

# **Breaking Bad News in Endoscopy - Full Clinical Guideline**

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This clinical guideline applies to <u>all</u> Endoscopists who find a suspected cancer at Endoscopy at University Hospitals of Derby and Burton NHS Foundation Trust.

Communicating bad news with patients and their families is a fundamental part of a healthcare professionals work.

These guidelines are designed to be a practical guide to help healthcare professionals of all levels 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 be doing, but also what words you could potentially say.

These guidelines will also provide examples of how you can communicate with patients before delivering bad news.

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

#### 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.

As healthcare 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 a patient's needs, attempting to understand the patient's perspective, thus ensuring that the patient understand what they are being told. The psychological sequelae of breaking bad news in an abrupt and insensitive way can be devastating and long lasting.

Although breaking bad news can be a weekly or even daily occurrence at work, very few healthcare professionals have been taught or guided how to break bad news effectively; consequently, it may be done inappropriately. Delivering bad news well is a skill, which can be learnt and maintained with practice.

It is essential for the bad news to be broken by the endoscopist who has performed the patient's Endoscopy, if this is a training list, the bad news should be broken by the senior endoscopist in the room. The endoscopist should always have a trained Endoscopy Nurse or Clinical Nurse Specialist in the room with them when breaking bad news. It is **not** acceptable or appropriate for the patient to receive bad news inside the procedure rooms, nor in the recovery area. It is important that when breaking bad news the patient should be in the quiet room. If this is unavailable the seminar room or one of the private admissions rooms can be used. The patient should be given the option of having a relative or friend with them when the bad news is delivered. If a patient's relative/friend has been contacted to come into the department for the news to be delivered, the endoscopist should **always** wait for the relative/friend to arrive.

Patients should always be given a contact number for the relevant Clinical Nurse Specialists to ensure that they are able to contact the correct person if/when necessary. It is also the responsibility to pass on the details of the patient to the relevant Nurse Specialists so that they are aware of the patient and can ensure they are booked onto MDT.

## 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 the 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
- Who should be present? It is best practice for the Endoscopist and a trained Endoscopy Nurse or Clinical Nurse Specialist to see the patient and relative/friend together. The patient should be given a chance to invite a spouse, relative or friend as appropriate.
- Set time aside Set time aside to talk to the patient, whether this is part way through the list or at the end. Avoid interruptions.
- Ensure privacy and set the scene Before delivering bad news, it is essential to get the physical context correct. Patients <u>must</u> be seen in a private room within the Endoscopy Department. Check that the patient is able to hear you. Bad news should be given with all parties sitting down

and with no obstruction between each other e.g. desks.

 Explain your name and role when introducing yourself and your colleagues. Clarify the purpose of the consultation – "I have come to talk to you about the findings from your Endoscopy test today".

## Step Two – What does the patient know?

It is important to start off by clarifying whether or not the patient is fully aware of why they have been sent for the Endoscopy and what they already know.

- "It would help me to know what you understand about why you have been sent for this test today."
- "What have you been told by the doctors before you came for the test today?"
- "When your symptoms started, what were your thoughts on what might be happening?"

Whilst the patient replies, you gather not only factual information but you also get a sense of what they have experienced and what they understand to be happening and how close their ideas are to what is actually happening.

## Step Three – Is more information wanted at that time?

The key task is for the Endoscopist to establish a patient's and relative's information needs. The need for information may range from the bare essentials to a desire to know in details all options available despite having no concrete diagnosis and results. Even if a patient wants to know all information it is best to proceed gently.

- "I have the findings from your Endoscopy today, would you like me to discuss them with you?"
- "It's not good news today, would you like to know all the details?"

It is best to check whether or not the patient would like you to continue with the conversation –

• "Would you like me to continue, or is that enough for today?"

If the patient does not wish to continue with the conversation, you must honour this decision and value the patient's right to decline any further information, at this time. Thrusting unwanted facts onto a patient can cause emotional damage. Therefore, further appointments should be made with the relevant specialists and make the patient aware that they are free to request more information at a later date. It is important to provide the patient with numbers for the Clinical Specialist Nurses so they have someone to contact if they need to talk about their probable diagnosis.

## Step Four – Give a warning shot

Providing the patient with a warning shot lets them know you have something important to discuss with them.

- "I'm afraid it looks more serious than we had hoped."
- "I'm afraid that it is not good news and we have found something abnormal on your Endoscopy today. Would you like me to go on?"

A pause after this sort of phrase will give the patient a little time to digest what they have just been told, at this time you can also observe their reaction. This reaction will almost certainly set the stage for the rest of the conversation.

## Step Five – Allow the patient to decline information at the time

If the patient does not want to be spoken to at this time, it is a form of personal care that protects the individual from threats to their self. This is specific to the time of the conversation and not necessarily permanent. It is vital that you inform the patient that they can ask for this information when they are ready to digest and be able to cope with the news. However, they must know that they will have upcoming tests within the next few weeks and people will be in touch with them to book these tests. Patients must be given contact numbers so that they are able to access support network.

• "It must be difficult for you to talk about this today. I have already informed my colleagues of your case and I will provide you with their contact details so you can talk to them at a time when you are 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 wants further information/explanation.

 "You went to visit your GP because you have had a change in bowel habit for the past few months and you were sent for a Colonoscopy today. Unfortunately I have found an abnormal area in the lower part of your Colon today and from experience I am afraid that it looks like a cancerous tumour. I have taken biopsies of the abnormal area today and until those biopsy results are back, I am unable to say that it is 100% cancer."

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

It is extremely important to pause and use silence after breaking bad news. This allows the news to sink in and to give the patient a chance to understand what this news means to them and the impact on their life. A common mistake clinicians make is to start reassuring the patient too soon or to give lots of information after breaking the bad news in the false belief that this minimizes 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 this make sense?"
- Repeat important points
- Avoid information overload/medical jargon
- If you cannot answer a question, be honest and tell the patient
- Use silence at important points to allow the information to sink in

#### Step Seven – Elicit and listen to concerns

After giving a patient bad news, eliciting and listening to patient's concerns is essential. These concerns are extremely individualised to patients. Allowing patients to list their concerns acknowledge and prioritise them, clarifies their perspective of the situation.

• "I know that this is not good news today, 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 imperative to give the patient the option of discussing their feelings, if they want to share them at the time. Do not assume you know how the patient is feeling. Some patients are also aware of the probable diagnosis before you even begin to talk to them. Each patient's ventilation of feelings will be individualised and personal to them.

• "How does this news leave you feeling?"

Acknowledgement of the patient's feelings can be helpful.

• "I can see how distressed you are by the news I have given you."

## Step Nine – Summary and Plan

Summarising the findings and making a limited plan involves listing the patient's concerns and combining this with the Endoscopist's knowledge of the options available e.g. CT Scan/MRI Scan. It is about making a plan and explaining it with the patient. At this point it is unable to provide the patient with a definitive plan and a way forward and this must be made aware to the patient. The summary and limited plan acknowledges the support already available, especially from friends and family.

- "Your main concerns at this moment in time seem to be...."
- "Is there anything you feel I have left out that you would like to discuss?"
- "Do you have any questions you would like to ask?"
- "I am aware that this is an awful lot of information to take on board at the moment, but I will give you the contact details of my colleagues for you to get in touch with if you have any questions at another time."

## Step Ten – Offer availability and support

Ensuring that the patient knows that they will be followed up by one of the members of the correct specialty is very important. The majority of patients will require further explanation after being given bad news, as they can often miss things that they wish to ask. Following a difficult conversation, patients can only recall limited amounts of information. The facts cannot always be retained by patients and relatives but the way they were told will be.

Support for the patient is essential. Offer contact numbers of the clinic/surgery and the Key Worker/Clinical Nurse Specialist. 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 is important that you cascade the relevant information to right teams, as they will have to support the patient after you have left. Document details of the conversation in the patient's notes or on their Endoscopy report. If you are sending a letter make a note of the breaking bad news conversation and its specific contents.

It is good practice for a member of staff to be with the patient after the Endoscopist has broken the bad news. That member of staff will have heard the conversation and be able to offer them initial support. This time is best used by giving the patient an opportunity to express their thoughts and feelings by listening to the patient 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?"

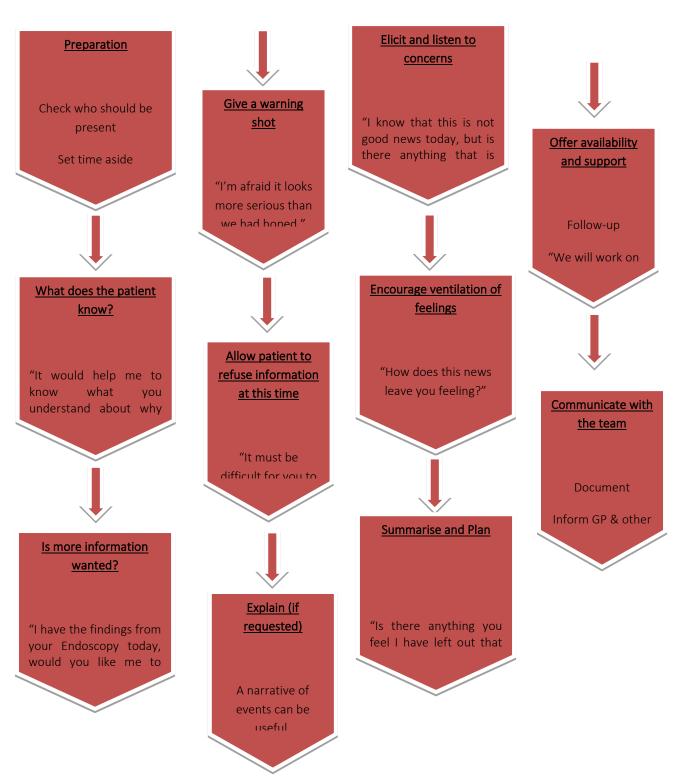
Things to consider:

#### 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 – does the patient fully understand the content of the conversation, does the patient need extra support, e.g. specialist nurse.



## Breaking Bad News Flowchart

## **Documentation Controls**

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