Delivering the Supportive and Palliative Care Improving Outcomes Guidance (IOG) across the East Midlands

Guidelines For Communicating Bad News with Patients and their Families

(Significant News Guidance)

Information for Staff



East Midlands Cancer Network

Document History

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This document is only valid on the day it was printed. The source of the document will be found at this location – <u>www.eastmidlandscancernetwork.nhs.uk</u>

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Foreword

Communicating bad news with patients and their families is a fundamental part of a health and social care professional's (HSCP) work and yet it is an area where many have had little guidance or training.

These guidelines are designed to be a practical guide to help HSCPs of all grades, in all care settings, to communicate bad news in an effective manner. These guidelines can be looked at shortly before seeing a patient and tell you not just what you should do, but also what words you could potentially say. Although this is the first edition of the East Midlands guidelines, they build on previous guidelines from the three local cancer networks in the region and other step wise approaches.

It should be stressed that these are guidelines and not a rigid protocol.

At the end of the guidelines is a summary in the form of a flowchart. It can be laminated and made accessible to all staff involved in the process of breaking bad news. These guidelines can be found on www.eastmidlands.nhs.uk

When breaking bad news, the facts may not be remembered - the way they are given will be.

These guidelines have been written by Dr. Greg Finn and Dr. Patrick Costello, Consultants in Palliative Medicine, East Midland Cancer Network in collaboration with members of the East Midlands Cancer Network Supportive and Palliative Care Group.

Introduction

Bad news is any news that drastically and negatively alters the patient's view of his or her future. This encompasses a wide variety of diagnoses and situations ranging, for example, from patients being no longer able to drive a car after a diagnosis of epilepsy, or needing to have an amputation as a complication of diabetes, to a life-threatening disorder such as cancer or ischemic heart disease.

As health care professionals the majority of us, at some time, will have to break bad news to a patient, relative or carer. Breaking bad news involves tailoring information to the patient's needs, attempting to understand the patient's perspective and working in a collaborative partnership. The psychological sequelae of breaking bad news in an abrupt and insensitive way can be devastating and long lasting.

Although it is a common part of our working lives, very few of us will have been taught or guided how to break bad news effectively, consequently we may do it inappropriately. Communicating bad news well is a skill, which can be learnt and maintained with practice. No one, however experienced, likes breaking bad news, as however well they handle the situation, the reality is that the news is bad.

Teams should ensure that a senior clinician usually undertakes the communication of significant news. In addition to having expertise in the disease and treatment options, he or she should have received appropriate communication skills training. Sometimes patients and carers ask less experienced staff searching questions about their condition and care. There should be appropriate levels of communication skills training available for all staff.

Eleven well recognised Steps to Breaking Bad News

- 1. Preparation
- 2. What does the patient know?
- 3. Is more information wanted?
- 4. Give a warning shot
- 5. Allow patient to refuse information at that time
- 6. Explain if requested
- 7. Elicit and listen to concerns
- 8. Encourage ventilation of feelings
- 9. Summary and plan
- 10. Offer availability and support
- 11. Communicate with the team

Step One – Preparation and scene setting

• Know all the relevant facts

Before seeing the patient, check their healthcare records. Talk to the other health and social care professionals caring for the patient.

• Who should be present?

It is often best for a doctor and a nurse to see the patient and relative(s) together. The patient should be given a chance to invite a spouse, relative, or friend as appropriate. The patient's existing Key Worker will be helpful to support the patient at this time.

• Set time aside

Set time aside and avoid interruptions, including phone and bleep.

• Ensure privacy and set the scene

Before starting, it is worth getting the physical context right. Patients should ideally be seen in a private room within the clinical setting. If this is not possible, simple measures to ensure and impression of privacy should be undertaken, e.g. drawing curtains around a bed. Check that the patient can hear you. Interviews should take place sitting down with a doctor and patient at the same level with no obstruction between them, such as a desk.

• Explain your name and role when introduce yourself and your colleagues. Clarify the purpose of the consultation. –

'I have come to talk to you about the results of your test'.

Step Two – What does the patient know?

It's important to start off by checking what the patient knows already. At first some patients may say they do not know much about their condition but in fact often have good insight into what is going on. It is essential therefore to check out what they know. Ask before telling.

- 'It would help me to know what you understand about your illness.'
- 'What did the previous doctors tell you about your illness?'
- 'What sense have you made of the illness so far?'
- 'When you had the first symptom what did you think it might be due to?'

As the patient replies, you get not just factual information but you also get an understanding of what the experience has been like for the patient. You also get an understanding of their impression of the illness and how close their ideas are to reality.

Step Three – Is more information wanted at that time?

This is a critical step in the interview. The key task for the HSCP is to establish a patient's information needs. This may range from the bare essentials to a desire to know everything including the detailed results of scans. Even if a patient wants to know everything it is still best to go gently.

- 'I have your results, would you like me to discuss them with you?'
- 'If this condition turns out to be serious, are you the kind of person who likes to know all the details?'

It is best to check the patient's information requirements at regular intervals throughout the consultation.

• 'Would you like me to go on....or is that enough for today?'

If the patient expresses a wish not to discuss information, at that time, then this decision must be honoured. Fear prevents some people asking for more information – this is usually not a permanent refusal. Thrusting unwanted facts onto a patient can cause emotional damage. Therefore, further appointments should be made available with the multidisciplinary team and the patient made aware that they are free to request more information later.

By giving the patient control over the amount of information they want, it helps to avoid distress and also helps build a trusting relationship.

Step Four – Give a warning shot

The warning shot lets the patient know that you have got some important news for them.

- *'I'm afraid it looks more serious than we had hoped.'*
- 'I'm afraid that it is not good news..... would you like me to go on?'

A pause after this sort of phrase gives time for your warning shot to sink in and also allows time to study the patient's reaction.

The patient's response sets the stage for the rest of the interview. They have control over whether more information is given to them at that time. The decision to carry on is then in the patient's hands.

Step Five – Allow patient to decline information at this time

If the patient does not want information at this time, it is a form of personal care that protects the individual from threats to the self. This is specific to the time of the interview and is not necessarily permanent. It is not necessarily maladaptive and should be respected as a coping strategy. It is vital that you confirm with the patient that they can always ask for additional information in the future. Few patients adopt a stance of permanently choosing to avoid information, most start to ask for more information in due course once they start to feel more secure.

• 'It must be difficult for you to talk about this today, I'm happy to see you again, when you're ready.'

Step Six – Explain (if requested)

A short narrative of events can be a useful technique in explaining things, checking as you go along that the patient want further information.

• 'When you had a cough your GP arranged a chest x-ray for you. This showed a shadow. The shadow looked suspicious and I'm afraid the results of the tests are more serious than we had hoped. The tests unfortunately show that the shadow on your lung is, in fact, a cancer'.

At the end of the narrative, it is important to be clear about the diagnosis. For example the word 'cancer' should be used and not euphemisms like 'suspicious lesion'.

It's very important to **pause** and to use **silence** after breaking bad news. This allows the news to sink in and to give the patient a chance to figure out what the news means to them and the impact on their life. It gives them a chance to recover and gives some control. A common mistake HSCP make is to start reassuring too soon or to give lots of information after breaking the bad news in the false belief that this minimises the shock.

When explaining anything to the patient the following should be kept in mind:

- Use clear, simple and unambiguous language
- Information should be given in small chunks
- Check understanding 'Does that make sense?'
- Repeat important points
- Avoid information overload
- Avoid medical jargon
- Premature reassurance doesn't reassure
- If you can't answer a question be honest with the patient
- Use silence at important points to allow news to sink in
- Use any written material available

Step Seven – Elicit and listen to concerns

After breaking the bad news, eliciting and listening to patient's concerns is essential. These concerns are individual to each patient. The patient's concerns may be quite different to the HSCP's concerns, although there may be some cross over. It is important not to assume what the patients concerns are. Listing their concerns, acknowledging them and prioritising them, clarifies their perspective of the situation and is therapeutic in itself.

• 'I know that this is bad news but is there anything that is particularly distressing or is on your mind?'

Step Eight – Encourage ventilation of feeling

This is another key phase but is often missed. It is important to give the person the option of discussing their feelings, if they are up to sharing them at that time. Do not assume you know how the patient is feeling. Some patient's feelings may surprise you. For example, some patients may tell you they feel relieved to finally have been given an explanation for things. It can also be helpful to explore the underlying reasons for the patient's distress.

• 'How does that news leave you feeling?'

Acknowledging the patients feelings can also be helpful.

• 'I can see that the news I've given you has distressed you.'

Step Nine – Summary and Plan

Making a summary and plan involves listing the patients concerns and combining this with the health care professional's knowledge of the options available. It is about making a plan, explaining it and distinguishing between the fixable and the unfixable. It acknowledges the support already available, especially from family and friends.

- 'Your main concerns at the moment seem to be......'
- 'Have I left any thing out?'
- 'Is there anything else you would like to discuss now?'
- 'Do you have any questions that you would like to ask me now?'

Step Ten – Offer availability and support

A clear short-term follow up appointment with one of the multidisciplinary team, that the patient is happy with, is important. Most patients need further explanation after being given bad news, as they often cannot think of anything to ask at the time. Following a difficult communication, patients often can only recall limited amounts of information. The facts may not be remembered but the way they are given will be. It also takes time to adjust emotionally to bad news.

- 'We can see you again next Wednesday at 2 pm, is that alright with you?'
- 'We will ring you at home tomorrow lunchtime to see how you are.'

Support for the patient is essential. Offer contact numbers for the clinic/surgery and the specialist nurse. Offer appropriate written information.

- 'We will work on this together'.
- 'You will not be left to cope with this on your own'.

Step Eleven – Communicate with the Team

It's important to communicate with the rest of the patient's team, including the patient's GP and Key Worker, as they will have to support the patient after you have left. Document details of the conversation in the patient's notes and if you are sending a letter make a note of the breaking bad news session and it is specific contents using "quotes". Consider offering a copy of the letter to the patient.

Other issues to consider

Picking up the Pieces

It is good practice for a member of staff, usually the Key Worker or a nurse, to be with the patient after bad news has been given. That member of staff would have heard the details of the consultation and be able to offer them some initial support. A common reaction is to try and inappropriately reassure the patient by softening the news – "*perhaps it won't be as bad as that, try to be positive*". This time is best used by giving the patient an opportunity to express their thoughts and feelings by listening to the patient and being silent.

- 'I just wanted to say I am sorry about your news'
- 'I know that must have been hard, would you like to talk about it?'

In some ways, this "picking up the pieces" is as difficult as the initial consultation as it does not have a clear defined task. Many patients will be very positive about this clarification and moral support given after they have initially been given bad news.

Many members of staff will be following up the patient. Therefore communication within the full multidisciplinary team in primary and secondary care is vital to ensure clear support is available for the patient.

Breaking bad news over the phone

Avoid doing this if at all possible. Occasionally it cannot be avoided if the family live far away. Be clear you know who you are speaking to on the phone. Speak slowly and clearly, clarifying frequently that the other person has understood what you have said. It's helpful to acknowledge the awkwardness of speaking on the phone and that ideally you would prefer to speak to them personally. Check who is available in the house and suggest having someone available if possible. Follow the breaking bad news steps above.

When English is not the first language

If the patient does not speak English, arrange for an interpreter in advance, as it is not good practice to rely on a family member.

Learning Disabilities

The basic model within these guidelines can be used for patients with learning disabilities but additional factors need to be taken into account. The patient's nominated key worker may be of particular value supporting the patient. There are a number of resources which can help.

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Breaking Bad News Flowchart

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