



Fast Facts Core Curriculum

Hospitalist

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**FAST FACTS AND CONCEPTS #3
SYNDROME OF IMMINENT DEATH**

David E Weissman MD

Background Virtually all dying patients go through a stereotypical pattern of symptoms and signs in the days prior to death. This trajectory is often referred to as “actively dying” or “imminent death”. Prompt recognition of this trajectory is key for clinicians to provide the most appropriate interventions for both the patient and family.

1. Stages

- **Early**
 - Bed bound
 - Loss of interest and/or ability to drink/eat
 - Cognitive changes: increasing time spend sleeping and/or delirium (see *Fast Fact #1*)
- **Middle**
 - Further decline in mental status to obtundation (slow to arouse with stimulation; only brief periods of wakefulness)
- **Late**
 - Death rattle – pooled oral secretions that are not cleared due to loss of swallowing reflex
 - Coma
 - Fever – usually from aspiration pneumonia
 - Altered respiratory pattern – periods of apnea, hyperpnea, or irregular breathing
 - Mottled extremities

2. Time Course The time to traverse the various stages can be less than 24 hours or as long as ~14 days. Patients who enter the trajectory who are nutritionally intact, with no infection (e.g. acute stroke), are apt to live longer than cachectic cancer patients

3. Common Family Concerns Family members present during the dying process often express the following concerns/questions. Clinicians can best help families by expecting these questions, providing education, reassurance, and responding to emotions (see also *Fast Fact # 29; #149*).

- Is my loved one in pain; how would we know?
- Aren't we just starving my loved one to death?
- What should we expect; how will we know that time is short?
- Should I/we stay by the bedside?
- Can my loved one hear what we are saying?
- What do we do after death?

4. Treatment

- Confirm treatment goals; recommend stopping treatments that are not contributing to comfort – pulse oximetry, IV hydration, antibiotics, finger sticks, etc.
- Communicate clearly to others what is going on. Write in progress notes: "patient is dying," not "prognosis is poor".
- Treat symptoms/signs as they arise: common among these are: oral secretions (see *Fast Fact* #109, #158); delirium (#1, 60); dyspnea (# 27), fever (#256) and pain (# 53, 54).
- Provide excellent mouth and skin care.
- Provide daily counseling and support to families.

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**FAST FACTS AND CONCEPTS #10
TUBE FEED OR NOT TUBE FEED?****James Hallenbeck MD**

Background Tube feeding is frequently used in chronically ill and dying patients. The evidence for much of this use is weak at best. The Fast Fact reviews data on the use of tube feeding in advanced illness.

For prevention of aspiration pneumonia

- Numerous observational studies have demonstrated a high incidence of aspiration pneumonia in those who have been tube fed. Reduction in the chance of pneumonia has been suggested for non-bed-ridden post-stroke patients in one prospective, non-randomized study. For bedridden post-stroke patients, no reduction was observed.
- Three retrospective cohort studies comparing patients with and without tube feeding demonstrated no advantage to tube feeding for this purpose.
- Swallowing studies, such as videofluoroscopy, lack both sensitivity and specificity in predicting who will develop aspiration pneumonia. Croghan's (1994) study of 22 patients undergoing videofluoroscopy demonstrated a sensitivity of 65% and specificity of 67% in predicting who would develop aspiration pneumonia within one year. In this study no reduction in the incidence of pneumonia was demonstrated in those tube fed.
- Swallowing studies may be helpful in providing guidance regarding swallowing techniques and optimal food consistencies for populations amenable to instruction. See *Fast Fact #128* for discussion of the role of swallowing studies.

For life prolongation via caloric support

- Data is strongest for patients with reversible illness in a catabolic state (such as acute sepsis).
- Data is weakest in advanced cancer. No improvement in survival has been found (see exceptions noted below).
- Individual patients may have weight stabilization or gain with tube feeding. However, when cohorts of patients have been studied in non-randomized retrospective or prospective studies, no survival advantage between tube fed and hand fed cohorts has been demonstrated.
- Tube feeding may be life-prolonging in select circumstances:
 - Patients with good functional status and proximal GI obstruction due to cancer
 - Patients receiving chemotherapy/XRT involving the proximal GI tract.
 - Selected HIV patients
 - Patients with Amyotrophic Lateral Sclerosis

For enhancing quality of life

- Where true hunger and thirst exist, quality of life may be enhanced (such as in very proximal GI obstruction).
- Most actively dying patients (see *Fast Fact #3*) do not experience hunger or thirst. Although dry mouth is a common problem, there is no relation to hydration status and the symptom of dry mouth – see *Fast Fact #133*.
- A recent literature review using *palliative care* and *enteral nutrition* as search terms found no studies demonstrating improved quality of life through tube feeding (results were limited to a few observational studies).
- Tube feeding may adversely affect quality of life if patients are denied the pleasure of eating.

Summary

Although commonly used, current data does not provide much support for the use of artificial enteral nutrition in advanced dementia, or in patients on a dying trajectory from a chronic illness. A recommendation to use, or not use, tube feeding should be made only after first establishing

the overall *Goals of Care* (see *Fast Fact #16*). Recommendations for how to discuss the issue tube feeding with patients/families can be found in *Fast Fact #84*.

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FAST FACTS AND CONCEPTS #13
DETERMINING PROGNOSIS IN ADVANCED CANCER
David E Weissman MD

Background *How long do I have, Doc?* is among the most common questions asked by cancer patients, especially when informed that there are no further effective anti-neoplastic treatment options. Although prognostication is not an exact science, there are data to help clinicians provide useful information to patients and families – information critical to making realistic end-of-life decisions and referrals for home hospice service (see *Fast Fact #30*).

Performance Status The single most important predictive factor in cancer is *Performance Status* ('functional ability,' 'functional status'): a measure of how much a patient can do for themselves, their activity and energy level. Patients with solid tumors typically lose ~ 70% of their functional ability in the last 3 months of life. The most common scales used to measure functional ability are the Karnofsky Index (100 = normal; 0 = dead) and the ECOG scale (Eastern Cooperative Oncology Group), (0 = normal; 5 = dead). A median survival of 3 months roughly correlates with a Karnofsky score ≤ 40 or ECOG ≥ 3 . Newer prognostic scales have been developed to help provide prognostic information (See *Fast Facts #124, 125*).

The simplest method to assess functional ability is to ask patients: *How do you spend your time? How much time do you spend in a chair or lying down?* If the response is $>50\%$ of the time, and is increasing, you can roughly estimate the prognosis at 3 months or less. Survival time tends to decrease further with increasing numbers of physical symptoms, especially dyspnea, if secondary to the cancer.

Other Factors Several common cancer syndromes have well-documented short median survival times:

- Malignant hypercalcemia: 8 weeks, except newly diagnosed breast cancer or myeloma (see *Fast Fact #151*)
- Malignant pericardial effusion: 8 weeks (see *Fast Fact #209*)
- Carcinomatous meningitis: 8-12 weeks (see *Fast Fact #135*)
- Multiple brain metastases: 1-2 months without radiation; 3-6 months with radiation.
- Malignant ascites (see *Fast Fact #176*), malignant pleural effusion (#209), or malignant bowel obstruction: < 6 months.
- Modified Glasgow Prognostic Score (mGPS): multiple studies have shown that an increased mGPS -- meaning an elevated serum c-reactive protein and a reduced serum albumin -- is associated with a reduced cancer specific survival curve irrespective of cancer type.

Other Comments In general, a patient with metastatic solid cancer, acute leukemia or high-grade lymphoma, who will not be receiving systemic chemotherapy (for whatever reason), has a prognosis of *less than 6 months*. Notable exceptions to this are patients with metastatic breast or prostate cancer with good performance status, as these cancers may have an indolent course. In these patients additional features suggesting short prognosis are needed (declining functional status, dyspnea, weight loss).

Discussing Prognosis When discussing prognosis with patients/families, the following four step approach is recommended: *Preparation; Content; Patient's Response; Close*. Remember to:

- Confirm that the patient/family are ready to hear prognostic information.
- Present information using a range: *a few days to weeks; 2-4 months*, etc.
- Allow silence after you provide information; respond to emotion (see *Fast Fact #29*).
- Use prognostic information for eliciting end-of-life goals (see *Fast Fact #65*).

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FAST FACTS AND CONCEPTS #23 DISCUSSING DNR ORDERS – PART 1

Charles F von Gunten MD, PhD and David E Weissman MD

Background ‘Code status’ discussions with seriously ill patients should always take place in the context of the larger goals of care, using a step-wise approach. This *Fast Fact* introduces an approach to having these discussions; *Fast Fact #24* discusses disagreements about ‘code status.’ Prior to any discussion of a do-not-resuscitate (DNR) order, physicians must know the data defining outcomes and morbidity of cardiopulmonary resuscitation in different patient populations (see *Fast Fact #179*) and care settings (see *Fast Fact #292* regarding DNR orders in the Operating Room).

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 with a phrase such as: *I’d like to talk with you about possible health care decisions in the future.*

2. What does the patient understand? An informed decision about DNR status is only possible if the patient has a clear understanding of their illness and prognosis. 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? 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.

3. What does the patient expect? Ask the patient to consider the future. Examples of ways to start this discussion are *What do you expect in the future?* or *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. Many 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, and 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 comfortable as possible when the time comes? Or – What you’ve said is – you want us to do everything we can to fight, but when the time comes, you want to die peacefully?* Whenever possible, ask patients to explain the values that underlie their decisions: *Can you explain why you feel that way?*

4. Discuss a DNR order. Use language that the patient will understand; give information in small pieces. Don’t introduce CPR in mechanistic terms (e.g. “starting the heart” or “putting on a breathing machine”). Never say *Do you want us to do everything?* “Everything” is euphemistic and easily misinterpreted. Using the word “die” helps to clarify that CPR is a treatment that tries to reverse death. To most lay-people, when the heart and/or lungs stop, the patient dies.

If the patient and doctor mutually recognize that death is approaching and the goals of care are comfort, then CPR is not an appropriate medical intervention and a clear recommendation against CPR should be made. You can say: *We have agreed that the goals of care are to keep you comfortable and get you home. With this in mind, I do not recommend the use of artificial or heroic means to keep you alive. If you agree with this, I will write an order in the chart that if you die, no attempt to resuscitate you will be made.*

If the clinical situation is more ambiguous in terms of prognosis and goals of care, and you have no clear recommendation, the issue of DNR can be raised by asking: *If you should die in spite of all of our efforts, do you want us to use heroic measures to attempt to bring you back?* Or, *How do you want things to be when you die?* If you are asked to explain “heroic measures”, then describe the purpose, risks and benefits of CPR in greater detail. The clinical pearl here is to start general and become specific later in the conversation.

5. Respond to emotions. Strong emotions are common when discussing death. Typically the 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*).

6. Establish a plan. Clarify the orders and plans that will accomplish the overall goals you have discussed, not just the DNR order. A DNR order does not address any aspect of care other than preventing the use of CPR. It is unwise and poor practice to use DNR status as a proxy for other life-sustaining therapies. Consider using words: *We will continue maximal medical therapy to meet your goals. However, if you die, we won't use CPR to bring you back. Or, It sounds like we should move to a plan that maximizes your comfort. Therefore, in addition to a DNR order, I'd like to talk further with you how we can best do that.*

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FAST FACTS AND CONCEPTS #24 DISCUSSING DNR ORDERS – PART 2

Charles F von Gunten MD, PhD and David E Weissman MD

Introduction The basic steps in the DNR discussion for seriously ill hospitalized patients were described in *Fast Fact # 23*. If you have followed those steps, what do you do if the patient or family/surrogate continues to want CPR and you think it is not in the patient's best interest? The seemingly unreasonable request for CPR typically stems from one of several themes:

1. Inaccurate information about CPR. The general public has an inflated perception of CPR success. While most people believe that CPR works 60-85% of the time, in fact the actual survival to hospital discharge is more like 10-15% for all patients, and less than 5% for the elderly and those with serious illnesses. This is a time to review/clarify the indications, contraindications, potential outcomes and morbidity of CPR. Start the discussion by asking, “*What do you know about CPR?*”

2. Hopes, fears, and guilt. Be aware that guilt (*I haven't lived nearby to care for my dying mother*) and fear (*I am afraid to make a decision that could lead to my wife's death*) are common motivating emotions for a persistent CPR request. Some patients or families need to be given an explicit recommendation, or permission from the physician, to stop all efforts to prolong life, to be told that that death is coming and that they no longer have to continue "fighting". Whenever possible, try to identify the underlying emotions and offer empathic comments that open the door to further conversation. *This decision seems very hard for you. I want to give you the best medical care possible; I know you still want CPR, can you tell me more about your decision?*

Agreeing to a DNR order for many patients feels equivalent to them "choosing" to die. Acceptance of impending death occurs over a vastly different time course for different patients/families; for some, it never occurs. Some patients see CPR as a "last chance" for continued life. Probe with open-ended questions: *What do you expect to happen? What do you think would be done differently, after the resuscitation, that wasn't being done before?* Many patients describe hope for a new treatment. Use the opportunity to respond by describing that you are doing everything in your power to prolong their life before a cardiopulmonary arrest – you wouldn't be "saving something" to do after they had died. If patients are not ready for a DNR order, don't let it distract you from other important end-of-life care needs; emphasize the goals that you are trying to achieve; save a repeat discussion for a future time; good care, relationship building and time will help resolve most conflicts.

3. Distrust of the medical care system. Patients or families may give you a clue that there is a fundamental distrust of doctors or the medical system; this should be addressed openly. *What you said makes me wonder if you may not have full trust in the doctors and nurses to do what is best for you? Can you tell me about your concerns?*

4. Managing persistent requests for CPR. Decide if you believe that CPR represents a futile medical treatment—that is, CPR cannot be expected to either restore cardiopulmonary function or to achieve the expressed goals of the patient (see *Fast Fact #136*). Physicians are not legally or ethically obligated to participate in a futile medical treatment, and some facilities have a policy that a physician may enter a DNR order in the chart against patient wishes. Aside from writing a DNR order without patient or family agreement, other options at this time include:

- Transfer care to another physician chosen by the patient/family.
- Plan to perform CPR at the time of death – *but don't end the discussion*. Engage the patient about her or his wishes if she or he survive the resuscitation attempt. Tell the patient that you need guidance because it is very likely that if she or he survives CPR, they will be on life support in the ICU, and they may not be able to make decisions for themselves; ask them (or the family) to help you determine guidelines for deciding

whether to continue life-support measures. If not already done, clarify if there is a legal surrogate decision-maker.

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**FAST FACTS AND CONCEPTS #42
BROACHING THE TOPIC OF A PALLIATIVE CARE CONSULTATION
WITH PATIENTS AND FAMILIES**

Robert Arnold MD and David E Weissman MD

Introduction Palliative care consultative services are becoming commonplace in academic and community hospitals and clinics. Patients and families may have negative perceptions of palliative care and hospice – viewing such a discussion as signaling that the physician is “giving up on the patient” and that the reality of impending death must be faced. For the attending physician, the decision to convey to a patient and family that a consultation is needed can provoke anxiety. Physicians may fear such a discussion will provoke anxiety, anger or a sense of hopelessness. This *Fast Fact* provides tips for beginning a discussion leading to a visit by a palliative care consultation team.

First, decide why you want assistance from the palliative care team. Typically, physicians seek assistance in four domains: 1) pain and non-pain symptom assessment and management; 2) assistance in making difficult decisions, usually about continued use or withdrawal of potentially life-prolonging treatments such as feeding tubes, antibiotics, dialysis, or ventilators; 3) assistance in planning for the most appropriate care setting to meet patient/family goals for end-of-life care; and 4) providing psychological support to patients, families and the health care team.

Second, contact the palliative care team. Discuss your reason(s) for consultation along with pertinent details of the patient’s history and family support structure. Describe both what your goals are for the consultation, as well as what the family’s/patient’s goals may be. This is a good time to discuss any concerns you have about using the term *palliative care* with the patient or family.

Third, engage the patient/family in a discussion of the current medical condition and goals of care. Introduce the topic of a consultation by saying: *To best meet some of the goals we’ve been discussing (fill in with the goals mentioned by the family/patient) I’d like to have some consultants from the Palliative Care Team visit with you.* You can follow this by saying, *They are experts in treating the symptoms you are experiencing (fill in symptom). They are also good at helping your family deal with all the changes brought on by your illness; they can answer your questions about (fill in previously discussed patient questions).*

You should not say that the reason you are asking Palliative care to be involved is “that there is nothing more to do” or because “I have nothing more to offer.” Talk about the positive goals Palliative Care can help you and the patient achieve.

Finally, emphasize your continued involvement: *You and I will talk about the recommendations of the palliative care experts. I’ll make sure all your questions are answered.* This can help relieve fears of abandonment. If a patient or family reacts negatively to the suggestion for a consultation, explore their concerns. Someone may have mentioned palliative care and this may have negative connotations to them. Ask, *What experience do you have with hospice/palliative care? What are your concerns?* It may be important to discuss that palliative care is compatible with aggressively treating the underlying disease. Emphasize the positive aspects of what palliative care can do, rather than focusing on how the palliative care team will help them accept death and dying. After all, the goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms and restoration of functional capacity, while remaining sensitive to the patient and family’s values. Palliative Care guides the patient and family as they face disease progression and changing goals of care, and helps those who wish to address issues of life completion and life closure.

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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 #222 PREPARING FOR THE FAMILY MEETING

David E Weissman MD, Timothy E Quill MD, and Robert M Arnold MD

Background A cornerstone procedure in Palliative Medicine is leadership of family meetings to establish goals of care, typically completed at a time of patient change in status, where the value of current treatments needs to be re-evaluated. As with any procedure, preparation is essential to ensure the best outcome. This *Fast Fact* reviews how to prepare for a Family Meeting. See also *Fast Fact #16* for a concise overview of family meetings, as well as *Fast Facts 223-227* for discussion of additional aspects of family conferences.

Data Review

- Review the medical history relevant to the current medical situation (e.g. history of disease progression, symptom burden, past treatments, treatment-related toxicity, and prognosis).
- Review all current treatments (e.g. renal dialysis, artificial nutrition, antibiotics) and any positive and/or negative treatment effects.
- Review all treatment options being proposed.
- Determine the prognosis with and without continued disease-directed treatments. Prognostic information includes data concerning future patient function (physical/cognitive), symptom burden, and time (longevity).
- Solicit and coordinate medical opinions about the utility of current treatments among consultants and the primary physician. If possible, families need to hear a single medical consensus—all relevant clinicians should be contacted and consensus reached prior to the meeting. If the consultants do not agree, then prior to the family meeting they should meet to negotiate these differences and attempt to reach consensus regarding the plan. If there is no consensus, a plan should be developed for how to describe these differences to families.
- If the patient lacks capacity, review any Advance Directive(s), with special attention to discover if the patient has named a surrogate decision maker, and if the patient has indicated any specific wishes (e.g. DNR status, 'no feeding tubes').
- Seek out patient/family psychosocial data. Focus on psychological issues and family dynamics (e.g. anger, guilt, fear) potentially impacting decision making. These issues may be long-standing, or due to the current illness. **Note:** talking to the patient's social worker, bedside nurses, and primary and consulting physicians can help you get a better sense of the family and how they make decisions.
 - Review what transpired in prior family meetings.
 - Learn about particular cultural/religious values and/or or social/financial issues that may impact decision making.

Information Synthesis Based on your review of the medical and prognostic data, make an independent determination of which current and potential tests/treatments will improve, worsen, or have no impact on the patient's function/quality of life (physical/cognitive) and time (longevity).

Meeting Leadership Leading a family meeting requires considerable flexibility to ensure that all relevant participants have the opportunity to have their points of view expressed. Though it is useful to have one person designated as the main orchestrator and coordinator of the meeting, the essential skills for making a family meeting successful can come from more than one participant. These skills include:

- Group facilitation skills.
- Counseling skills.
- Knowledge of medical and prognostic information.
- Willingness to provide leadership/guidance in decision making.

Invitations A decisional patient can be asked who he/she wants to participate from his/her family/community, including faith leaders; in general it is wise not to set any arbitrary limits on the number of attendees. The medical care team should likewise decide who they want to participate. **Note:** it is important not to overwhelm a family with too many health professionals.

On the other hand, a physician from the primary team as well as a nurse and social worker should attend when possible; these individuals can help ensure the consistency of information as well as help deal with complicated dynamics. If the patient has a long-time treating physician whom he/she trusts, this person should ideally be present.

Setting The ideal setting is private and quiet, with chairs arranged in a circle or around a table. Everyone should be able to sit down if they wish. For non-decisional patients, the clinical team should negotiate with the surrogate whether or not to have the meeting in the presence of the patient.

The Pre-Meeting Meeting The participating health care members should meet beforehand to confirm: a) the goals for the meeting (e.g. information sharing, specific decisions sought), b) who will be the meeting leader to start the meeting, and c) likely sources of conflict and initial management strategies.

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FAST FACTS AND CONCEPTS #223 THE FAMILY MEETING: STARTING THE CONVERSATION

David E Weissman MD, Timothy Quill MD, and Robert M Arnold MD

Background *Fast Fact #16* gives a concise overview of running a family meeting. *Fast Fact #222* provides a list of preparatory steps in planning for a family meeting to discuss end-of-life goals; this *Fast Fact* reviews the early steps of the actual meeting.

1. Introductions & setting goals for the meeting

- The meeting leader begins the meeting by introducing him or herself, and suggesting that each person present (medical team and family/community) introduce themselves including their relationship to the patient.
- The meeting leader should summarize the meeting goals (e.g. *We are here to discuss next steps in the care of Mr. Jones*) and ask the family to confirm these goals and/or add other agenda items.
- **Note:** if you do not know the patient or family well, take a moment to build relationship. Ask a non-medical question such as *I am just getting to know you. I had a chance to look at your chart and learn about your medical condition but it does not say much about your life before you got sick. Can you tell us about the things you liked to do before you got sick?* Similarly, if the patient is not able to participate in the meeting, ask family to describe the patient prior to his becoming ill: *As we get started, can you describe what Mr. Jones was like before he became ill?*

2. Determine what the patient/family already knows This step is essential as it guides you in providing a synthesis of the medical information (see below). Always invite the patient and all family members to provide their understanding of the medical information. Examples of opening lines:

- *Tell me what the doctors have told you about your condition?*
- *Can you describe for me your sense of how things are going?*
- For patients who have been declining from a chronic illness, you can ask: *Tell me about the past 3-6 months: what types of changes have you noted?* The patient or family will typically describe changes in terms of function (physical or cognitive) and quality of life.

3. The Medical Review Once you know what the patient/family understands, you are in a good position to confirm their understanding, or provide new information/correct misunderstandings. First, ask if you can bring them up-to-date about what is going on; asking shows politeness and also signals that they should attend to what you are trying to say. The clinician most closely aligned with the patient's ongoing treatment should begin this discussion, supplemented with information from consulting services if relevant. Do not provide information using medical jargon or in an organ system approach (e.g. *The creatinine is improving, but there is a new pleural effusion and the heart rate has become irregular*). A more patient-centered approach is to provide a succinct summary of the current condition, without any medical jargon, focusing on the issues of most importance, which are usually function/quality/time. Give a 'bottom-line' statement: 'getting worse,' 'not going to improve,' 'dying and time is likely very short.'

- *The worsening weakness and pain you describe is from the cancer which is growing despite the chemotherapy.*
- *You are telling me that despite the recent hospitalization, you are not able to do as much around the house; unfortunately your lung disease is getting worse despite all our best treatments.*
- *Despite our best efforts, your wife's brain injury from the car crash is getting worse. She can no longer stay awake or move her arms/legs.*

Using the 'D word' if relevant: when a patient is clearly deteriorating and death is likely within the next days to weeks, or even a few months, it is appropriate to use the word *dying* in the conversation. Both patients and surrogates find that saying the word *dying*, if done compassionately, is helpful in clearing what is often a confusing and frightening situation. *I'm afraid we have run out of options to shrink the cancer. Based on your declining function, I believe you are dying.*

4. Silence Whether or not you use the word *dying*, when you have presented bad news (such as information about disease progression), the next step is for you to allow silence, and let the

family/patient respond. In truth, no matter what you might imagine the response from the patient/family to be once the bad news is delivered, you really cannot predict their emotional reaction (e.g. relief, anxiety, anger, regret, fear). This silence can be uncomfortable; resist the urge to fill it with more facts as they will not be heard. Not all patients/families express emotions at this point and instead respond practically (*Well, what happens next then?*). This is fine, but you need to wait, silently, to see what response the patient/family demonstrates. In addition, even practical questions have underlying emotions (*Are you sure? Or – There must be something you can do?*). It is important to respond to both the factual aspect of the question (*Yes I am sure. Or – There are no more effective treatments available.*), as well as the emotional level (*I wish I had better news for you. Or – I wish our treatments worked better than they do.*).

When the patient/surrogates openly acknowledge that current treatments are no longer effective, that death is coming, they will generally ask one or all of the following questions: *How long? What will happen? Will there be suffering? What do we do now?* Your response at this point should be to address prognosis in terms of time, function, and symptoms, as best you can (see *Fast Facts* #13,141,143,149,150). This will answer the first two questions; the last questions will require more discussion of patient-centered goals (see *Fast Fact* #227).

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FAST FACTS AND CONCEPTS #224 RESPONDING TO EMOTION IN FAMILY MEETINGS

David E Weissman MD, Timothy E Quill MD, and Robert M Arnold MD

Background Family meetings are stressful events, often provoking strong emotional reactions. *Fast Fact #29* presents a general outline on the topic of how clinicians can respond to emotions. The *Fast Fact* will provide a more detailed approach to emotions that arise during family meetings.

Consider your role. It is important to reflect on the role of clinicians in responding to patient/family emotions at the time life-altering information is shared. The goal is not to prevent a patient/family from having those emotions. Sadness, fear, anger, and loss are normal responses to unwelcome news. Instead your role is: 1) to maintain a trusting therapeutic relationship and safe/supportive environment that allows emotions to be expressed in a way that meets the patient's/family's needs; and 2) not to worsen the experience for the patient/family by ignoring or delegitimizing their responses, or confusing them with medical information when they are not ready to hear it. Recognize that most families find clinicians' expressions of empathy tremendously supportive and these are associated with family satisfaction.

Acknowledge that emotion is being expressed. If you have a good sense of what the emotion is, then it is useful to name it. If not, using more general language is preferable.

- *I can see this is really affecting you.*
- *This information is very upsetting.*

Legitimize the appropriateness and normalcy of the reaction. Medical professionals are in a powerful position to help patients and families feel that strong emotions under these circumstances are normal and to be expected.

- *Anyone receiving this news would feel devastated.*
- *It is completely expected to be very distressed by this kind of news.*

Explore more about what is underneath the emotion. It is tempting to try to limit the emotion, and be prematurely reassuring. But it is generally more helpful and ultimately more time-efficient to allow the patient and family to more deeply explore their feelings and reactions.

- *Tell me what is the scariest (most difficult) part for you.*
- *Tell me more about that....* (Keep the exploration going until it is fully expressed and understood.)

Empathize (if you genuinely feel it). Empathy means being able to emotionally imagine what the patient is going through. Clinicians can initiate the prior responses (acknowledge, legitimize, explore) without having a clear feeling for the patient's experience. These responses can be adequate in themselves. If the clinician cannot imagine the patient's experience, he or she can still sensitively explore the experience and provide caring and support. But if you have a strong sense of what the patient is experiencing, it can be very therapeutic to express it.

- *This seems really unfair.*
- *I can imagine that you might feel very disappointed.*

Explore strengths/coping strategies. This may occur at this phase of the interview, or it may be postponed to a later phase when planning for next steps begins.

- *In past circumstances, what has helped?*
- *How have you adapted to difficult circumstances in the past?*
- *What are you hoping for now?*

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**FAST FACTS AND CONCEPTS #225
THE FAMILY MEETING: CAUSES OF CONFLICT**

David E Weissman MD, Timothy E Quill MD, and Robert M Arnold MD

Background When family meetings are conducted with the goal of helping a patient/family cope with a shift in goals from life-sustaining treatments to a more comfort focused approach, communication can break down. This *Fast Fact* reviews the common causes of conflict.

Recognizing Conflict When the patient/surrogates are not psychologically ready to accept the limits of medical interventions or the finality of the impending death, you will hear comments such as these: *There must be some mistake; I know there are other treatments available; We want a second opinion; We believe in miracles; She is fighter, she will never give up; There must be something (medically) you can do.* Health professionals may interpret these statements as 'denial.' But the term denial, by itself, is insufficient to help the clinician understand what is causing the impasse. Understanding the cause is essential in planning an effective strategy to move beyond the conflict to meet the needs of the patient and surrogates.

Information Gaps

- Inaccurate understanding of the patient's medical condition (e.g. overly optimistic/pessimistic prognosis).
- Inconsistent information (*One doctor tells us one thing and another something else.*).
- Confusing information (e.g. use of medical jargon, multiple treatment options presented without a clear recommendation).
- Excessive information (well-meaning family/friends/clinicians providing information without full awareness of the problems).
- Genuine uncertainty (e.g., predicting functional outcome from a brain injury in its immediate aftermath may be impossible).
- Language/translation/cultural issues (*We never tell someone they are dying in our culture.*).

Treatment Goal Confusion

- Inconsistent treatments and unclear goals, often due to physician/patient/surrogate emotional issues (see below):
 - Clinician initiated: *We will keep your husband on blood pressure raising medicine but stop antibiotics.*
 - Family initiated: *We want you to do CPR, but not intubate her.*
- Differing priorities about disease-directed treatment and comfort-oriented treatment between clinicians and patient/family.
- Lack of clarity about goals when several things are going on simultaneously (advanced cancer, severe infection, respiratory failure – *Isn't the pneumonia potentially treatable?*)

Emotions

- Grief (*I don't know how I will live without him.*)
- Fear/anxiety (*I don't want to be responsible for ending my father's life. My family will be angry at me for doing this.*)
- Guilt (*I haven't visited my sister in 20 years. I should have been here for her.*)
- Anger (*My mother was very abusive, I've never forgiven her; you are just giving up on her.*)
- Hope (*I'm still hoping and praying she can pull through this.*)

Family/Team dynamics

- Patient/family conflicted within themselves; may want different things at different times
- Dysfunctional family system (family members unable to put the patient's needs/values/priorities above their own).
- Surrogate lack of ability (cognitive deficit, psychological/psychiatric trait/illness). In pediatrics, this can be conflict between what is in the best interest of a child vs. a caregiver or family.

- Consulting teams disagree about the optimal approach, putting the patient/family in the middle of the dispute.

Relationship between the Clinician and the Patient/Surrogate

- Lack of trust in the health care team/health care system.
- Past experiences where the patient has had a better outcome than predicted.
- Genuine value differences:
 - Cultural/religious values concerning life, dying, and death.
 - Clinician value to protect the patient from invasive, non-beneficial treatment while the family values wanting to prolong life no matter how much suffering it might entail.

All of these issues represent a degree of conflict and will need to be addressed before proceeding to set end-of-life goals. See *Fast Facts* #183,184 for additional discussion on managing conflict.

Debriefing Conflicts are stressful for all involved health professionals. It is helpful to debrief the process – what went well, what could have been improved, and – most importantly – addressing the emotional reaction and needs of the care team. See *Fast Fact* # 203 on managing clinician emotions.

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HELPING SURROGATES MAKE DECISIONS

David E Weissman MD, Timothy E Quill MD, and Robert M Arnold MD

Background Surrogate decision makers are often placed in the difficult position of making what feels to them as life or death decisions. This *Fast Fact* reviews an approach to help surrogates through the decision process when patients cannot participate in decision-making themselves.

Surrogate decision making The surrogate's role is clearly to exercise "substituted judgment" – that is, to make decisions as the patient would make them using the patient's values and preferences as previously expressed. The challenge was clearly expressed by the New Jersey Supreme Court in the Quinlan case: *if (the patient) could wake up for 15 minutes, understand his current medical situation completely, and then had to go back into it, what would he tell us to do?* In the case of children, surrogate decision makers (usually parents) are expected to make decisions that represent the child's 'best interests'; depending on the age and capacity of the child to participate in his/her own healthcare decision making, the applied 'best interest' judgment by the surrogate and healthcare providers may incorporate the patient's values and preferences to the extent possible, or may be solely based on the decision maker's interpretation of best interest. If there is conflict about what is in a child's best interest, or in cases of developmentally disabled adults who have never had capacity, consultation from ethics and law may be appropriate, as the rules governing decision-making vary considerably.

Helping surrogates

1. Before making a recommendation, make sure there is a common understanding of the patient's condition and prognosis. Following this, the next step is to try to understand the patient's goals in light of these medical facts.
2. Bring the patient's "voice" into the decision process even if he/she cannot participate directly: *If your father were sitting here with us, what would he say?* If available, share a copy of any advance care planning document with the surrogate. Realize that it is common for the surrogate never to have seen the document.
3. Whenever possible, frame the decision around the treatment goals (e.g. life prolongation, allowing a peaceful death) in light of the patient's current condition, rather than focusing on very specific treatments (e.g. thoracentesis, antibiotics). The details of the medical plan should flow from the overall goals of care.
4. Do not make the surrogate feel that they are taking full responsibility for medical decisions, especially those which may result in the death of their loved one (*We can do option a or b; what would like me to do?*). Once you have a sense of the patient's goals in light of his/her medical condition, offer to make a recommendation that reflects those goals. **Note:** Many families are looking for support and guidance from medical professionals, especially the physician. *Given what you have told me about your mother, and what we know about her medical condition, I would recommend....* Start with what you are going to do to achieve the patient's goals and then talk about what does not make sense given those goals. Remember, however, that some families may want information but not your recommendation. It is therefore important to offer your recommendation (*Would it be helpful for me to say what medically makes the most sense, given what you've told me about your Dad?*).
5. Remember that we are talking about the potential death of the surrogate's loved one. Emotions – sadness, frustration and guilt – are appropriate and to be expected. Use previously discussed emotion management skills to acknowledge, legitimize, empathize and support the family's emotional response (see *Fast Facts* #29 and #224).
6. Do not argue over the facts; repeating the facts over and over again is not likely to be effective. When the surrogate says *He is a fighter*, acknowledge that he is and has really fought hard. The surrogate saying *I want you to do everything* is as much a sign of emotional desperation as it is a factual request. Respond with empathy: *It seems this is really hard for you.* If hope for a miracle is expressed, it is appropriate to acknowledge that you hope for an unanticipated recovery as well, but that a miracle is truly what it would take at this point.
7. Rather than reiterating what medicine cannot do, consider using "*I wish*" statements to keep you in touch with the surrogate's feelings, while simultaneously expressing medicine's

limitations (*I wish our medicines were more effective; I wish we had more medical treatment to offer than we do...*).

8. Recognize the importance of time and support for surrogates to do their necessary grief-work. Offer counseling services, either informal through the work of a palliative care team, or more formal resources available at your institution. Bring together your clinical care team and strategize potential resources for support such as chaplaincy, social services, psychology, palliative care or ethics consultation.

Remember that time is your ally. The surrogate needs to process that their loved one is dying and conceptualize what life will be like without him or her. This grief work takes time and psychological support. Often, letting people think about what you have said and talking again over subsequent days provides them the space to do grief work. It also allows them to see for themselves that what you have advised is coming true (e.g. the patient is not getting better).

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**FAST FACTS AND CONCEPTS #227
THE FAMILY MEETING: END OF LIFE GOAL SETTING AND FUTURE PLANNING**

David E Weissman MD, Timothy E Quill MD, and Robert M Arnold MD

Background End-of-life goal setting is a key palliative care skill, typically occurring as part of a family meeting (see *Fast Facts* #16, 65, 222-226). This *Fast Fact* discusses an approach to goal setting when the expected length of life is short.

Establishing patient-centered goals Here is an example of how to start the conversation (the patient should be given sufficient time to respond to each of these questions):

I/we have discussed your current condition and that time may be short. With that in mind –

- *What are you hoping for now?*
- *What is important to you?*
- *What do you need to accomplish?*
- *Who do you need to see in the time that is left?*

Common responses invoke family, home, and comfort; often surviving until a specific future family event/date or visit with a key family member is described as an important goal. Re-state your understanding: *What I hear you saying is that you want to be home, comfortable, and survive until your daughter gives birth – you hope to meet your next grandchild.* **Note:** if you believe the patient's goal of survival to a specific event/date is not practical, it is important to say so and discuss alternative plans.

Recommend a care plan based on the goals Once the goal(s) is/are established, you can then review the patient's current treatments (e.g. antibiotics, chemotherapy), monitoring (e.g. pulse oximetry), planned tests (e.g. colonoscopy), and medications (e.g. anti-hypertensives), and decide which will help meet, or not, the patient's goals. Anything that will not help meet the goals should be discussed for potential discontinuation. Depending on the specific disease/patient condition, other issues that are naturally discussed at this point include:

- Future hospitalizations, ICU admissions, laboratory and radiology tests.
- Resuscitation orders/code status (see *Fast Facts* #23-24).
- Current/future use of blood products, antibiotics, artificial hydration/nutrition.
- If present, the potential continuation or stopping of dialysis or cardiac devices.
- Role of a second (or third) opinion.
- Exploration of experimental therapy.
- Exploration of treatment options the patient or family may bring into the conversation.
- Disposition options to best meet the goals (e.g. home hospice referral).

Note: There is *no* need to ask about each option as a yes/no question (*Do you want blood products?*). Based on what you know about the patient's goals, make a recommendation about what should and should not be done in light of the patient's goals, condition and prognosis. If you are unsure, you can explore the issue with the patient/family (*Given that your dad wanted to get home as soon as possible and yet he was also willing to do easy things that might help him live longer, I am unsure whether it makes sense to stay in the hospital an extra day or two to finish the antibiotics. What do you think he would say?*).

'Long-shot' goals If patients are going to pursue 'long-shot' or experimental therapy, perhaps even against the recommendation of the treating team, it is useful to ensure the following:

- Reinforce the team's respect for the decision, and desire to make sure the treatment has the best possible chance of working.
- Simultaneously try to maximize quality of life *in the present*, including the best possible pain and symptom management and support.
- Encourage the patient and family to prepare in case treatment is not successful and the patient dies sooner rather than later. Useful language is to say, *I'd encourage us all to hope for the best, but prepare for the worst.*
- Reinforce that the team will not abandon the patient and family even if the decision is not what is being recommended.

Close the meeting Following this discussion, restate your understanding of the patient's goals and agreed-upon next steps to meet those goals, invite and answer questions, and close the meeting.

Discussion & documentation Discuss the goals with key staff not in attendance (e.g. consulting physicians, patient's nurse, discharge planner, primary care provider). Document the goals, preferably using a templated family meeting note (see Reference 1): who was present, what was discussed (e.g. treatment options, prognosis), what was decided, next steps.

Debriefing A useful step after every family meeting is to debrief the process – what went well, what could have been improved and, most importantly, addressing the emotional reaction and needs of the care team.

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FAST FACTS AND CONCEPTS #326 ILLNESS TRAJECTORIES: DESCRIPTION AND CLINICAL USE Paige Comstock Barker, MD and Jennifer S. Scherer, MD

Illness trajectories can provide a framework for addressing patient and family expectations of what will happen with regards to their anticipated health. Distinct illness trajectories have been recognized in the medical literature (see Figure 1). This *Fast Fact* will review the medical evidence of these trajectories as well as their utility as a patient teaching tool.

General Evidence: A large observational study, described distinct illness trajectories at the end of life for frailty/dementia, cancer, and organ failure (1). Subsequent research has cast some

controversy about the validity of these findings, particularly whether hospitalizations may have a more significant role on the pattern of decline than the specific illness itself (2-4).

Illness Trajectories:

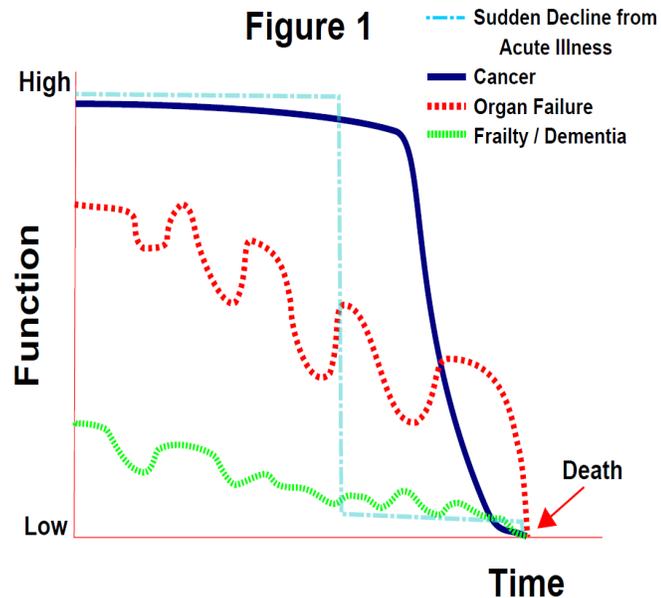
Frailty / Dementia: A pattern of dwindling cognitive and/or physical disability that may progress over several years (1). Seventy percent of dementia patients require assistance in ≥ 3 ADLs, in the last year of life, making these patients at heightened risk for nursing home placement and caregiver breakdown (2). Many clinicians and families may not recognize that dementia by itself is a terminal illness.

Cancer: A relatively stable period of physical function followed by an acute decline in the last few months of life. Multiple studies have supported this trajectory however, the timing of steep decline ranges between 1 to 5 months before death depending on the study (1,5-7). Cancer patients may also experience more predictable patterns of spiritual distress with peaks at diagnosis, disease recurrence, and the terminal phase of illness (8). Because the physical decline and psycho-spiritual distress can be better anticipated, especially in solid tumors, more accurate prognostication and implementation of specialized palliative care services can occur. One study of Medicare patients showed that cancer patients were more likely to utilize hospice in comparison to other chronic illnesses because of the more predictable trajectory (9). More research is needed to validate this trajectory in the face of new targeted treatment modalities.

Organ failure: A more erratic trajectory with punctuated periods of decline likely correlating with acute exacerbations (1). Each exacerbation may result in death but is often survived with gradual deterioration in health and functional status. Timing of death is less certain than in cancer. Perhaps as a result, patients with congestive heart failure (CHF) and chronic obstructive pulmonary disorder are more likely to die in the hospital and less likely to receive hospice services nor understand the likely progression of their illness (9-12). Other take home points regarding the organ failure trajectory include:

- The functional decline for CHF has been shown to be particularly heterogeneous (2,13). Some hypothesize this may be related to co-morbidities and/or research methodologies (13).
- Often prognosis is more centered around patient specific goals regarding acceptance or not of repeat hospitalizations and treatment of potentially reversible complications.
- Although observational studies have shown inconsistent findings, elderly end stage renal disease patients who forgo initiating hemodialysis may be more likely to have an illness trajectory similar to sudden death – stable function for months with a rapid end of life deterioration (14-16).

Sudden Death or Decline: An abrupt change from normal physical function to either death or significant medical disability, often as a result of trauma or an acute cardiopulmonary/neurologic event. Many times there is little or no prior interaction with the health system nor a recognizable pattern of functional decline preceding the event (1,9). Thus, intense displays of shock or anger are common from family members when clinicians break bad news. See *Fast Fact #305*. Loved ones are at increased risk for depression and complicated grief as they adjust to the new medical reality after the event (17,18).



Clinical Use: Although there is no known published data assessing the effectiveness of utilizing the illness trajectories as a clinical teaching tool, describing or even diagramming these illness trajectories with patients and families may be a concise communication technique to set expectations and offer guidance regarding the anticipated impact of chronic illness on daily life. Clinicians should be aware of the significant variability in the medical literature regarding the validity of these illness trajectories as well as the limitations in the way functional decline is measured between studies. Therefore, it is vital that illness trajectories be reevaluated as the condition evolves. In particular, certain patterns such as an abrupt functional decline or frequent hospitalizations may indicate the need to readdress goals of care.

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FAST FACTS AND CONCEPTS #360
THE SURPRISE QUESTION AS A PROGNOSTIC TOOL
Kate S. Jennings, MD¹, Sean Marks, MD², and Hillary D. Lum, MD, PhD^{1,3}

Background: Clinicians have been encouraged to utilize the surprise question (SQ) -- “*Would I be surprised if this patient died within 12 months?*” – to identify patients at high 1-year mortality risk. When clinicians answer “No – I would NOT be surprised if this patient died within 12 months,” the SQ may help clinicians identify patients with unmet palliative care needs who could benefit from advance care planning discussions and/or a palliative care referral (1). This *Fast Fact* reviews the clinical utility of the SQ.

Rationale of the SQ: As difficult as it is for clinicians to prognosticate accurately, multiple studies have shown that patients with incurable disease desire more prognostic information the sicker they get and prognosis is a major factor in preferences for rehospitalizations, life support,

and CPR (2-4). Although, patients and surrogates often want *temporal prognostic predictions* (the clinician's estimated length of time he or she predicts the patient will live), clinicians are more accurate and willing to offer *probabilistic predictions* (the clinician's estimate, often in a percentage, of the chance of death in a set time frame, such as 1 year) (4-6). The SQ was designed as a clinical tool that generalist clinicians would utilize willingly and routinely to identify patients at risk of death in a year and thereby lead to more appropriate advance care planning, goals of care discussions, symptom management, and hospice referrals.

Effectiveness of the SQ: Although variations on the SQ have been described in the published literature including "Would I be surprised if this patient died this hospitalization?" or "Would I be surprised if this patient died in 3 months?", the SQ most commonly referred is "Would I be surprised if this patient died within 12 months?" This SQ has been studied in diverse populations, including a general inpatient setting (7), high-risk primary care clinic (8), pediatric patients (9), advanced kidney disease (10-12), cancer (13,14), acute surgical patients (15), emergency department settings (1,16), and nursing home settings (17). In general, the SQ has performed modestly well in identifying patients with a prognosis of < 1 year across these various patient populations (18,19). Notable findings from these studies include:

- A meta-analysis of the SQ among 26 studies across these patient populations found that it had a pooled accuracy of 75%, a sensitivity of 67% and specificity of 80% (18).
- "Yes" answers appear to be much more accurate than "No" answers. The predictive value of a "Yes" answer was 93%, while only 37% for a "No" answer (18). This means that the SQ is likely better designed to identify patients who will live more than a year vs the patients who live less a year. It also suggests that there is "false positives" are relatively common when clinicians answer "No" to the SQ.
- The SQ may be slightly more accurate for cancer patients (pooled accuracy 79%) and renal patients (76%) vs other disease groups (72%) (18). This may reflect a more predictable illness trajectory in cancer and renal disease. See *Fast Fact #326* for more information on illness trajectories.
- In most studies, the SQ was utilized as one aspect of a broad prognostic assessment which included clinician gestalt and/or other prognostic tools. Hence, used in isolation, its accuracy is unclear (18).

Implementing the SQ Into Clinical Practice: The SQ can be helpful in identifying patients at risk of medical decline and death in a certain time frame when used as part of a larger prognostic assessment (19). Yet, considering the relatively high false positive rate of a "No" answer, it is not established if the SQ is a cost-effective tool nor an effective way to trigger a palliative care consultation on its own. A consensus panel of experts suggested that a "No" answer trigger generalist clinicians to perform a primary palliative care assessment or screening for unmet palliative care needs (20). Sentinel medical events like hospitalization, decline in performance status, or disease progression are reasonable triggers to implement the SQ into clinical practice. Note templates, medical rounding tools, and electronic medical record prompts are potential system-based approaches to accomplish this. Reasonable components of the primary palliative care assessment triggered by a "No" include (20):

- Assessment for distressing physical, psychological, social, or spiritual concerns.
- Identification of whether the patient completed an advance directive such as a health care power of attorney that is available in the medical records.
- Assessment of patient, family, and/or surrogate's understanding of the underlying illness, treatment options, and prognostic trajectory.
- Assessment of decision-making capacity.
- Engagement in honest conversations about prognosis and medical expectations.
- Elicitation of the patient's care preferences and values.
- Consideration of whether a hospice referral would be appropriate.
- Consideration of whether a palliative care consultation may be beneficial.

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