

NATIONAL COUNCIL  
FOR HOSPICE  
AND SPECIALIST  
PALLIATIVE CARE  
SERVICES

# Breaking Bad News ...Regional Guidelines

Developed from  
Partnerships in Caring (2000) DHSSPS  
February 2003

Department of Health, Social Services & Public Safety  
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## Section 1 Breaking Bad News - Regional Guidelines

### **Department of Health, Social Services and Public Safety. Northern Ireland Group of the National Council for Hospice and Specialist Palliative Care.**

These guidelines have been developed to assist clinical staff break bad news to patients, relatives and carers. While many of the themes are of a general nature, the emphasis of these guidelines are on breaking bad news to adults. The development of this document has drawn on the work of the Scottish Intercollegiate Guidelines Network (SIGN) and "A Guideline Developers' Handbook".

#### **Scope and Purpose**

"*Breaking Bad News*", outlines a pathway for medical and other professional staff to deliver bad news to patients, clients, their families and carers.

#### **Stakeholder Involvement**

This document has been developed as one part of the recommendations identified in the Regional Review of Palliative Care Services, 'Partnerships in Caring'.<sup>1</sup> The development of the "Breaking Bad News" guidelines was led by the Northern Ireland Group of the National Council for Hospice and Specialist Palliative Care, guidelines subgroup, whose membership is detailed in Appendix A.

Consultation on the detail of the guidelines involved the stakeholders outlined in Appendix D.

#### **Rigour of Development**

These guidelines for Breaking Bad News have been developed using the best research evidence available and have been externally reviewed by Professor Peter Maguire, Christie Hospital, Manchester.

The guidelines will be reviewed and updated in two years by the Northern Ireland Group of the National Council for Hospice and Specialist Palliative Care.

## **Applicability**

These guidelines are applicable to all Health and Social Care Staff who are involved in breaking bad news to adult patients and clients.

## **Implementation**

Local ownership of the implementation process is crucial to success in changing practice. For this reason the guidelines group is responsible for the development of the guidelines but not for implementation.

Implementation of the Regional Guidelines for Breaking Bad News is the responsibility of each HPSS Trust, HPSS and Voluntary Providers, in partnership with education providers and individual professionals.

A chart summarising the steps to take in breaking bad news is attached at Appendix B.

## Section 2

### Breaking Bad News

#### Guidelines for the Health and Personal Social Services

##### Background

No one likes breaking bad news. Although doctors and other professionals have always broken bad news the increase in chronic illness and the issues related to quality of life, heighten the importance of understanding how the delivery of bad news affects patients, their family /carers and doctors/other professionals.<sup>2</sup>

##### What is bad news?

Bad news can mean different things to different people. There have been numerous definitions of bad news including, "any information, which adversely and seriously affects an individuals view of his or her future"<sup>3</sup> or, in situations where there is either a feeling of no hope, a threat to a person's mental or physical well-being, risk of upsetting an established lifestyle, or where a message is given which conveys to an individual fewer choices in his or her life'.<sup>4</sup>

Examples include:

- A patient who is told they are HIV positive.
- The man who is told his partner has Alzheimer's disease.
- The patient who is told the lump has been diagnosed as cancer.
- The couple who are told they cannot have children.

The common denominator is that bad news is a message, which has the potential to shatter hopes and dreams leading to very different lifestyles and futures.

Bad news situations can include, disease recurrence, spread of disease, or failure of treatment to affect disease progression, the presence of irreversible side effects, results of genetic tests, or raising the issue of palliative care and resuscitation. Studies have consistently shown that the way a doctor or other health or social care professional delivers bad news places an indelible mark on the doctor/professional-patient relationship.

### **Whose information is it?**

The issue of who to tell bad news to has been debated for many years. This has been given greater emphasis more recently with the Data Protection Act<sup>5</sup> and the European Convention on Human Rights, Article 8, the respect for private and family life.

There is some evidence that doctors are failing to inform patients when they diagnose cancer, particularly in older patients.<sup>6,7,8</sup> This is despite evidence that some patients with malignancy want to know if their illness is cancer, and others want to know as much as possible about their illness, often more than a doctor assume they want to know.<sup>9,10,11,12</sup>

At the same time it has been common practice in some areas to give relatives large amounts of confidential information without the expressed permission of the patient, and often before the patient themselves are aware of their condition. This practice ought to stop. While the ramifications of the Human Rights Act are not entirely clear, practitioners must make sure they respect the private and family lives of patients. While each case is different, clinicians must be careful to fully consider the needs of the patient and their family when they are disclosing information.

### **What are the skills required?**

Breaking bad news is a complex communication task that requires expert verbal and non-verbal skills. This complexity can create serious miscommunications, such as the patient misunderstanding the prognosis of the illness or purpose of care.<sup>13,14</sup> When bad news is delivered poorly the experience may stay in a patient's or family's mind long after the initial shock of the news has been dealt with.<sup>15</sup> Where English is not a first language staff should avail of interpreting services. When patients have other special needs such as sensory impairment, learning or physical disabilities staff should ensure that the appropriate support mechanisms are available.

## **What do patients want?**

The debate about the levels of truth given to patients about their diagnosis has developed significantly over the last few years. While doctors and professionals now increasingly share information it has been the practice to withhold information because it was believed to be in the best interests of the patient.<sup>16</sup>

The evidence indicates that patients increasingly want additional information regarding their diagnosis, their chances of cure, the side effects of therapy and a realistic estimate of how long they have to live.<sup>17,18,19</sup> Patients want their doctor to be honest, compassionate, caring, hopeful and informative. They want to be told in person, in a private setting, at their pace, with time for discussion and if they wish, with a supportive person present.<sup>20</sup>

## **What is the impact on you as a health care professional?**

Breaking bad news can be extremely stressful for the doctor or professional involved. The evidence suggests that the bearer of bad news experiences strong emotions such as anxiety, a burden of responsibility for the news and fear of a negative response. This stress can result in a reluctance to deliver bad news.<sup>21</sup> When staff are uncomfortable breaking bad news they can avoid discussing distressing information, such as poor prognosis or convey unwarranted optimism to the patient that may predispose to depression.<sup>22</sup>

The process of breaking bad news can also have an adverse effect on those delivering the news. This is particularly evident when the doctor or professional is inexperienced, the patient is young, or there are limited options for treatment.<sup>23</sup>

Clinicians are often uncomfortable discussing prognosis and possible treatment options if the information is unfavourable. The evidence suggests that this is due to a number of reasons including:

- Uncertainty about the patient's expectations
- Fear of destroying the patient's hope.
- Fear of their own inadequacy in the face of uncontrollable disease.
- Not feeling prepared to manage the patients anticipated emotional reactions.
- Embarrassment at having previously painted too optimistic a picture for the patient.<sup>24,25,26,27</sup>

Patients and their relatives rely on professional staff breaking bad news as well and as effectively as they can. It is not always possible to get this very complex and emotional exchange of information right.

It is important to recognise the potential stresses that breaking bad news can cause. It is important, for all staff, including senior staff, to reflect on the experience as appropriate with their clinical supervisors, mentors or education facilitators as soon as possible after the event.

*Communicating bad news to patients well is not an optional skill; it is an essential part of professional practice.*

## Section 3 A Strategy for Breaking Bad News.

The following strategy is developed from the work of SPIKES.<sup>28</sup>

### Preparation - Setting up the Interview

#### *Prepare yourself -*

It is natural for the bearer of bad news to be anxious about the interview with the patient or carer.

- Familiarise yourself with the patient's background, medical history and test results. You will also need to have some knowledge of the choices in the future management of the patient's condition.
- It is helpful to mentally rehearse the interview, the likely questions you will be asked, the patient's emotional and potential responses.
- While it is important to remember that the bad news may be very sad for the patient, the information that you will be giving will be important in allowing him/her to plan for the future.
- It is strongly recommended that a colleague such as the patient's named nurse or specialist nurse accompanies you. This individual may remain with the patient if appropriate and help provide continuing support to the patient.
- The patient may want a member of their family with them, however this must be established prior to the interview. The clinician must be guided by the wishes of the patient. It can be helpful to suggest to the patient, when investigations are being carried out, that they may wish a family member or friend to accompany them for support, when results are discussed with them.

#### *Prepare your setting -*

- Arrange some privacy. Ideally an interview room or where a patient is confined to bed, pull the curtains around the bed. The latter is not an ideal situation, but can occasionally be difficult to avoid. (A practical hint is to have some tissues at hand in case the patient becomes upset.)

- Do not stand over the patient. Sit down, as this is less intimidating and shows that you are not going to be rushed. It is important to have no barriers between you and the patient. If you have recently examined the patient allow them to dress before the discussion.
- It is important to gain a rapport with your patient. The mechanisms by which you do this will depend very much on the patient, their condition, cultural background and age.
- It is important that you balance the time available with the needs of the patient and that you conduct the interview accordingly. You may need to switch off your pager or get a colleague to answer calls on your behalf. If the interview is rushed the doctor/other professional may be perceived as uninterested.

### *Prepare your Patient -*

- Patient perceptions. It is important before you begin breaking bad news that you assess the patients' understanding of their condition. At this stage you can correct any misunderstandings and it will enable you to assess if the patient is engaging in either denial, wishful thinking or unrealistic expectations of treatment.<sup>29</sup>
- Obtaining the Patients' Permission. While many patients increasingly want to have details about their disease and diagnosis, some patients do not and this should be respected and appropriately managed. One mechanism to help you is to assess the level of information the patient wants. If this is not explicit, broach the subject when tests are being ordered, by asking questions such as, "How would you like me to give you the results of these tests?" or "Are you the type of person who likes detailed information, or would you like a general overview?" or "Have you had any thoughts as to what may be wrong".

### **The Interview**

#### *Providing the Information -*

There is no easy way to give a patient bad news. Warning a patient that bad news is coming may help lessen the shock and may help the patient to go on to process the information they receive.<sup>30,31</sup> Examples include terms such as, "Unfortunately I've got some bad news to tell you" or "I am sorry to tell you".

In providing the facts to the patient it is important to remember:

- a) Start at the level of comprehension and vocabulary of the patient.
- b) Use non-technical words such as 'spread' instead of 'metastases'. Remember patients may not understand the words 'malignancy' or 'tumour' to mean 'cancer'.
- c) Provide information simply and honestly, avoiding excessive bluntness, as it is likely to leave the patient isolated and angry, with a tendency to blame the messenger.
- d) Give the information in small chunks and stop periodically to check the patients understanding. One helpful approach is to provide information in steps, introducing more specific language at each step. For example this allows the patient with cancer to introduce the word 'cancer' themselves.
- e) When the prognosis is poor, avoid using terms such as "there is nothing more we can do for you", as goals in care will change to good pain control and symptom relief, all of which are possible.
- f) Encourage questions and allow time.
- g) Remember it is likely that the patient may not be able to recall all of the conversation you have had. You may need to return and repeat the process at a later stage.
- h) Offer to speak to family members or carers should the patient wish.

Where possible and appropriate, information given verbally should be supported with written information.<sup>32,33</sup> It is of equal importance to share this information and the patients response with the multidisciplinary care team and the patient's General Practitioner who may feel it is necessary to repeat the information when the patient is at home. Some patients may find it helpful if you offer to tape the interview for them.

### *Providing Support*

Providing support to the patient begins with responding to the patient's emotions, which can range from silence to disbelief, crying, denial or anger. An empathetic response consists of five steps:

- a) Observe for emotions such as tearfulness, silence or shock.

- b) Acknowledge and identify with the emotion experienced by the patient. When a patient is silent use open questions, asking them how they are feeling or thinking. This will help them articulate what their emotions are. Allow time for silence and tears.
- c) Do not say "I know how you feel". Even if you have had personal experience of the disease or condition, you cannot know how an individual feels. Empathy can be shown by using terms such as "I think I understand how you must be feeling".
- d) Check the reason for the response. This will usually be related to the news you have just given them or the impact the news will have on their family or children.
- e) Encourage and allow the patient time to express their emotions and let the patient know you understand and acknowledge their emotions. This reduces the patient's isolation, expresses solidarity and validates their feelings or thoughts as normal and to be expected.<sup>34,35</sup>

Unless the emotions of the patient are adequately addressed it is difficult for the doctor/other professional and patient to move on to discuss other relevant issues.

### *Providing a Plan -*

Patients who have a clear plan for the future are less likely to feel anxious and uncertain. An important part of this is providing treatment and care options to the patient. For example in chronic illnesses such as diabetes, a clear management plan or when malignant disease is confirmed, the options for treatment and if appropriate ongoing support and palliative care. It may be helpful if the patient has the option to speak to the professional delivering the bad news at a later stage.

### **After the Interview**

#### *Documentation -*

It is important that accurate records are maintained of the conversation and the information and details exchanged. These will assist in the future care of the patient and enhance communication within the multidisciplinary team including the patient's General Practitioner.

This record should be documented in the patient's notes. The specific words used to describe the disease should be recorded, for example, tumour, growth or malignant disease.

A template to record the information given (Appendix C), is provided for local adaptation and use. It is suggested that this should be sent immediately by secure fax if available to the patients' General Practitioner.

Despite following these guidelines patients may not be able to absorb the detail of the news being delivered. A well informed multi-disciplinary team is the key if the news is to be reinforced ensuring the patient and where appropriate, the family have the fullest understanding possible.

Taking the time to prepare for an interview to break bad news to patients will help ensure the process is more effective. That said it has to be acknowledged that receiving a diagnosis of bad news may be overwhelming for the patient and their family or carers regardless of the care the doctor or professional takes in communicating it.

## Appendix A

### Sub Group Membership

| Name  | Organisation   |
|---|--|
| Dr Sheila Kelly,<br>Consultant Palliative Medicine          | Marie Curie Cancer Care, Belfast.                    |
| Dr Bernie Corcoran,<br>Consultant Palliative Medicine       | Belfast City Hospital Trust                          |
| Dr Kiran Kaur,<br>Consultant Palliative Medicine            | Northern Ireland Hospice/Royal Group Hospitals Trust |
| Dr Yvonne Duff,<br>Consultant Palliative Medicine           | United Hospitals Trust                               |
| Pauline Douglas<br>Allied Health Professions Representative | Belfast City Hospital Trust                          |
| Dr Jenny Jingles,<br>Consultant Public Health Medicine      | Eastern Health and Social Services Board             |
| Heather Monteverde<br>Service Development Manager           | Macmillan Cancer Relief                              |
| Jane Graham,<br>Chief Officer                               | Eastern Health and Social Services Council           |
| Dr Brid Farrell,<br>Consultant Public Health Medicine       | Southern Health and Social Services Board            |
| Mary Hinds,<br>Director of Nursing & Quality                | Mater Hospital Trust                                 |

## Appendix B Breaking Bad News - A Guide for Clinical Staff

|                                     |   |
|-------------------------------------|---|
| <p><b>Prepare Yourself</b></p>      | <ul style="list-style-type: none"> <li>• Familiarise yourself with the patient's background, medical history, test results and future management / treatment choices.</li> <li>• Mentally rehearse the interview including likely questions and potential responses.</li> <li>• Arrange for a colleague such as the patient's named nurse or specialist nurse to accompany you. Relatives can be in attendance, however you must be guided by the wishes of the patient.</li> </ul>   |
| <p><b>Prepare Your Setting</b></p>  | <ul style="list-style-type: none"> <li>• Arrange some privacy.</li> <li>• Do not stand over the patient, sit down as this relaxes the patient and shows that you are not going to be rushed. If you have recently examined the patient allow them to dress before the interview.</li> <li>• Switch your pager off or get a colleague to answer calls on your behalf.</li> </ul>   |
| <p><b>Prepare Your Patient</b></p>  | <ul style="list-style-type: none"> <li>• Assess the patients understanding of their condition. <i>"Can you help me by telling me what you understand about your illness?"</i></li> <li>• While many patients want to have details about their disease and diagnosis, some patients do not want this detail and their wishes should be respected and appropriately managed. Never impose information.</li> </ul>   |
| <p><b>Providing Information</b></p> | <ul style="list-style-type: none"> <li>• Start at the level of comprehension and vocabulary of the patient.</li> <li>• Use non-technical words such as 'spread' instead of 'metastases'.</li> <li>• Avoid excessive bluntness, as it is likely to leave the patient isolated and later angry.</li> <li>• Set the tone. <i>"I am afraid I have some bad news"</i></li> <li>• Give the information in small chunks and stop periodically to check the patients understanding. <i>"Is this making sense?"</i> or <i>"Would you like me to explain more?"</i></li> </ul> <p>When the prognosis is poor, avoid using terms such as "there is nothing more we can do for you," as goals in care will change to pain control and symptom relief.</p>   |
| <p><b>Providing Support</b></p>     | <ul style="list-style-type: none"> <li>• Acknowledge and identify with the emotion experienced by the patient. When a patient is silent use open questions, asking them how they are feeling or thinking. This will help them articulate what their emotions are. <i>"How are you feeling now?"</i></li> <li>• Do not say "I know how you feel". Even if you have had personal experience of the disease or condition, you cannot know how an individual feels. Empathy can be shown by using terms such as, <i>"I think I understand how you must be feeling."</i></li> <li>• Allow the patient time to express their emotions and let the patient know you understand and acknowledge their emotions.</li> <li>• Unless patients' emotions are adequately addressed it is difficult for the doctor and patient to move on to discuss other important issues but remember the patient's crisis is not your crisis - Listen.</li> </ul> |
| <p><b>Providing a Plan</b></p>      | <ul style="list-style-type: none"> <li>• Provide a clear plan for the future, with treatment options or management plan discussed.</li> <li>• Offer to meet and talk to the family if not present.</li> </ul>   |
| <p><b>After the Interview</b></p>   | <ul style="list-style-type: none"> <li>• Make a clear record of the interview, the terms used, the options discussed and the future plan. Ensure the detail of the interview is shared with the multi-disciplinary team, including the General Practitioner.</li> </ul>   |

## Appendix C

### Breaking Bad News Record Template

|   |   |
|---|---|
| <b>Patients Name/Address:</b>   | <b>Hospital Number:</b>                         |
| <b>Date and time of interview:</b>  |   |
| <b>Location: Ward</b>   | <b>Outpatients</b>                              |
| <b>Names of those present:</b>  |   |
| <b>Name:</b>  | <b>Position/Relationship:</b>                   |
|   |   |
|   |   |
| <b>Clinical Diagnosis:</b>  |   |
| <b>Clinical Options for future management and immediate plan discussed:</b> |   |
| <b>Detail of the words used when breaking the bad news:</b>                 |   |
|   |   |
|   |   |
| <b>Copy to General Practitioner:</b>  | <b>Referral to Palliative Care Team: Yes/No</b> |
|   | <b>Referral to District Nurse: Yes / No</b>     |
| <b>Filed in Patients Notes:</b>   | <b>Referral to Others (Please Specify)</b>      |
| <b>Signature of the Clinician:</b>  | <b>Date:</b>                                    |

### Appendix D

#### Key Stakeholders Involved in Consultation

- DHSS&PS Board Members
- DHSS&PS Directors
- Chief Executives/Directors of Nursing/Directors of Public Health, Health & Social Services Boards
- Chief Executives/Directors of Nursing/Medical Directors, Health & Social Services Trusts
- Nurse Leaders Network
- Chief Executives, Health & Social Services Councils
- Hospice and Palliative Care Organisations
- Regional Advisory Committee on Cancer
- Campbell Commissioning Group
- Marie Curie Cancer Care
- NI Hospice
- Foyle Hospice
- Newry Hospice
- Macmillan Cancer Relief
- Action Cancer
- Age Concern
- Help the Aged
- NI Practice and Education Council for Nursing & Midwifery
- Postgraduate Medical & Dental Education Council
- Central Services Agency
- NI Social Care Council
- Community Practitioners & Health Visitors Association
- Central Nursing Advisory Committee
- Royal College of Nursing
- Royal College of Midwifery
- GP Forum Members
- Education Providers
- Queens University of Belfast
- University of Ulster
- The Beeches Management Centre, Nursing & Midwifery Education
- North & West In-Service Education Consortium
- In-Service Education, United Hospitals Trust

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