

University of Rochester Medical Center
ACGME COMPETENCY PROJECT

Communicating Bad News

READING MODULE

This module has been adapted from:

Participant's Handbook; Module 2: "Communicating Bad News." © EPEC Project, The Robert Wood Johnson Foundation, 1999. Authored by Emanuel LL, von Gunten CF, Ferris FD. The Education for Physicians on End-of-life Care (EPEC) curriculum, 1999.

Fast Facts and Concepts #76 and #77 Telephone Notification of Death Part 1 and Part 2. RR Osias, D H Pomerantz, and JM Brensilver. October 2002. End-of-Life Physician Education Resource Center @ www.eperc.mcw.edu.

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Introduction

Communicating bad news is an essential skill for physicians. Many physicians find it challenging to convey bad information, especially when it involves a life-threatening illness. It can be uncomfortable to deal with the strong emotions that bad news can elicit both in ourselves and from our patients. Some physicians feel inadequately prepared or inexperienced. Others struggle with their desire to protect the patient and preserve hope, while trying to be honest and develop realistic expectations. Despite these challenges, bad news can be conveyed clearly and compassionately with careful preparation and practice. Although legitimate cultural variations are important, effectively breaking bad news can improve the patient's and family's ability to plan and cope, encourage realistic goals and autonomy, support the patient emotionally, strengthen the physician-patient relationship, and foster collaboration among the patient, family, physicians, and other professionals.

6-step protocol for communicating bad news

The recommended 6-step protocol has been adapted from *How to Break Bad News: A Guide for Health Care Professionals* by Robert Buckman:

1. **Preparation and Planning**
2. **What does the patient know?**
3. **How much does the patient want to know?**
4. **Sharing the information**
5. **Responding to emotions**
6. **Planning and follow-up**

Step 1: Preparation and Planning

- **Prepare yourself.** Before starting to communicate any news, plan what will be discussed. Confirm the medical facts of the case. Ensure that all the needed information is available. Rehearse what you will say. Don't delegate the task.
- **When possible, prepare the patient.** Let the patient (and family) know what you are thinking about at the time of a diagnostic test, including both benign and potentially worrisome possibilities. This allows the patient /family to prepare psychologically, and may give you some clue as to the meaning they attach to a given diagnosis.
- **Choose an appropriate setting.** Create an environment conducive to effective communication. Find a quiet, private place with adequate seating. A box of facial tissues should be handy. Allot adequate time for the discussion. Don't rush. If possible, do not slip this into a short interval between other critical tasks. Try to avoid interruptions by arranging to hold telephone calls and pages.
- **Identify Support Persons.** Determine who else the patient would like to have present for the discussion. This might include family, significant others, surrogate decision makers, or other members of the interdisciplinary team (nurse, social worker, chaplain, etc).

Step 2: What does the patient know?

Start the discussion by establishing what the patient and family already know about the patient's health. With this information, ascertain if the patient and family will be able to comprehend the bad news.

Questions might include:

- *What do you understand so far about your illness?*
- *What did other doctors tell you about your condition?*
- *Have you heard anything so far about what the test showed?*
- *Did you think something serious was going on when...?*

Occasionally a patient will fall silent and seem completely unprepared or unable to respond. To ease the situation and stimulate discussion, try to clarify what the patient understands about his or her medical history and recent investigations. If it appears the patient requires more support, it may be better to reschedule the meeting for another time, and invite other family members.

Step 3: How much does the patient want to know?

Before you tell, ask. Establish what and how much each patient wants to know. People handle information differently. Each person has the right to voluntarily decline to receive any information and may designate someone else to communicate on his or her behalf. Ask the patient and family how they would like to receive information.

Possible questions include the following:

- *Are you ready to hear about the results of the test?*
- *Would you like me to tell you the full details of your condition?*
- *Some people really do not want to be told what is wrong with them, but would rather their families be told instead. What do you prefer?*

Ask a patient about general preferences for the handling of medical information and decision making early in the clinical relationship before significant information needs to be shared (this is ideally done in the pretest counseling period). This will help the clinician to avoid making a misstep. *If your condition turns out to be serious, do you want to know? If not, whom should we tell?*

When the family says “don’t tell”

Many times, family members will ask the physician not to tell the patient the diagnosis or other important information. While it is the physician's legal obligation to obtain informed consent from the patient, an effective therapeutic relationship generally requires a meaningful alliance with the family. Rather than confronting their request with “I have to tell the patient,” ask them why they don't want you to tell the patient, what it is they are afraid you will say, or what their experience has been with bad news. Inquire whether there is a personal, cultural, or religious

context to their concern. Suggest that you go to the patient together to ask how much he or she wants to know about his or her health and what questions there might be.

After discussion with the patient, it may ultimately be decided that details of diagnosis, prognosis and/or treatment will be discussed only with the family. However, unless the patient has previously indicated that he or she wants no information, hiding the diagnosis or important information about prognosis or treatment from the patient, especially if the patient is asking to be fully informed, is neither ethical nor legally acceptable. These situations may require significant negotiation. In particularly difficult cases, support from the institutional ethics committee may be very helpful.

Step 4: Sharing the information

Deliver the information in a sensitive but straightforward manner. Many experts recommend starting with a “warning shot,” which helps to prepare the patient for bad news (such as “*I don’t have good news...*”). Give the news using clear, easily understood language, and then **stop**. Do not use technical jargon or euphemisms (use the word “cancer”, not “carcinoma” or “tumor”). Avoid delivering all implications of the information in a single, steady monologue. Provide information in small chunks, pausing frequently to allow silence and time for patient and family to ask questions about each aspect. Check for understanding. Use silence and body language as tools to facilitate the discussion. Do not minimize the severity of the situation. Well-intentioned efforts to “soften the blow” may lead to vagueness and confusion.

You might choose to break bad news by using language like:

- *I feel badly to have to tell you this, but the growth turned out to be cancer.*
- *I’m afraid the news is not good. The biopsy showed that you have colon cancer.*
- *Unfortunately, there’s no question about the test results: you have been infected by HIV.*
- *The report is back, and it’s not as we had hoped. It showed that it is cancer.*
- *I’m afraid I have bad news. The tests show that you had a heart attack.*

Step 5: Responding to emotions

It is part of your job to balance emotional support with informational needs. Patients and families respond to bad news in a variety of ways. Responses can be affective (tears, anger, anxiety, fear), cognitive (denial, blame, guilt, disbelief), spiritual (why me?), or even visceral (numbness, disorientation, fight/flight response).

Outbursts of strong emotion make many physicians uncomfortable. Rather than immediately trying to limit emotion, give the patient and family time to react. Be prepared to support them through a broad range of reactions.

Some very basic skills are useful to respond to emotions:

- Acknowledge the emotion.
I can see that this is very upsetting.
You seem overwhelmed by this news.
- Legitimate the emotion.
Anyone in your shoes would be upset.
A lot of people would feel angry right now.
- Explore the emotions and be sure you understand them before providing reassurance
Tell me what is most upsetting to you....
Tell me what worries you the most...
- Empathize
I imagine it feels overwhelming.
I would probably feel the same way.
- Provide support
We will work through this together.
Is there anyone you would like me to call?

The phrase “I’m sorry” can effectively communicate empathy, but it may also be misinterpreted to imply that the physician is responsible for the situation. It may also be misinterpreted as pity or aloofness. If you use the phrase, try adjusting it to better show empathy. For example, “I’m sorry to have to tell you this.” (See also the attached Article: “I wish things were different...”)

Remind patients and families that their responses are normal. Have a box of facial tissue available. Nonverbal communication may also be very helpful. Consider touching the patient in an appropriate, reassuring manner.

Allow time for the patient and family to express all of their immediate feelings. Don’t rush them. Once the emotion is “spent,” most people will be able to move on. A shared understanding of the news and its meaning will enhance the physician-patient relationship and facilitate future decision-making and planning.

Step 6: Planning and follow-up

Establish a plan for the next steps. This may include gathering additional information or performing further tests or telling other family members. Arrange for appropriate referrals. Discuss potential sources of emotional and practical support (e.g., family, significant others, friends, social worker, spiritual counselor, peer support group, professional therapist, hospice, home health agency). Reassure the patient and family that they are not being abandoned and that the physician will be actively engaged in an ongoing plan to help. Indicate how the patient and family can reach the physician to answer additional questions. Establish a specific time for a follow-up appointment or phone call.

Assess the patient’s safety. Ensure that the patient will be safe when he or she leaves. Is the patient able to drive home alone? Is the patient distraught, feeling desperate or suicidal? Is there someone at home to provide support?

When language is a barrier

This same 6-step protocol for communicating bad news can be used when the patient and physician do not speak the same language. The assistance of an experienced translator who understands medical terminology and is comfortable translating bad news is required.

Brief translators before the interview and reassure them their role is only to translate. Verify that they will be comfortable translating the news you are about to give.

Ideally, avoid using family members as primary translators. Use knowledge of the patient and family to guide this decision. It could confuse their roles in the family unit and may raise issues of confidentiality. When working with a translator, sit in a triangular arrangement so that you can face and speak directly to the patient, yet still turn to look at the translator. Speak in short segments, and then give the translator time to convey the information. Verify the patient's and family's understanding and check for an emotional response.

Communicating prognosis

Patients frequently ask about prognosis. There are many motivations for this request. Some want to have a sense of their future so they can plan their lives. Others are terrified and hope that you will reassure them that things are not so serious.

Before directly answering their questions about prognosis, inquire about their reasons for asking. Questions might include:

- *How specific do you want me to be?*
- *What experiences have you had with others with a similar illness?*
- *What have you been told about the future?*

Consider the implications of the prognostic information you provide. Patients who wish to plan their lives want information that is more detailed. Those who are terrified may do better with answers that are more general. Overly definitive answers, e.g., "You have 6 months to live," run the risk of producing disappointment if the time proves to be less, and anger or frustration if you have underestimated the patient's lifespan.

Consider responding by giving a range of time that encompasses an average life expectancy. For example, "On average patients with your condition live"... "hours to days," "days to weeks," "weeks to months," "months to years," etc. Then follow with, "Of course, there can be exceptions in either direction." Alternatively, indicate averages such as "one third of people will do well a year from now, half will live about 6 months, exactly what will happen for you, I don't know." After giving a range, it may help to emphasize the limits of prediction by saying something like "What this will mean for you I can't tell. We'll have a better sense over time how things will evolve for you."

Physicians tend to be optimistic in an attempt to preserve hope. When using this approach, there is a danger of fostering false hope and developing unrealistic expectations. Always caution patients and families that unexpected surprises can happen. Suggest that they get their affairs in order so they won't be as vulnerable if something unexpected does occur. Reassure them that you will be available to help with issues and support them throughout their illness, whatever

happens. Help clarify what can be realistically expected and distinguish this from what might be wished for, or what is most feared. Identify the miraculous for what it is—something outside of usual experience that happens exceedingly rarely. It may be helpful to say something like “*we need to hope for the best, while we plan for the worst. We can't predict surprises and should plan in case something happens.*”

Telephone Notification of Death

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. Telephone notification does not allow the same level of interaction possible with direct personal contact.

Preparing for the Call

- Positively identify the patient (hospital ID tag) and confirm death.
- Obtain relevant information; e.g. patient's name, age, gender, SS# and other ID numbers.
- 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.
- Establish the circumstances of death; expected or sudden. Write down the key information you need and thoroughly review what you will say.
- 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 death
- Find a quiet or private area with a phone.

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 don't 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.
 - 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.

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.
9. If you feel uncomfortable about telephone notification, ask for help.

In rare circumstances, it may seem more appropriate to ask family members to first come to the hospital, rather than telling them about the death over the telephone. Few would disagree that it is always preferable to present death notification in person. However, 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:

- 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.

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).

Summary

Step 1: Preparation and Planning

Create an environment conducive to effective communication.

Step 2: What does the patient know?

Start by establishing what the patient and family already know and what they might expect.

Step 3: How much does the patient want to know?

Ask before telling.

Step 4: Sharing the information

Deliver the information in a sensitive but straightforward manner. Stop. Give the patient and family time to respond.

Step 5: Responding to emotions

Learn how to cope with the strong emotions associated with hearing bad news.

Step 6: Planning and follow-up

Establish a concrete plan for immediate next steps. Reassure the patient and family that they are not being abandoned.

When language is a barrier

Verify that translators will be comfortable and sufficiently skilled in translating the news you are about to give. Avoid using family members as translators when possible.

Communicating prognosis

Give an accurate, average estimate of prognosis when requested, and leave room for exceptions in both directions. Distinguish between what can be realistically expected and what might be hoped for.

Telephone Notification

Clearly identify the person you are talking to and their relationship to the patient. Carefully consider the risks and benefits of delaying disclosure of a patient's death.

Pearls

- Be prepared.
- Sit down.
- Ask before telling.
- Use a “warning shot;” such as, “I do not have good news.”
- Use simple, straight-forward language.
- Say it, then stop and listen.
- Respond to emotion in verbal and non-verbal ways.
- Have tissues handy.
- Use a range of time when communicating prognosis.

Potential pitfalls

- Delivering news in a noisy public place. Find a quiet, private location.
- Interruptions. Turn off your pager. Avoid other interruptions.
- Communicating news over the telephone. Avoid this unless the patient or family is prepared ahead of time.
- Physicians talk too much when nervous, uncomfortable. Allow silence.

Resources

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