consider osmotic agents such as Miralax, lactulose, or magnesium citrate, or bulk agents such as psyllium (if the patient is able to drink sufficient volumes of fluid). If a patient has not had a bowel movement in over three days, an enema or suppository may be ordered. These agents are also the first-line therapy for opioid-induced constipation. If these fail, treatment with Methylnaltrexone is available but requires an injection and is expensive. High-fiber diets with green leafy vegetables, sweet potato, and prunes may be helpful and offer a sense of control to the patient. Skin hygiene for the perirectal area should be a priority.

Anorexia and cachexia are common symptoms experienced by patients near the end-of-life. Anorexia is the loss of appetite for food, while involuntary weight loss is known as cachexia. Cachexia results from production of inflammatory mediators that lead to an increase in metabolic rate and ongoing loss of skeletal muscle mass. Interventions are most effective if begun during the precachexia stage. Patients who have had inadequate access to food as a consequence of homelessness may be malnourished even prior to the onset of their illness and thus more vulnerable to a critical decline in muscle mass. Nutritional support early in the course of a serious illness is particularly important for these individuals.

Providing education to family and caregivers of patients with anorexia and cachexia near end of life is crucial to decrease guilt and anxiety. They may view a decrease in food intake as the primary reason for their loved one's decline. They should be informed about the emotional and physical discomfort that forcing food and fluids may cause. Some simple dietary adjustments may be helpful, such as offering favorite foods and frequent, small meals. Pharmacologic interventions have limited efficacy; they may provide some appetite stimulation, but weight gain is primarily adipose tissue rather than muscle mass, and such interventions have not been shown to improve survival or quality of life. Medications that stimulate appetite are most useful when they provide other benefits such as steroids for treatment of bone pain or nausea or mirtazapine for treatment of depression and insomnia. Use megestrol acetate with caution because of the associated risk of thromboembolic disease and limited efficacy. Cannabinoids significantly improve appetite in AIDS patients and may be useful in combatting cancer-associated anorexia.

Skin. As appetite and mobility lessen and the patient loses muscle mass, the terminally ill person is at risk for pressure ulcers. Skin care becomes extremely important. Frequent position changes, either by using a bed with varying pressure zones or patient turning, helps with comfort and is good for pressure points; use of supports such as pillows and pads will also help. Keeping skin clean, administering frequent massages, and using lotion are simple and effective measures to prevent suffering. Durable medical equipment may be available through palliative or hospice services.

Substance Use and Mental Health

Major Recommendations:

1. Adopt nonexclusionary practices that facilitate engagement in care. This includes eliminating policies that require sobriety as a precondition for admission; such is the case in many shelter-based programs.
2. Consider a harm reduction framework in the provision of hospice and palliative care. Examples might include interventions such as having needle exchange services readily available and prescribing medications that address opioid withdrawal such as methadone and suboxone.
3. Provide medications that reduce alcohol cravings and implementation of Managed Alcohol Programs for individuals who desire to continue alcohol consumption at the end-of-life.
4. Prioritize therapeutic alliance and flexible treatment approaches over rigid treatment adherence. (This includes supporting a patient's decision to discontinue psychotropic medication.)
5. Ensure parity in the availability of mental health treatment and medical care.

The delivery of palliative and/or hospice care can be complicated for many populations, but it is especially complicated for patients experiencing homelessness. Exclusionary operating practices create substantial barriers to accessing palliative care, particularly for individuals living with behavioral health conditions. Unaddressed behavioral health issues can both hasten the development of life-limiting illness and complicate treatment at the end of life. It is well noted in the literature that many people experiencing homelessness at the end of life carry a high burden of behavioral health issues (McNeil et al, 2012). Importantly, approach the treatment of behavioral health problems as a core component of palliative and hospice care rather than as an adjunct. For instance, make mental health care available on par with medical care, and make it focus on the goals that the patient develops. In some instances, patients may feel that relieving symptoms of anxiety and depression is best accomplished through pharmacological interventions and talk therapy; others might prefer medication alone. Normalize any

expressions of extreme anxiety during the end of life, and address and destigmatize historical aversions to pharmacological approaches to management of mental health symptoms.

Lack of housing during a terminal illness can contribute to factors that hasten the need for palliative care (Podymow et al., 2006). In such instances, lack of housing can lead to poor symptom management, admissions to various care settings, lack of care coordination, and decreased attention to behavioral health needs (McNeil & Guirguis-Younger, 2012). Moreover, rigidity in mainstream health care systems can obstruct access to end-of-life care for terminally ill patients experiencing homelessness who have co-occurring behavioral health disorders.

If the patient desires, interventions might be centered on supportive therapy and reconciliation with family and important others. Fear, and more specifically, the fear of dying alone and anonymously, is a common sentiment that homeless individuals nearing the end of life express (Song et al., 2007). Make efforts both to validate and to reconcile these feelings through establishing a therapeutic alliance and a supportive environment. If family or important others are unavailable, an important component to hospice and palliative care is volunteer services. Volunteers are a core piece of the hospice/palliative care team who provide much-needed companionship to those patients needing socialization, comfort, and compassion. At the end of life, individuals could benefit from interventions that help them feel heard and visible.

Dependency on alcohol or other illicit substances does not disappear in the setting of a terminal illness. In most cases the increased stress of coping with a terminal illness exacerbates reliance on the drug of choice. One of the most challenging aspects of palliative or hospice care for patients with current substance abuse disorders or those in recovery is pain management. Finding ways to infuse harm reduction approaches into palliative and hospice care will be essential to increase access and enhance quality at the end of life. The first choice for many families and health care providers includes

practices that prioritize withdrawal management and ensure access to medication-assisted treatments when appropriate. Conceptualizing harm reduction programs as an alternate health care delivery model for individuals experiencing homeless and substance dependency at the end of life may help to reduce barriers to care (McNeil et al., 2012). This framing allows for increased awareness of the social, political, historical, and economic conditions that converge and increase the vulnerability to the harms of illicit drug use among people experiencing homelessness, rather than an overreliance on personal factors that lead to poorer outcomes among people experiencing homelessness at the end of life. This paradigm would include practices that prioritize withdrawal management and ensure access to medication-assisted treatments when appropriate.

However, when withdrawal management is not an option, the patient is still entitled to and is afforded pain management; an effective therapeutic plan of care must be established. Research has found that “safe and effective care of patients with substance use disorders includes maintaining a balance between the provision of pain relief, monitoring for appropriate use of prescribed medications and other substances, and recommendations for viable treatment alternatives” (Oliver et al., 2012). All health care providers should advocate for pain management across all treatment settings, regardless of the patient’s addiction status.

Many hospice inpatient units routinely serve an alcoholic beverage at mealtime for their terminally ill patients. Physicians will write an order for the beverage to be served at mealtime, and staff carefully monitor the intake amount. Although some staff and family members will comment negatively at first on this practice, in many cases alcohol is actually a comfort measure, not a detriment to the patient’s health at the end stage of life.

Social Supports

Major Recommendations:

1. Engage the terminally ill patient in a conversation regarding life review.
2. Access community, government, and societal resources necessary to ensure that the terminally ill patient experiencing homelessness receives the care necessary to ensure a good death.
3. Discuss family dynamics: who needs to be contacted; who should NOT be contacted?
4. Consider shelter pets that may need placement after death.
5. Inventory personal belongings; do not forget storage units and secret hiding places.
6. Discuss funeral arrangements and care of remains after death.
7. Explain to the patient bereavement services for family and loved ones, which are provided free of charge after the patient's death.

Rationale. Terminally ill people face many challenges, which homelessness compounds. These challenges must be addressed quickly because end-of-life issues are acute: there are no second chances. Social workers are educated to assess and determine what resources are available to assist both the terminally ill and homeless populations. Open communication about goals and values must take place. Fostering a therapeutic alliance is essential to the process.

Evidence. Recommendations are based on expert consensus of practitioners in end-of-life care.

(Sources. Meier et al., 2016; SWPI, 2010.)

Psychosocial interventions occur across many different practice settings and may involve individuals, families, groups, medical care teams, and peer groups or groups of friends. Care providers seeking to implement psychosocial interventions should have a strong knowledge of topics, including

- Family systems
- Financial assessment and availability of aid
- Coping strategies
- Physical and multidimensional stages of the dying process
- Physical, psychological, and spiritual manifestations of pain
- Range of psychosocial interventions that can alleviate discomfort
- The biopsychosocial needs of patients and their families
- Specialized knowledge and understanding of ethnic, religious, and cultural differences
- Illness-related issues such as decision making, relationship with health care providers, and death and dying
- Special needs within the population

As always, the specific implementation of interventions varies depending on the range of settings in which care is provided, such as on the streets, in a shelter, in a nursing home or group home, or in a hospital. Care providers should be conscious of their operational contexts and the options available to patients, such as funerary options and body and tissue donation.

Crucially, care providers must engage in self-care and self-management practices to cultivate self-awareness and develop flexibility and adaptability in their daily routine. Care providers who can communicate and work collaboratively to achieve goals and who are willing to advocate for holding the focus on treatment approaches that conform with the patient's preferences, values, and beliefs will be more effective and engaged with patients as individuals. Care providers working with patients at the end of their lives should also develop an awareness of the risk of compassion fatigue and their ethical responsibility to mitigate this risk.

Benefits and Entitlements

Major Recommendations:

1. Multiple types of benefits are available through Social Security, Medicaid, the Veterans Administration, and Health Care for the Homeless Services.
2. Connect the person to the local Health Care for the Homeless grantee for homeless-specific resources and care.
3. Working with a benefits and entitlements case manager or specialist to assist in evaluating and applying for entitlement benefits at end-of-life can help maximize supports.

Funding is often a challenge in providing health care for people experiencing homelessness, including end-of-life care. The largest insurer of health care provided in the last year of life is Medicare, which insured about eight out of 10 of the 2.6 million Americans who died in 2014 (Henry J. Kaiser Foundation, 2016).

Medicare. Medicare covers curative care, palliative care, and an array of hospice services, including nursing care, medications, and counseling. Hospice care under Medicare is most often provided where the patient is living. This does include shelters, respite care facilities, single-room-occupancy hotels, and other supportive housing. Medicare patients who select the hospice benefit have little to no cost-sharing liabilities for most hospice services. For a patient to qualify for hospice coverage under Medicare, a physician must confirm that the patient is expected to die within 6 months if the illness runs a normal course. If the Medicare patient lives longer than 6 months, hospice coverage may continue if the physician and the hospice team recertify the eligibility criteria. Medicare allows hospice respite stays for limited periods; supplemental Medicaid may assist for other long-term care options such as skilled

nursing facilities. In some cases, Medicare Part A pays for hospice services, and Part B pays for the durable medical equipment a person may need.

Not all persons qualify for Medicare. People over the age of 65 are eligible. If a person is under 65 years old, he or she may qualify for Medicare if he or she has received Social Security Disability Insurance (SSDI). There is a 24-month waiting period to apply for Medicare after receiving SSDI.

Social Security Disability Insurance. When a person with a terminal illness applies for SSDI or SSI disability benefits, the Social Security Administration will process the application quickly under the terminal illness program (TERI). Documentation of disease is generally required. TERI, however, is not the only way to expedite benefits for the gravely ill. The other options include expedited treatment through the Presumptive Disability program for SSI (such as AIDS or ALS or any patient in hospice), or the Compassionate Allowances program (e.g., many cancers can be expedited through either the TERI program or the Compassionate Allowances program), or the Quick Disability Determination program (QDD).

Medicaid. Medicaid will pay for hospice care. States are required to offer hospice benefits for at least 210 days (approximately 7 months). As with Medicare, hospice care is usually provided in the home. There are also other locations, such as assisted living facilities, rehabilitation centers, or hospitals, where hospice services can be covered. Medicaid may pay for skilled nursing facilities, but checking with the SMA for long-term care benefits and other options that may be considered the patient's home under the Medicaid hospice benefit is advisable (CMS, 2016).

Veterans. A person who has served in active military service may qualify for benefits under the Veterans Administration (VA). The first step in accessing benefits is to apply with the VA by calling 1-877-222-VETS (8387) Monday through Friday between 8 a.m. and 8 p.m., EST. Hospice care is part of the VHA Standard Medical Benefits Package; all enrolled veterans are eligible if they meet the clinical

need for the service. There are no copays for hospice care, whether it is provided by the VA or an organization with a VA contract. The VA may also provide housing at a VA nursing home or community nursing home if the veteran meets certain eligibility criteria (VA, n.d.). Additionally, all veterans who served in active combat can be buried for free in any U.S. service cemetery.

Primary care and other services for veterans are always available through Health Care for the Homeless programs across the United States.

Spiritual Components

Major Recommendations:

1. Allow for expression of spirituality as defined by the patient.
2. Engage patient in the life review process, mindfully aware of grief-related issues that may emerge because of the patient's medical condition, housing status, and comorbidities.
3. Identify patient's friends and loved ones to assess for anticipatory grief and grief responses to the death of the patient and make necessary referrals to community resources for aftercare.

Rationale. Terminally ill patients often experience a spiritual crisis or awakening when coming to terms with their own mortality. Being able to explore their spirituality is a hallmark of end-of-life care, regardless of outcome. Often this exploration also involves a life review process whereby patients look back to recall significant events in their life. Grief is a real symptom of pain, both physical and emotional, and needs to be addressed as much as the physical pain associated with dying. People experiencing homelessness may have complicated grief issues arising not only from dealing with a terminal illness but also from the compounded losses of being homeless. In addition, recognize that

family and loved ones of the patient have related grief issues and, if they can be located and identified, should be afforded the same counseling services and referrals to community resources for support.

Evidence: Recommendations are based on expert consensus of practitioners in end-of-life care.

(**Sources:** Puchalski, 2014; Leadership Council on Long-term Care of the Institute to Enhance Palliative Care, n.d.)

In the National Consensus Conference on Inter-professional Spiritual Care in Palliative Care, the consensus definition of spirituality reads: “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski et al., 2009). With this definition, spirituality is highlighted as an ongoing process; people not only find meaning but seek meaning throughout their lives and continue to express it in different ways. Spirituality also involves a sense of connectedness to the sacred, however people understand it.

Care providers are recommended to use a nonjudgmental approach to explore the beliefs and attitudes of patients and to identify nondenominational spiritual advisors or assessment takers for the initial plan of care. If the patient is interested, a care provider may use spiritual assessment tools such as HOPE, SPIRIT, or FICA; see <http://www.spiritualcompetency.com/recovery/lesson7.html> for more information on these tools, which may be used to identify spiritual strengths, facilitate coping mechanisms, help the patient develop a connection to a faith community, or explore the patient’s sense of the meaning and purpose of his or her life. Some patients may benefit from assistance with a life review wherein they develop successful stories about their lives and their important spiritual turning points. For patients, becoming engaged in end-of-life care often involves a recognition of their mortality

(the expectation of early death for patients engaged in palliative care and the expectation of imminent death for patients engaged in hospice care), and the fear of death can become present.

Some patients want to have their spiritual needs addressed by their health care professionals, including physicians, nurses, and social workers, not just chaplains. All health care providers can cultivate a compassionate presence by developing attentiveness to the patient's needs, maintaining eye contact as appropriate, facilitating responses, refraining from interrupting or interjecting, and allowing for silence. Some patients may want to explore afterlife beliefs in a nonjudgmental context or to do legacy work for any survivors. They may also need assistance in their bereavement process—both anticipatory grief and active grief. Care providers who undertake this work should be continuously developing their own self-awareness and nonjudgmental presence while also building and maintaining healthy boundaries.

Models of Care

Major Recommendations:

1. Evaluate the continuum of existing local services to identify gaps in end-of-life care for those experiencing homelessness.
2. Determine how the HCH organization can build relationships with existing community resources and create programs designed to fill-in the gaps identified.

Rationale. Homeless individuals at the end of life have complex care needs requiring a wide spectrum of services. HCH organizations seeking to build programs to address these needs can tailor their design depending on existing local services, program resources, and state regulatory requirements. Models of such programs, ranging from street/shelter-based services to medical respite to full-scope inpatient services, exist nationally in the United States and in Canada.

Evidence. Expert consensus.

The specific model of care selected to implement a patient's care plan depends largely upon the patient's setting. While many patients experiencing homelessness receive end-of-life care through inpatient settings and home hospice, other developing models of care may be available in some areas. Increasingly, innovative programs are being developed to provide palliative care for those who experience homelessness while facing terminal illness, including mobile programs that operate on the street and in shelters. Medical respite programs play a key role in end-of-life care, as do medical clinics, although every setting involves challenges. In some cases, community resources may be able to help fill

the gaps in services; collaboration between organizations and care providers is an important method for meeting patients' needs.

Street and Shelter-Based Care

To meet the needs of the large numbers of people living in homelessness who require end-of-life care, some care providers have developed mobile programs that can reach out to individuals who are having health problems or are in need of palliative care while living on the street or in shelters. In addition to providing health care and treatment options, these programs promote independence and allow patients to be involved in making their medical decisions. Mobile programs such as these enable care providers to provide care for patients who are hard to reach, unable to travel to clinics, or suspicious of or uncomfortable in traditional medical facilities.

For example, **the Mobile Palliative Care Program for Homeless Individuals (MPCH)** was piloted in Seattle in 2014. Data suggests that for patients enrolled in the program for six months, the participation in the project has reduced emergency room visits by 50% and hospital stays by 25% (Aleccia, 2017). Run by the University of Washington's School of Public Health and UW Medicine's Harborview Medical Center, the program connects with seriously ill individuals, helps them access funding sources through Medicaid or the hospital, and provides them with health care and follow-up services. One key service is helping patients understand their symptoms and their trajectory and assess their various treatment options, which may be complicated.

Palliative Education and Care for the Homeless (PEACH) in Toronto is a service of the Inner City Health Associates (IHC) that provides community-based services on the streets and in shelters in collaboration with Toronto Central Community Care Access Centre (CCAC). The program is based on principles of prioritizing dignity for all individuals while managing basic and complex symptoms of

individuals facing the end of life. Providing information to other homeless service providers and increasing the competency of agencies serving patients facing end-of-life are key goals for PEACH.

Medical Respite

HCH organizations may choose to build on existing medical respite services to provide end-of-life care to their patients. This involves expanding programs to provide more long-term supportive services (versus acute), as well as staff development and extensive relationship-building to community resources (see Community Resources section) to meet the complex needs of those with advanced/terminal illness. As with HCH medical respite programs, a wide spectrum of on-site service delivery options may fall into this category depending on program resources and state regulatory requirements.

One example of a medical respite center providing end-of-life care for individuals experiencing homelessness is **The Inn Between** in Salt Lake City, Utah. This center is a 16-bed medical respite facility designed to provide a safe, comfortable environment for individuals experiencing homelessness with advanced illness to receive outpatient palliative care and hospice services. It has 24/7 staffing by non-licensed program and house managers, as well as peer support and volunteers who fulfill the role traditionally held by family caregivers. When established caregiver relationships are present, efforts are made to accommodate those individuals on-site as well. The program operates as a 501(c)(3) and does not receive insurance reimbursement. Referral sources include local hospitals, shelters, and HCH clinics.

Another example is **Circle the City Medical Respite** in Phoenix Arizona, a 50-bed medical respite facility that provides acute medical care for patients who are homeless. Circle the City partners with a local hospice provider, Hospice of the Valley, to provide hospice services to patients experiencing homelessness. The facility has two providers in clinic 7 days a week and provides 24-hour nursing

services for all patients with an additional Hospice of the Valley nurse and social worker assigned specifically to hospice patients. Two private rooms are available on-site for those experiencing symptoms at the very end of life. Treatment focuses on symptom management and providers are experienced with the varied circumstances specific to this patient population (i.e., determining capacity for decision making, obtaining and implementing advance directives, and treatment of pain in patients with a history of illicit drug use). Arrangements can be made for family, friends and pets to accompany the patient in the last hours, and chaplain services are available. Hospice patient stays can range from 2 days to 6 months or more, with some patients' symptoms improving dramatically and resulting in discharge to permanent support housing. Referral sources include local hospitals, skilled nursing facilities, local clinics, and self-referral.

In general, care providers in medical respite settings seek to use integrated care and multidisciplinary teams as appropriate (including medical providers, nursing, case management, and mental health services) and understand comorbid mental illness, offering therapy services as needed. Medical respite providers may have the opportunity to determine whether local hospice programs will offer services in a respite facility with management by respite staff in conjunction with the hospice program.

Other suggestions for medical respite care providers include the following:

- Determine if local hospice program(s) will offer services in a respite facility with management by respite staff/providers in conjunction with hospice program.
- Understand drug addiction issues in the homeless population when deciding end-of-life medication dosing.
- On admission to a respite facility, ensure completion of advance directives, determine next of kin and funeral preferences, and post DNR over bed.

- Decide if dying patients should be isolated in a separate room/area from other non-hospice respite patients and when this is most appropriate (patients often want to be with others in the beginning and likely should be isolated near the end).
- Assist patients with reconnecting with family members and/or friends as the patient wishes.
- Have staff available to ensure safety/comfort of patient at the very end of life (preventing falls in setting of confusion, turning patient).
- Have a plan set up for declaring death of the patient, funeral service planning, notification of next of kin, and managing the deceased's belongings.
- Arrange follow-up services for patients/family/friends in remembrance of the patient.

For communities looking to develop medical respite programs, the Respite Care Providers' Network has developed Standards for Medical Respite Programs, https://www.nhchc.org/wp-content/uploads/2011/09/medical_respite_standards_oct2016.pdf, a framework to help medical respite programs operate safely, effectively, and seamlessly with local health care systems while promoting program development and growth.

Inpatient Models

When existing local agencies are unable to meet the needs of the patient experiencing homelessness at end of life, HCH organizations may also choose to build licensed residential care facilities (RCFs) or inpatient palliative and hospice programs that can provide full-scope services internally. It is important to consider state regulatory requirements (i.e., staffing, documentation standards, etc.) and funding

sources when undertaking this type of project, as operational complexity and cost are much than those of medical respite programs.

For example, in San Francisco, a large skilled nursing facility, **Laguna Honda Hospital**, has a 60-bed palliative care unit that cares for medically underserved residents of San Francisco, regardless of their ability to pay. Operated by the San Francisco Department of Public Health, Laguna Honda offers a variety of services for aging adults and people at end of life, including long-term palliative treatment for patients with chronic health conditions who also require medical interventions. An interdisciplinary team that works to provide multi-dimensional palliative care for patients at end-of-life provides these services.

The **Ottawa Mission Diane Morrison Hospice** in Ontario, Canada, located directly adjacent to the Ottawa Mission Shelter, provides full medical hospice services, including 14 acute hospice beds and seven chronic/palliative care beds. Additionally, a palliative-care RN performs home visits throughout supportive housing units. The staffing model includes 24/7 RN staffing, medical providers, and psychiatric care. The hospice obtains funding from the Ottawa Inner City Health program as well as philanthropic donations. Referral sources include Ottawa Inner City Health and other local hospice agencies that identify patients who do not fit with traditional services because of behavior or lifestyle.

Transitions in Care Environments

Different settings encounter different challenges in providing end-of-life care. Medical respite programs, for example, may be limited in the number of beds that are available at any given time. Existing hospice inpatient unit beds may have similarly limited resources as well as other barriers to providing care. Hospitals often impose a limited length of stay. Patients living on the street face a number of logistical challenges, including the care provider's ability to reliably locate the patient, the

risk of stolen medications or supplies, noncompliance, and the availability of hygiene care, including bathing and incontinence care. Sheltered patients may also be difficult to locate if the shelter forces the patient to leave during the day; stolen medications or supplies pose a similar risk. Awareness of these logistical challenges can help care providers develop plans to mitigate them and, whenever possible, select the best care option for individual patients.

Recognize and prepare for the reality that individuals with advanced illness who begin receiving supportive services may experience significant improvements in their health status. HCH sites should take this into consideration when determining guidelines for length of stay in end-of-life respite programs and involve case management to pursue options for transition to suitable permanent housing arrangements.

Community Resources

Depending on the service delivery design, HCH agencies will have different limitations on available resources for providing end-of-life care. Therefore, close partnerships with community resources are essential and may include the following:

- Local palliative and hospice care agencies
- Home health care agencies
- Community paramedicine
- Inpatient palliative/hospice care (freestanding or within hospitals)
- Caregiving services (for ADL and IADL support when family/informal caregivers are not available)
- Durable medical equipment (DME) agencies
- Medical transportation

- Chaplains/spiritual support
- Proxy decision makers
- Meal services
- Pet respite services
- Interpreter services
- Peer support and other volunteers

Given the unique population needs, these partnerships should be based on a foundation of shared trauma-informed and harm-reduction principles.

Social workers work with patients to access societal resources and determine needed resources for care delivery. In selecting the most appropriate model of care for an individual, social workers may be able to consider and coordinate with health and mental health care agencies, homeless shelters, homeless outreach programs, hospitals, hospice programs, homecare programs, nursing homes, senior centers, the courts, agencies serving immigrants and refugees, substance abuse programs, employee assistance programs, and/or family services.

CASE STUDY #1:

Mr. W is a 52-year-old male with cirrhosis secondary to hepatitis C, uncontrolled diabetes mellitus, and post-traumatic stress disorder. He is a former heroin user now on methadone maintenance at 100 mg/day with ongoing episodic injection methamphetamine use. After an extended hospitalization for sepsis from an abscess, he developed multisystem organ failure, including chronic renal failure and end-stage liver disease. He also developed refractory ascites and anasarca with diuretics limited by renal failure and is not a candidate for dialysis or transplantation. He met with the inpatient palliative care team while at the hospital, and completed a POLST indicating DNR/DNI, comfort measures only, and no artificial nutrition. He was then discharged to a skilled nursing facility (SNF) for 2 weeks of IV antibiotics via PICC line and presents in clinic for post-hospital follow-up visit and further discussion of goals of care with his primary care provider (PCP). At the first post-hospital visit, Mr. W is able to express a clear understanding of his prognosis (less than 6 months) and treatment options, and he wishes to prioritize comfort over additional treatment interventions. An appointment for permanent abdominal drain placement is scheduled to avoid need for repeated paracentesis for comfort. He is open to transitioning from the SNF to residential care to receive Hospice services and ADL support given recognition of his limitations for self-care and the chaotic nature of his home environment (with a long-term significant other currently in active relapse). Additionally, his goals of care include reconnecting with his estranged adult children and making recordings for them.

The following day, PCP receives a call from an outreach social worker stating that Mr. W has changed his mind and now wishes to spend his final days at home with his family. He expresses that the emotional suffering of isolation outweighs the potential for increased physical suffering at home, including the possibility of methadone withdrawal if he is unable to make the trip for daily dispense at his methadone clinic. His social worker and PCP and the medical director at the methadone clinic and SNF staff all make intensive care coordination efforts, and he discharges to home the next day.

After one week of failed attempts to contact the patient, the local hospice agency begins home visits and medication management, including methadone. There is evidence of diversion by the significant other and daughter despite attempts to minimize risk (lock box, short-term dispense), and arrangements are made for short-term respite at a local inpatient hospice facility. However, the night before the planned transfer, Mr. W dies at home.

CASE STUDY #2:

Mr. C is a 64-year-old male with end-stage chronic obstructive pulmonary disease (COPD), cirrhosis, failure to thrive (BMI = 17), and ongoing tobacco and binge alcohol use. He has frequent (sometimes weekly) emergency room visits and hospital admissions for air hunger and COPD exacerbations as well as injuries from ground-level falls while intoxicated. He is able to clearly express his wishes via POLST to be DNR/DNI with comfort measures and no artificial nutrition, and one of his primary goals of care is to remain in close proximity to his wife of nearly 40 years. He is evicted from his single-resident occupancy (SRO) unit because of property destruction while intoxicated and begins couch-surfing with his wife and son, who stay in another downtown low-income apartment building. After two months, he is excluded from this building because of altercations and begins living outside on the street across from his wife's apartment, where he stays for approximately nine months. During this time, he declines screening by Aging and Disability Services for supportive housing placement. His wife tends to his activities of daily living (ADLs), including meals and incontinence care, on the street. He is frequently victimized (e.g., giving strangers his bank card to buy alcohol for him) and unable to obtain palliative or hospice care services because of lack of local street-based programs. He is also unable to obtain or keep equipment such as oxygen tanks and a motorized wheelchair despite profound dyspnea with minimal exertion.

After lengthy involvement of multiple hospital and community-based social workers, Mr. C eventually accepts placement at a low-barrier assisted living facility (ALF) in close proximity to his wife's apartment. He is briefly enrolled with a local hospice program but is discharged for "not meeting criteria" for oxygen dependence, even though this behavior is based on adherence rather than physical need. His short-term memory is significantly impaired, and he is increasingly cachectic; a referral is made to palliative care. PCP continues prescribing PRN Ativan/morphine for air hunger despite ongoing alcohol use after discussion of risks with Mr. C and the facility staff dispensing his medication. One month later he is evicted from the ALF for continuing to smoke in his room (resulting in two small fires) despite multiple warnings and harm-reduction efforts, and he is admitted directly to the hospital.

After numerous placement attempts (and having been declined by 25 care facilities), he is ultimately discharged to an adult foster care (AFC) facility located across town from his wife, against his wishes. Ongoing efforts are made to find closer placement but are unsuccessful. Six weeks later, Mr. C dies peacefully with comfort measures in a hospital setting surrounded by his family.

CASE STUDY #3:

K. H. is a 40-year-old female who was diagnosed four years ago with invasive breast cancer and treated over a two-year period with both chemotherapy and radiation. When chemotherapy was finished, she was prescribed Tamoxifen, but she stopped taking it because she felt she was cured. As a result of one of her chemotherapy agents (Adriamycin), she developed a cardiomyopathy, with ejection fraction estimated at 10–15%, and a pacemaker/AICD was placed. Patient was living with her boyfriend for a while, and they both smoked methamphetamine, which seemed to make her shortness of breath worse; it also made her boyfriend abusive, and she left his house along with her 7-pound white corgie, “Georgie.” She goes to the emergency room for her shortness of breath, where a chest x-ray showed florid heart failure as well as a “cancer spot in her rib.” She was to have CT done for staging but could not tolerate the procedure because of shortness of breath. When told that she had end-stage heart disease as well as metastatic breast cancer, she elects for no more aggressive treatment and is discharged from the hospital to the hospice inpatient unit. Cardiac meds are stopped but then restarted for patient comfort. She was on continuous oxygen. K. is felt to have a very poor prognosis with death imminent from heart failure, and she is discharged from the hospice to the Respite Center for terminal care, along with Georgie. K. is uninsured. Her last meth use was “a couple weeks ago,” but she says it never made her feel good, and she does not want to use again. She has elected DNR status, refusing further hospital treatment and interventions.

K. remains clean while at the Respite Center and, as clean time increases, heart failure symptoms and need for oxygen decrease. K. continues to receive services from both the hospice and then respite center. Her terminal diagnosis now is metastatic breast cancer, although no adequate survey has been performed to assess the extent of her disease. She is now performing all her own ADLs without assistance, ambulating and participating in social activities around the Center, and not using any oxygen supplementation.

Two months after K. comes to the Respite Center, she obtains health insurance when her state expands Medicaid. Providers dread the possibility of giving her false hope but want her to realize that work-up will now be possible to see if the disease is limited to her chest wall, and the possibility of restarting Tamoxifen could give her time with good quality of life. K. decides she wants to know. A PET scan is done that shows metastatic cancer in both lungs, liver, brainstem, and multiple bones. K. is tearful and comprehends the reality of her situation. Her immediate reaction is, “What’s going to happen to Georgie?”

K. lives for two more months at the Respite Center until her death. She is moved to a private room for her last months, but many patients are in and out to visit. Bone pain becomes very difficult to control. High doses of morphine are required, with morphine eventually converted to Methadone. Adjunct treatment with Tylenol and Naproxen is ineffective and steroids are started. Seizures develop and steroids are increased. Breathing becomes labored in the last few days of K.’s life; agitation and eventually terminal delirium develop, treated with lorazepam and haloperidol. The Respite Center is able to keep patient through death, with the hospice providing support for extra staffing. Georgie is able to be on the patient’s bed through final illness. Staff has bonded with K. throughout these months, and grief support is provided for them. One staff members takes Georgie home, and his or her family adopts him.

CASE STUDY #4

Mr. D. is a 48-year-old man with AIDS (Cd4 count of 45), severe complex PTSD, alcohol and methamphetamine addiction, and severe neurocognitive disorder (multiple causes, traumatic brain injury, AIDS, ETOH). He had been living outside in a park for 5 years after losing his housing when his wife died. He was referred to an Integrated Mobile Medical program after a hospital stay for dehydration from a HIV-related infectious gastroenteritis. Mr. D had a very difficult time communicating and accepting help from medical providers because of severe trauma from prior medical experiences, one in which his wife died from necrotizing fasciitis when providers in the emergency room did not care for her in a timely fashion. Complicating his hospital tolerance was severe claustrophobia when in hospital rooms from prolonged stays in solitary confinement when previously incarcerated. Upon his discharge he was placed in a skilled nursing facility, but after 8 hours became disoriented and left the facility, walking 5 miles back to the park where he had hung out before his admission. When asked why he left, he said he was “itchy and needed a Benadryl but didn’t know how to ask the nurses.” It was then that care providers realized that Mr. D had a tenuous neurocognitive baseline and could have waxing and waning cognitive functioning (delirium) as seen in elder and frail adults, although no documentation of this condition existed at that time. Mr. D agreed to placement in a SRO stabilization room, and with intense support from his friend Dottie and the mobile medical team, he did well for three months. His HIV became undetectable, and he gained weight and strength. He significantly decreased his substance use, began to use our drop-in center for support, and quickly became a well-liked part of the community. When transitioned into a larger room, Mr. D became increasingly confused and sometimes aggressive. He destroyed the SRO room, causing thousands of dollars in damages. He stopped taking his HIV meds and increased his drinking. When cognoscente, Mr D was remorseful about his behavior, and continued to accept care and support from our team and Dottie. He could eat meals at our center with navigation support, but was denied service at several food pantries and shelters due to his labile behavior.

Mr. D also had several hospital admissions for mental status changes (temporary hold for lack of capacity) and diarrhea. During one of these stays, providers were able to conduct a MOCA (Montreal Cognitive Assessment) in which he scored a 15/30. This is the level consistent with dementia. During his lucid moments, Mr. D was able to have insightful and reflective conversations about his advance care planning, advanced directives, and placement choices. He stated he would like to be comfort care only and wanted to be inside only if he could tolerate it without chemical restraint. He agreed to be held against his will for mental status changes if he was sick with something that could be reversed easily (i.e., pneumonia). He agreed to our pursuit of probate conservatorship only if he was a danger to others or if he jeopardized Dottie’s housing situation with a behavioral outburst.

Our team worked to secure admission into an inpatient hospice program for people with HIV/AIDS. While waiting for this placement Mr. D was sent to by our team to the emergency room with concern for a medical cause of his mental status changes. The doctors could not find anything overtly wrong and concluded he was intoxicated from ETOH and methamphetamine (he had positive urine toxicity scening). Despite the care team’s advocacy that something was medically wrong—as it was not like Mr. D to want to stay in the hospital—he was discharged to the street. Two days later, Mr. D was brought in by ambulance and admitted to another hospital, and his cultures from his prior ED stay were positive for an HIV-related infection. During this hospital stay Mr. D became assaultive, ripped a hospital room apart when the security guards tried to calm him, and had to be chemically restrained to the point of almost needing mechanical ventilation. The hospital changed his code status against his documented outpatient plan because they felt the Ativan

could “iatrogenically stop his respiratory drive.” Luckily, he did not need respiratory support but remained in the ICU because of his delirium, intermittent fevers, and weakness. When he regained his strength, he was determined to have capacity and, upon his request, was discharged to the street.

Later that week he was accepted to the inpatient hospice program and brought to a center. Mr. D stated that he did not want to take any pills until he became accustomed to the space.

Unfortunately, after his first dinner, he became confused and tried to lash out at a volunteer.

Because the hospice center did not have security or intensive one-on-one support, Mr. D had to be escorted to the street after only 6 hours in the center. The care team visited him at the park for the next few days until he was too weak to stand and then sent him by ambulance with advance care plan in hand to the hospital. He was discharged within hours from the ED medical area because they felt he was again only intoxicated. Upon walking out to the parking lot, he began to damage a car and was restrained and brought to the psychiatric emergency department next door. There, he became aggressive and tried to stab a staff RN with a pen. During the process of the psychiatric workup, Mr D spiked a high fever, and the hospital realized that he was ill and not just “acting out.” The center’s care team was called at that time and was able to communicate the patient’s wishes with use of his advance care plan. After 24 hours Mr. D was made comfort care only and passed away two days later without pain, his friend Dottie and case manager by his bedside.

Sources and Resources

Primary Sources

Accessed 3/14/2017

Bandy, R., Sachs, G.A., Montz, K., Inger, L., Bandy, R.W. & Torke, A.M. (2014). Wishard volunteer advocates program: An intervention for at-risk, incapacitated, unbefriended adults. *Journal of the American Geriatrics Society*, 62(11), 2171–2179.

Centers for Medicare and Medicaid Services (CMS). (2016, February). *Hospice Toolkit: An overview of the Medicaid hospice benefit*. Retrieved from <https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/hospice-overviewbooklet.pdf>

Connor, D. M., Elkin, G.D., Lee, K., Thompson, V., Whelan, H. (2016). The unbefriended patient: An exercise in ethical clinical reasoning. *Journal of General Internal Medicine*, 31(1), 128–32.

Culhane, D., Metraux, S., Byrne, T., Stino, M., Bainbridge, J. (2013, December). The age structure of contemporary homelessness: Evidence and implications for public policy. *Analyses of Social Issues & Public Policy* [serial on the Internet], 13(1), 228–244.

Estores, I. M., & Frye, J. (2015, September). Healing environments: integrative medicine and palliative care in acute care settings. *Critical Care Nursing Clinics of North America*, 27(3), 369–382.

Everplans. (n. d.) *State-by-state POLST forms*. Retrieved March 2, 2017 from <https://www.everplans.com/articles/state-by-state-polst-forms>.

Farrell, T. W., Widera, E., Rosenberg, L., Rubin, C.D., Naik, A.D., Braun, U., Torke, A., Li, I., Vitale, C., Shega, J. (2016, November). Ethics, clinical practice and models of care, and public policy committees of the American Geriatrics Society." AGS position statement: Making medical

- treatment decisions for unbefriended older adults." *Journal of the American Geriatric Society*. doi: 10.1111/jgs.14586. [Epub ahead of print] <https://www.ncbi.nlm.nih.gov/pubmed/27874181>
- Healthcare Association of New York State. (n. d.) *Healthcare proxy wallet cards*. Retrieved December 15, 2016 from http://www.hanys.org/community_health/health_care_proxy.
- Henry J. Kaiser Foundation. (2016). *10 FAQs: Medicare's role in end-of-life care*. Retrieved from <http://kff.org/medicare/fact-sheet/10-faqs-medicares-role-in-end-of-life-care/>
- Hui, D., dos Santos, R., Chisholm, G., Bansal, S., Silva, T.B., Kilgore, K.,...Bruera,E. (2014). Clinical signs of impending death in cancer patients. *The Oncologist*, 19(6), 681–687. doi:10.1634/theoncologist.2013-0457.
- Hwang, S., O'Connell, J., Lebow, J., Bierer, M.F., Orav, E.J, Brennan, T.A. (2001). Health care utilization among homeless adults prior to death. *Journal of Health Care for the Poor and Underserved*, 12(1), 51–58.
- Karp, N. & Wood, E. (2003, July). Incapacitated and alone: Health care decision-making for the unbefriended elderly. *American Bar Association Commission on Law and Aging*. Retrieved from https://www.americanbar.org/content/dam/aba/administrative/law_aging/2003_Unbefriended_Elderly_Health_Care_Descision-Making7-11-03.authcheckdam.pdf
- Knopf-Amelung, S. (2013, September). Aging and housing instability: Homelessness among older and elderly adults [Special issue]. *FOCUS: A Quarterly Research Review of the National Health Care for the Homeless Council*, 2(1).
- Kübler-Ross, E. (1969). *On death and dying*. New York: Macmillan.
- Leadership Council on Long-term Care of the Institute to Enhance Palliative Care. (n.d.). *Hospice fact sheet for spiritual care staff*. Retrieved March 14, 2017 from <http://www.dom.pitt.edu/DGIM/iepc/HospiceFactSheets/SpiritualCare.pdf>

- Leong, M., Smith, T.J., Rowland-Seymour, A. (2015). Complementary and integrative medicine for older adults in palliative care. *Clinics in Geriatric Medicine*, 31(2), 177–191
- Leung, A. K., Nayyar, D., Sachdeva, M., Song, J., Hwang, S.W. (2015). Chronically homeless persons' participation in an advance directive intervention: A cohort study. *Palliative Medicine*, 29(8), 746–55.
- McNeil, R. , & Guirguis-Younger, M. (2012). Illicit drug use as a challenge to the delivery of end-of-life care services to homeless persons: Perceptions of health and social services professionals. *Palliative Medicine*, 26(4), 350–359.
- McNeil, R., Guirguis-Younger, M., Dilley, L. B., Aubry, T.D., Turnbull, J., & Hwang, S. W. (2012). Harm reduction services as a point-of-entry to and source of end-of-life care and support for homeless and marginally housed persons who use alcohol and/or illicit drugs: A qualitative analysis. *BMC Public Health*, 12, 312.
- Meier, E. A., Gallegos, J. V., Montross Thomas, L. P., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): Literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry*, 24(4), 261–271.
- Morrison, R. S., Olson, E., Mertz, K.R., Meier, D.E. (1995). The inaccessibility of advance directives on transfer from ambulatory to acute care settings. *JAMA*, 274(6), 478–82.
- National Guideline Clearinghouse (NGC). (2003, November). *Guideline summary: Palliative care for adults*. Rockville (MD): Agency for Healthcare Research and Quality (AHRQ). Retrieved from <https://www.guideline.gov/summaries/summary/47629/palliative-care-for-adults>
- National Palliative Care Research Center. (2013). *Measurement and evaluation tools*. <http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx>

National Palliative Care Research Center. (2013). *Resources*. Retrieved from

<http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx> .

Norris, W. M., Nielsen, E.L, Engelberg, R.A., Curis, J.R. (2005). Treatment preferences for resuscitation and critical care among homeless persons. *Chest*, 127(6), 2180–2187.

Oliver, J., Coggins, C., Compton, P., Hagan, S., Mattellano, D., Stanton, M., St. Marie, B., Strobbe, S., & Turner, H. (2012). American Society for Pain Management Nursing position statement: Pain management in patients with substance use disorders. *Journal of Addiction Nursing*, 23(3), 210–222.

Podymow, T., Turnbull, J., & Coyle, D. (2006). Shelter based palliative care for the homeless terminally ill. *Palliative Medicine*, 20(2), 81–86.

Puchalski, C. M., Vitillo, R., Hull, S. K., & Reller, N. (2014). Improving the spiritual dimension of whole person care: Reaching national and international consensus. *Journal of Palliative Medicine*, 17(6), 642–656.

Puchalski, C. M., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J....Sulmasy, D. (2009). Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *Journal of Palliative Medicine*, 12(10), 885-904.

Rousseau, P. (1998). The homeless terminally ill and hospice & palliative care. *American Journal of Hospice & Palliative Care*, 196–197.

Social Work Policy Institute (SWPI). (2010, September). *Hospice social work: Linking policy, practice, and research*. Fact sheet. <http://www.socialworkpolicy.org/wp-content/uploads/2010/09/SWPIHospiceBrief.pdf>

Song, J., Bartels, D. M., Ratner, E. R., Alderton, L., Hudson, B., & Ahluwalia, J. S. (2007). Dying on the streets: Homeless persons' concerns and desires about end-of-life care. *Journal of General Internal Medicine*, 22(4), 435–441.

Song, J., Ratner, E., Wall, M., Bartels, D.M., Ulvestad, N. Petroskas, D....Gelberg, L. (2010). Effect of an end-of-life planning intervention on the completion of advance directives in homeless persons. *Annual of Internal Medicine*, 153, 76–84.

U.S. Department of Veterans Affairs (VA). (n.d.). *Health benefits*. Retrieved March 14, 2017 from <https://www.va.gov/HEALTHBENEFITS/apply/index.asp>

Williamson, D. L., Lesandrini, J., Kamdar, J. (2016). Incapacitated and surrogateless patients: Decision making for the surrogateless patient: an attempt to improve decision making. *American Journal of Bioethics*, 16(2).

Related Resources

Accessed 3/14/2017

Alecia, J. (2017, January 5). Mobile team offers comfort care to homeless at life's end. *Kaiser Health News*. Retrieved from <http://www.usatoday.com/story/news/2017/01/05/kaiser-mobile-team-offers-comfort-care-homeless-lifes-end/96217246/>

American Bar Association Commission on Law and Aging. (n. d.) *Health care wishes app wallet cards*. Retrieved December 15, 2016 from http://www.americanbar.org/content/dam/aba/images/law_aging/app_walletcard.pdf

Bernacki, R. E., & Block, S. D. (2014, October 20). Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Internal Medicine*. Retrieved from https://www.acponline.org/system/files/documents/about_acp/chapters/va/15mtg/yanni.pdf

Ciambrone, S., & Edgington, S. (2009). *Medical respite services for homeless people: Practical planning.*

Nashville: Respite Care Providers Network, National Health Care for the Homeless Council, Inc. 2009. Retrieved from <http://www.nhchc.org/Respite/FINALRespiteMonograph.pdf>

Eller, P., & Tommasulo, P. (2011, September) Advance directive registries: A policy opportunity. *Center for Healthcare Research and Transformation.*

Emanuel, L. L., von Gunten, C. F., & Ferris, F. D. (1999). *The education for physicians on end-of-life care (EPEC) curriculum.* Retrieved from http://endlink.lurie.northwestern.edu/whole_patient_assessment/module3.pdf

Fraser Health. (2006, November 24). *Terminal secretions/congestion. Hospice palliative care program symptom guidelines.* Retrieved from <https://www.fraserhealth.ca/media/18FHSymptomGuidelinesTerminalSecretions.pdf>

Gregg, J., Solotaroff, R., Amann, T., Michael, Y., and Bowen, J. (2008). Health and disease in context: A community-based social medicine curriculum. *Acad Medicine*, 83, 14-19. Retrieved from http://www.nhchc.org/Publications/Health_Disease.pdf

Grudzen, C. R., Buonocore, P., Steinberg, J., Ortiz, J.M., Richardson, L.D. (2016). Concordance of advance care plans with inpatient directives in the electronic medical record for older patients admitted from the emergency department. *Journal of Pain and Symptom Management*, 51(4), 647-51.

HCH Clinicians' Network, National Health Care for the Homeless Council. (2003). A comprehensive approach to substance abuse and homelessness. *Healing Hands*, 7(5), 1-6. Retrieved from <http://www.nhchc.org/Network/HealingHands/2003/hh-1003.pdf>

HCH Clinicians' Network, National Health Care for the Homeless Council. (2006). Addiction on the streets: Clinical interventions. *Healing Hands*, 10(4), 1-6. Retrieved from

<http://www.nhchc.org/Network/HealingHands/2006/Oct2006HealingHands.pdf>

HCH Clinicians' Network, National Health Care for the Homeless Council, Inc. (2008). *Title*.

Retrieved from <http://www.nhchc.org/HIVguide2008.pdf>

HCH Clinicians' Network, National Health Care for the Homeless Council. (2010). *Harm reduction: Preparing for change*. 2010. Retrieved from

http://www.nhchc.org/harmreductionfactsheet_Apr10.pdf

Hui, D., dos Santos, R., Chisholm, G., Bansal, S., Souza Crovador, C. & Bruera, E. (2015). Bedside clinical signs associated with impending death in patients with advanced cancer: Preliminary findings of a prospective, longitudinal cohort study. *Cancer*, 121, 960-967.

doi:10.1002/cncr.29048

Irwin, K. E., Henderson, D. C., Knight, H. P., & Pirl, W. F. (2014). Cancer care for individuals with schizophrenia. *Cancer*, 120, 323-334. doi:10.1002/cncr.28431

Jaco, M. (2011). *Medical respite program development workbook*. (2011) Nashville, TN: National Health Care for the Homeless Council, Inc. Retrieved from

<http://www.nhchc.org/Respite/FINALMedicalRespiteWorkBook.pdf>

Kraybill, K., & Zerger, S. (2003). *Providing treatment for homeless people with substance use disorders: Case studies of six programs*. National Health Care for the Homeless Council. Retrieved from

<http://www.nhchc.org/Advocacy/FactSheets/CA05RCaseStudies-FINAL5.pdf>

Lebrun-Harris, L. A., Baggett, T.P., Jenkins, D.M, Sripipatana, A., Sharma, R., Hayashi, A.S., Daly, C.A., Ngo-Metzger, Q. (2013). Health status and health care experiences among homeless

- patients in federally supported health centers: Findings from the 2009 Patient Survey. *HSR: Health Services Research*. 48(3), 992–1027.
- McMurray-Avila, M. *Organizing health services for homeless people* (2nd ed.). (Year). Nashville, TN: National Health Care for the Homeless Council. Retrieved from URL
- Montauk, S. L. (2006). The homeless in America: Adapting your practice. *American Family Physician*, 74(7), 1132-1138. Retrieved from <http://www.aafp.org/afp/2006/1001/p1132.html#afp20061001p1132-b15>
- Morrison S. *Self management support: Helping clients set goals to improve their health*. (2007). Nashville, TN: National Health Care for the Homeless Council. Retrieved from <http://www.nhchc.org/SelfManagementSupport052907.pdf>
- National Health Care for the Homeless Council. (2008). Use of complementary & alternative therapies in homeless care. *Healing Hands*, 12(3). Retrieved from <https://www.nhchc.org/wp-content/uploads/2011/09/Jun2008HealingHands.pdf>
- National Public Radio. (2016, October 16). “Harnessing social media to connect homeless people with their families.” *Weekend Edition Sunday*. Retrieved from <http://www.npr.org/2016/10/16/498074856/harnessing-social-media-to-reconnect-homeless-people-with-their-families>
- O’Connell, J. J. (Ed.). (2004). *The health care of homeless persons: A manual of communicable diseases and common problems in shelters and on the streets*. Boston, MA: Boston Health Care for the Homeless Program. Retrieved from <http://www.bhchp.org/BHCHP%20Manual/index.html>
- Office of the National Coordinator for Health Information Technology. (2016, May). *Interoperability among U.S. non-federal acute care hospitals in 2015* (ONC Data Brief 36). Retrieved from

<https://dashboard.healthit.gov/evaluations/data-briefs/non-federal-acute-care-hospital-interopability-2015.php>

Pauly, B., Gray, E., Perkin, K., Chow, C., Vallance, K., Krysowaty, B. & Stockwell, T. (2016). Finding safety: A pilot study of managed alcohol program participants' perceptions of housing and quality of life. *Harm Reduction Journal*, 13(15).

Post, P. (Ed.). (Year). *Adapting your practice: Treatment and recommendations for homeless patients with HIV/AIDS*. Nashville, TN: National Health Care for the Homeless Council. Retrieved from <http://www.nhchc.org/wp-content/uploads/2011/09/AIDS.pdf>

Post, P. A. (Ed.). (2007). *Documenting disability: Simple strategies for medical providers*. Nashville, TN: National Health Care for the Homeless Council. Retrieved from <http://www.nhchc.org/DocumentingDisability2007.pdf>

Post, P. A. (2008). *Defining and funding the support in permanent supportive housing: Recommendations of health centers serving homeless people..* Nashville, TN: National Health Care for the Homeless Council. Retrieved from <http://www.nhchc.org/PSHReport.pdf>

Puchalski, C. M. (2001). The role of spirituality in health care. *Proceedings (Baylor University Medical Center)*, 14(4), 352-357.

Scottish Palliative Care Guidelines. (2014). *Bleeding*. Retrieved from <http://www.palliativecareguidelines.scot.nhs.uk/guidelines/palliative-emergencies/Bleeding.aspx>

Song, J., Wall, M., Ratner, E., Barteis, D., Ulvestad, N., and Gelberg, L. (2003). Engaging homeless persons in end-of-life preparations. *Journal of General Medicine*, 23(12), 2031-2045.

White, D. B., Curis, J.R., Lo, B, Luce, J.M. (2006). Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers. *Critical Care Medicine*, 34(8), 2053–2059.

White, D. B., Curis, J.R., Wolf, L.E., Pendergrast, T.J., Taichman, D.B., Kuniyoshi, G....Luce, J.M. (2007). Life support for patients without a surrogate decision maker: Who decides? *Annals of Internal Medicine*, 147(1), 34–40.

About the Health Care for the Homeless Clinicians' Network

Founded in 1994, the Health Care for the Homeless Clinicians' Network is a national membership group that unites hands-on care providers from many disciplines who are committed to improving the health and quality of life of our neighbors experiencing homelessness. The Network is engaged in a broad range of activities, including publications, training, research, and peer support. The National Health Care for the Homeless Council, Inc., operates the Network, and a Steering Committee that represents diverse community and professional interests governs the Network. To learn about more clinical resources for providing care to individuals who are homeless, visit www.nhchc.org/clinicians.