

# 4 Communication in palliative care: a practical guide

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## Introduction: objectives of this chapter

Effective symptom control is impossible without effective communication. The most powerful analgesics will be of little value if health-care professionals do not have an accurate understanding of the patient's pain, and this can be obtained only by effective communication. Despite its cumbersome form, 'health-care professionals' is the only acceptable phrase that encompasses members of all health disciplines: doctors, nurses, social workers, psychologists, psychiatrists, chaplains, or any other. The words 'professional' and 'practitioner' are used interchangeably in this chapter to refer to this group. Almost invariably, the act of communication is an important part of the therapy: occasionally it is the only constituent. It usually requires greater thought and planning than a drug prescription, and unfortunately it is commonly administered in subtherapeutic doses.

There is no lack of published literature concerning the emotional and psychosocial needs of the dying patient<sup>1-7</sup> and the importance of communication as a major component of the delivery of all medical, and particularly palliative, care.<sup>8-16</sup> There is also some published work on the obstacles to, and the deficiencies in, communication between the dying patient and the health-care professional.<sup>17-19</sup> However, there is very little in the general medical literature that provides detailed practical assistance for the palliative care practitioner in improving his or her communication skills. The major objective herein is to remedy that omission, and to provide an intelligible and coherent approach to communication in a palliative care setting between professionals and their patients. Much of this material may be known to experienced professionals, but very little of it has previously been published or documented. The objectives of this chapter are, therefore, practical and pragmatic, and its somewhat unusual structure and style reflect that emphasis.

The details of communication can be considered under three headings.

1. Basic listening skills;
2. The specific communication tasks of palliative care:
  - (a) breaking bad news;
  - (b) therapeutic dialogue;

3. Communicating with the family and with other professionals.

However, before considering the details of doctor-patient communication, it is worthwhile undertaking a brief survey of the major obstacles to good communication with the dying patient. It is an undeniable fact that in our society any conversation about death and dying is awkward and difficult, and even more so when it occurs between doctor and patient. Some of that awkwardness is social and has its origins in the way society currently views death, some of it originates with the individual patient, and some originates with the professional, since our own professional training, while it prepares us to treat sick people, paradoxically leads us to lose touch with our own human skills when the medical treatment of the disease process fails.

In addition, there is no adequate working concept of the process of dying. Currently accepted systems do not provide a good working model of the transition from living to dying. Without such a conceptual framework or model to guide us, communication will always be suboptimal because we will be unable to understand or interpret what we are hearing, and will be unable to anticipate what may happen next, or to place the patient's feelings within the broader context of the dying process or of that individual's life and experience.

Therefore, the following two sections of this chapter will provide an overview of these issues, starting with a summary of the main areas of difficulty in discussing death and dying, and moving on to put forward a new three-stage concept of the process of dying which, it is hoped, will be of practical value to all practitioners in palliative care.

## Sources of difficulty in communication with dying patients

Whatever the experience—or lack of it—of the health-care professional, a conversation with a dying patient almost always causes some degree of discomfort or awkwardness. It is important to recognize the fact that this discomfort is universal and is not the product of any personal fault or deficiency of the health-care professional. The major causes of this sense of unease originate long before the individual patient and the individual doctor begin the conversation. Therefore, a brief overview of the causes of that

discomfort may have some value in relieving the sense of awkwardness, personal inadequacy, or even guilt which so commonly hinders communication in palliative care.

The sources of difficulty can be divided into three groups: first, those related to society (the social causes), second those related to the individual patients, and third those related to the health-care professional, arising from the professional's own social background and also from the professional's training—in medical school or nursing college for example.

### *The social denial of death*

Contemporary society is going through a phase of virtual denial of death.<sup>20</sup> Such attitudes are probably cyclical, and we may now be seeing this denial phase beginning to fade. However, the price of the current attitude of denial or avoidance is paid by the person whose life is threatened and who has to face death, and by those who look after and support the patient—the family and the professionals. The major social roots of the contemporary fear of dying are discussed below.

#### *Lack of experience of death in the family*

Nowadays, most adults have not witnessed the death of a family member at home when they themselves were young and still forming their overall view of life. Whereas a century ago approximately 90 per cent of deaths occurred in the home, for the last few decades over 65 per cent (varying with regional demographics) occur in hospitals or institutions. This is associated with a change in family structure as the norm has changed from the extended family to the nuclear family. Thus, elderly people are less likely to be living with their grandchildren and are usually without young, fit relatives to support them at the time of their last illness. By the same token, a normal childhood and adolescence in contemporary society does not include a personal experience of death in the family occurring in the home.

Another factor in determining the place of most deaths is the rise and range of modern health services and the increase in facilities and treatments on offer. While these services undoubtedly offer advantages in medical and nursing care for the person dying in an institution, it means that there is disruption of family support for the patient as well as a lack of experience and understanding of the dying process for the surviving relatives.

This is not to imply that witnessing a death at home in the past was always a serene or tranquil experience. But even if a death at home was not a pleasant event, a child growing up in such a home would be imprinted with a sense of the continuity of life, the process of ageing and the natural inevitability of death ('when you are older you look like dad, when you are much older you look like grandad, when you are very very old you die'). As the extended family has disappeared, so dying has become the province of the health-care professional and/or institution; most people have lost that sense of continuity and now regard the process of dying as intrinsically alien and divorced from the business of living.

#### *High expectations of health and life*

Advances in medical sciences are often over-reported in the media and hailed as major breakthroughs. The constant bombardment of the public with news of apparently miraculous advances in the fight against disease subconsciously raises expectations of health and even offers tantalizing hopes of immortality. It, thus, becomes even

harder for an individual to face the fact that he or she will not be cured despite the many miracles seen on television or in the papers.

#### *Materialism*

It is beyond the scope of a textbook to assess the materialist values of the modern world, except to point out that our society routinely evaluates a person's worth in terms of material and tangible values. This is our current social system of values and is neither good nor bad. However, it is universally accepted in our society that dying means being parted from material possessions. Hence, a society that places a high and almost exclusive value on material possessions implicitly increases the penalty of dying for its members.

#### *The changing role of religion*

The role of religion has changed, and the previously near-universal view of a single exterior anthropomorphic God is now fragmented and individualized. Religion is currently much more of an individual philosophical stance than it was in the last century, and it is no longer possible to assume that everyone shares the same idea of a God or of an after-life. Whereas a Victorian physician might have said to a patient 'Your soul will be with your Maker by the ebb-tide' and may have meant it genuinely as a statement of fact and of consolation, we cannot nowadays assume that such a statement will bring relief to all, or even most, patients.

For all these reasons, then, our society is passing through a phase of development during which the process of dying is perceived as alien and fearsome, and during which the dying person is separated and divided from the living. This increases the discomfort that surrounds any conversation about dying.

#### *Patients' fears of dying*

The fear of dying is not a single emotion. It can be composed of any or all of many individual fears, and it is probably true to say that every human being will have a different and unique combination of fears and concerns in facing the prospect of dying. An illustration of some of these is shown in Table 1. This concept of the patient's fear of dying has important implications for communication in palliative care. First, recognizing that fear of dying is not a single monolithic emotion should prompt the professional into eliciting from the patient the particular aspects of terminal illness that are uppermost in his or her mind. Thus, a patient's statement that he or she is afraid of dying should become the beginning of a dialogue, not the end of one.<sup>21</sup> Second, being aware that there are so many different aspects of dying that may cause fear will help the professional recognize some triggers of the patient's feelings. This recognition and the ensuing familiarity with the causes of fear often enhances the professional's ability to empathize with the patient and thus increases the value of his or her support.

#### *Factors originating in the health care professional*

As professionals in any health-care discipline we are subject to several sources of pressure that add to the discomfort caused by talking about dying. Some of these factors arise simply because we are human beings (albeit professionals whose behaviour has been ostensibly modified by training) and are in the presence of another person, the patient, who is in distress. Other factors arise from, or

**Table 1** Common fears about dying

Fears about physical illness e.g. physical symptoms (such as pain, nausea), disability (paralysis, loss of mobility)
Fears about psychological effects e.g. not coping, 'breakdown', losing mind/dementia
Fears about dying e.g. existential fears, religious concerns
Fears about treatment e.g. fear of side-effects (baldness, pain), fears of surgery (pain, mutilation), fears about altered body image (surgery, colostomy, mastectomy)
Fears about family and friends e.g. loss of sexual attraction or sexual function, being a burden, loss of family role
Fears about finances, social status and job e.g. loss of job (breadwinner), possible loss of medical insurance with job, expenses of treatment, being 'out of the mainstream'

are amplified by, the same professional training that purports to prepare us for the death of our patients, but which usually has not. The following is a brief survey of the factors operating on the health-care professional (fuller discussions have been published elsewhere).<sup>19,22</sup>

#### Sympathetic pain

We are likely to experience considerable discomfort simply by being in the same room as a person who is going through the distress of facing death. This sympathetic pain may seem so patently obvious that it does not need to be stated, but it is often the case that professionals feel distressed by a painful interview and markedly underestimate the intensity of feeling that has originated from the patient. Commonly, and particularly with trainees and junior staff, a consideration of the intensity of the patient's distress leads to the realization that this was indeed the major source of the professional's stress. Until this is openly acknowledged, the professional may feel personally inadequate or guilty—another factor blocking good communication.

#### Fear of being blamed

As professionals we have a fear of being blamed that is partly justified. There are two main components of this fear.

First, if we are bearing bad news we are likely to be blamed for the news itself ('blaming the messenger for the message'). This is probably a basic human reaction to bad news and one with which we are all familiar in daily life (for instance, blaming a traffic-warden for writing out a parking ticket). We, thus, justifiably expect it when it is our role to bring bad news. Furthermore, many of the trappings of our profession (such as uniforms, jargon, ward rounds) help support the concept that we are in control of the situation. This may be valuable when the patient's condition is improving, but the same trappings increase the likelihood that we will become targets for blame when the patient's clinical condition begins to deteriorate.

Second, there is the concept imbued into us during our training that when a patient deteriorates or dies there must be somebody at fault. This attitude is strongly reinforced by medicolegal practice in which monetary sums are attached to deteriorations in health. For physicians, training in medical school inadvertently reinforces this feeling. Medical school education prepares doctors (appropriately) to deal with the myriad of reversible or treatable conditions (whether they are common or rare). However, there is usually little or no teaching on the subject of what to do when the disease cannot be reversed (hence, the need for this textbook). Most medical schools do not teach palliative medicine in the undergraduate curriculum and as a result most medical students evolve into physicians who are keen to treat the curable conditions and who have little training in what to do with chronic, irreversible diseases. This omission makes it even more difficult for the physician to deal with his or her own sense of therapeutic failure when communicating with the dying patient.<sup>23</sup>

#### Fear of the untaught

We also fear talking to a dying patient if we do not know how to do it properly. In all professional training, trainees are rewarded for doing a particular task 'properly'. In essence this means 'by following conventional procedures' and avoiding deviations from standard practice. While this is the accepted and justifiable norm for any procedure for which there are established guidelines, if it happens that there are no guidelines—as is the case with communicating with the dying—then the professional will naturally feel ill at ease and will show a tendency to avoid the area entirely.<sup>24</sup>

#### Fear of eliciting a reaction

In the same way in which, as professionals, we dislike doing tasks for which we have not been trained, we also avoid the side-effects or reactions caused by any intervention unless we have been taught how to cope with them.<sup>25</sup> It is an axiom of medical practice that we 'don't do anything unless you know what to do if it goes wrong'. If there has been no effective training in this form of interview,<sup>26</sup> there will also have been no training in dealing with complications or side-effects of these interviews (such as the patient becoming angry or bursting into tears). Not knowing how to cope with these reactions to the interview will further increase the aversion of an untrained person to communicating with a dying patient.<sup>27</sup>

Furthermore, interviews in which patients show emotional reactions may earn discouraging responses from other professionals. Although it is now less common than a few years ago, there are still senior physicians and senior nurses who think it is a bad thing to 'get the patient all upset'. It should be an obvious fact (but it is often ignored) that if you have had an interview about a patient's grave prognosis and if the patient, for example, bursts into tears, it is not the interview that has caused the tears but the medical situation.

#### Fear of saying 'I don't know'

No matter what discipline we are trained in, health-care professionals are never rewarded for saying 'I don't know'. In all training, and particularly in examinations, we expect our standing to be diminished if we confess that we do not know all the answers. In everyday clinical practice, by contrast, any honesty shown by the professional strengthens the relationship, increases trust, and encourages honesty from the patient in return. Conversely, attempts to 'flannel' or 'snow' the patient, or attempts to disguise ignorance or to pretend

greater knowledge or experience weaken the bond between the patient and the doctor or nurse and discourage honest dialogue. Thus, our fears of displaying our ignorance—appropriate in examinations but not in clinical practice—make communication increasingly difficult when the answers are unknown and, often, unknowable.

#### Fear of expressing emotions

We are also encouraged and trained to hide and suppress our own emotions (more true of medical students than of nursing students or trainees in other disciplines). It is, of course, essential for truly professional behaviour that we do not show such emotions as irritation or panic (or that we try not to show them). However, while we are being trained not to show panic or rage, inadvertently we are being encouraged to envisage the ideal doctor as one who never shows any emotions and is consistently calm and brave. While that is not necessarily a bad paradigm for a doctor dealing with emergencies or reversible crises, it is unhelpful in the palliative care setting. When a patient is facing death, a professional who expresses no emotions is likely to be perceived as cold or insensitive.

#### Ambiguity of the phrase 'I'm sorry'

Even if we want to show some human sympathy, the moment we begin there are some linguistic problems that threaten to create further difficulties. Most of us do not realize that the word 'sorry' has two quite distinct meanings. It can be a form of sympathy ('I am sorry for you') and can also be a form of apology accepting responsibility for an action ('I am sorry that I did this'). Unfortunately both are customarily abbreviated to 'I am sorry'. This reflex abbreviation can commonly lead to misunderstanding, for example:

A. . . . and then my mother was brought into hospital.

B. Oh, I am sorry.

A. You've got nothing to be sorry for.

The first speaker is so used to hearing the word 'sorry' as an apology, that she or he responds with a reflex reply to an apology before realizing that it was not an apology that was being offered, but an expression of sympathy. This has relevance to all of us as professionals. Not only is it difficult for us to overcome some of our trained responses in order to express our own emotions of sympathy and empathy, but the moment we try to do so, we fall foul of a linguistic slip and appear to be accepting responsibility (with the associated medicolegal implications) instead of offering support. (The solution to this ambiguity lies in paying careful attention to your own speech patterns: make sure that if you want to say 'I am sorry' you use the specific words 'I am sorry for you'.)

#### Own fears of illness/death

Most of us have some degree of fear about our own deaths—perhaps more so than the general population.<sup>28</sup> In fact, some psychologists would suggest that the desire to deny one's own mortality and vulnerability to illness is a component of every health-care professional's desire to be a doctor or nurse. This is sometimes called counter-phobic behaviour, and means in real terms that each time we go into an encounter with a sick person and emerge from the encounter unharmed we are reinforcing our own illusions of immortality and invulnerability. If this is indeed a

major constituent of the desire to be a health-care professional, then it might lead to avoidance of those situations in which those illusions are challenged.<sup>29</sup> Hence the professional's own fear of dying will lead to avoidance or block of any communication with the dying patient.

#### Fear of the medical hierarchy

Finally, there is the discomfiting fact that not all professionals think of these issues as important, perhaps because of their own fears of illness and death, or fears of the untaught and so on. A junior member of a medical team may, thus, be under pressure from a senior staff member when trying to hold conversations with patients about dying. In more old-fashioned hierarchical systems (in the United Kingdom in the 1960s for instance) it was quite possible for a senior physician to state 'no patient of mine is ever to be told that they have cancer'. Nowadays that stance is less tenable for ethical and legal reasons, but there are still occasional instances of this attitude which then make it difficult to respond to the patient's desire for information and support. (Fortunately, this problem has a solution since in any circumstances, however adverse, the health-care professional can always perform advocacy and transmit the patient's questions and reactions and knowledge or suspicions upwards to the senior person concerned.)

## The stages of dying—a new conceptual framework

### *An appraisal of the five-stage model of the process of dying*

The Kubler-Ross staging system of dying—which divides the process of dying into five consecutive stages termed denial, anger, bargaining, depression, and acceptance—has achieved considerable professional and public attention and is widely thought to be the only appropriate model of dying.<sup>30</sup> Within the community of palliative care practitioners, however, this staging system is often regarded as a model with many flaws and deficiencies,<sup>31</sup> requiring some modification, and alternatives have been put forward (for an overview see Rando<sup>32</sup>). Without demeaning the considerable achievement of Kubler-Ross in devising the system, and in considering the process of dying as a transition in the first place, it does seem that an alternative framework can be put forward which more accurately reflects the dying patient's progress and which will allow the professional greater power of analysis and prediction.

The major flaws in the Kubler-Ross five-stage system can be considered under two headings—first, deficiencies in the overall concept itself, and second, several reactions to dying which are seen commonly in clinical practice but are not included in the five-stage schema.

#### Some deficiencies of the five-stage system

In the very concept of stages numbered 'first' through to 'fifth' (even with the caveat that patients do not behave in sequence and may dart back and forth) there is a central flaw. It seems closer to reality to conceive human emotions not as serial and universal, but as idiosyncratic (characteristic of the individual) and simultaneous. When confronted with any serious threat, particularly the prospect of dying, each individual exhibits reactions that are characteristic of that person and of the way in which that person has reacted to

difficulties in the past, not of the stage in the process or the diagnosis.

We all develop our own in-built repertoire of emotions as we grow up (subject presumably to our experiences in childhood and other factors). Thus, some individuals are easily roused to anger and others are not. Some greet every reverse or trouble by turning their backs and shutting it out—others face it directly and wish to know the worst possible outcome as early as they can. Each of us, therefore, carries with us our personal internal palette of emotions from which we pick our own emotional reactions. These are not in fact stages of a universal process but are the essential components of the emotional side of that person's character. It is more useful, then, to view the emotions or responses exhibited by the patient facing death as sources of insight into that individual and not indicators of the stage that he or she is passing through.

Further, those emotions are usually exhibited simultaneously, not serially. A common example of simultaneous responses to stress is what happens when a parent loses a child temporarily in a supermarket and then finds the child again. At the moment of reunion, the parent experiences relief, guilt, happiness, anger (at both child and self), fear (at what might have happened), and regret. These emotions, some of which are conflicting, occur simultaneously and are not consecutive stages. This is a useful analogy to what happens to a person facing the prospect of dying. Denial and anger, for example, are often experienced at the same time. A patient may easily be angry with the disease but may express the anger as resentment at the doctor while simultaneously exhibiting denial (in, for instance, accusing the doctor of making a mistake in the diagnosis). Intellectually, these emotions are incompatible (how can one be angry at something whose very existence is being denied?) but in the reality of human emotions they frequently coexist.

It is, therefore, more useful to view the patient's emotions as a mosaic, comprising different personal emotions often expressed simultaneously, but in a pattern that is a feature of that individual. By contrast, in the Kubler-Ross staging system, the patient is seen as a chameleon, changing from one emotion to another as he or she progresses through the stages (albeit with the caveats stated in the original work about the sequence and inconsistency of individual patients' reactions).

Thus the first, second, and fourth stages of dying (denial, anger, and depression) can be more usefully considered as reactions to dying experienced by some patients, but not all, and which are exhibited (in those patients who experience them) not serially but simultaneously. It is also likely that the third stage in the five-stage system (bargaining) is a false entity. Bargaining is more usefully viewed as an attempt by the patient to construct a rational link between a hope and a fear. ('I hope that my disease will respond to chemotherapy, I fear that it will not respond—therefore if I promise to perform actions X and Y, perhaps what I hope for will occur.') Bargaining is more usefully considered, then, as an individual strategy for coping and not as a universal or even common stage in the dying process.

#### Emotions and responses missing from the five-stage system

While there are paradigmatic problems with the five stages of the Kubler-Ross system there are also several responses to dying which

are seen commonly in palliative care practice and which the system does not include. The most obvious omission is fear. Fear of dying is so universal<sup>20</sup> that if a particular patient does not exhibit it, the professional's first thought should be 'has this patient understood the situation?'. There are the rare individuals who are so comfortable and well-balanced in their lives that they can face the end of life with perfect equanimity and without any fear at any stage of the process. Such instances are extremely uncommon and any attempt to describe the process of dying should include some mention of fear within the model.

Second, there is guilt which is seen commonly, and is quite often expressed with great force and with considerable influence on the patient's state. Guilt is not universal, but it is undoubtedly common enough to be accommodated in any practical framework that relates to the clinical picture.

Third, it is a common occurrence in palliative care that a patient experiences hope and despair as alternating emotions, replacing each other on a cyclical basis. It is as if hope and despair were mutually exclusive emotional reactions to the same data. Thus, if a patient's condition has a 40 per cent chance of responding to therapy, on one day the patient might hope and feel that she or he is in that fortunate 40 per cent and will improve. The following day, the same patient may feel that she or he is in the unlucky 60 per cent. The facts have not changed, but the patient's emotional response to those facts has altered. Unless one sees hope and despair as mutually displacing emotional reactions, there will be great difficulty in tracking the patient's progress.

Another response that is seen very commonly but which is missing from the five-stage system is humour. Humour is commonly used by some patients to maintain a sense of perspective in the face of potentially overwhelming news. It is an individual coping strategy that, like denial defends the ego and reinforces the central personality of the patient when external forces threaten it. Humour during grave illness is usually only used by those who have habitually used it as a coping strategy in their past, but it is certainly important enough to warrant consideration in any conceptual system of the dying process.

#### *A three-stage model of the process of dying*

A better approximation of common clinical experience can be obtained with a different staging system. The three-stage system (detailed at greater length elsewhere<sup>22,33</sup>) is based on two central principles.

1. Patients facing death exhibit a mixture of reactions and response which are characteristic of the patient, not of the diagnosis or the stage of the dying process.
2. Progress through the dying process is marked, not by a change in the type or nature of emotions, but by resolution of the resolvable elements of those emotions.

The system proposed here divides the process of dying into three stages—the initial stage, the chronic stage, and the final stage.

The initial stage is defined as starting when the patient first faces the possibility of dying from his or her disease, not as an abstract concept but as a concrete reality. At that stage, popularly termed 'facing the threat', the patient may show a combination of

**Table 2** The three-stage model of the dying process

Initial stage (‘facing the threat’)	Chronic stage (‘being ill’)	Final stage (‘acceptance’)
A mixture of reactions which are characteristic of the individual and which may include any, or all, of:  Fear Anxiety Shock Disbelief Anger Denial Guilt Humour Hope/despair Bargaining	1. Resolution of those elements of the initial response which are resolvable 2. Diminution of intensity of all emotions (‘monochrome state’) 3. Depression is very common	1. Defined by the patient’s acceptance of death 2. Not an essential state provided that the patient is not distressed, is communicating normally, and is making decisions normally

emotional responses which represents that person’s individual recipe of coping strategies and reactions. For instance, individuals who have met every stress with anger will exhibit anger now and patients who have always used denial will use denial at this stage. That mixture may be selected from any of the emotions listed in Table 2.

The middle or chronic stage (‘being ill’) follows the initial stage as the patient resolves those elements of the initial reactions that are resolvable (with or without assistance). It is the process of resolution that identifies the second stage, not a change in the emotions themselves. A few patients do not achieve any resolution of their emotions and remain with unmodified reactions until the end of their lives. In such patients, the chronic stage does not exist and the total absence of any form of resolution should prompt the professional to seek help for that patient. For the patients that do achieve some resolution, the intensity of their emotional responses diminishes but the nature of those feelings usually does not. This phase is, therefore, marked by the beginnings of what will later develop, in many patients, into acceptance.

An important characteristic of the second stage is depression. Often the patient may be functioning with high emotional intensity in the first stage and may be surrounded by friends and relatives who have equally intense responses (both helpful and unhelpful). As the dying process continues and as the most intense emotions diminish, the patient and family often experience an almost anticlimactic sense of depression. This was most perceptively identified by one patient ‘as if my life was now being photographed in monochrome’. At this time, the patient is aware that he or she is going to die from this disease, but that death is not imminent. The patient is likely to become withdrawn and may appear apathetic and depressed. It is during this period that the patient may require more support from the professional (as well as from relatives and friends).

The third stage is defined (as in the five-stage system) by acceptance. It should be noted that many practitioners in palliative care believe that acceptance is helpful but not an absolute necessity.<sup>34</sup> A few patients die without ever overtly acknowledging the imminence of their death, and if they are not distressed by this, if they are communicating normally with friends and family, and are

able to function and to make decisions normally (for example concerning their treatment or social arrangements) then there seems to be no rationale for intervening and forcing acceptance on them.

#### The potential value of this model

It is, of course, impossible to prove definitively that the system set out here is a closer approximation to the dying process or is a more useful framework than the five-stage system. There are no objective data available to support either and it is virtually impossible to envisage any studies that could achieve this. The only criterion by which a staging system can be assessed is its pragmatic utility. If the three-stage system helps the professional to understand what she or he is hearing from the patient, to respond with greater sensitivity, to provide more effective support, and to predict what is most likely to occur next, then it will have proved its worth.

## A practical guide to communication in palliative care

This section will provide a series of practical steps that can be taken by any health care professional to make her or his communication more effective. First there is a summary of general listening skills which are essential for all professional–patient interviews, not just those in palliative care. Next, the two most common tasks of palliative care—breaking bad news and therapeutic (or supportive) dialogue—are discussed. The criteria by which the patient’s response can be assessed, together with some suggestions for resolving conflict are considered. Finally some guidelines for improving communication between health-care professionals and family, and between different health care disciplines are offered.

### *Basic listening skills for palliative care*

All medical interviews, and particularly those with a dying patient, contain the potential for going wrong. Often the seeds of failure are sown in the first few minutes. Even though readers of this textbook may already be familiar with the rules of effective listening it is worth stressing them again since under the pressure of a difficult

interview it is often the simplest omissions that cause the biggest problems.<sup>35</sup> Furthermore, patients are more likely to disclose their understanding of their medical situation to those staff who demonstrate that they are prepared to listen and discuss.<sup>36</sup>

The basic listening skills that are most crucial in palliative care may be considered under the headings of physical context, facilitation techniques, and the empathic response. (For a general review of interviewing skills see Lipkin *et al.*<sup>37</sup>)

### Physical context

The physical context of an interview sends important signals to the patient even before verbal communication begins.<sup>38</sup> It is, therefore, extremely important to observe with particular care the usual rules of good interviewing. A few seconds spent establishing the physical context may save many minutes of frustration (for both the professional and the patient). The rules are not complex but are often omitted in the heat of the moment.<sup>39</sup> Although privacy is difficult to obtain in institutions, consider the patient's dignity and ensure that trenchant conversations of great import are carried out in a private setting if at all possible.

### Introductions

Ensure that the patient knows who you are and what you do. Many practitioners, including the author, make a point of shaking the patient's hand but this is a matter of personal preference. Often the handshake tells you something about the family dynamics as well as about the patient. Frequently the patient's spouse will also extend his (or her) hand. It is worthwhile making sure that you shake the patient's hand before that of the spouse (even if the spouse is nearer) in order to demonstrate that the patient comes first, and the spouse (although an important member of the team) comes second.

### Sit down

This is an almost inviolable rule. It is virtually impossible to assure a patient that she or he has your undivided attention and that you intend to listen seriously if you remain standing up. Only if it is absolutely impossible to sit should you try and hold a medical interview while standing. Occasionally, in hospitals or hospices, the only available seat is a commode. If so, it is worth asking permission to sit and then saying that you are aware of what you are sitting on to reduce embarrassment. Whatever you sit on, the result will be better than if you remain standing.

Clinical impressions (B. Mount, personal communication) suggest that when the doctor sits down, the patient perceives the period of time spent at the bedside as longer than if the doctor remains standing. Thus, not only does the act of sitting down indicate to the patient that he or she has control and that you are there to listen, but it also saves time and increases efficiency.

Next, get the patient organized if necessary. If you have just finished examining the patient, allow or help him or her to dress and to restore the sense of personal modesty.

Then, get any physical objects out of the way. Move any bedside tables, trays, or other impedimenta out of the line between you and the patient. Ask for any televisions or radios to be turned off for a few minutes. If you are in an office or room, move your chair so that you are adjacent to the patient not across the desk. If you find the action embarrassing, state what you are doing ('It may be easier for us to talk if I move the table/if you turn the television off for a moment').

### Your body language

It is important to be seated at a comfortable distance from the patient. This distance (sometimes called the 'body buffer zone') seems to vary from culture to culture, but a distance of 50 to 90 cm will usually serve the purpose for intimate and personal conversation.<sup>40</sup> This is another reason why the doctor who remains standing at the end of the bed ('six feet away and three feet up' known colloquially as 'the British position') seems remote and aloof.

The height at which you sit can also be important; normally your eyes should be approximately level with the patient's. If the patient is already upset or angry, a useful technique is to sit so that you are below the patient, with your eyes at a lower level. This often decreases the anger. It is best to try and look relaxed, particularly if that is not the way you feel. To achieve an air of relaxation, sit down comfortably with both your feet flat on the floor. Let your shoulders relax and drop. Undo your coat or jacket if you are wearing one, and rest your hands on your knees.

### Touching the patient

Most of us have not been taught specific details of clinical touch at any time in our training.<sup>41</sup> We are, therefore, likely to be ill at ease with touching as an interview technique until we have had some practice. Nevertheless there is considerable evidence (although the data are somewhat 'soft') that touching the patient (particularly above the patient's waist to avoid misinterpretation) is of benefit during a medical interview, even though patients may not expect to be touched the first time that they meet the physician.<sup>42</sup> It seems likely that touching is a significant action in the context of palliative care and should be encouraged, with the proviso that the professional should be very sensitive to the patient's reaction. If the patient is comforted by the contact, continue: if the patient is uncomfortable, stop. Touch can be misinterpreted (as lasciviousness, aggression, or dominance for example) so be aware that touching is an interviewing skill that requires extra self-regulation.

### Facilitation techniques

As dialogue begins, the professional should show that she or he is in 'listening mode'. This is the fundamental interviewing skill known as facilitating. The most important guidelines to good facilitation are listed below.

### Let the patient speak

If the patient is speaking, don't talk over him or her. Wait for the patient to stop speaking before you start your next sentence. This, the simplest rule of all, is that most often ignored, and is most likely to give the patient the impression that the doctor is not listening.<sup>43</sup>

### Encourage the patient to talk

You can use any or all of the following gestures: nodding, pauses, smiling, saying 'Yes', 'Mmm hmm', 'Tell me more', or anything similar. Maintain eye contact for most of the time while the patient is talking (sometimes if things are very intense it may be helpful to the patient for you to look away briefly).

### Tolerate short silences

Silences are important and revealing.<sup>44</sup> Usually, a patient will fall silent when he or she has feelings that are too intense to express in words. A silence, therefore, means that the patient is thinking or feeling something important, not that he or she has stopped

thinking. If you can tolerate a pause or silence, the patient may well express the thought in words a moment later. If you have to break the silence, the ideal way to do so is to say 'What were you thinking about just then?' or 'What is it that's making you pause?', or something to that effect.<sup>45</sup>

Having encouraged the patient to speak, it is necessary to prove that you are hearing what is being said. The following techniques enhance your ability to demonstrate this.

#### *Repetition and reiteration*

Repetition is probably the single most important technique of all interviewing skills (apart from sitting down). To show that you are really hearing what the patient is saying, use one or two key words from the patient's last sentence in your own first one. Reiteration means repeating what the patient has told you but in your words, not hers or his. If the patient says 'Since I started those new tablets, I've been feeling sleepy' a response such as 'You seem to be getting some drowsiness from the tablets' is reiterative (using the word 'drowsiness' where the patient said 'sleepy') and confirms to the patient that she or he has been heard.

#### *Reflection*

Reflection, the restating of the patient's statement in terms of what it means to the listener, takes the act of listening one step further, and shows that you have heard and have interpreted what the patient said. (For example 'If I understand you correctly, you're telling me that you lose control of your waking and sleeping when you're on these tablets . . .'.)

#### *The empathic response*

The empathic response is an extremely useful technique in an emotionally-charged interview, and yet is frequently misunderstood by students and trainees. There are three essential components of the empathic response.

- (a) identifying the emotion that the patient is experiencing;
- (b) identifying the origin and root cause of that emotion;
- (c) responding in a way that tells the patient that you have made the connection between (a) and (b).

Often the most effective empathic responses follow the format of 'You seem to be . . .' or 'It must be . . .'; for example 'It must be very distressing for you to know that all that therapy didn't give you a long remission'. The objective of the empathic response is to demonstrate that you have identified and acknowledged the emotion that the patient is experiencing, and by doing so you are giving it legitimacy as an item on the patient's agenda. In fact, if the patient is experiencing a strong emotion (rage or crying, for example) you must acknowledge the existence of that emotion or all further attempts at communication will fail. If strong emotions are not acknowledged in some way, you will be perceived as insensitive and this will render the rest of the interaction useless.

In making an empathic response, however, you do not necessarily have to feel the emotion yourself—you do not have to 'cry and bleed for every patient'. In fact, if you experience the same emotion as the patient, your feelings are termed sympathetic rather than empathic (see under sympathetic pain above). It is therefore possible to formulate an empathic response for all your patients, provided that you identify and acknowledge the feelings that they are describing.

**Table 3** Six-step protocol for breaking bad news

1. Getting the physical context right
2. Finding out how much the patient knows
3. Finding out how much the patient wants to know
4. Sharing information (aligning and educating)
5. Responding to the patient's feelings
6. Planning and following through

## Two specific tasks of communication in palliative care

Communication in palliative care is important from the moment that the patient first meets a palliative care professional until the last moment of life. Most significant conversations in palliative care comprise two major elements: one in which medical information is transmitted to the patient ('bearing the news'), and the other in which the dialogue centres around the patient's feelings and emotions and in which the dialogue itself is a therapeutic action ('therapeutic or supportive dialogue'). In practice most conversations are a mixture of the two, although commonly there is more medical information transmitted in the early conversations shortly after starting palliative care, and there is usually a greater need for therapeutic dialogue in the later stages.

For the purposes of clarity, the two components will be considered separately.

### *Breaking bad news*

In palliative care, there are many occasions when new medical information needs to be discussed. This is almost universal when the patient is first assessed in palliative care, and is quite common later on. Hence it is essential to have a logical and systematic approach to the sharing of medical information.<sup>46</sup> The following protocol has been detailed at greater length elsewhere.<sup>22</sup> In practice, it has been found to be useful in all interviews concerning bad news, whether the patient and the professional know each other well or not. However, formal studies of this protocol (or any other) have not been carried out, and even the design of such investigations pose major difficulties.<sup>47</sup> It consists of six steps or phases, which are summarized in Table 3.

#### *Physical context*

The physical context of the interview has already been reviewed. It is of even greater importance for the interview in which bad news is shared than for any other.

#### *Finding out how much the patient knows or suspects*

It is always important to obtain directly from the patient an impression of what he or she already knows about the seriousness of the medical condition and about its effect on the future before providing further information. In fact, sharing information may be awkward, superfluous, or even impossible without first knowing what the patient already knows.<sup>48</sup> In all cases, you should be trying to establish what the patient knows about the impact of the illness on his or her future, not about the fine details of basic pathology or nomenclature of the diagnosis. There are many ways in which this



information can be gathered. Some of the phrases that may be useful include:

'What have you made of the illness so far?'

'What did the previous doctors tell you about the illness/operation etc?'

'Have you been worried about yourself?'

'When you first had symptom X, what did you think it might be?'

'What did Dr X tell you when he sent you here?'

'Did you think something serious was going on when . . .?'

As the patient replies, analyse the response. Important information can be obtained from three major features of the reply.

#### *The factual content of the patient's statements*

It must be established how much the patient has understood, and how close to the medical reality is the impression. Some patients may at this point say that they have been told nothing at all. This may or may not be true, but even if you know it to be false, accept the patient's statement as a symptom of denial and do not confront it immediately. First, the patient may be about to request information from you, and may, in part deliberately, deny previous information to see if you tell the same story. Second, if the patient has previously been given information, you are unlikely to appear supportive to a patient in denial by immediate confrontation.

In fact, a patient denying previous information quite often precipitates anger or resentment on the professional's part ('My goodness, doesn't Dr Smythe tell his patients what he found at the operation!'). If you find yourself feeling this, pause and think. You may be seeing a patient in denial and this may be causing you to suffer from the professional syndrome known as the 'nobody-ever-tells-their-patients-anything-until-I-do' syndrome. It is very common when patients are sick and the emotional atmosphere is highly charged.

#### *The style of the patient's statements*

Much can be gleaned from the patient's emotional state, educational level, and articulatory ability by the manner in which she or he is speaking. Listen to the vocabulary, the kind of words being said, and the kind of words being avoided. Note the style so that when you come to speak, you can start at the right level.

You should, however, ignore the patient's profession in making this assessment, particularly if he or she happens to be a member of a health-care profession. Far too often you will find yourself making assumptions. Even physicians when they are patients may not be experts in their own disease and may not understand something like 'It's only a Stage II but I don't like the mitotic index' when they hear it as a patient.

#### *Emotional content of the patient's statements*

There are two major sources of these—verbal and non-verbal. Both may yield information about the patient's state, and discordance between the two (for instance, apparent calm in the speech, but major anxiety in the body language) may give valuable signals regarding state and motivation.

#### Finding out how much the patient wants to know

This is the single most crucial step in any information-giving discussion. It is far easier to proceed with giving the news if there is a clear invitation from the patient to do so. Conversely, although it is universally acknowledged that in contemporary society patients have a right to truth and information,<sup>49,50</sup> it is often impossible to predict which patients will not want to hear the truth<sup>51</sup> (for fuller reviews see Billings and Reiser<sup>52,53</sup>). The exact proportion of patients who do want full disclosure varies from study to study, but current figures range from 50 to 98.5 per cent depending on patient demographics and the diagnosis suspected<sup>51,54-57</sup> (for a detailed review see McIntosh<sup>58</sup>). Since no characteristics predict whether a patient desires disclosure,<sup>54</sup> it seems logical simply to ask him or her.<sup>59</sup> The way in which this important and sensitive question is phrased is largely a matter of personal style. Some examples are given below.

Are you the kind of person who likes to know exactly what's going on?

Would you like me to tell you the full details of the diagnosis?

Are you the kind of person who likes the full details of what's wrong—or would you prefer just to hear about the treatment plan?

Do you like to know exactly what's going on or would you prefer me to give you the outline only?

Would you like me to tell you the full details of your condition—or is there somebody else that you'd like me to talk to?

Note that in all of these, if the patient does not want to hear about the full details you have not cut off all lines of communication. You are saying overtly that you will maintain contact and communication (for example about the treatment plan) but not about the details of the disease. If the patient does not want to hear the information, you should add that if, at any time in the future, the patient changes her or his mind and wants further information, you will provide it. The phrase '. . . the sort of person who' is particularly valuable because it suggests to the patient that there are many patients like him or her, and that if he or she prefers not to discuss the information, this is neither unique, nor a sign of extraordinary feebleness or lack of courage.

#### Sharing medical information

The process by which medical information is transmitted can be thought of as consisting of two crucial steps.

##### *Aligning*

At this point in the interview, you have already heard how much the patient knows about the situation, and something of the vocabulary used to express it. This is the starting point for sharing the information. Reinforce those parts which are correct (using the patient's words if possible) and proceed from there. It gives the patient a great deal of confidence in himself or herself (as well as in you) to realize that his or her view of the situation has been listened to and is being taken seriously (even if it is being modified or corrected).

This process has been called 'aligning',<sup>46,60</sup> a useful term to describe the process by which you line up the information you wish to impart on the baseline of the patient's current knowledge. (Maynard uses the word 'aligning' to describe one particular style

of doctor-patient communication.<sup>60</sup> The meaning has been extended in this schema to describe the first part of the information-sharing process.)

### *Educating*

In the next phase of the interview, having started from the patient's starting point (i.e. having aligned your information on the patient's original position) you now have to bring his or her perception of the situation closer to the medical facts as you know them.

There is no word in current usage that fully describes this part of the interview, but perhaps 'educating' is the closest. The process of sharing information should be a gradual one in which the patient's perception is steadily shifted until it is in close approximation to the medical reality. This part of the interview can usefully be compared to steering an oil tanker. You cannot make sudden lurches and expect the patient's perception to change instantly. You have to apply a slow and steady guidance over the direction of the interview, observing the responses as you do so. In the process, you build upon those responses from the patient that are bringing him or her closer to the facts, and emphasize the relevant medical information if it becomes apparent that the patient is moving away from an accurate perception of the situation. The key ingredients are steady observation and continued gentle guidance of the direction of the interview rather than sudden lurches.

### *Give information in small amounts: the warning shot*

Medical information is hard for patients to digest and more so if it concerns a grave prognosis or threat of death. Recall of information is poor at the best of times and likely to be very poor if medical facts are grim ('The moment you said 'cancer', doctor, . . . I couldn't remember a thing from that moment on . . .'). The rule is, therefore, give the information in small amounts.

One of the most useful principles is the idea of 'the warning shot'. If there is clearly a large gap between the patient's expectations and the reality of the situation, you can facilitate understanding by giving a warning that things are more serious than they appear ('well, the situation was more serious than that . . .') and then grading the information, gradually introducing the more serious prognostic points, waiting for the patient to respond at each stage.<sup>61,62</sup>

### *Use English*

Technical jargon ('medspeak') is an efficient language for transmitting codified information in a short time. Since it takes many years to learn, it is also comforting to the professional. However, the patients have not learned to speak it and cannot express their emotions in it; hence it reinforces the barrier between patient and professional, and is most likely to make the former feel angry, belittled, and isolated. We should avoid jargon if we are trying to support the patient at a difficult time.

### *Check reception frequently*

Check that your message is being received—and check frequently.<sup>63</sup> You can use any phrase that feels comfortable—anything to break the monologue. Examples are:

Am I making sense?

Do you follow what I'm saying?

Does this all seem sensible to you?

This must be a bit bewildering, but do you follow roughly what I'm saying?

Do you see what I mean?

These interjections serve several important functions: (a) they demonstrate that it matters to you if the patient doesn't understand what you are saying; (b) they allow the patient to speak (many patients feel so bewildered or shocked that their voices seem to seize up, and they need encouragement and prompting to speak); (c) they allow the patient to feel an element of control over the interview; (d) they validate the patient's feelings and make them legitimate subjects for discussion between you.

You should also check that you are transmitting the information at the same intellectual level as the patient is receiving it, by ensuring that your vocabulary and that of the patient are similar.

### *Reinforce the information frequently*

There are several ways in which you can reinforce what you are telling the patient.

1. Get the patient to repeat the general drift of what you have been saying.
2. Repeat important points yourself: because it is difficult to retain information, particularly if the news is serious, and even more so if denial is operating, you may have to repeat crucial points several times. Accept this as a fact of life when looking after seriously ill patients (you can cover this with a phrase such as 'I know it's difficult to remember all this stuff at one go . . .').
3. Use diagrams and written messages. A few simple scribbles on the back of an envelope or a scrap of paper may serve as a useful *aide-memoire*.

### *Blend your agenda with that of the patient*

While transmitting information to the patient, it is important to elicit his or her agenda or 'shopping list' of concerns and anxieties, so that further information can be tailored to answer major problems. The following are useful guidelines.

**Elicit the 'shopping list'** Quite often the patient's major concerns are not the same as those of the professional. For instance, patients may be more worried about severe pain or loss of mental functioning, than about the primary disease itself (see above). You do not necessarily have to deal with the items at that particular moment, but you should indicate that you understand what the patient is talking about and will return to it in a moment. ('I know you're very worried about drowsiness, and I'll come to that in a moment, but can I first cover the reasons that we recommend increasing the painkillers in the first place?').

**Listen for the buried question** Deep personal worries may not emerge easily. Sometimes the patient asks questions while you are talking. These questions ('buried questions') are often highly significant to the patient. When the patient does this, finish your own sentence and then ask the patient what he or she was saying. Be prepared to follow that train of thought from the patient—it is quite likely to be important.

**Be prepared to be led** Quite often you may draw an interview to a close and then find that the patient wants to start part of it again.

This is not simply contrary behaviour. It often stems from fear and insecurity; by restarting the interview the patient is exerting some measure of control.

### Responding to the patient's feelings

In many respects the patient's reactions to his or her medical condition, and the professional's response to those reactions, define their relationship and determine whether or not it offers support for the patient. Hence, the professional's ability to understand and respond sensitively to the emotions expressed by the patient are central to all communication in palliative care. In essence, this part of the communication becomes therapeutic (or supportive) dialogue.

In the short space of this chapter it is not possible to illustrate the wide range of patients' reactions to dying or to bad news in general. However, a detailed analysis has been published elsewhere,<sup>22</sup> together with several options available to the professional in each situation. The central components of the professional's response are (a) assessment of the response and (b) empathic responses from the professional. For the sake of convenience, these two topics are discussed under the heading of therapeutic dialogue below.

### Organizing and planning

The sixth and final step in the breaking bad news protocol is the stage at which the professional summarizes the situation and makes an operational plan and a contract for the future. This process is of great importance to the patient, and is a process that should conclude every interview with a palliative care patient, not just an interview in which bad news is discussed.

Frequently, after hearing news that is new or distressing, the patient may feel bewildered, dispirited, and disorganized. While the professional should be sensitive to those emotions and be capable of empathy, our responsibilities consist of more than simply reflecting the patient's emotions. The patient is looking to us to make sense of any confusion and to offer plans for the future. At this point in the interview, therefore, it is important to try to put together what is known of the patient's agenda, the medical scenario, the plan of management, and a contract for the future. This process can be logically divided into six tasks.

### Demonstrate an understanding of the patient's problem list

If the interview has been effective so far, this is what you have been achieving since the beginning. From the outset, you have been demonstrating that you have been hearing what bothers the patient most, and a brief 'headline' reference to the major concerns of the patient reinforces the fact that you have been listening.

### Indicate that you can distinguish the 'fixable' from the 'unfixable'

With both medical problems and psychosocial problems, some are 'fixable' and some are not. We shall be discussing this further in relation to the patient's responses in the next section but it is a pragmatic step without which your support will appear to be less effective. If the interview gets stuck or bogged down as the patient explores her or his problems, it is often helpful to try to enumerate the problems as a list, getting the patient to arrange them in order of priority. You can then begin to set your own agenda—stating the problems you are going to try and tackle first. This leads logically to the next step.

### Make a plan or strategy and explain it

When making a plan for the future, it is quite permissible for that plan to include many uncertainties, 'don't knows', and choices ('if the dizziness doesn't get better, then we'll . . .'), acknowledging that uncertainty is often a painful and difficult state to cope with.<sup>64</sup> What you are actually doing is presenting a decision-tree or algorithm. Patients need to know that you have some plan in mind—even if it consists of little more than 'we'll deal with each problem as it arises'—which, at least, implies that you will not abandon the patient. The act of making a plan and explaining it to the patient is part of what the patient sees as support—it defines the immediate future of your relationship with this particular patient and reinforces the individuality of this person and what you are going to do for him or her.

### Identify coping strategies of the patient and reinforce them

There is a lot of emphasis in our training on what we do to patients or for patients. Obviously in acute emergencies the professionals have to do all of the work. However, this attitude of 'we will do it all for you' may influence the professional's approach to all patients in every situation, particularly if the patient is feeling overwhelmed and helpless in the face of bad news. This may be bad for the patient, and also bad for us as we may later become overwhelmed by the sense of our responsibilities. At this point in the interview, then, it is important to look at the resources available to the patient, both internally and externally.<sup>65</sup> We cannot, and should not, live the patient's life for him or her. Hence, as the problem list and the plan begin to take shape the professional should begin helping the patient to evaluate what he or she can do for himself or herself. This part of the process involves helping the patient to identify his or her own coping strategies and is a continuous process, not usually completed in one interview. It also leads logically on to the next component.

### Identify other sources of support for the patient and incorporate them

Not only do we tend to forget that the patient has capabilities of his or her own, we also tend to forget that there is anyone outside the professional-patient relationship who can assist. Most people have at least one or two friends or relatives who are close in some way and can add support. For those patients who have no social supports of their own, it will be necessary to enrol and co-ordinate the other services available.

### Summary and conclusion

The final part of the interview is the summary and contract for the future. The summary—which also requires a great deal of thought—should show the patient that you have been listening and that you have picked up the main concerns and issues. It is not a particularly easy task but you should try to give an overview of the two agendas (yours and the patient's). It need not be a long statement, and often consists of no more than one or two sentences.

Having summarized the main points, you should then ask 'Are there any (other) questions that you'd like to ask me now?'. Sometimes the patient has been bottling up concerns over some issue that simply has not arisen, or one aspect of the treatment or the disease that you have merely touched on. This part is as important as the question period after a lecture—it is the time when any unresolved issues can be discussed.

Finally, you should make a contract for the future. Even though this may be very simple ('I'll see you at the next visit in two weeks' or 'We'll try the new antisickness medicine and I'll see you tomorrow on the ward-round') patients may otherwise be left at the conclusion of the interview with the feeling that there is no future and may be glad to hear that there is one.

### *Therapeutic (or supportive) dialogue*

Many physicians under-rate the value of therapeutic dialogue because it is not included in the curricula of most medical schools, and they are thus unfamiliar with its use. Supportive communication is obviously central to psychiatric and psychotherapeutic practice, but is generally not taught to medical or nursing students outside those disciplines.<sup>66</sup> Hence, it often seems an alien idea that a doctor or nurse can achieve anything by simply listening to the patient and acknowledging the existence of that individual's emotions.

Nevertheless, supportive dialogue, during any stage of palliative care, is an exceptionally valuable resource and may be the most important (and sometimes the only) ingredient in a patient's care. The central principle of effective therapeutic dialogue is that the patient should perceive that his or her emotions have been heard by the professional and acknowledged. It may then become apparent that there are problems that can be solved, emotions that can be resolved, and needs that can be met, but even if there are no solutions, the simple act of supportive dialogue can reduce distress.

For the main objective of acknowledging the patient's emotions, the empathic response is of prime importance, although it cannot be the only component of the professional's side of the dialogue. Obviously a single technique cannot create an entire relationship; nevertheless, many professionals are unfairly perceived as being insensitive or unsupportive, simply because they do not know how to demonstrate their abilities as listeners. The empathic response is one of the most reliable methods of demonstrating effective listening. In addition to responding in this way, the professional should also attempt to assess the nature and value of the patient's responses in coping with the situation, to disentangle the emotions that have been raised by the discussion, and to try to resolve any conflicts that may have arisen.

### *Assessment of the patient's responses*

Even though we have not, in this chapter, detailed all the possible reactions that a patient might experience it is possible to offer some brief guidelines for assessing those emotions, so that the professional may know which emotions are best reinforced and which require intervention. In essence, there are three criteria by which patients' responses may be assessed.

#### *Acceptability*

First, a patient's reactions must meet the broadest definitions of socially acceptable behaviour. These definitions vary from culture to culture (and some of the gravest misunderstandings arise from misinterpretation—behaviour that is normal in one culture being seen as aberrant in another). In the context of palliative care, however, interpretation of 'socially acceptable' should be very wide. The professional should err on the side of generosity and only if extreme behaviour is a genuine danger to the patient, staff, other

**Table 4** Some adaptive and maladaptive responses

Adaptive	Maladaptive
Humour	Guilt
Denial	Pathological denial
Abstract anger	
Anger against disease	Anger against helpers
Crying	Collapse
Fear	Anxiety
Fulfilling an ambition	The impossible 'quest'
Realistic hope	Unrealistic hope
Sexual drive	Despair
Bargaining	Manipulation

patients, or family members should assistance be called in. For all but these very rare cases, you should accept the behaviour even if you do not like it, and assess it on the other two criteria—does it help the patient, and (if it does not) can it be improved by intervention?

### *Distinguishing the adaptive from the maladaptive*

Second, facing the end of life usually induces major stress and distress: an individual's response to that distress may either help the person to reduce it (an adaptive response) or may increase it (a maladaptive response). Frequently, it is difficult to distinguish one from the other at the first interview and it may require several interviews over a longer period to decide whether a patient is adapting to the medical circumstances.

It is not easy to be dogmatic about which responses are always maladaptive but some guidelines are shown in Table 4. There seems to be a consensus opinion that, for example, a feeling of guilt is always maladaptive and cannot help a patient. It may be somewhat more controversial, but still helpful, to regard denial in the early stages as an adaptive response, allowing the patient to adjust to the situation in small 'bites' when otherwise the threat would be overwhelming. It is also important to note that some responses will buy the patient an immediate short-term decrease in distress, but will accumulate trouble later on. For instance, denial that is prolonged and which prevents a patient from making decisions with which he or she is comfortable ('We won't even think about that . . .') may later increase distress. Only the professional's clinical experience and the passage of time can define the situation in some cases.

### *Distinguishing the 'fixable' from the 'unfixable'*

The third criterion by which responses may be assessed is what might be termed 'fixability'. If there is a problem that is increasing the patient's distress or obstructing adaptation, can it be remedied? This is largely a matter of clinical experience, and depends on the professional's confidence and competence in addressing psychosocial problems.<sup>67</sup> Two points, however, are worth stressing. First, the chance of damage is higher when the professional feels that he or she can fix a problem, and then perseveres without seeking help, than when a professional knows his or her own limitations. Second, it is even more important that, if there appears to be a problem that is not 'fixable', a second opinion is sought—preferably from a psychologist or psychiatrist. In problems that appear to the medical

**Table 5** In the event of conflict

1. Try to take a step back
2. Identify your own emotions and try to describe them, not display them
3. Try to define the area of conflict that is unresolved
4. Try to obtain agreement on that area of difference, even if it cannot be resolved
5. Find a colleague and talk about it

team to be 'unfixable', some improvement can be achieved by psychologists in up to two-thirds of cases.<sup>68</sup>

#### Distinguish your emotions from those of the patient

Another task that often has to be undertaken during therapeutic dialogue is the disentangling of the emotions experienced during the interview by both the patient and the professional. We have already seen that strong emotions cannot be ignored without jeopardizing all communication. We should also try to be aware of our own emotions in dealing with an individual person who is dying. We may experience strong emotions because of our own previous experience (counter-transference) or we may be moved, attracted, or irritated and intolerant as a result of the patient's behaviour patterns. In any event, whenever emotions arise it is essential to try to take a step back and ask yourself what you are feeling and where that feeling comes from. If the professional can recognize a strong emotion in himself or herself, the recognition itself partly negates the effect of the emotion on judgement and communication. If the emotion goes unrecognized, it is far more likely to produce damage.

#### Dealing with conflict

We all want to do our best for the patient, but we all have our limits. Sometimes we simply cannot ease a patient's distress, sometimes the patients do not wish to be relieved, and sometimes they appear to have a need for antagonism or conflict in order to give themselves definition or some other gain.

Despite pretences to the contrary, all of us at some time feel exhausted, frustrated, and intolerant. This is unavoidable. There are, however, a few guidelines that may reduce the impact of those feelings in our professional life.<sup>69</sup> The most useful are shown in Table 5.

In summary, the single most useful tool of therapeutic dialogue is the empathic response which indicates to the patient that the emotional content of his or her reaction is being heard and is legitimized. In addition, the professional should attempt to assess the patient's response, disentangle his or her emotions from those of the patient, and try to resolve conflict.

These, then, are some of the most important aspects of communicating with the dying patient. However, there are almost always other parties involved, and in the next section we shall deal with communication issues concerning the family and those that may arise between health-care disciplines.

### Communication with other people

All efforts in palliative care are directed to ameliorating the situation of the patient. However, there are other parties to be

considered who may assist or hinder efforts at effective communication (for a major review of communication issues with cancer patients, their families, and professionals see Northouse and Northouse.<sup>70</sup>). Only a few broad guidelines can be offered in this limited space, but attention to even these simple issues can improve quality of care noticeably.

#### *Communication with friends and family*

The responses of friends and family to the imminent death of the patient may be as varied as those of the patient himself. Similarly, they may assist the patient and be of support, or they may be counter-productive and form part of the patient's problem rather than part of the solution. They may be similar in nature to the patient's responses or they may be qualitatively different. Even when they are the same as those of the patient, they may be asynchronous with the patient's responses; for example the patient may have resolved his or her anger and may have come to accept his or her death, while the family are still angry or in denial. In the same way, therefore, as the patient's responses may be considered adaptive or maladaptive, so the family's responses may also serve to decrease or increase the patient's distress and increase or decrease support.

When a patient's treatment is palliative, some effort should always be made to identify leading members of his or her support systems (friends and family). However, in communicating with the family, there are two principles which may at first seem mutually exclusive.

#### The patient has primacy

A mentally competent patient has the right (ethical and legal) to determine who shall be informed about his or her medical condition. All rights of friends or family are subsidiary to this. If a patient decides not to share information with anyone else, although that may be an aggressive and vengeful action, it cannot be countermanded by the professional at the family's request. Similarly, however well intentioned, a relative stating that 'the patient is not to be told' does not have primacy over the patient's wishes if the patient wishes full disclosure.

#### The family's feelings have validity

Despite the secondary rank of the family's feelings, those feelings have validity and must be acknowledged even if their wishes or instructions cannot be acceded to. Often a family's wishes arise from a desire to show that they are good and caring sons or daughters (rationalizing their own feelings as 'If I cannot stop mother becoming ill, I can at least stop her finding out too much about it.') It is important for the professional to identify the family's emotions and to acknowledge them; for this purpose, the empathic response is of great value.

#### *Communication between physicians*

Doctors are notoriously bad at communicating with each other. We do not do it frequently enough, and more importantly, when we do communicate with each other, we are often disorganized and unfocused in our communication. Perhaps the most dangerous gaps in doctor-doctor communication occur when a patient moves from one care setting to another—for example into a palliative care unit or from a hospital to home.

It is difficult to give useful guidelines about something as ill-defined as interspecialty communication, but perhaps the key principles are that all communication should be task-orientated and should clearly define frontiers of responsibility. This means that communications should be related to those aspects of the patient's situation that may have an impact on the care. Much of what is discussed between doctors is found to be, on analysis, simply opinion or conjecture. Although there is nothing wrong with this in itself, it often gives us the feeling that we have thoroughly discussed the case, when in fact vital management issues have not been discussed at all.

The five-point checklist that follows may be of some value when considering a letter or telephone call to another physician about a palliative care patient.

1. Am I addressing the right person? (For instance, does the patient know the family practitioner well? Have I asked the patient whom he or she wished me to contact?)
2. What do I know about this patient that the other person should know? (and/or what do I want to know from the other person?)
3. What does this mean for the patient's future care?
4. Who is going to do what? Who is now 'the doctor' for this patient?
5. How shall we communicate again if things are not going well?

Even if communications are limited to these five points, they will be more effective than many of the current communications between doctors—not because we are negligent or malevolent, but because we are often too polite and too afraid of stepping on each other's toes in making suggestions for the patient's benefit.

### *Communication between physicians and nurses*

By definition, professionals belong to different teams because they have special expertise and training that identifies them with that discipline. This is essential for good patient care. However, there is a side-effect—namely that we each speak a different language and we all tend to believe that our particular language is the only one truly relevant to the patient's care. As a result, different aspects of the patient's problems are often poorly integrated and there are often large gaps in communication between the teams. The most common gaps—because of the way the jobs inter-relate—occur between doctors and nurses.

One of the greatest paradoxes (and perhaps one of the greatest losses) in the recent evolution of the nursing profession has been the diminishing of the ward-round as the standard method for exchanging information between patient, doctor, and nurse. Although this idea that the ward-round is essential in patient care is a controversial one, it is a view that is now receiving increasing support from all disciplines and from patients and families. The days of the three-hour ward-round during which four patients are reviewed are over—nursing time is at a premium and nursing tasks have increased greatly in number and complexity. However, without the 'trinity' of patient-doctor-nurse present in the same place at the same time, inpatient care is rendered unnecessarily complex

and incomplete. In hospitals or hospices where time is limited, it is often possible to agree on time-limits (for example an average of 10 min per patient can accomplish almost all of the necessary exchanges).

In our own unit, we ensure that the three following points are addressed during the minimum 10-min period allotted to each patient for discussion.

1. The medical game-plan: what is known about the patient's medical status, what measures are planned or being considered. What is the prognosis?
2. Nursing concerns: what are the main difficulties in the day-to-day care of the patient?
3. What does the patient know and what are the patient's major concerns? For instance, does the patient have strong views about the type of therapy or where she or he would like to be looked after?

It is surprising how efficient communication can be if all concerned are aware that time is limited and that these three main areas must be covered in the discussion.

### **Conclusion**

In palliative care, everything starts with the patient—including every aspect of symptom relief and every aspect of communication. There is no doubt that we all want to do our best, but often the major challenges in palliative care arise because we do not know how to approach the problem. Nowhere is this more true than in communication—a professional who feels ill-equipped and inept at communication will become part of the problem instead of part of the solution. The act of following relatively straightforward guidelines, however simplistic they may appear, will at least give us a feeling of competence and enhance our ability to learn as we practise.

An expert in palliative care is not a person who gets it right all the time: an expert is someone who gets it wrong less often—and is better at concealing or coping with his or her fluster and embarrassment. We are, after all, only human beings.

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