



Fast Facts Core Curriculum

Hospice

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FAST FACTS AND CONCEPTS #38 DISCUSSING HOSPICE

Charles F von Gunten MD, PhD, FACP

Introduction Hospice discussions with seriously ill patients should always take place in the context of the larger goals of care, using a step-wise approach. *Fast Facts* #82, 87, and 90 discuss the hospice benefit and regulations in more detail.

1. Establish the setting

Ensure comfort and privacy; sit down next to the patient. Ask if family members or others should be present. Introduce the subject: *I'd like to talk with you about the overall goals for your care.*

2. What does the patient understand?

Ask an open-ended question to elicit patient understanding about their current health situation. It is important to get the patient talking – if the doctor is doing all the talking, it is unlikely that the rest of the conversation will go well. Consider starting with phrases such as: *What do you understand about your current health situation? Or, What have the doctors told you about your condition?*

If the patient does not know/appreciate their current status this is time to review that information. An informed decision about hospice is only possible if the patient has a clear understanding of her or his illness and prognosis.

3. What does the patient expect?

Next, ask the patient to consider the future. *What do you expect in the future? What goals do you have for the time you have left—what is important to you?* This step allows you to listen while the patient describes a real or imagined future. Most patients with advanced disease use this opening to voice their thoughts about dying—typically mentioning comfort, family, and home, as their goals of care. If there is a sharp discontinuity between what you expect and what the patient expects, this is the time to clarify. Listen carefully to the patient's responses; most patients have thought a lot about dying, they only need permission to talk about what they have been thinking. Setting up the conversation in this way permits the physician to respond with clarifying and confirming comments such as: *So what you're saying is, you want to be as independent as possible and stay out of the hospital. Or, What you've said is, you don't want to be a burden on your family.*

4. Discuss Hospice Care

Use language that the patient will understand; give information in small pieces. *Never say, There's nothing more we can do.* "Nothing" is euphemistic and easily misinterpreted; to a patient "nothing" means abandonment. Summarize the patient's goals as part of your

introducing a discussion of hospice care: *You've told me you want to be as independent and comfortable as possible. Hospice care is the best way I know to help you achieve those goals.* Listen carefully to the response; patients often have a distorted view of hospice care, others have never heard the term. Ask what the term means to them; patients frequently describe hospice as a *place* to go to die or what you do when you give up. Probe for previous experiences or how they developed their point of view. Respond by describing hospice as *A program that helps the patient and family achieve the goals you've just described; it's a team of people that help meet the patient's and family's physical, psychological, social and spiritual needs.* Offer to ask someone from the hospice program to meet with them to give information.

5. Offer your recommendation

From what you've told me, I would recommend that hospice care begin so that I can do the best possible job in meeting the goals we discussed today. I think it would be best if we got hospice involved. Normalize your recommendation: *I always ask hospice to get involved for my patients at this stage of their illness.* Reinforce that entering hospice care does *not* mean that the patient can never return to the office or hospital for care, that the decision is revocable, and that the patient can continue seeing their current physicians.

6. Respond to emotions

Strong emotions are common when discussing death. Typically the acute emotional response is brief. The most profound initial response a physician can make may be silence, providing a reassuring touch, and offering facial tissues (see *Fast Fact* #29).

7. Establish a plan

Summarize the plan: *I'll ask hospice representatives to come by to give information, then you and I can discuss it.*

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FAST FACTS AND CONCEPTS #82 MEDICARE HOSPICE BENEFIT – PART I: ELIGIBILITY AND TREATMENT PLAN

Robin Turner MD and Drew A Rosielle MD

Background In the United States, the Medicare Hospice Benefit (MHB) pays for 80% of all hospice care. Established in 1983, the MHB pays for medical, nursing, counseling, and bereavement services to terminally ill patients and their families. The original goal of the MHB was to support families caring for a dying relative at home. Under certain circumstances, hospice services under the MHB can also be provided in a nursing home or the acute care hospital. Referral for hospice care is appropriate when the overall plan of care is directed toward comfort rather than reversing the underlying disease process. *Fast Facts #87, 90, 139, and 140* further discuss the MHB.

Eligibility—Medicare Hospice Benefit

1. The patient must be entitled to Medicare Part A (hospital payments); once the patient decides to enter hospice care, they sign off Part A and sign on (elect) the MHB. Note: this process is reversible—patients may at a future time elect to return to Medicare Part A.
2. The patient must be *certified* by the Hospice Medical Director and primary physician to have a life expectancy < 6 months “*if the patient’s disease runs its natural course.*” Patients can continue to be eligible if they live beyond 6 months as long as the physicians believe death is likely within 6 months.
3. Under the MHB, DNR status **cannot** be used as a requirement for admission.

Covered Services (100% coverage with no co-pay)

- Case oversight by the physician Hospice Medical Director
- Nursing care: symptom assessment, skilled services/treatments and case management. The nurse visits routinely; 24-hour/7-day per week emergency contact is also provided.
- Social work: counseling and planning (living will, DPOA).
- Counseling services including chaplaincy.
- All medications and supplies *related* to the terminal illness. The hospice can charge a \$5 copay per medication, but most choose not to charge this. Medications for conditions not related to the terminal condition are not covered.
- Durable medical equipment: hospital bed, commode, wheelchair, etc.
- Home health aid and homemaker services.
- Speech, nutrition, physical, and occupational therapy services as determined by the plan of care (see below).
- Bereavement support to the family after the death of the patient.
- Short term *General Inpatient Care* for problems that cannot be managed at home—most commonly intractable pain, delirium, or caregiver breakdown.
- Short term *Respite Care*—up to 5 days to permit family caregivers to take a break.
- *Continuous care* at home for short episodes of acute need.

Not Covered: Continuous nursing assistance (i.e. extended supervisory care) or nursing home room and board charges.

Plan of Care (POC): The hospice team and the patient’s physician work together to maximize quality of life by jointly developing the *Plan of Care*. The POC is based on the patient’s diagnosis, symptoms, and other needs. The hospice program and the patient’s physician must together approve any proposed tests, treatments, and services. In general, only those treatments that are necessary for palliation and/or management of the terminal illness will be approved.

Physician Role: At the time of enrollment the patient indicates the primary physician who will direct care; the patient may select a hospice physician for this role or may select their usual primary doctor. The primary physician is responsible for working with the hospice team to determine appropriate care.

Non-Medicare Hospice Plans: Medicaid hospice benefits closely mirror the MHB. Private insurance plans generally emulate the MHB but occasionally depart from it dramatically (e.g. capping the total number of days a patient may receive hospice care).

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**FAST FACT AND CONCEPT # 87
MEDICARE HOSPICE BENEFIT – PART II: PLACES OF CARE AND FUNDING**

Robin Turner MD and Drew A Rosielle MD

Introduction *Fast Fact #82* described eligibility for the Medicare Hospice Benefit (MHB) and the services it covers. This *Fast Fact* will review where services are provided and the reimbursement system for hospice care. *Fast Fact #90* reviews special interventions under the MHB, and #140 further discusses levels of care.

Places of Care

- **Home:** The majority (~95%) of hospice care takes place in the home. Hospice team members visit the patient and family on an intermittent basis determined by the Plan of Care (see *Fast Fact #82*), which changes based on the patient's needs. Medicare rules do not require a primary caregiver in the home, but as death nears, it becomes increasingly difficult to provide care for a patient who does not have someone (family, friends, hired caregivers) who can be present 24 hours a day in the home.
- **Long-term care facility:** 25% of patients in the US die in nursing homes. Medicare recognizes that this can be the resident's 'home' and that the patient's 'family' frequently includes the nursing home staff. Hospice care under the MHB can be provided to residents *in addition* to usual care provided by the facility. Individual hospice programs must establish a contract with the facility to provide hospice care. The MHB does not pay for nursing home room and board charges.
- **Hospice inpatient unit:** Dedicated units, either free-standing or within other facilities (such as nursing homes or hospitals) are available in some regions. Patient eligibility (e.g, whether or not a patient requires general inpatient care or not), permitted length-of-stay, and fees for room and board vary between facilities.
- **Hospital:** When pain or other symptoms related to the terminal illness cannot be managed at home, the patient may be admitted to a hospital for more intensive management, still under the MHB. The inpatient facility must have a contract with the hospice program to provide this service.

Payment Medicare pays for covered services using a per diem capitated arrangement in one of four categories (see *Fast Fact #140*). The rates below reflect 2015 Medicare and Medicaid reimbursements.

- **Routine Home Care:** care at home or nursing home (~\$159/day).
- **Respite Care:** care in an inpatient setting (nursing home, hospice facility, or hospital) for up to 5 days to give caregivers a rest (~\$164/day).
- **General Inpatient Care:** acute inpatient care (at a hospital or hospice facility) for conditions related to the terminal illness such as pain and symptom control, caregiver breakdown, or impending death that requires inpatient-level interventions (~\$709/day).
- **Continuous Home Care:** provides acute care at home with around-the-clock nursing for a crisis that might otherwise lead to inpatient care (~\$930/day).

The rates of reimbursement are fixed for each category of care on an annual basis, but they vary by geographical location. Cited rates are approximate and are intended to convey general orders of magnitude of payment. Payment is made from Medicare to the hospice agency, which then pays the hospital or nursing home (for respite or acute care), depending on the specifics of the contractual arrangement between the hospice agency and the facility.

Physician Services Direct patient care services by physicians, for care related to the terminal illness, are reimbursed by Medicare, and are not included in the per diem. If the attending physician is not associated with the hospice program via employment or similar contract, the physician bills Medicare Part B in the usual fashion. The bill must indicate that the physician is not associated with the hospice program or the claim may be denied. If the attending is associated

with the hospice program (e.g. as a medical director) the physician submits the bill to the hospice program, which in turn submits the claim to Medicare under Part A. The physician is then reimbursed based on a contract with the hospice program. Patients can see consulting physicians under the MHB if the hospice agency contracts with the consultant to do so. The hospice agency submits the claim under Medicare Part A and reimburses the consultant per their contract.

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**FAST FACTS AND CONCEPTS #90
MEDICARE HOSPICE BENEFIT – PART III: SPECIAL INTERVENTIONS**

Robin Turner MD and Drew A Rosielle MD

Introduction This *Fast Fact* will discuss the use of interventions in hospice care that can be controversial due to high cost and/or uncertainty whether they constitute ‘palliative’ interventions. When a patient elects the Medicare Hospice Benefit (MHB), the patient, the doctor, and the hospice team develop a Plan of Care (POC) that lists a) the patient’s goals for care and b) the services needed to achieve these goals. A hospice program is fiscally responsible for all services outlined in the POC, and these services are paid for from the pool of money the hospice program gets from per diem payments (physician fees are billed separately – see *Fast Fact* #87).

Note: since there is no Medicare regulation that specifies what treatments are deemed ‘palliative,’ it is up to the individual hospice agency to determine whether or not they can financially and philosophically provide the interventions listed below. Most hospice agencies are not able to provide high-cost interventions due to financial limitations; patients may elect to be discharged from hospice care if they wish to pursue these options. Hospices with a large number of enrolled patients have greater financial resources and thus are better able to provide high-cost treatments. Recently, some hospices have introduced ‘open-access’ programs which more freely provide costly and even life-prolonging therapies to dying patients who would otherwise benefit from hospice services. The hope is that the increased costs will be covered by increased revenue from enrolling more patients earlier in the course of their illness.

Indications for use in Hospice Care In general, the interventions listed below are potentially indicated in patients with a) a *good functional status* (up, out of bed > 50% of the time; Karnofsky Performance Status >50; ECOG ≤2 – see *Fast Facts* #13, 124), or b) a *clear goal* to be met (e.g. wedding anniversary in two weeks). These interventions are not indicated solely to assist patients or families psychologically cope with impending death – to give the impression that ‘something is being done.’

- **Parenteral Fluids.** Indication: symptomatic dehydration where there is a patient-defined goal (e.g. upcoming family event). Fluids are not indicated to treat dry mouth or solely to reverse dehydration occurring as a normal aspect of the dying process; fluids may be of benefit to treat delirium in selected patients (see *Fast Fact* #133).
- **Enteral feeding.** Indication: patient is hungry *and* there is a reason oral nutrition cannot be given (e.g. upper GI obstruction from esophageal cancer). See *Fast Facts* #10 and 84 for a complete review of the indications/contraindications for tube feeding.
- **Total Parenteral Nutrition.** Indication: patient has short-gut syndrome or bowel obstruction *and* good functional status *and* a functional goal. See *Fast Fact* #190 for further discussion.
- **Radiation Therapy.** Indication: symptoms of pain, bleeding, or neurological catastrophe (e.g. acute spinal cord compression) *and* the patient is expected to live long enough to experience benefit (> 4 weeks) *and* the potential benefits outweigh logistic burdens (e.g. travel to the radiotherapy site, getting on and off the treatment table). See *Fast Facts* # 66, 67.
- **Red Blood Cell Transfusions or Erythropoietin.** Indication: Symptomatic anemia (dyspnea or fatigue) in ambulatory patients who demonstrate *continued functional* benefit from treatment.
- **Platelet Transfusions.** Indication: active bleeding and severe thrombocytopenia (Platelet count < 10,000).
- **Chemotherapy.** Indication: symptoms from the cancer are causing distress; the likelihood of effectiveness is high (expected Response Rate greater than 25% - see *Fast Facts* #14, 99); patient will live long enough to benefit (> 4-8 weeks, ECOG 0-2); *and* benefits outweigh burdens.
- **Antibiotics.** Indication: oral antibiotics are appropriate to treat simple symptomatic infections (e.g. UTI). Parenteral antibiotics are not indicated unless there is an identified

susceptible organism, there is a clear functional goal to be met, the likelihood of successful treatment is high, *and* the patient is expected to live long enough to achieve benefit.

- **Laboratory/Diagnostic services.** Indication: to monitor aspects of POC (e.g. warfarin monitoring) or as part of a diagnostic evaluation for a new symptom for which the testing is likely to substantially alter patient management. Note: diagnosis of a new problem that does not relate to the terminal illness can be evaluated and treated by the patient's primary care provider under usual Medicare billing (e.g. acute myocardial infarction).

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FAST FACTS AND CONCEPTS #139
HOSPICE REFERRAL: MOVING FROM HOSPITAL TO HOME
Tara C Friedman MD

Background The transition from hospital to home for the patient about to be enrolled in home hospice care is complex. Miscommunication between hospital staff and hospice care providers regarding goals of care and medications occurs commonly and only heightens existing stress and fear among patients and their caregivers. This *Fast Fact* reviews key steps in the transition from the acute care hospital setting to home hospice care.

Clarify goals *Fast Fact* #38 reviews key do's and don'ts of the initial hospice discussion with patients and families. Prior to discharge additional steps to clarify the goals of care include:

- Confirm in the records that you believe the patient meets hospice eligibility requirements (see *Fast Fact* #82): *"In my medical judgement, the patient has a prognosis of less than 6 months if the disease follows its usual course."*
- Review all medications and interventions (e.g. tube feedings, oral antibiotics). Any medications and interventions that do not help the patient and family meet their goals of care or enhance quality/comfort should be discussed with patients/families, and a recommendation made to discontinue them.
- Project ahead to the coming days to weeks: what symptoms/problems do you anticipate will likely occur (e.g. dyspnea in a lung cancer patient)? Ask yourself if the current medications/interventions will likely meet these needs or do additional medications/interventions need to be made available in the home?

Contact the Hospice Agency Whoever makes the initial contact with a hospice agency (physician, discharge planner, palliative care nurse, etc.) should have the following information in hand:

- Patient's address – confirm the patient lives within the hospice's catchment area.
- Birth date and medical insurance information.
- Terminal diagnosis (e.g. dementia, cancer).
- Name of physician who will be physician of record for hospice care.
- Overall goals of care and special issues (e.g. family needs special bereavement support for children who live in the home or patient has two days of palliative radiation left).
- Medical equipment needs (e.g. hospital bed, oxygen).
- Anticipated discharge date/time.

Coordinated Discharge

- Whenever possible, have someone from the hospice program meet the patient and their caregiver in the hospital prior to discharge to review hospice eligibility and covered services. If not feasible, arrange for the initial hospice referral visit to occur when the patient arrives home, or within 24 hours of hospital discharge at the outside.
- Include the hospice staff in the discharge plan.
- Inquire if the home hospice team can offer continuous care for patients with acute symptom management needs or in patients in whom discontinuation of life supporting therapies will be occurring during the transition to home. There is some published evidence that continuous care can significantly improve the chances that the patient can die at home.
- Review symptoms and confirm treatments for the terminal illness with hospice staff.
- Review symptoms and confirm treatments for diseases unrelated to the terminal illness.
- Plan to have durable medical equipment and medications available when the patient arrives at home; coordinate this with your hospice agency provider. Most hospice agencies need at least 24 hours to coordinate the delivery of these items to the home.

With careful planning, the stress of transitioning to home hospice care will be minimized, allowing your patients, their families and yourself the opportunity to focus on important issues near the end of life.

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**FAST FACTS AND CONCEPTS #140
MEDICARE HOSPICE BENEFIT: LEVELS OF HOSPICE CARE**

Tara C Friedman MD

Background In the United States, modern hospice care is guided by the Medicare Hospice Benefit (MHB), which pays for 80% of all hospice care (see *Fast Facts* #82, 87, 90). Because most of hospice care is in the form of routine home care, clinicians may not be aware that the MHB specifies four different levels of hospice services to meet the diverse needs of dying patients and their family.

1. Routine Home Care:

- The most common type of hospice services in the United States.
- Hospice interdisciplinary team provides core services (see *Fast Fact* #82) in the patient's home.
- The patient's home may be a private home, an assisted living facility, a boarding home, or a long-term care facility – wherever the patient lives.

2. Respite Care:

- Respite care is short-term inpatient care to relieve the family/primary caregiver. Caregivers often schedule respite in order to travel or tend to their own healthcare needs.
- Respite is limited to 5 consecutive days.
- The hospice agency may provide respite in a variety of contracted settings (e.g. inpatient facility, local nursing home, etc.).

3. General Inpatient Hospice Care (GIHC): The MHB provides for care to be provided in an acute care hospital or other setting where intensive nursing and other support is available outside of the home. Criteria for this level of care include:

- Uncontrolled distressing physical symptoms (e.g. uncontrolled pain, intractable nausea, respiratory distress, severe wounds, etc.).
- Psychosocial problems (e.g. unsafe home environment or imminent death where family can no longer cope at home).
- GIHC may be provided in a variety of settings
 - Dedicated inpatient hospice facilities, where the patient is cared for by dedicated hospice staff.
 - Contract beds, where the facility (hospital/nursing home) staff provides routine care, with supplemental services provided by hospice personnel.

4. Continuous Home Care: For hospice patients who qualify for GIHC, but desire to remain in their own home, continuous care (CC) intends to support the patient and their caregiver through brief periods of crisis. There is some published data that patients who did not have access to continuous care were more likely to be transferred from their home prior to death.

- CC provides care for 8-24 hours a day.
- Home health aide and homemaker services or both may be used to cover the care needs.
- Care must be primarily provided (more than 50%) by an LPN or RN.

Under the MHB patients may be admitted into a hospice program at any level of care as determined by their individual needs and the patient may transfer between the levels of care as needed. For patients whose hospice care is covered by a pay source other than Medicare, there may be limitations or specifications for the different levels of care.

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FAST FACTS AND CONCEPTS #246 EMERGENCY DEPARTMENT MANAGEMENT OF HOSPICE PATIENTS

Sangeeta Lamba MD, Tammie E Quest MD, David E Weissman MD

Background Patients enrolled in hospice programs will occasionally be transported to the Emergency Department (ED). Emergency medicine training focuses on life-prolonging measures and may fail to address hospice as a system of care. This *Fast Fact* provides information for clinicians practicing in EDs on management issues when a hospice patient arrives. *Fast Fact* #247 discusses initiating hospice care from the ED and #298 addresses Palliative Care Consultation in the ED.

Why do Hospice Patients come to the ED? ED providers should never assume that arrival in the ED equates a desire for aggressive/life-prolonging treatment. Even when a patient/family requests such services, an assessment is needed to understand the concerns that prompted a shift in care goals. Frequently such requests arise from fear about the dying process or guilt about prior medical decisions to limit life-prolonging treatments. Common triggers for an ED visit include:

- Stress/inability to cope with impending loss of life. This may be expressed as a request to start a life-prolonging treatment previously used and discontinued (e.g. chemotherapy) or never begun (e.g. renal dialysis).
- Poor symptom control.
- Malfunction/loss of a support device such as a gastrostomy tube.
- Failure of the hospice program to provide timely patient support and communication.

Management Guidelines

1. **Notify hospice** staff as soon as possible. Under the Medicare Hospice Benefit, hospice agencies are legally/financially responsible for the patient's plan of care and all medical costs related to the terminal illness. See *Fast Facts* # 82, 87, 90.
2. **Determine the trigger** for the ED visit. Pay attention not only to distressing physical signs and symptoms but also emotional and psycho-social issues. Involve social services, chaplaincy, and Palliative Care consultative services early if needs are identified.
3. **Treat distressing symptoms.** See *Fast Facts* for specific symptom treatment guidelines.
4. **If deterioration is imminent** and rapid decisions are needed regarding the use of life-sustaining treatments (e.g. intubation for respiratory failure) a focused discussion around goals of care must occur in the ED
 - Determine the legal decision maker if available and review any completed advance directives.
 - Complete a rapid goals of care discussion (see *Fast Facts* #223-227).
 - *Make recommendations.* For example, 'According to what you want for [the patient], I would/would not recommend....'
5. **If the patient is actively dying** (see *Fast Fact* #3) assess for cultural/spiritual needs; assure privacy and endeavor to identify if there are any preferred locations a patient can be safely transferred to to die (e.g. back home; to a private hospital room).
6. **Laboratory tests/diagnostics** should be limited or withheld until discussion with the patient's hospice care team. Testing should be based on patient-defined goals of care. Generally, low burden, non-invasive methods which may reveal reversible pathology or clarify prognosis should be used first.
7. **Therapeutic modalities** should be based on patient-defined goals of care rather than automatic 'ED indications' (e.g. antibiotics for pneumonia should only be used if they meet a patient or surrogate defined goal of care).
8. **Disposition** should be planned *after* discussion with hospice staff based on the patient's goals. Returning home or a direct admission to an inpatient hospice facility may be the best disposition rather than hospital admission. At times, hospices can arrange 24h professional support in the home for patients with difficult to manage symptoms who wish to remain home ('continuous care' – see *Fast Fact* #87).

9. **Notify** the inpatient palliative care service if the patient is to be admitted to the hospital. Hospice agencies may revoke a patient's enrollment in hospice care if care goals have changed, or may continue a patient under hospice care during an admission for palliation (see *Fast Fact #87*).

Summary Patient-centered care for hospice patients may be enhanced by emergency clinicians who acquire skills to quickly adapt to a supportive role in the care of a terminally-ill patient. Recognizing common triggers for the ED visit, using a multi-disciplinary approach with early involvement of hospice, social services and palliative team consults may assist in providing optimal care for ED patients under hospice care.

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**FAST FACTS AND CONCEPTS #247
INITIATING A HOSPICE REFERRAL FROM THE EMERGENCY DEPARTMENT**

Sangeeta Lamba MD, Tammie E Quest MD, David E Weissman MD

Background Patients with an end-stage illness often present to the Emergency Department (ED) with a crisis event (1). This *Fast Fact* provides information for ED providers on how to refer a patient to hospice care directly from the ED (2). *Fast Fact #246* suggests strategies for caring for patients receiving hospice care who present to the ED; *Fast Fact #298* covers Palliative Care consultation in the ED.

1. Assess Medicare Hospice Benefit eligibility (see *Fast Fact #82*). Fundamentally, this means the patient has a prognosis that is 6 months or less if his/her disease runs its expected course, and the patient's care goals are compatible with hospice (see #3 below). Broad guidelines for many cancer and non-cancer related conditions exist (3, 4, 5, 6). A useful starting point is to ask yourself, *Would I be surprised if this patient died within the next 6 months?* For disease specific prognostic information, see *Fast Facts #13, 99, 124, 125, 141, 143, 150, 189, 191, 213*.

2. Discuss hospice as a disposition plan with the patient's physician. Contact the patient's personal physician: discuss the current condition, prognosis, and prior goals of care conversations. If you are considering hospice care, ask if the physician is willing to be the following physician for hospice services.

3. Assess whether the patient's goals are consistent with hospice care. Generally this means a patient wants medical treatments and other support aimed at alleviating symptoms and maintaining quality of life, without life-prolongation. Patients may enroll in hospice care if their *preeminent* care goal is symptom relief, even if they are not entirely sure they want to completely discontinue life-prolonging therapies, as long as the hospice agency indicates they can accommodate those wishes. These four questions will help you get the discussion started to elicit if the patient and family are psychologically ready to accept hospice care (see also *Fast Facts #222-227*).

- "What have you been told about the status of your illness and what the future holds?"
- "Has anyone talked to you about your prognosis; how much time you likely have?"
- "Are there plans for new treatments designed to help you extend your life?"
- "Has anyone discussed with you hospice services? What do you know about Hospice?"

4. Introduce hospice to the patient and family/surrogates.

- Discuss the core aspects of hospice care and how these features can help the patient and family (e.g. 24/7 on-call assistance, home visits for symptom management, coordinated care with the patient's physician, emotional and chaplaincy support).
- Address concerns and clarify misconceptions.
- Phrase your recommendation for hospice care in positive language, grounded in the patient's own care goals. *"I think the best way to help you stay at home, avoid the hospital, and stay as fit as possible for whatever time you have left is to receive hospice care at your home...."*
- Discuss location of hospice care: usually this is the patient's residence such as a private home or long-term care facility. Direct admissions to hospice facilities can occur depending on bed availability and ability of local hospice agencies to arrange an immediate, direct facility admission. This is not available in all communities and requires a discussion with the hospice agency.

5. Make a referral and write orders (see *Fast Fact #139*).

Call a hospice agency; anticipate these questions:

- What is the terminal illness? Who will be the following physician? (Step 2)

- What equipment will be needed immediately (e.g. home oxygen)? Is there a caregiver at home?
- Code status (patients cannot be denied hospice enrollment if 'full code', however the hospice team will need to know if code status needs to be addressed further.)

Questions you may need to ask the hospice agency:

- *How soon can you make an intake visit to the patient's home? Can you visit the patient immediately, even in the ED (this is available in some communities)?*
- *How should I coordinate filling of new prescriptions I want the patient to have?*

Example of ED Initiated Hospice Referral Orders:

- Evaluate and Admit/Enroll in hospice care
- Terminal Diagnosis: _____.
- Expected Prognosis: Terminal illness with less than 6 month survival likely if disease runs its normal expected course [or more specific if indicated].
- Physician who will follow patient: _____.

6. Ensure patient/surrogate understanding and secure the plan. Communicate the plan following ED discharge; provide the name and contact number for the hospice agency.

7. What if hospice enrollment is appropriate, but cannot be arranged in a timely manner? If the patient can be cared for at home safely for 1-2 days without extra services, send her or him home with appropriate prescriptions and care instructions. In most communities, patients can be enrolled in hospice care within 24-48 hours, even on weekends. If they cannot be cared for safely at home, observation vs inpatient admission is likely necessary until a safe discharge plan can be established.

Summary Patient-centered care for hospice-eligible, terminally-ill patients may be enhanced by emergency clinicians who acquire skills to make early appropriate hospice referrals from the ED.

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**FAST FACTS AND CONCEPTS #286
MEDICATION DISPOSAL**

Susan Nathan MD and Catherine D Deamant MD

Background Patients receiving home hospice or palliative care often have a residual supply of opioids and other pharmaceuticals at the time of the patient's death. A number of agencies have recommendations and resources on safe medication disposal, including the Food and Drug Administration (FDA), Environmental Protection Agency (EPA), and the Drug Enforcement Agency (DEA) (1-3). Educating families on proper disposal of medications is an important patient safety measure.

Medicine Take-Back Events or Programs Ideally, medications should be given to a secure medication collection site or disposed of through an official take-back program. These programs dispose of medications in accordance with federal, state and/or local environmental regulations. Many collected medications are incinerated.

Medication collections sites include police stations, pharmacies, chemical plants; sometimes programs included locked drop-boxes associated with these facilities. There is no unified resource that identifies all of these options in every state, but the website <http://www.awarerx.org/get-local> provides information on these sites by state. If the patient does not have internet access, they can call 311 or the FDA: 1-888-INFO-FDA for information about local resources.

Disposal in Household Trash If the patient cannot access a secure collection site, they should be instructed on safe medication disposal in the household trash. The FDA, EPA and other safety programs have created consumer education materials and recommend the following (4, 5):

- Remove medications (liquids, tablets, or capsules) from their original container.
- Mix medications (do not crush tablets or capsules) with unpalatable substances (such as kitty litter or used coffee grounds) and seal in a plastic zip lock bag or empty container (such as a margarine tub) and place in the trash.
- Remove identifying information about the patient and medication by covering with permanent marker or scratching off labels.
- Empty pill bottles should be thrown in the trash or recycling (depending upon local guidelines).

Flushing Medications If a drop-off program is unavailable or impractical, the FDA recommends flushing down the toilet certain medications that can be harmful to unintentional users. These medications include all opioids, rectal diazepam, and transdermal methylphenidate and buprenorphine (1).

In 2013, the FDA issued an update regarding the disposal of fentanyl patches in response to 32 cases of accidental exposure to fentanyl since 1997, most of them involving children younger than 2 years old (6). The patches should be folded in half, sticky sides together, and flushed down the toilet. While not explicitly stated, it is reasonable to dispose of transdermal buprenorphine and methylphenidate similarly.

Environmental Impact of Unused Medications There has been controversy and media coverage around concerns with flushing medications. The EPA has advised against flushing medications down the toilet because of environmental concerns (2). However, others have noted the main way drug residues enter water systems is by passage of drug and drug-metabolites in urine and feces (7,8). Additionally, there is no clear scientific evidence of actual ecological harm brought about by pharmaceutical contamination of waste water. Given this, the FDA's recommendation to flush certain drugs which are very harmful if unintentionally ingested should be followed.

Hospice and Medication Disposal There are no consensus guidelines or best practices specific to the hospice community around disposal of medication after a patient's death. The National Hospice and Palliative Care Organization and the Hospice and Palliative Nurses Association recommend following the FDA and DEA guidelines listed above and stress the requirement for individual hospice agencies to have organizational policies and procedures on the disposal of controlled substances in accordance with the Centers for Medicare and Medicaid Services Hospice Conditions of Participation, Sec. 418.106. (9-11) In a recent study, nearly 1/3 of hospice nurses were not familiar with these rules (12).

Because of prognostic uncertainty in hospice many patients have unused medications at the time of their death, many of which are opioids or benzodiazepines. There is significant cost associated with discarded medications (13, 14) and concern by hospice staff about legal and environmental impact and risk for drug diversion (12). At the time of first ordering controlled medications, the hospice should provide the patient or patient representative a copy of the hospice written policy on the management and disposal of controlled drugs. After the patient dies, the medications remain the property of the family and hospice staff should advise family on safe disposal.

Bottom Line Ideally, medications should be disposed of at take-back programs, or thrown in the trash. **Opioids, including patches, should be flushed down the toilet and not thrown in the trash.** Providers should educate patients and families about safe medication disposal, particularly with opioids which can be deadly if unintentionally ingested.

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FAST FACTS AND CONCEPTS #341
BLEEDING MANAGEMENT IN HOSPICE CARE SETTINGS
Pamela Liao, MD, Candice Johnstone, MD, Shayna E. Rich, MD, PhD

Background Bleeding is a distressing, complex, and relatively common symptom in palliative care (1). It can present at many anatomical sites and vary in acuity and presentation. This *Fast Fact*, provides an approach to managing non-catastrophic bleeding in terminally ill patients in home or hospice settings.

General Considerations Severity is not the only important clinical consideration when evaluating bleeding in a seriously ill patient. Some imminently dying patients may not benefit from diagnostic workup or intervention even if the bleeding is profuse, while more stable patients can benefit from investigations if they would prevent a terminal bleed or symptom burden (2). Clinicians need to consider goals of care and prognosis in bleeding assessment, as these factors can dictate the degree of investigation and intervention. Additionally, clinicians should be mindful of what testing and interventions can be done in the current environment, as many terminal patients may want to avoid being transferred. A routine CBC or serum INR level, for example, often can be coordinated at home, whereas an advanced intervention such as a bronchoscopy or gastroscopy cannot be.

Initial Management Steps Prior to initiating other interventions, clinicians should remember to:

- Apply pressure if anatomically possible with an appropriate gauze or dressing.
- Consult with a pharmacist to identify offending agents (1). For example, medications such as enoxaparin, oral anticoagulants (see *Fast Fact* #236 and #278), aspirin, NSAIDs, and chemotherapeutics all can cause or exacerbate bleeding. Over-the-counter supplements such as fish oil, omega fatty acids, ginseng, and ginkgo biloba are known to increase bleeding risk.

Systemic Treatments:

- **Vitamin K:** For terminally ill patients on warfarin or with clotting factor deficiencies (e.g. end stage liver failure), consider an empiric dose of 2.5-3 mg oral or subcutaneous Vitamin K (3-6) and/or consumption of Vitamin K-rich foods (e.g. green leafy vegetables, broccoli, prunes, or cabbage).
- **Transfusions:** Platelet, fresh frozen plasma, and clotting factor concentrate transfusions can prevent or stop active bleeding in select patients with thrombocytopenia (e.g. platelet count < 50K) or certain coagulopathies (7). Red blood cell transfusions can improve symptoms such as fatigue, chest pain and shortness of breath, especially when hemoglobin <8. Yet, transfusions are difficult to coordinate in a home or hospice care setting, as they typically necessitate transfer to a specialty clinic or hospital for administration. They may even require revocation of hospice. Therefore, many experts avoid transfusions in imminently dying patients with comfort goals of care.

Local Site Management Prevention and preparation are crucial aspects of bleeding management in dying patients at home or a hospice facility. For at-risk patients with thrombocytopenia, coagulopathy, or specific anatomic concerns, clinicians should ensure that necessary supplies and therapies are available in the care setting before bleeding occurs.

- **Head and Neck:** Patients with erosive tumors of the head and neck are at risk for bleeding. Prophylactic measures such as elevating the head of the bed to 45 degrees, maintaining a soft diet, and minimizing traumatic brushing/flossing are recommended (8). A suction kit at bedside can be useful for patients at risk for epistaxis. For active mucosal bleeding, the effective use of topical agents like silver nitrate, surgicell dressing, or sucralfate gel 1 g in 5 mL water soluble applied to the wound has been described (9). Some experts recommend trying 5% tranexamic acid (TXA) oral rinse TID either as a 10-mL swish and spit x 10 minutes or as a soaking gauze (1,9). If pre-fitted dental molds are available, apply them with a topical agent, in wakeful patients with gingival bleeding (8).
- **Respiratory Tract:** Elevate the head of the bed and consider prophylactic use of cough suppressants (see *Fast Facts* # 199 & 200). For active bleeding from a known location, position the patient on the side of bleeding to reduce the compressive force on the contralateral side.
- **Urinary Tract:** Finasteride may help reduce the recurrence of hematuria in male patients with benign prostatic hypertrophy (9). For hemorrhagic cystitis, intermittent bladder irrigations with saline or TXA 5 g in 50 mL water daily or BID may help (10). If bleeding continues, continuous bladder irrigation with 0.5% or 1% silver nitrate in water solution could be pursued; however, bladder irrigation can induce bladder spasms, so caution should be heeded.
- **Gastrointestinal (GI) Tract:** Effective use of TXA given 1-2 g orally 4-6 times per day, or intravenously at 10 mg/kg 3-4 times per day has been described for active GI bleeding (11). Intravenous infusion of vasopressin 0.1-0.4 mg/hr can reduce GI bleeding in select patients, but it requires hospital monitoring (12). Octreotide 50-100 ug SQ BID or as a 48-hour 50 ug/hr SQ infusion has been described as a home alternative (13). For rectal bleeding, packing with dressings coated with TXA or sucralfate paste may help (10). For minor, hemorrhoid-induced bleeding, Sitz baths or over-the-counter hemorrhoid medications may minimize bleeding by decreasing local inflammation (14).

Advanced Interventions and Treatments When bleeding is brisk, patients and families may reconsider their choice to stay at home and/or pursue comfort care. Consequently, clinicians may need to direct these patients to the emergency department for urgent specialist consultation (e.g., gastroenterology for possible colonoscopy; urology for possible cystoscopy; interventional radiology for possible vessel embolization). Short-course radiotherapy is worthy of special consideration to prevent or treat oozing from a malignant lesion. In some circumstances, it can be coordinated without revocation of hospice services. Regardless, all interventions must be considered in the context of the treatment burden and the duration of recovery from treatment, especially when life-expectancy is limited.

Caring for Caregivers *Fast Facts* #251 & 297 have more information on the management of brisk, catastrophic bleeding. When preparing family members for this possibility do so in a sensitive manner so as not to invoke fear (1). Educate family on how to deliver fast-acting sedative from an emergency kit if needed, as well on the importance of dark sheets, towels, and

clothing to reduce the visibility of blood (1,9). Social workers and other team members may be able to coach family members in distraction techniques such as relaxation and mental imagery.

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