

# **EPEEC**

**Education for Physicians on End-of-life Care**

## **Participant's Handbook**

**Module 2**

# **Communicating Bad News**

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## Abstract

Communicating bad news is an essential skill for physicians. This module presents a 6-step approach to communicating bad news. The steps include getting started, finding out what the patient knows, finding out how much the patient wants to know, sharing information, responding to feelings, and planning/follow-up. Approaches for handling the family who says “don’t tell” the patient, for using a translator, and for communicating prognosis are also discussed.

## Key words

bad news, communication skills, information sharing, language barriers, planning, responding to emotion, translators

## Objectives

The objectives of this module are to:

- know why communication of bad news is important
- understand the 6-step protocol for delivering bad news
- know what to do at each step of the protocol
- know how to apply the protocol to communicate any news

## Clinical case on trigger tape

Mr Gonzales is a 67-year-old mechanic who immigrated to the United States from Mexico 10 years ago. Dr O’Brien has cared for his family for 3 years. One week ago Mr Gonzales presented to Dr O’Brien with a chief complaint of weakness. On physical exam, he had occult blood in his stool. Laboratory testing revealed iron-deficiency anemia. Mr Gonzales underwent colonoscopy, which demonstrated a mass in the descending colon. The biopsy confirmed the diagnosis of adenocarcinoma. The video shows a scene in which Dr O’Brien gives him the news of his colon cancer.

## Introduction

Communicating bad news is an essential skill for physicians. Many of them find it challenging to convey bad information, especially when this involves a life-threatening illness. Some feel inadequately prepared or inexperienced. Others fear the news will be distressing and adversely affect the patient, family, or the therapeutic relationship.

However, the vast majority of Americans want to know if they have a life-threatening illness. Although legitimate cultural variations are important, breaking bad news in a direct and compassionate way 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

This module is designed as a systematic guide to the communication of bad news. However, it may be viewed more generally as a model for communicating any important information.

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

- Getting started
- What does the patient know?
- How much does the patient want to know?
- Sharing the information
- Responding to patient and family feelings
- Planning and follow-up

The first 3 steps deal with preparatory activities that could be completed before the session at which the physician actually delivers the bad news. At the fourth step, the news is delivered. The last 2 steps permit the physician to respond to the patient's reactions and constructively plan for follow-up.

### Step 1: Getting started

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. If this is an unfamiliar task, rehearse what you will say. Don't delegate the task.

Create an environment conducive to effective communication. For pediatric patients, have staff available to be with the child while information is conveyed to the parents first. Ensure privacy and adequate seating. A box of facial tissues should be handy.

Allot adequate time for the discussion. Do not slip this into a short interval between other critical tasks. Prevent interruptions. Arrange to hold telephone calls and pages.

Determine who else the patient would like to have present for the discussion. This might include family, significant others, surrogate decision makers, and/or key 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 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 about your illness?
- How would you describe your medical situation?
- Have you been worried about your illness or symptoms?
- What did other doctors tell you about your condition or any procedures that you have had?
- When you first had symptom X, what did you think it might be?
- What did Doctor X tell you when he sent you here?
- Did you think something serious was going on when...?

Occasionally a patient (or a parent if the patient is a child) 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. Identify absent family members or others on whom the patient relies. If this is ineffective and the patient remains silent, or if it appears the patient requires more support, it may be better to reschedule the meeting for another time.

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

Next, establish what and how much each patient, or parent if the patient is a young child, wants to know. People handle information differently, depending on their race, ethnicity and culture, religion, and socioeconomic class. 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. If the patient prefers not to receive critical information, establish to whom information should be given.

Possible questions include the following:

- If this condition turns out to be something serious, do you want to know?
- Would you like me to tell you the full details of your condition? If not, is there somebody else you would like me to talk to?
- 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?

- Do you want me to go over the test results no, and explain exactly what I think is wrong?
- Whom should I talk to about these issues?

## **Advance preparation**

All of the discussion to this point is about preparation to give the bad news. Some of that preparation might best occur well before the bad news is actually given. The initial assessment, and subsequent discussions that prepare the patient for critical tests, all provide opportunities to determine what the patient already knows and how he or she would like to have information handled.

## **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 requires a congenial 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, 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.

When the patient is a child, the parents may not want the child told about the illness. This protective instinct is understandable, but may ultimately be problematic. As the child experiences treatments and procedures, he or she will perceive there is a problem. The child may feel distrustful and misled when this happens. To avoid this, a better initial plan is to help the parents to understand that this is likely to occur. Make a child life or child psychology staff member available to help the parents and the medical team communicate important medical information to the child at an age-appropriate level.

These situations may require significant negotiation. In particularly difficult cases, support from the institutional ethics committee may be very helpful. Ultimately, it may be decided, after discussion with the patient, that details of diagnosis and prognosis and treatment decisions 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 is neither ethical nor legally acceptable. Physicians do not need to feel constrained to practice in a way that compromises care or feels unethical. If the physician and the family cannot come to agreement, the physician may choose to withdraw from the case and transfer care to another physician.

There are ethnic and cultural differences in the preferred handling of information. While knowledge of such differences is useful as a background, global conclusions about them

rarely help with decision making for an individual. 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 will help the clinician to avoid making a misstep.

## **Step 4: Sharing the information**

Deliver the information in a sensitive but straightforward manner. Say it, then stop. Avoid delivering all of the information in a single, steady monologue. Use simple language that is easy to understand. Avoid technical jargon or euphemisms. Pause frequently. 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:

- Mr Gonzales, 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: it’s cancer.
- The report is back, and it’s not as we had hoped. It showed that there is cancer in your colon.
- I’m afraid I have bad news. The bone marrow biopsy shows your daughter has leukemia.

The phrase “I’m sorry” may be interpreted to imply that the physician is responsible for the situation. It may also be misinterpreted as pity or aloofness. If you use the phrase, adjust it to show empathy. For example, “I’m sorry to have to tell you this.”

## **Step 5: Responding to feelings**

Patients and families respond to bad news in a variety of ways. Some respond emotionally with tears, anger, sadness, love, anxiety, relief, or other strong emotions. Others experience denial, blame, guilt, disbelief, fear, or a sense of loss or shame, or may even intellectualize why the situation is happening. A few may demonstrate reflexive psychophysiological responses such as “fight or flight” and may even try to bolt from the room or totally withdraw into themselves. Parents may become very emotional when thinking about actually telling their child the diagnosis.

Outbursts of strong emotion make many physicians uncomfortable. Give the patient and family time to react. Be prepared to support them through a broad range of reactions. Listen quietly and attentively. Acknowledge their emotions. Ask them to describe their feelings:

- I imagine this is difficult news...
- You appear to be angry. Can you tell me what you are feeling?
- Does this news frighten you?
- Tell me more about how you are feeling about what I just said.
- What worries you most?
- What does this news mean to you?
- I wish the news were different.
- I'll try to help you.
- Is there anyone you would like for me to call?
- I'll help you tell your son.
- Your Mom and Dad are sad now. They'll feel better when you get better.

Remind them that their responses are normal. Make a box of facial tissue available. Non-verbal communication may also be very helpful. Consider touching the patient in an appropriate, reassuring manner. Offer a drink of water, a cup of tea, or something else that might be soothing.

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. Treat current symptoms. It may include helping parents to tell their child about their illness and what treatment will be like for them. Arrange for appropriate referrals. Explain plans for additional treatment. Discuss potential sources of emotional and practical support, eg, family, significant others, friends, social worker, spiritual counselor, peer support group, professional therapist, hospice, home health agency, etc. Discuss sources of support for an ill child's siblings.

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 time for a follow-up appointment.

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?

At future visits, elements of this protocol may need to be revisited. Many patients and families require repetition of the news to gain a complete understanding of their situation.

## 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. There are several services in North America that offer translation by telephone if there is no one directly available. 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.

If possible, avoid using family members as primary translators. It confuses their roles in the family unit and may raise issues of confidentiality. Additionally, family members may not know how to translate the medical concepts the physician is trying to convey, and/or they may modify the news to protect the patient. Instead, when family members are present who do speak both languages, ask them to supplement the primary translation and support the patient and other members of the family.

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, 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:

- What are you expecting to happen?
- How specific do you want me to be?
- What experiences have you had with others with a similar illness?
- What experiences have you had with others who have died?
- What do you hope/dream will happen?
- What is your nightmare about what will happen?

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. Definitive answers, eg, “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, such as “hours to days,” “days to weeks,” “weeks to months,” “months to years,” etc. 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 need to hope for the best, while we plan for the worst. We can’t predict surprises and should plan in case something happens. We’ll have a better sense over time how things will evolve for you.”

Always caution patients and families that unexpected surprises can happen. Suggest that they get their affairs in order so they won’t be so vulnerable if something unexpected does occur. Reassure them that you will be available to them to deal 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.

## Caregiver communication

The sharing of information among caregivers is critical. Maintain a chart or log book close to the patient that can be shared by all who provide care, including physicians. Pooled information can facilitate a continuous plan of care, avoid constant repetition of questions, and avoid unwanted activities. It will be most effective if the chart or log book includes goals for care, treatment choices, what to do in an emergency, likes and dislikes, things to do and or not to do, and contact information for family, physicians, and other members of the interdisciplinary team. Ensure that data is recorded accurately and accessible to everyone.

## Summary

This 6-step protocol for delivering bad news offers guidelines and practical suggestions on how to communicate any medical information effectively and compassionately, and respond to a patient’s and family’s feelings and needs. Approaches for handling the family who says “don’t tell” the patient, the use of a translator, and the communication of prognosis are also discussed. Tips are provided for when language is a barrier, for communicating uncertain prognoses, and for coordinating communication among caregivers.

The protocol is a framework for approaching this essential task for physicians and all other members of the interdisciplinary team. It is not meant to be a rigid set of rules that

must be followed in all cases. When provided effectively, clear communication can only strengthen the physician-patient relationship.

## Key take-home points

1. The vast majority of Americans (>90%) want to know about it if they have a life-threatening illness.
2. Use the 6-step approach, particularly when learning this skill.

### Step 1: Getting started

3. Create an environment conducive to effective communication.
4. Ensure that the right people are present.

### Step 2: Finding out what the patient knows

5. Start by establishing what the patient and family know about the patient's health.

### Step 3: Finding out how much the patient wants to know

6. People handle information differently.
7. Each person has the right to voluntarily decline to receive any information and may designate someone else to communicate on his or her behalf. Find out how the patient would like to receive information.
8. Rather than confronting family members' request not to tell with "I have to tell the patient," explore why they do not want you to tell the patient. Suggest going to the bedside together to find out what the patient wants to know.

### Step 4: Sharing the information

9. Deliver the information in a sensitive but straightforward manner.

### Step 5: Responding to patient and family feelings

10. Outbursts of strong emotion are an expected component of information sharing. Learn how to cope with this.

### Step 6: Planning, follow-up

11. Establish a plan for next steps.

### When language is a barrier

12. Verify that translators will be comfortable and sufficiently skilled in translating the news you are about to give.

13. Avoid using family members as primary translators. It confuses their role, frequently compromises the therapeutic quality of the interview, and may compromise some patients' desires for confidentiality.

## Communicating prognosis

14. Inquire why the patient and family are asking in order to have a sense of their context for the question.
15. Give an accurate estimate of prognosis when requested.

## Pearls

1. Sit down.
2. Use a "warning shot;" that is, say something to prepare such as, "I do not have good news."
3. Say it, then stop and listen.
4. Have tissues handy.
5. Consider "I would not be surprised if [the patient] died within the next year/month/week/day" as a way to communicate prognosis.

## Potential pitfalls

1. Delivering news in a public place, such as in the hallway.
2. Interruptions. Turn off your pager. Avoid other interruptions.
3. Communicating news over the telephone. Avoid this unless the patient is prepared ahead of time.
4. Physicians talk too much when nervous, uncomfortable.

## Resources

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