

What to Do When a Patient Refuses Treatment. ★★★

First Author: Robert Arnold, MD

A core aspect of American bioethics is that a competent adult patient has a right to refuse treatment, even when the physician believes that the treatment would be beneficial. At such a time it is easy to either question the patient's capacity to make the decision or try even harder to convince them to change their mind. The empirical literature — both in decision making and in medicine — suggest that this is a false dichotomy and that there is a third more productive way to proceed. The method described below is applicable to all situations of conflict between clinicians and their patients/families; the astute reader will note the similarity between this approach and that presented in Fast Fact #26, The Explanatory Model, designed to assist mediating conflicts that arise in cross-cultural encounters.

Clarify Decisionality. Distinguish between patients who can not understand the medical situation (and thus may lack decision-making capacity) and those who understand your viewpoint but do not agree with it. Ask, I have talked with you about the medical problems you are facing and possible treatments for these problems. Just to make sure we are on the same page, can you describe for me the medical problems you are dealing with now? Can you also describe the possible treatments we have discussed? (See Fast Fact: #55 Decision Making Capacity)

Understand their story. Try to understand the patient/family's story before you try to change their mind. This means suspending your attitude toward their decision and as openly and non-judgmentally as possible, understanding the reasons for their decision. This can be done by asking, Tell me more about your decision; What leads you to this conclusion?

Validate concerns. Often when we try to convince others of our position, we forget to acknowledge the reality of their concerns. This makes them feel unheard and under appreciated. More effective are responses which first let the person know they were heard (so you are concerned that if you have surgery you will X) or that normalize their concerns (it is not that unusual for people to be afraid of XX) before you respond to these issues.

Explore fears. Fears are stronger motivators than positive inducements. Try to understand your patient/family's fears/concerns with your plan of action; you can only address their fears if you understand them. Ask, Can you tell me if there is something about this decision that frightens you.

Establish a win-win position. If the patient's concern is the lack of control in the hospital and your concern is her/his health if s/he leaves the hospital, what can you do to provide more control in the hospital? Negotiate so both of you can achieve what each of you care about the most.

Related Fast Facts: 16, 17, 24, 26, 29, 59

References

1. Drane, J. F. (1985). □The Many Faces of Competency.□ Hasting Center Report: 17-19.
2. Stone, D., Patton, B. et al. (1999). Difficult conversations : how to discuss what matters most. New York City, Penguin Group.
3. Appelbaum, P. S., Roth and L. H. (1983). □Patients who refuse treatment in medical hospitals.□ JAMA 250: 1296-1301.

Fast Facts are edited by David E. Weissman, MD; Palliative Care Center, Medical College of Wisconsin. For comments/questions write to: dweissma@mcw.edu. The complete set of Fast Facts are available at EPERC: www.eperc.mcw.edu

Copyright/Referencing Information: Users are free to download and distribute Fast Facts for educational purposes only. Citation for referencing: Arnold R. Fast Facts and Concepts #56 Patient Refusal of Treatment, 2nd Edition. July 2006. End-of-Life Physician Education Resource Center www.eperc.mcw.edu.

Discussing Hospice

First Author: Charles F. von Gunten, MD PhD FACP

Hospice discussions with seriously ill patients should always take place in the context of the larger goals of care, using a step-wise approach.

1. Establish the setting

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

2. What does the patient understand?

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

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

3. What does the patient expect?

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

4. Discuss Hospice Care

Use language that the patient will understand, give information in small pieces. **Never say, "There's nothing more we can do."** "Nothing" is euphemistic and easily misinterpreted; to a patient "nothing" means abandonment. Summarize the patient's goals as part of your introducing a discussion of hospice care; *You've told me you want to be as independent and comfortable as possible. Hospice care is the best way I know to help you achieve those goals.* Listen carefully to the response; patients often have a distorted view of hospice care, others have never heard the term. Ask what the term means to them; patients frequently describe hospice as a place to go to die or what you do when you give up. Probe for previous experiences or how they developed their point of view. Respond by describing hospice as, *a program that helps the patient and family achieve the goals you've just described; it's a team of people that help meet the patient's and family's physical, psychological, social and spiritual needs.* Offer to ask someone from the hospice program to meet with them to give information.

Offer your recommendation, *From what you've told me, I would recommend that hospice care begin so that I can do the best possible job in meeting the goals we discussed today or I think it would be best if we got the hospice involved or I always ask the hospice to get*

involved for my patients at this stage of their illness. Reinforce that entering hospice care does not mean that the patient can never return to the office or hospital for care, that the decision is revocable, and that you will continue to be their physician (see future Fast Fact on Hospice Regulations).

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 FastFact #29 Responding to emotions).

6. Establish a plan

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

Reference

von Gunten CF. Discussing Hospice Care. *Journal of Clinical Oncology* 2002;20:1419-1424

Fast Facts are edited by David E. Weissman, MD; Palliative Care Center, Medical College of Wisconsin. For comments/questions write to: dweissma@mail.mcw.edu . The complete set of Fast Facts are available at EPERC: www.eperc.mcw.edu

Copyright/Referencing Information : Users are free to download and distribute Fast Facts for educational purposes only. Citation for referencing: von Gunten CF, Ferris F, and Weissman DE. Fast Fact and Concept #38: Discussing Hospice; 2nd Edition. July 2005. End-of-Life Palliative Education Resource Center www.eperc.mcw.edu.

Disclaimer: Fast Facts provide educational information, this information is not medical advice. Health care providers should exercise their own independent clinical judgment. Some Fast Fact information cites the use of a product in dosage, for an indication, or in a manner other than that recommended in the product labeling. Accordingly, the official prescribing information should be consulted before any such product is used.

Dealing with the Angry Dying Patient ★★★

First Author: Becky Wang-Cheng, MD FACP

Anger is a common emotion expressed by seriously ill patients and their families. The most typical reaction by the health professional, confronted by the angry patient or family, is to either get angry back or to physically and psychologically withdraw; neither are helpful coping strategies. A guide to managing these situations is presented below:

Look for the underlying source of anger.

Fear is probably the most common source of anger, especially in the dying and their families-- fear of the unknown, being in pain or suffering, the future well-being of family members, abandonment, leaving unfinished business, losing control of bodily functions or cognition, being a burden to the family, and dying alone.

Other sources of anger include: 1) a genuine insult--so called "rational anger" (e.g. waiting six hours to see the doctor); 2) organic pathology: frontal lobe mass, dementia or delirium; 3) personality style/disorder--the person whose approach to much of life is via anger or mistrust.

Recognize the direction of anger.

Recognizing the difference between internal and external anger is critical to effective management, because internal anger may lead to potentially harmful patient consequences. When the patient directs anger internally because of fear and guilt (eg "I didn't take care of myself; I'm abandoning my family."), this can lead to withdrawal, self-neglect, anxiety, depression, and/or a combination.

Others direct their anger outward at physicians, hospitals, family members or a deity. Particularly in the case of an angry parent of a dying child, he or she may feel helpless and guilty about many things-- not bringing the child for medical care soon enough, not being a loving enough or "great" parent (1). This internal guilt and blame can then be displaced towards the physician.

Engage rather than withdraw from the patient.

The natural tendency for the physician or health professional is to cut short the office or hospital visit, find ways to avoid contact with the angry patient or family member, or to try to mask his/her own anger in order to continue to interact with the patient. Robert Houston, MD, has written a very helpful article listing 10 rules for engaging the dying patient which will have a beneficial impact on the physician/patient relationship and the quality of the patient's end-of-life experience (2). One of his most important tips is to refrain from personalizing the anger when the patient accuses you of "missing the diagnosis" or under treating the pain.

Rules for Engaging the Angry Dying Patient (adapted from Houston)

1. Engage but do not enmesh and do the emotional work for the patient.
2. Maintain adult-adult communication rather than fostering the patient's dependency
3. Do not personalize the patient's anger.
4. Adopt a patient-centered worldview by ascertaining his/her values, priorities, hopes.
5. Normalize anger so that the patient can move through this stage.

Use the "BATHE" approach to create an empathic milieu (3).

As with any difficult patient situation, communication techniques are especially important so that both the patient and physician do not become further embittered and frustrated.

Background: Use active listening to understand the story, the context, the patient's situation.

Affect: Name the emotion; "you seem very angry" "It is crucial to validate feelings so the angry person feels that you are listening. Attempting to defuse it, counter it with your own anger or ignore it, will be counter-productive. Acknowledging their right to be angry will help start the healing process and solidify the therapeutic relationship.

Troubles: Explore what scares or troubles them the most about their present and future. Just asking the question, "tell me what frightens you", will help them to focus on circumstances they may not have considered.

Handling: Knowledge and positive action can help mitigate fears and reduce anger. How are they handling the dying---are they making concrete plans about their finances, their things, their family? Have they thought about formal counseling to help deal with the depression, the anger?

Empathy: By displaying empathy and concern you can help the person feel understood, less abandoned and alone. Avoid trite statements, "I know what you're going through." Paraphrasing the patient's comments is an effective way to convey that you heard and are seeking to understand. "So you feel like it's so unfair that the cancer appeared out of nowhere after all these years."

Summary

The journey from life to a good death almost always is accompanied by some degree of anger. A caring, patient physician can assist the patient and the family in recognizing, mobilizing, and modifying the anger into positive emotional energy.

References

1. Grossman L. Understanding anger in parents of dying children. *Am Fam Physician*. 1998;58(5):1211-2.
2. Houston RE. The Angry Dying Patient. *Prim Care Companion J Clin Psychiatry*. Feb;1(1):5-8, 1999.
3. M R Stewart, J Lieberman III. *The Fifteen Minute Hour: Applied Psychotherapy for the Primary Care Physician*, 2nd Edition. Praeger Publishing, Westport, Connecticut, 1993.
4. Rueth TW, Hall SE. Dealing with the anger and hostility of those who grieve. *A J Hosp Pall Care* 1999; 16:743-746.

Fast Facts are edited by David E. Weissman, MD; Palliative Care Center, Medical College of Wisconsin. For comments/questions write to: dweissma@mail.mcw.edu. The complete set of Fast Facts are available at EPERC: www.eperc.mcw.edu

Copyright/Referencing Information: Users are free to download and distribute Fast Facts for educational purposes only. Citation for referencing: Wang-Cheng R. Fast Facts and Concepts #59. Dealing with anger September 2006. End-of-Life Physician Education Resource Center www.eperc.mcw.edu.

First Author: Bruce Ambuel, PhD and David E. Weissman, MD

Case Scenario: You are caring for a previously healthy 52 y/o man with a new problem of 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 (more than 10) 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 whom they want to participate--clarify relationships to patient. Decide if you want others present (e.g. nurse, consultant, chaplain, social worker) and obtain patient/family permission.
3. Think through your goals for the meeting as well as possible goals of the patient.
4. Make sure you know basic information about the patient's disease, prognosis, treatment options.
5. Special circumstances: Patient not competent (developmentally delayed, dementia, etc.) Make sure legal decision-maker is present.
6. Special circumstances: Patient doesn't speak English. Obtain a skilled medical interpreter if the patient or family do not speak English. Use ATT translation service or other phone service is necessary.

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. As a preceptor, you will want to support the resident. Key teaching points:

1. Residents may not spontaneously discuss their own emotional reaction with a preceptor, therefore you will want 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; □Its normal to have strong feelings□.
3. Three methods for coping with these feelings: 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); Responding to Patient Emotion (#29); Dealing with Anger (#59).

References

- Buckman R. How to break bad news: A guide for health care professionals. Johns Hopkins University Press, 1992.
- Faulkner A. Breaking bad news--a flow diagram. Palliative Medicine 1994;8:145-151.
- Iverson, VK. Pocket protocols□Notifying survivors about sudden, unexpected deaths. Galen Press, Inc., Tuscon, Arizona, 1999.
- Ptacek, JT, Eberhardt, TL. Breaking bad news: A review of the literature. JAMA, 157:323, 1996.
- Sim, I. How to give bad news. <http://www-med.stanford.edu/school/DGIM/Teaching/Modules/badnews.html>
- Quill TE. Bad news: delivery, dialogue and dilemmas. Arch Intern Med 1991; 151:463-468.
- Girgis A and Sanson-Fischer RW. Breaking bad news: consensus guidelines for medical

practitioners. J Clin Onc 1995;13:2449-2456.

Von Gunten CF, Ferris FD and Emanuel LL. Ensuring competency in end-of-life care: Communication and Relational Skills. JAMA 2000; 284:3051-3057. Fast Facts are edited by David E. Weissman, MD; Palliative Care Center, Medical College of Wisconsin. For comments/questions write to: dweissma@mail.mcw.edu. The complete set of Fast Facts are available at EPERC: www.eperc.mcw.edu

Copyright/Referencing Information: Users are free to download and distribute Fast Facts for educational purposes only. Citation for referencing. Fast Fact and Concept #6 Ambuel B and Weissman DE. Delivering Bad News: Part 1. July, 2005. End-of-Life Palliative Education Resource Center www.eperc.mcw.edu.

Disclaimer: Fast Facts provide educational information, this information is not medical advice. Health care providers should exercise their own independent clinical judgment. Some Fast Fact information cites the use of a product in dosage, for an indication, or in a manner other than that recommended in the product labeling. Accordingly, the official prescribing information should be consulted before any such product is used.

First Author: Bruce Ambuel, PhD and David E. Weissman, MD

Case Scenario: You are caring for a previously healthy 52 y/o man with one-month of abdominal pain and weight loss. On exam he had a 2 cm hard left supraclavicular lymph node. A CAT 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? Or 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); Moderating a Family Conference (#16); Responding to Patient Emotion (#29); Dealing with Anger (#59).

-
-
-

- **Resources**

Buckman R. *How to break bad news: A guide for health care professionals*. Johns Hopkins University Press, 1992.

Faulkner A. Breaking bad news--a flow diagram. *Palliative Medicine* 1994;8:145-151.

Iverson, VK. *Pocket protocols? Notifying survivors about sudden, unexpected deaths*. Galen Press, Inc., Tuscon, Arizona, 1999.

Ptacek, JT, Eberhardt, TL. Breaking bad news: A review of the literature. *JAMA*, 157:323, 1996.

Sim, I. How to give bad news. <http://www-med.stanford.edu/school/DGIM/Teaching/Modules/badnews.html>

Quill TE. Bad news: delivery, dialogue and dilemmas. *Arch Intern Med* 1991; 151:463-468.

Girgis A and Sanson-Fischer RW. Breaking bad news: consensus guidelines for medical practitioners. *J Clin Onc* 1995;13:2449-2456.

Von Gunten CF, Ferris FD and Emanuel LL. Ensuring competency in end-of-life care: Communication and Relational Skills. *JAMA* 2000; 284:3051-3057.

Fast Facts are edited by David E. Weissman, MD; Palliative Care Center, Medical College of Wisconsin. For comments/questions write to: dweissma@mail.mcw.edu. The complete set of Fast Facts are available at EPERC: www.eperc.mcw.edu

Copyright/Referencing Information: Users are free to download and distribute Fast Facts for educational purposes only. Citation for referencing. Fast Facts and Concepts #11 Ambuel B and Weissman DE. *Delivering Bad News; Part 2*. September 2005. 2nd Edition End-of-Life Palliative Education Resource Center www.eperc.mcw.edu.

Disclaimer: Fast Facts provide educational information, this information is not medical advice. Health care providers should exercise their own independent clinical judgment. Some Fast Fact information cites the use of a product in dosage, for an indication, or in a manner other than that recommended in the product labeling. Accordingly, the official prescribing information should be consulted before any such product is used.