



## Fast Facts Core Curriculum

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**FAST FACT AND CONCEPT #6  
DELIVERING BAD NEWS – PART 1**

**Bruce Ambuel PhD and David E Weissman MD**

**Case Scenario:** You are caring for a previously healthy 52 year old man with new abdominal pain. After conservative treatments fail, a diagnostic abdominal CT scan is done showing a focal mass with ulceration in the body of the stomach and numerous densities in the liver compatible with liver metastases. The radiologist feels that the findings are absolutely typical of metastatic stomach cancer. How do you prepare to discuss these test results with the patient?

**Preparing to Deliver Bad News**

1. Create an appropriate physical setting: a quiet, comfortable room, turn off beeper, check personal appearance, have participants – including yourself – sitting down.
2. Determine who should be present. Ask the patient who they want to participate and clarify their relationships to the patient. Decide if you want others present (e.g. nurse, consultant, chaplain, social worker) and obtain patient/family permission.
3. Make sure you know basic information about the patient’s disease: prognosis, treatment options, next steps.
4. Special circumstances: If the patient lacks decision-making capacity (e.g. developmentally delayed, demented, delirious, etc.), make sure the legal decision-maker is present. See *Fast Fact # 226 Helping Surrogates Make Decisions*.
5. Special circumstances: If the patient or family does not speak English, obtain a skilled medical interpreter. Use phone translation services if necessary. See *Fast Fact #154*
6. Special circumstances: If the patient or family is of another cultural background, see *Fast Fact # 216 Asking About Cultural Beliefs in Palliative Care*.

**Precepting self-reflection** Residents will invariably have strong emotions when they have to give bad news. This emotional response can be heightened by various factors—a young patient, an unexpected diagnosis, a patient with whom the physician has a long-standing relationship, etc. Preceptors need to support the resident. Key teaching points:

1. Residents may not spontaneously discuss their own emotional reaction with a preceptor, therefore preceptors need to introduce this topic. “This is a really hard case, how are you doing?”

2. Physicians often have strong emotional reactions when a patient encounters bad news. Normalize the experience for the resident. “It’s normal to have strong feelings”.
3. Three methods for coping with these feelings are: Identify your feelings (anger, sadness, fear, guilt); Talk with a colleague; Keep a personal journal.
4. Role play the discussion with the resident *before* you go into the room; ask them to reflect on how it “feels”...what is hard...what is easy. Encourage continued self-reflection.

**See related *Fast Facts*:** Delivering Bad News Part 2 (#11); Death Pronouncement (#4); Moderating a Family Conference (#16, #222, 223, 224, 225, 227); Responding to Patient Emotion (#29); Dealing with Anger (#59).

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2. Faulkner A. Breaking bad news – a flow diagram. *Palliative Medicine*. 1994; 8;145-151.
3. Iverson, VK. *Pocket protocols—Notifying Survivors About Sudden, Unexpected Deaths*. Tuscon, AZ: Galen Press; 1999.
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6. Girgis A, Sanson-Fischer RW. Breaking bad news: consensus guidelines for medical practitioners. *J Clin Onc*. 1995; 13:2449-2456.
7. Von Gunten CF, Ferris FD and Emanuel LL. Ensuring competency in end-of-life care: Communication and Relational Skills. *JAMA*. 2000; 284:3051-3057.

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## FAST FACTS AND CONCEPTS #11 DELIVERING BAD NEWS – PART 2

Bruce Ambuel PhD and David E Weissman MD

**Case Scenario:** You are caring for a previously healthy 52 year old man with a one-month of abdominal pain and weight loss. On exam he had a 2 cm hard left supraclavicular lymph node. A CT scan showed a focal mass with ulceration in the body of the stomach and numerous densities in the liver compatible with liver metastases. The radiologist feels that the findings are consistent with metastatic stomach cancer. How do you discuss these test results with the patient?

### Steps in Delivering Bad News

1. Determine what the patient & family knows; make no assumptions. Examples: *What is your understanding of your present condition? What have the doctors told you?*
2. Before presenting bad news, consider providing a brief overview of the patient's course so that every one has a common source of information.
3. Speak slowly, deliberately and clearly. Provide information in small chunks. Check reception frequently.
4. Give fair warning – *I am afraid I have some bad news* – then pause for a moment.
5. Present bad news in a succinct and direct manner. Be prepared to repeat information and present additional information in response to patient and family needs.
6. Sit quietly. Allow the news to sink in. Wait for the patient to respond.
7. Listen carefully and acknowledge patient's and family's emotions, for example by reflecting both the meaning and emotion of their response.
8. Normalize and validate emotional responses: feeling numb, angry, sad, and fearful.
9. Give an early opportunity for questions, comments.
10. Present information at the patient's or family's pace; do not overwhelm with detail. The discussion is like peeling an onion. Provide an initial overview. Assess understanding. Answer questions. Provide the next level of detail or repeat more general information depending upon the patient's and family's needs.
11. Assess thoughts of self-harm
12. Agree on a specific follow-up plan (*I will return later today, write down any questions.*). Make sure this plan meets the patient's needs. Involve other team members in follow-up.

### Precepting Points

Residents often feel strong emotions when they have to give bad news to a patient. This emotional response can be heightened by various factors—a young patient, an unexpected diagnosis, a patient with whom the physician has a long-standing relationship, etc. As a preceptor, you will want to support the resident. Key teaching points:

- Residents may not spontaneously discuss their own emotional reaction with a preceptor, therefore you will want to introduce this topic.
- Physicians often have strong emotional reactions when a patient encounters bad news. This is normal and OK.
- Three methods for coping with these feelings: Identify your feelings (anger, sadness, fear, guilt); Talk with a colleague; Keep a personal journal.

**See related *Fast Facts*:** Delivering Bad News – Part 1 (#6); Death Pronouncement (#4); Responding to Patient Emotion (#29); Dealing with Anger (#59); Family Conferences (#222, 223, 224, 225, 227).

### Resources

1. Buckman R. *How to break bad news: A guide for health care professionals*. Baltimore, Johns Hopkins University Press: 1992.
2. Faulkner A. Breaking bad news – a flow diagram. *Palliative Medicine*. 1994; 8:145-151.
3. Iverson, VK. *Pocket protocols—Notifying survivors about sudden, unexpected deaths*. Tuscon, Arizona, Galen Press: 1999.
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**FAST FACTS AND CONCEPTS #19**  
**TAKING A SPIRITUAL HISTORY 3<sup>rd</sup>****Bruce Ambuel PhD**

**Background** Illness raises fundamental questions – *For what may I hope? Why do I suffer? Does my suffering have meaning? What happens after I die?* When a physician stands with a patient as they face death, the physician inevitably plays a role in supporting the patient's inquiry into these spiritual questions (see *Fast Fact #31 Confronting Personal Mortality*). In addition some patients have specific preferences regarding medical care, death and dying that are based upon their religious beliefs. The physician often plays an important role in supporting a patient's exploration of these issues. Taking a spiritual history is one way to support the patient in this exploration. Maugans (1997) presents a framework for taking a spiritual history; the interview below comes primarily from Maugans' article with some modification based upon the other sources cited. See *Fast Fact #274* for information on the FICA Spirituality History Tool.

**Taking a Spiritual History****S—Spiritual belief system**

- *Do you have a formal religious affiliation? Can you describe this?*
- *Do you have a spiritual life that is important to you?*
- *What is your clearest sense of the meaning of your life at this time?*

**P—Personal spirituality**

- *Describe the beliefs and practices of your religion that you personally accept.*
- *Describe those beliefs and practices that you do not accept or follow.*
- *In what ways is your spirituality/religion meaningful for you?*
- *How is your spirituality/religion important to you in daily life?*

**I—Integration with a spiritual community**

- *Do you belong to any religious or spiritual groups or communities?*
- *How do you participate in this group/community? What is your role?*
- *What importance does this group have for you?*
- *In what ways is this group a source of support for you?*
- *What types of support and help does or could this group provide for you in dealing with health issues?*

**R—Ritualized practices and restrictions**

- *What specific practices do you carry out as part of your religious and spiritual life (e.g. prayer, meditation, services, etc.)*
- *What lifestyle activities or practices do your religion encourage, discourage or forbid?*
- *What meaning do these practices and restrictions have for you? To what extent have you followed these guidelines?*

**I—Implications for medical care**

- *Are there specific elements of medical care that your religion discourages or forbids? To what extent have you followed these guidelines?*
- *What aspects of your religion/spirituality would you like to keep in mind as I care for you?*
- *What knowledge or understanding would strengthen our relationship as physician and patient?*
- *Are there barriers to our relationship based upon religious or spiritual issues?*
- *Would you like to discuss religious or spiritual implications of health care?*

**T—Terminal events planning**

- *Are there particular aspects of medical care that you wish to forgo or have withheld*

- *because of your religion/spirituality?*
- *Are there religious or spiritual practices or rituals that you would like to have available in the hospital or at home?*
- *Are there religious or spiritual practices that you wish to plan for at the time of death, or following death?*
- *From what sources do you draw strength in order to cope with this illness?*
- *For what in your life do you still feel gratitude even though ill?*
- *When you are afraid or in pain, how do you find comfort?*
- *As we plan for your medical care near the end of life, in what ways will your religion and spirituality influence your decisions?*

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## FAST FACTS AND CONCEPTS #21 HOPE AND TRUTH TELLING

Eric Warm MD and David E Weissman MD

*'The miserable have no other medicine; But only hope.'* Claudio, in *Measure for Measure* Act 3, Sc.1, by William Shakespeare (1564-1616).

This *Fast Fact* discusses the difficult balance between maintaining hope and truth telling, especially as it applies to giving bad news. One of the most difficult things physicians do is give bad news. Medical students and residents are often afraid that by telling someone the truth about his/her diagnosis, they will be responsible for taking away hope. And yet, are physicians really that powerful? Isn't it possible that our fear of causing the loss of hope is just another way we can avoid the harsh reality of impending death? This conflict, between truth-telling and fear of destroying hope, is commonly noted by patients and families who feel that "the doctor is not really telling me everything," a feeling that is highly corrosive to the doctor-patient relationship.

Brody (1981) writes, *'Hope means different things to different people, and different things to the same person as he/she moves through stages of illness.'* The physician can play a valuable role in helping the individual patient define her or his hopes and fears. When close to death, hope often becomes refocused away from long-term goals and towards short-term or spiritual goals. Hope may mean a pain-free day, a sense of security, love and non-abandonment, or a wedding to attend in the near future. *'When we talk to patients and find out what is really worrying them, we can almost always give them realistic assurances'* (Brody 1981). Factors that often increase hope in the terminally ill include feeling valued, meaningful relationships, reminiscence, humor, realistic goals, and pain and symptom relief. Factors that often decrease hope include feeling devalued, abandoned or isolated ("there is nothing more that can be done"), lack of direction and goals, and unrelieved pain and discomfort.

Some strategies for beginning a dialogue about hope and goals include:

- Ask the patient, *"Do you have long term hopes and dreams that have been threatened by this illness?"* Support the patient in recognizing and grieving their possible losses.
- **Ask the person if there are particular upcoming events they wish to participate in – a wedding, birth, trip, etc.**
- Ask *"What are your hopes for the future?"* and *"Do you have specific concerns or fears?"*
- Encourage the patient to make short, medium, and long range goals with an understanding that the course of terminal illness is always unpredictable.
- Utilize *"I wish..."* statements when conveying bad clinical news in order to convey an appropriate degree of humility – *"I wish there was more we could do for your cancer but I'm afraid time may be getting short."*

### Teaching Tips

- Use the Brody article as a starting point for discussion with trainees
- When faced with the need to give bad news, ask trainees how they *feel* before they give the news; are they worried about causing a loss of hope? Ask them to reflect further – do they feel *hopeless* because of the situation? Whose feelings are they trying to protect, their own or the patient's?
- Ask trainees to make a list of risks and benefits of truth telling. Use the list as a starting point for group discussion of the hope-truth telling conflict.

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## FAST FACTS AND CONCEPTS #22 WRITING A CONDOLENCE LETTER

Ron Wolfson PhD and Elizabeth Menkin MD

**Introduction** One of the most meaningful acts of kindness you can do for a mourner is to write a letter of condolence. The words of sympathy and memory are comforting to the bereaved. More importantly, mourners are very appreciative that you took the time to sit and compose a personal message to them or share a memory of the deceased. For professionals who work with dying patients, writing a condolence letter is an opportunity to reflect on both the pain and the rewards of our work. When we can appreciate the privilege it is to bear witness to the courage, kindness, caring and dignity that our patients and their families exhibit under duress, it gives us strength to continue this work.

A good condolence letter has two goals: to offer tribute to the deceased and to be a source of comfort to the survivors. The best letters are like conversations, as if you were talking during a visit. Most often, they are written to the bereaved person to whom you feel closest, although it could be a general letter to the family. It should be written and sent promptly, generally within two weeks after the death. Use any standard stationery and write it by hand. Here are some specific guidelines for writing a good condolence letter:

- **Acknowledge the loss and name the deceased.** This sets the purpose and tone of the letter. Let the bereaved know how you learned of the death and how you felt upon hearing the news. Using the name of the deceased is a tribute that comforts most mourners.
- **Express your sympathy.** Use words of sympathy that remind the bereaved that they are not alone in their feelings of sadness and loss.
- **Note special qualities of the deceased.** Acknowledge those characteristics that you cherished most about the person who has died. These might be qualities of personality (courage, sensitivity), or attributes (funny, affable), or ways the person related to the world (religious, devoted to community welfare).
- **Recall a memory about the deceased.** Talk about how the deceased touched your life. Try to capture what it was about the person in the story that you admired, appreciated or respected. You may use humor – the funny stories are often the most appreciated by the bereaved.
- **Remind the bereaved of their personal strengths.** Bereavement often brings with it self-doubt and anxiety about one's own personal worth. By reminding the bereaved of the qualities they possess that will help them through this period, you reinforce their ability to cope. Qualities to mention might be patience, optimism, religious belief, resilience, and competence. If you can recall something the deceased used to say about the mourner in this regard, you will really be giving the bereaved a gift. An example: *"I was (impressed, inspired, awed, strengthened) by the devotion you and your family evidenced during the period of Mort's illness. Your presence (concern, care, attentiveness) was only one indication of your love for him."*
- **Offer help, but be specific.** *"If there is anything I can do, please call"* actually puts a burden on those in grief who may be totally at a loss about what needs to be done. A definite offer of help is more appreciated. Whatever you offer, do it – don't make an offer you cannot fulfill.
- **End with a word or phrase of sympathy.** Somehow, "sincerely," "love," or "fondly," don't quite make it. Try one of these: *"You are in my thoughts and prayers."* Or, *"My fond*

*respects to you and yours.”*

If you don't have enough to say for a formal condolence letter, you may prefer to send a sympathy note. These are shorter communications that can be written on personal stationery or added to a commercially available card. As with a condolence letter, the major goal is to offer a tribute to the deceased and to offer comfort to the bereaved.

#### **Reference**

Wolfson, R. *A Time to Mourn, A Time to Comfort*. Woodstock, VT: Jewish Lights Publishing; 1993: pp 223-226.

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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 #47**  
**WHAT DO I TELL THE CHILDREN?**

**Paula Rauch and Robert Arnold MD**

**Background** The death of a young adult is always difficult, even more so when there are young children survivors. A common question asked by dying adults or their family members is *What do I tell the children?* Physicians and other health care providers can provide leadership and guidance to help young families through this crisis.

**I. Screening and awareness**

- Ask if the ill person has children at home. Ask about their age, personality, and coping style.
- Ask what the ill person has told the children about the illness.
- Ask if they have a specific worry about the child.
- Ask if the child has had recent problems in school, at home or with relationships.
- Ask who they would like to talk to if they have concerns?

**II. Give them some words.**

- Often a parent's biggest worry is what to say if the child asks if he or she is dying. Here are two examples of words a parent might use. Asking a parent if these words would feel comfortable to say can begin a dialogue between patient and clinician to arrive at language that is honest, and life affirming.
- "X" can kill people, but I am taking the best care of myself I can. I am following the doctor's plan so that I can live as long as possible.
- Even with trying my hardest and getting the best possible care, my \_\_\_\_\_ is getting worse; still I plan to live every day.

**III. Give adults concrete examples to guide their interactions.**

- Express interest in the child's day.
- Work to maintain normal routines (e.g. maintain family rituals: Friday night supper, Monday night pizza, watching television together).
- Welcome all questions but do not force discussions. Make sure you understand the real question before answering. Take your time to think about how you want to answer.
- Overhearing bad news is the worst way to hear it. Talk with children from diagnosis onward, being sure to give updates when there are changes in prognosis or treatment.
- Avoid euphemisms (e.g. lump, boo-boo, or sickness) that may confuse children.
- Ask children to share what they are thinking, or hear from others, so they do not worry alone.
- Prepare children for visits with the sick person. Describe what they are likely to see. Bring along another adult who is comfortable to stay only as long as the child wants. Bring along markers and paper, so children can leave the parent with a picture or message.
- Talk to the child's teacher or guidance counselor to alert the teachers. Ask teachers and the child's friends' parents to let the parent know if the child talks about worries.

**IV. Refer adults to one of the popular books on the subject (Kroen, McCue)**

**V. Know the resources for parents and children in your hospital and community**

**VI. Consider referral to a child life specialist or mental health professional when any of the following occur:**

- Symptoms of depression or anxiety that interfere with school, home or with peers
- Risk taking behavior

- Significant discord between the child and the surviving parent
- Significant discord between the parents
- The child says he or she wants to talk to someone outside of the family.

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## FAST FACTS AND CONCEPTS #64 INFORMING SIGNIFICANT OTHERS OF A PATIENT'S DEATH

Diane Midland BSW, MS

**Introduction** This *Fast Fact* reviews the components of a sensitive notification of loved ones when a patient dies. The physician is a key figure in the death notification process. Family and friends who are present at the time of death look to the physician for information, reassurance and direction regarding the weeks and months ahead. The lasting impression and memories that family members have regarding the manner in which they received word that their loved one died may affect the grief process and eventual integration of the loss within the survivors' world. Research has demonstrated that the skills of compassion and sensitivity can be learned and must be incorporated into the practice of all physicians.

### **A. Preparation**

1. Confer with nursing and other staff working with the family/significant others. Review the medical record (including any advance directive).
2. Examine the patient; confirm death (see *Fast Fact #4*).
3. Find a private place to meet with family/significant others.
4. Involve other members of the interdisciplinary team (e.g. nurse or chaplain) in the notification process.
5. If possible, learn the names of those you will be talking with and their relationship to the deceased.

### **B. Meeting with the Family/Significant Others**

1. Introduce yourself and identify those present. In situations where there are family and friends present, ask the next-of-kin who they would like with them during the conversation.
2. Identify and respect ethnic, cultural or religious traditions (see *Fast Fact #26*).
3. Invite those present to sit down with you. Use body language, eye contact and touch (introductory hand shake or clasp), if appropriate and accepted by family/significant others.
4. Express your condolence (e.g. *I'm sorry for your loss; My condolences to you and your family.*)
5. Talk openly about the death. Use "died" or "dead" during the initial conversation. Listen for the words used by the family/significant others to describe death and use their term(s) throughout the remaining discussion. Refer to the deceased by name.
6. If requested, explain the cause of death in non-medical terms. Allow time for questions; be open to acknowledging that there may be things you don't know. Offer assurance that everything possible was done to keep the patient comfortable.
7. Be prepared for a range of emotional expression. Do not offer sedation as a way to deal with expressions of emotion. (Mild sedation for a brief time period may be considered to assist with insomnia.)
8. Offer the opportunity to view the deceased. Prepare family/significant others for how the deceased will appear; model touching and talking to the deceased. Offer time alone with the deceased and assurance that survivors will not be rushed.
9. Provide time for the family/significant others to process the reality of the death before discussing autopsy or tissue/organ donation.
10. **Let family/significant others know that you will return, should questions arise or they desire additional information. Provide information about how the family can reach you after they leave the facility.**

### **C. Follow-up**

1. Personalize and sign a sympathy card to the bereaved (see *Fast Fact #22*).
2. Consider attending the wake, funeral, or memorial service.

3. Consider referral to a bereavement support service or agency, particularly if children are involved.
4. Encourage the bereaved to schedule a physical exam four to six months after the death.
5. Invite the bereaved to meet with you regarding autopsy results or to discuss unresolved questions.

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## FAST FACTS AND CONCEPTS #76 TELEPHONE NOTIFICATION OF DEATH – Part I

Rosalia R Osias MD, Daniel H Pomerantz MD, Jeffrey M Brensilver MD, FACP

**Background** Telephone notification to family members about a death is one of the most challenging and stressful communication skills, especially for cross-covering housestaff who may have had no direct interactions with the patient or family. Unpredictable variables are involved; telephone notification does not allow the same level of interaction possible with direct personal contact. This *Fast Fact* offers some guidelines when telephone notification is unavoidable; *Fast Fact #77* discusses issues surrounding whether or not to delay notification of death until loved ones arrive at the hospital.

### I. Preparing for the Call

1. Review death pronouncement protocol (See *Fast Facts* # 4 and 64).
2. Positively identify the patient (hospital ID tag) and confirm death.
3. Obtain relevant information; e.g. patient's name, age, gender, identification numbers.
4. Obtain the full name, address, phone number(s) of the person/s you are calling. Try to establish from the chart and nursing staff the relationship of the contact to the deceased patient.
5. Establish the circumstances of death; expected or sudden. Write down the key information you need and thoroughly review what you will say.
6. Find a quiet or private area with a phone.

### II. Timing

The call should be made as soon as possible following the death. *Whenever possible, inform the family of a grave turn of events prior to the patient dying.* When substantial delay is likely, the responsibility for informing the family should be taken by the covering doctor (or the resident).

### III. The Actual Notification

1. Identify yourself. Ask the identity of the person you are talking to and their relationship to the patient. Ask to speak to the person closest to the patient (ideally, the health care proxy or the contact person indicated in the chart). Avoid responding to any direct question until you have verified the identity of the person to whom you are speaking. Ask if the contact person is alone. Do not give death notification to minor children.
2. If you do not have a prior relationship with the person you are speaking to, ask what they know about the patient's condition: *What have the doctors told you about \_\_\_\_\_'s condition?*
3. Provide a warning shot: *I'm afraid I have some bad news.*
4. Use clear and direct language, no medical jargon: *I'm sorry, \_\_\_\_\_ has just died.* Words like "dead" or "died" should be used. "Expired", "passed away" or "didn't make it" can be misinterpreted.
5. Speak clearly and slowly, allow time for questions. Be empathetic. A perceptive family can easily tell whether the notifier cares or is merely "going through the motions."
6. If the family chooses to come to see the body, arrange to meet them personally.
7. Provide contact information for the physician or hospital official who can meet with them and answer questions about the patient's death and other administrative issues.
8. Ask if you can contact anyone for them. Assess their emotional reaction (see *Fast Fact #77*).
9. If you feel uncomfortable about telephone notification, ask for help.
10. **Never** deliver the news of death to an answering machine or voice mail. Instead, leave specific contact information. If you are unable to make contact within 1-2 hours, contact a hospital representative (e.g. social worker) to assist you in **locating family or others.**

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2. Iserson KV. The gravest words: notifying survivors about sudden, unexpected deaths. *Resident and Staff Physician.* 2001; 47:66-72.

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## **FAST FACTS AND CONCEPTS #77**

### **TELEPHONE NOTIFICATION OF DEATH – PART II**

Rosalia R Osias MD, Daniel H Pomerantz MD, Jeffrey M Brensilver MD, FACP

**Introduction** In Part I (*Fast Fact # 76*), the basic steps and precautions of telephone notification of death were outlined. This *Fast Fact* discusses the dilemma of whether to provide telephone information versus asking family members to first come to hospital before telling them that death has occurred.

**Delay vs. Disclose Immediately** Few would disagree that it is always preferable to present death notification in person. However, when families live at a great distance, or are physically unable to travel, telephone discussion will be necessary. In other situations, clinicians must weigh the benefits of truthfulness against the risk of potential harm resulting from abrupt disclosure of the bad news. Factors to consider in making this decision include:

- Whether death was expected or not, including the nature and chronicity of the illness.
- How well the death notifier knows the patient and the patient's family.
- The relationship of the contact person to the patient.
- The anticipated emotional reaction of the contact person based on prior information.
- Whether the contact person will be alone when receiving the information
- The contact person's level of understanding.
- Distance, availability of transport, and time of day.

For example, when death is expected due to progressive cancer and the notifier knows both the patient and the contact person, telephone notification is very acceptable. In fact, you should have prepared for this moment ahead of time by asking the contact how he or she wishes to be contacted at the time of death. In contrast, if the death is sudden, especially of a minor, notification in person is always preferred, although time and distance issues may make this impractical.

The notifier must be prepared to quickly integrate all these factors to decide whether to reveal that the patient is dead, or whether to describe the patient as gravely ill and request that the contact person come to the hospital immediately. If you decide to delay disclosure of the death, be prepared to make immediate admission of such nondisclosure as soon as you meet the family (e.g. *I'm sorry for not telling you the whole thing right away over the phone*; then give your reason for doing so).

**Responding to Emotions** *Whether in person or by telephone, you should expect an emotional reaction to the death notification (see Fast Fact #29). Responding to emotions via telephone is especially difficult. Some tips include:*

- Ensure that the contact has someone else with them. Offer to contact family members, friends, clergy or others.
- Offer to meet with the contact in person.
- Contact your hospital social worker for advice on contacting other local resources such as the Red Cross, local police, or other service agencies.

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## FAST FACTS AND CONCEPTS #155 COMPLETING A DEATH CERTIFICATE

Nikkisha Prentice and Robert Arnold MD

**Background** Physicians are responsible for providing proper documentation of death. This *Fast Fact* reviews key steps in the completion of a death certificate.

**Importance of Proper Completion** Death certificate information is a permanent record of death. It is usually necessary for burial and settlement of the deceased's estate. Documentation of the cause of death, in addition to direct communication, may provide family members with closure and peace of mind. Death certificates are also used to 1) evaluate the general health of the population, 2) assess the prevalence of medical problems among specific groups, 3) triage medical research needs, and 4) apportion health services, grants, and other resources to common illnesses.

**Basic Guidelines** Death certificates are governed by state statutes; variations exist in who can complete a death certificate and how they should be filled out. Certification and completion of death certificates is usually the primary responsibility of the attending physician. However, in some states, death may be certified by the attending advanced practice nurse.

- Verify the correct spelling of names.
- Personally sign the death certificate; stamps are unacceptable.
- Complete all required items. If necessary, write "unknown" or "pending further study."
- Common Errors
  - Do not delay completion of the certificate. Some states have specific time periods and civil and/or criminal penalties for non-completion. Moreover, funeral homes will typically not proceed with burial without the death certificate.
  - Do not use abbreviations.
  - Some state forms require you spell out the month.
  - Use 24 hour clock rather than 12:00 midnight.
  - Some state forms do not allow alteration of the document; avoid erasing or using white-out.
  - Avoid cursive writing; print clearly or type using black ink.

**Causality of Death** This section of the certificate often consists of two parts. The first part asks for a sequential chain of events that led to death and the time interval between onset of a condition and death. The most immediate cause of death is stated on line *a* and the underlying causes follow on lines *b*, and so on. In assessing the approximate interval between onset and time of death, terms such as "unknown" or "approximately" may be used and general terms such as "minutes," "hours," and "days" are acceptable. The second part asks about other significant conditions that contributed to death, but that did not result in the underlying cause stated previously.

**Mechanism vs. Cause of Death** It is important not to write the *mechanism* of death (i.e. cardiac arrest, respiratory arrest) as the *cause* of death. The mechanism of death is the physiologic derangement or biochemical disturbance by which the cause of death exerts its lethal effect. *For accurate public health records, the cause of death (e.g. chronic obstructive pulmonary disease) is more helpful than the mechanism of death (e.g. respiratory failure).* When there is doubt as to the cause of death, it is acceptable to enter "unknown" or "pending further study." In some states, a condition may also be listed as "probable." As additional medical information, such as an autopsy report, becomes available, the certifying physician should report amendments to the state vital records office or local registrar.

**Note:** Listed below are common terms and definitions that are generally interchangeable between states. The table presents some examples.

- **Immediate (or Principle) Cause** = Final complication resulting in death.

- **Intermediate (or Antecedent or Underlying) Cause** = Disease or condition causing the immediate cause of death.
- **Underlying (or Contributory) Cause** = The condition present before and leading to the intermediate or immediate cause of death.

	Example 1	Example 2	Example 3	Example 4
<b>D. Line A</b>	Acute Myocardial Infarction	Acute Exacerbation of Obstructive Airway Disease	Pulmonary Embolism	<i>Pneumocystis jiroveci pneumonia</i>
<b>Line B</b>	Coronary Artery Disease	Chronic Bronchitis	Deep Venous Thrombosis	Acquired Immunodeficiency Syndrome
<b>Line C</b>	Chronic Ischemic Heart Disease		Metastatic Non-Small Cell Lung Cancer	Human Immunodeficiency Virus
<b>Mechanism of death</b>	Cardiac Arrest	Respiratory Arrest	Respiratory Arrest	Septic Shock
<b>Other Significant Conditions</b>	Diabetes	Smoking	Stroke, Hemiparesis	

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## **FAST FACTS AND CONCEPTS #162**

### **ADVANCE CARE PLANNING IN CHRONIC ILLNESS**

Sara N Davison MD

**Background** A cornerstone of excellent medical care is helping patients decide how future medical interventions match their personal goals and values for care near the end-of-life. This *Fast Fact* reviews key concepts of the Advance Care Planning (ACP) process.

**Advance Care Planning** is a **process of communication** between the patient, the family/health care proxy, and staff for the purpose of prospectively identifying a surrogate, clarifying treatment preferences, and developing individualized goals of care near the end of life. *Advance Directives* (e.g. living wills, durable powers of attorney for health care) are *legal* documents with capabilities and requirements that vary between jurisdictions.

#### **Primary Goals of ACP**

- Enhance patient and family education about their illness, including prognosis and likely outcomes of alternative care plans.
- Define the key priorities in end-of-life care and develop a care plan that addresses these issues.
- Shape future clinical care to fit the patient's preferences and values.

#### **Other Potential Benefits of the ACP process**

- Help patients find hope and meaning in life, and help them achieve a sense of spiritual peace.
- Strengthen relationships with loved ones.

**Timing** At a minimum, ACP should be considered whenever the health care provider *would not be surprised if that patient died within the next 12 months*.

#### **Facilitating ACP**

- **Take the lead in starting the discussion.** Many patients are reluctant to initiate an ACP discussion; physicians and nurses can “open the door” to such discussions by asking, *How do feel things are going? Have you given any thought to how you wish to be cared for should your illness worsen?*
- **Explain the rationale for ACP.** Patients identify ACP as an important part of medical care if they have a clear idea of how the process will benefit them: *I'd like to spend some time talking to you about the future course of your illness so that I have a clear understanding of your wishes.*
- **Use good communication skills.** Do not use medical jargon (e.g. ‘ventilator’); language used should be positive (*I want to ensure you receive the kind of treatment you want*). Use empathetic listening skills (using words, posture and appropriate touch to convey sense of caring) to help build a trusting relationship. Ensure privacy and allow sufficient time for the discussion.
- **Provide information.** Patients require realistic information on prognosis and treatment options with an emphasis on how you expect their illness will impact their daily function.
- **Identify a surrogate.** Patients should be encouraged to both identify a surrogate decision-maker and, most importantly, discuss their wishes with this individual. The power of the ACP discussion is the sharing of information between patient and the patient’s surrogate decision maker and other family members, and the health care team. The surrogate should have the greatest knowledge of the patient’s preferences and values. If desired, offer to facilitate a discussion between the patient and their surrogate or other family members.
- **Identify how future decision-making will occur.** A patient may have specific desires for how information is shared among family members – this needs to be explicitly discussed.

- **Determine goals of care.** If decisions need to be made at the same time as an ACP discussion, this is an appropriate venue to establish the goals of care (see *Fast Fact* #16, 65).

#### **Cautions**

- The ACP process must be sensitive to disease, gender, age, social and cultural contexts.
- Providing opportunities to discuss end-of-life issues does not mean everyone will want or be able to do so at that moment. ACP is an evolving process that requires varying amounts of time to be effective. Patients often need time to reflect on information and how it impacts their lives.

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**FAST FACTS AND CONCEPTS #183**  
**CONFLICT RESOLUTION I: CAREFUL COMMUNICATION**

**Adam Kendall MD, MPH and Robert Arnold MD**

**Background** Conflicts about medical care occur frequently at the end of life. These conflicts threaten therapeutic relationships and lead to patient, healthcare provider, and family dissatisfaction. Conflict between the patient/family and physician may arise from simple factual misunderstandings about medical care. Frequently, however, conflict is driven by a patient's or family's emotions such as feeling unheard or ignored, as well as having goals that conflict those of the medical team. In these instances, attempting to convince a patient or family through providing additional medical information will not work. This *Fast Fact* provides an alternative approach to conflict resolution based on understanding a patient's or family's story, attending to their emotions, and establishing shared goals. A subsequent *Fast Fact* (#184) will focus on conflict resolution employing the techniques of *Principled Negotiation*.

**1. Learn the patient's and family's story**

- Begin discussions with a genuine curiosity to learn what they perceive to be the course of events during the illness.
- Explore the context of the patient's illness narrative with attention paid to their relationships with doctors, their sources of medical information, and their life goals (see *Fast Fact* #26)
- Avoid presenting agenda items for a meeting that are defined by the medical team's priorities. Instead, focus on the patient's and family's concerns.
- If a patient or family is asking for treatment against the recommendation of the medical team, focus on the context of the request. Have they been let down by the medical system in the past? Have they found that others in their family have benefited from the treatment they request?
- Find out how they want information presented to them. Do they want specific benefits and risks? Do they want written information?

**2. Attend to emotions**

- Conflict can cause strong emotions in healthcare providers including guilt, anger, and resentment. Acknowledge these emotions to yourself and other professionals, but strive to prevent them from interfering with your interactions with the patient and family.
- Patient and family emotions such as grief, disappointment, and anger are to be expected in these situations. Compassionately acknowledge and address these emotions as they arise, and allow the patient and family to express what is making a situation frustrating for them (see *Fast Facts* #29, #59). When people are emotionally stressed, they may have trouble cognitively processing information. Empathically attending to emotions often allows a patient or family to move on to understanding medical information.
- If a family is focusing on what they believe was an error in care, be transparent about where a mistake may have been made (see *Fast Facts* #194, 195). Apologize. Even if it was not an error, one can acknowledge how frustrating the situation is. Saying "I can tell that this situation is frustrating for you," is not an admission of error—it is empathic.

**3. Establish shared goals for treatment**

- Use the patient's core values as a foundation for developing a treatment plan. "I would like to know more about your mother and what her values have been during her life."
- Ask about a patient's goals including what they would want if they were dying or if there were no curative treatments available for their condition.
- When there are requests for ineffectual treatment, describe instead where the medical team can make a difference for the patient, in relation to their goals. "Please correct me if I'm wrong, but it sounds like your mother really values her independence and freedom from being in pain. Let's try to figure out how we can best help her achieve these goals."

**Summary** Providing medical information to patients and families may seem at first to be the most natural approach to resolving conflict. Addressing the underlying roots of conflict will have a longer lasting effect. The above approach emphasizes resolving conflict through finding mutual trust and shared goals between physicians, patients, and families.

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**FAST FACTS AND CONCEPTS #184**  
**CONFLICT RESOLUTION II: PRINCIPLED NEGOTIATION**

**Adam Kendall MD, MPH and Robert Arnold MD**

**Background** When conflicts about medical care persist despite gaining mutual trust and a deep understanding of goals (see *Fast Fact #183*), it may be effective to use principled negotiation. *Principled negotiation* is an approach to resolving conflict that avoids power struggles and unwanted compromises. The following is an illustration of the steps that are involved. Within each step, we will refer to a case example: a family who is requesting artificial feeding against medical advice for their father who is dying from end-stage dementia.

- 1. Separate people from the problem.** Identify the fundamental problem, separating that from individuals'—on both sides—intentions and culpability.
  - The problem is not that the family members are “in denial” that their loved one is dying or “uneducated” when they do not hear the medical team’s recommendations.
  - The problem is not that the family is acting out their frustration by making unreasonable demands.
  - Nor is the problem that the medical team and hospital are trying to withhold treatment from the patient or “giving up” on him.
  - The problem *is* that the patient is dying, no longer able to eat properly, and that artificial nutrition does not improve quality or quantity of life in this situation.
  
- 2. Focus on interests.** Listen to requests and demands but try to look into underlying interests. In addition, express the intentions and goals of the medical team.
  - The family wants what is best for the patient. Their intent may be to provide comfort and to build up the patient’s strength, and to prevent a painful starvation.
  - The medical team wants to provide the best medical care for the patient. Their intent may be to avoid an intervention that has no clear benefit for the patient, may cause harm, and may not have been desired by the patient.
  
- 3. Invent solutions.** Avoid contrasting different philosophies of medical care. Instead, propose a plan of care that meets a family’s expectations without detracting from good medical care. Consideration could be given to:
  - Meeting the family’s goals of providing food by allowing for the patient to taste home cooked meals.
  - A short trial of tube-feeding with the plan to continue only if the overall quality of life for the patient improves.
  - A trial of attentive oral feeding with a plan to reconsider tube feeding if the patient appears to be hungry or otherwise suffering.
  - Solutions that do not promote mutual interests are: placing a feeding tube without a plan to measure its success or failure at meeting a goal, arranging for another medical team to take over the patient’s care, or referring the case to an ethics committee.
  
- 4. Outline objective criteria.** If a time trial is being pursued, agree upon what the deciding factors would be in determining a trial’s success. Provide objective information to substantiate medical recommendations.
  - Establish signs of improvement or worsening such as functional ability, weight, ability to interact, and level of consciousness.
  - Establish criteria for harm such as infections, restraint or sedative use, hospitalizations or emergency department visits.
  - Consider providing publications from organizations that advocate for patients and families, and are not associated with physicians or hospitals.
  - Provide opinions or guidance from individuals outside of the conflict. These could include social workers, case managers, chaplains, or therapists.

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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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## **FAST FACTS AND CONCEPTS #226**

### **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 un-anticipated 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 #274 THE FICA SPIRITUAL HISTORY TOOL

Christina Puchalski MD

**Background** Spirituality is defined as “the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (1). Taking a spiritual history is an important patient assessment skill, and most American patients report they want medical professionals to be aware of the importance of religion or spirituality to them (2). *Fast Fact #19* presents one approach to taking a spiritual history. This *Fast Fact* discusses the FICA Spiritual History Tool© (Faith, Importance/Influence, Community, Action/Address in care).

**Spirituality & Health** There is a large body of evidence that demonstrates a relationship between spirituality, religion and healthcare outcomes (3-9). Spirituality and religion are strong contributors to how people cope with illness and suffering (10-12). Providing for spiritual and religious needs benefits both patients and the health care system (13).

**Spiritual History & the Healthcare Team** A National Consensus Conference (NCC) developed models and guidelines for interprofessional spiritual care (1). While the conference highlighted the importance of board-certified or board-eligible chaplains as the spiritual care experts and essential members of palliative care and other care teams, it recommended that all members of the health care team be responsible for addressing patients’ spiritual issues within the biopsychosocial/spiritual framework (14). The NCC recommended that all patients should have a spiritual screening or history, that spiritual distress should be diagnosed and attended to, and that validated assessment tools should be used.

### Taking a Spiritual History – Key Principles

1. Consider spirituality as a potentiality important component of every patient's life. Spirituality can impact a patient's quality of life; it is an inherent part of most people's wellbeing.
2. Address spirituality at each new visit, at annual examinations, and at follow-up visits if appropriate.
3. Respect a patient's privacy regarding spiritual beliefs.
4. Be aware of your own beliefs; don't impose your spiritual/religious beliefs on others.
5. Make referrals to chaplains, spiritual directors, or community resources as appropriate.

**FICA** The FICA Spiritual History Tool© was developed to help healthcare professionals address spiritual issues with patients. FICA serves as a *guide for conversations* in the clinical setting. It is also used to help identify spiritual issues patients face, spiritual distress, and patients’ spiritual resources of strength. The FICA tool has been evaluated in cancer patients (15). This study suggests FICA is a feasible tool for the clinical assessment of spirituality, and responses to the FICA were correlated to many aspects of quality of life. Healthcare professionals are encouraged not to use the FICA tool as a checklist, but rather to rely on it as a guide to aid and open the discussion to spiritual issues.

**F - Faith, Belief, Meaning** *Do you consider yourself spiritual or religious? Do you have spiritual beliefs that help you cope with stress?* If the patient responds *No*, the health care provider might ask, *What gives your life meaning?* It is important to contextualize these questions to the reason for the visit – e.g., wellness, stress management, breaking bad news, the end of life. Meaning might be found in family, career, nature, arts, humanities or other spiritual, cultural or religious beliefs and practices.

**I - Importance and Influence** *What importance does your faith or belief have in your life? Have your beliefs influenced you in how you handle stress? Do you have specific beliefs that*

might influence your health care decisions? If so, are you willing to share those with your healthcare team?

**C – Community** Are you part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you?

**A - Address/Action in Care** How should I address these issues in your healthcare? This is also to remind clinicians to develop a plan to address patient spiritual distress or other spiritual issues.

**Further Resources** More information and educational materials about FICA are available at <http://www.gwish.org/>.

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