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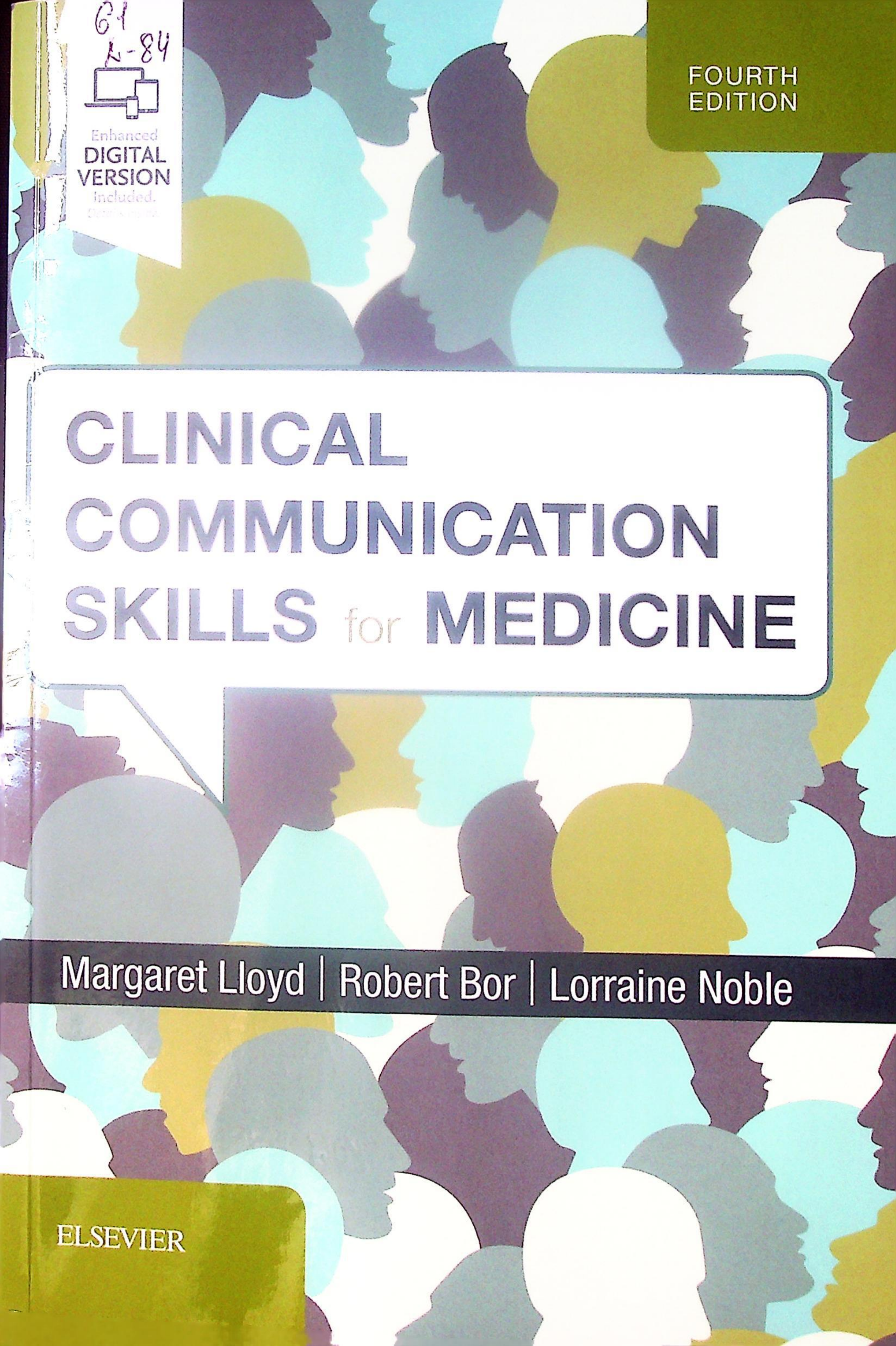

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FOURTH
EDITION

CLINICAL COMMUNICATION SKILLS for MEDICINE

Margaret Lloyd | Robert Bor | Lorraine Noble

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CLINICAL COMMUNICATION SKILLS for MEDICINE

4TH EDITION

Professor Margaret Lloyd MD FRCP FRCGP
Emeritus Professor of Primary Care and Medical Education,
UCL Medical School, University College London

Professor Robert Bor MA (Clin Psych) DPhil CPsychol CSci FBPsS FRAeS UKCP Reg EuroPsy
Consultant Clinical Psychologist, Royal Free Hospital, and Organisational Consultant, London

Dr Lorraine Noble BSc MPhil PhD Dip Clin Psychol AFBPsS
Senior Lecturer, UCL Medical School, University College London

Contributions by

Zack Eleftheriadou MA MSc CPsychol CSci FBPsS (BPS/HCPC Reg) Dip IMH Dip NCFED
Integrative, Psychoanalytic & Child Psychotherapist (UKCP Reg),
Noema Psychology & Psychotherapy, London

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Preface to the fourth edition

By the time the first edition of this book was published in 1996, there was solid evidence to show that communication between doctors and patients needed to be drastically improved. People receiving health care reported that doctors frequently used language they could not understand and that they failed to listen, broke bad news without compassion or failed to break it at all. To address these complaints, appropriate training was introduced at undergraduate and postgraduate levels and the observed assessment of communication became standard practice in summative examinations, yet the expectations of those delivering health care and those receiving it continued to differ. Access to health care information remained variable and *NHS Choices*, a popular UK website providing information for patients, was still a decade away.

The principle of shared decision making was to become the norm, however, and the UK Government's *Equity and Excellence: Liberating the NHS*, published in 2010, was built around the precept of *'no decision about me without me'*. The right of patients to be treated with respect, dignity and sensitivity and their right to make decisions about their own care have since become embedded in the values of health care services. These are echoed by the professional requirements that doctors are expected to meet, which are set out, for example, in the *Duties of a Doctor* from the UK General Medical Council's *Good Medical Practice.*

Achieving these goals requires skill: skill in gathering and sharing information in a range of settings and for a variety of purposes, skill in responding effectively and sensitively in challenging situations, and skill in supporting people so that they can make the health care decisions that are right for them. We do know that these skills can be learned and that they require practice and reflection. We also appreciate that communicating effectively with people receiving health care and those close to them goes beyond our everyday social skills and the friendly personalities of candidates training in medicine. Learning to communicate well in clinical practice involves lifelong learning.

This book is a practical guide to developing a set of techniques that will be of value to health care professionals throughout their careers. The chapter order reflects this development, progressing from the core competences through to the skills a doctor will need to respond effectively and compassionately in challenging situations, including breaking bad news and disclosing medical error. There are also sections that focus on the specific aspects of communicating with those at different stages of life (such as children and older adults) and when there are barriers to communication (such as the doctor and patient not speaking the same language). The text includes case examples, guidelines and prompts that encourage the reader to stop and think.

We hope that the fourth edition of this book will continue to act as a route map to guide readers as they acquire the effective and powerful communication tools that will serve them well throughout their medical practice.

Margaret Lloyd
Robert Bor
Lorraine M Noble
June 2017

Introduction

1

Margaret Lloyd, Robert Bor, Lorraine Noble

"Effective communication lies at the very heart of good patient care."[1]

"Communication has such a massive impact on the experience you have as a patient. Poor communication can cause lasting psychological distress. Good communication can have huge benefits beyond just the mechanical sharing of information and may even improve patient outcomes. Learning to communicate is a lifelong journey that never ends in medicine."[2]

The aim of this book is to help you to develop your skills in communicating effectively and sensitively with your patients, those close to them and your colleagues. The importance of good communication between people receiving care and those who care for them cannot be disputed. Effective communication is essential in order to:

- gather information to establish a diagnosis
- share information about the medical problem and treatment options
- support decision-making
- break bad news
- work with colleagues in many different settings and navigate a variety of difficult situations

to name but some of the conversations doctors have in their professional role. However, as we shall see later, patients' experiences of the care they receive sometimes fall far short of the ideal. With exciting scientific and technological advances being made in medicine, it is easy to be swept along by the science and to forget the ancient aim of the physician: 'To cure sometimes, relieve often, comfort always'.

The General Medical Council in the UK has emphasised the importance of communication with patients in the duties of a doctor:[3,4]

"You must:

- work in partnership with patients
- listen to, and respond to, their concerns and preferences
- give patients the information they want or need in a way they can understand
- respect patients' right to reach decisions with you about their treatment and care
- support patients in caring for themselves to improve and maintain their health."

What is clinical communication?

When you think about your role as a doctor, what does 'communication' mean to you? Think about:

- *a definition of communication*
- *the methods of communication*
- *the purpose of communication.*

Some things you may have thought about are shown in Figs 1.1. and 1.2.

The *Oxford English Dictionary* tells us that the word 'communicate' comes from the Latin 'to impart, to share'. 'Communication' is imparting, conveying or exchanging ideas and knowledge. *Clinical communication* is about the interactions that you have with others in your role as a medical professional, either with patients or about patient care. These interactions are often face-to-face discussions, but also use other media (e.g. telephone, written, electronic) and may be with patients and those close to them, or colleagues. The content often involves an exchange of information but can also include a discussion of thoughts, opinions, ideas and feelings. Situations may be routine (such as gathering information about a patient's medical problem) or difficult (such as breaking bad news), they may be planned or unexpected, and they may involve brief or more lengthy discussions.

So in a typical day, a doctor might:

- have face-to-face consultations with patients in an outpatient clinic
- have conversations with patients and colleagues during a ward round
- speak to patients' family members over the phone
- have handover meetings with colleagues
- liaise with colleagues in other health and social care services
- write medical notes and letters.

What is *'good'* communication?

We shall deal with this in more detail in the next chapter, but it is appropriate here to mention a study carried out some years ago by Dr Peter Maguire and colleagues in Manchester.[5] Patients who had spoken with medical students were asked for their opinions about the students' communication. Patients preferred students who:

- were warm and sympathetic
- were easy to talk to
- introduced themselves
- appeared self-confident
- listened to the patients and responded to their verbal cues
- asked questions that were easily understood and were precise
- did not repeat themselves.

This mirrors other research which has identified aspects of doctor–patient communication that are important to patients[6,7] (Table 1.1).

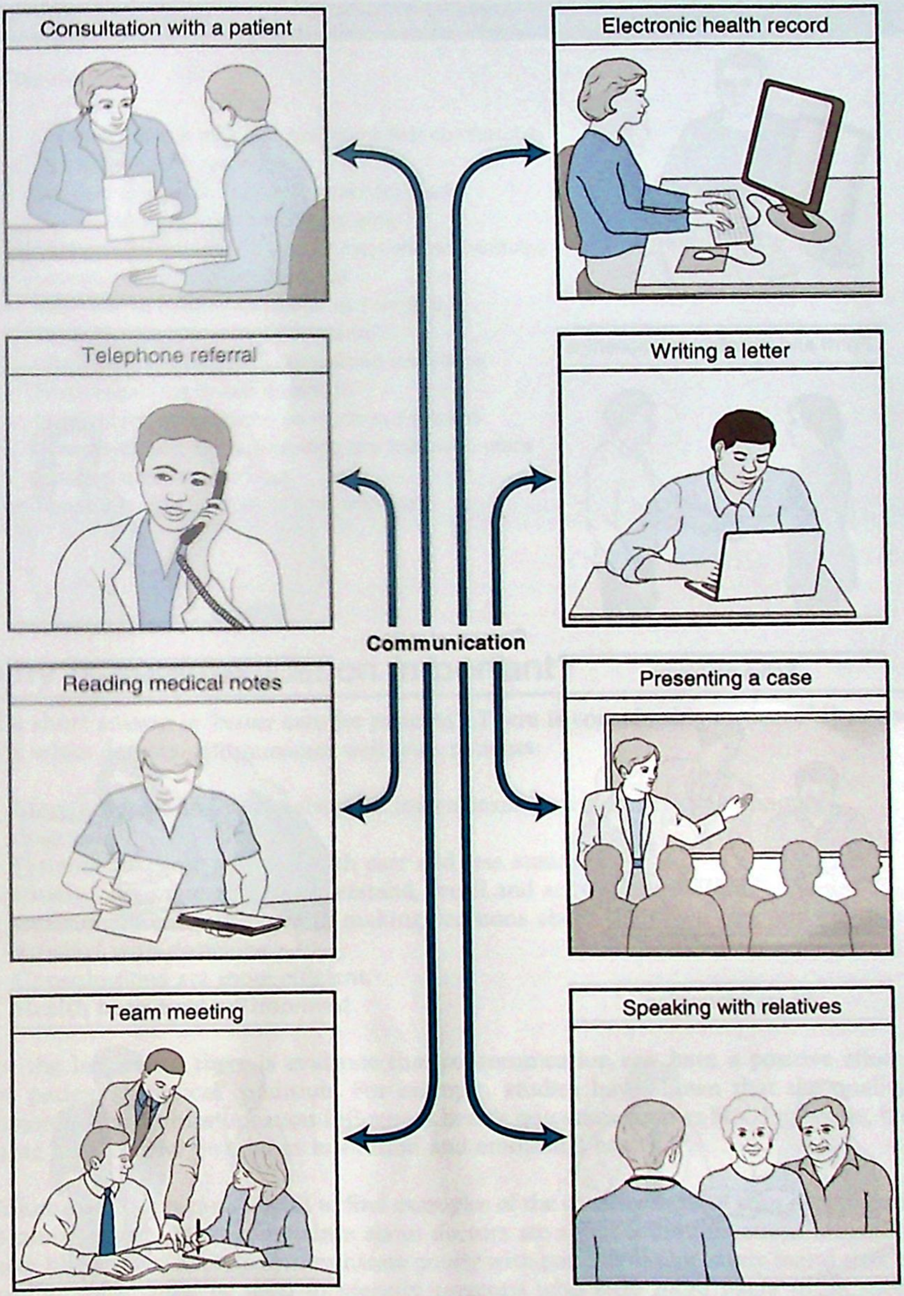

Fig. 1.1 Some methods of communicating.

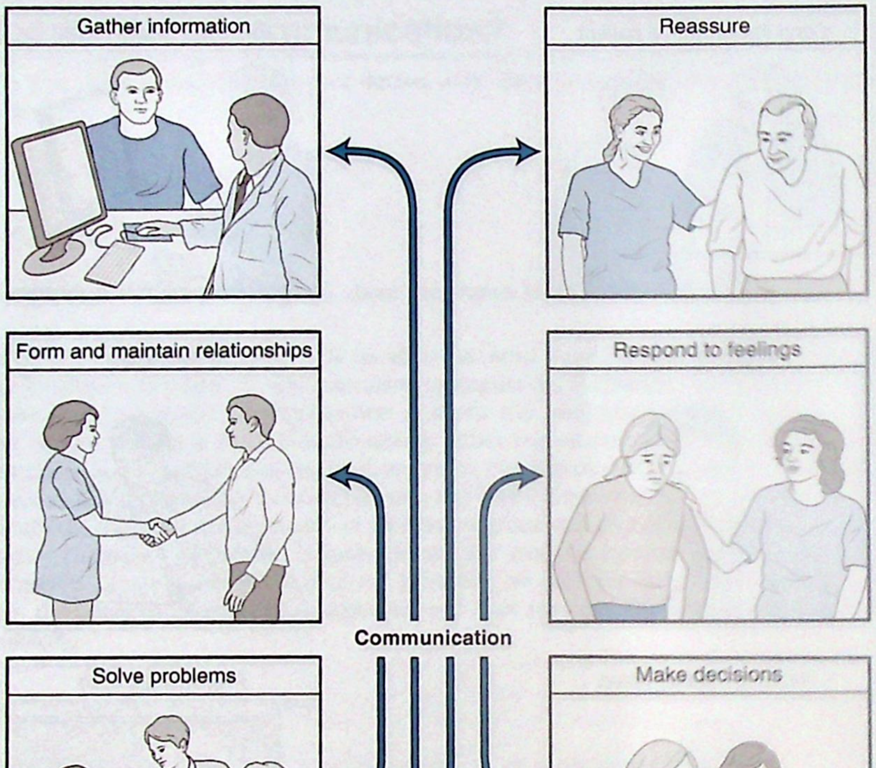

Fig. 1.2 Some purposes of communicating.

Table 1.1 Aspects of communication that are important to patients[6,7]

The doctor:

- Greeted me in a way that makes me feel comfortable
- Treated me with respect
- Showed interest in my ideas about my health
- Understood my main health concerns
- Paid attention to me (looked at me, listened carefully)
- Let me talk without interruptions
- Gave me as much information as I wanted
- Talked in terms I could understand
- Checked to make sure I understood everything
- Encouraged me to ask questions
- Involved me in decisions as much as I wanted
- Discussed next steps, including any follow-up plans
- Showed care and concern
- Spent the right amount of time with me

Why is communication important?

The short answer is 'better care for patients'. There is considerable evidence[8–11] to show that when doctors communicate well with patients:

1. More accurate and comprehensive information is gathered, aiding accurate diagnosis.
2. Patients are more satisfied with care and less anxious.
3. Patients are more able to understand, recall and act on information.
4. Patients are more involved in making decisions about their own care and are more satisfied with decisions.
5. Consultations are more efficient.
6. Health outcomes are improved.

On the last point, there is evidence that communication can have a positive effect on the patient's physical condition. For example, studies have shown that the quality of doctor–patient communication influences health outcomes such as blood pressure, blood sugar, pain control, symptom resolution and emotional health.[8,9]

Unfortunately, it is not difficult to find examples of the consequences of poor doctor–patient communication. Most complaints about doctors are about communication. Litigation is more likely when doctors communicate poorly with patients.[12] One study found that even tone of voice could be used to identify surgeons who were more likely to be sued by patients.[13]

Developing clinical communication skills

Training to be a doctor involves the acquisition of knowledge and skills, a commitment to high personal and professional values, and the ability to establish and maintain good relationships with patients and colleagues.[4] It was assumed until fairly recently that students were able to develop good clinical communication skills – for example, to conduct effective consultations with patients – by a sort of 'osmosis', simply observing doctors and modelling their behaviour. There was an assumption that students and doctors with good, everyday social skills needed no further training. However, a very large amount of evidence contradicted this assumption, as doctors obtained incomplete medical histories, failed to establish the reason the patient had attended, provided information that patients could not understand, shared bad news insensitively, and liaised ineffectively with colleagues, resulting in errors and omissions in care. Studies of medical students also showed a deterioration in the quality of communication with patients during medical training, as students focused less on the patient as a person and more on the technical and practical aspects of medical intervention.[14] As evidence mounted that the quality of doctor–patient communication affected outcomes of care, medical schools, as well as postgraduate and professional organisations, responded by introducing formal training and assessment of clinical communication.

What is the evidence for the effectiveness of clinical communication training?

In the 1970s, a series of studies was carried out on medical students during a fourth-year clinical attachment.[5] When students met with patients, a number of problems were observed. These included:

- not obtaining all the necessary information about the patient's problem
- forgetting to ask about the impact of the problem on the patient and his or her family
- failing to notice and respond to verbal and non-verbal cues from the patient
- looking bored during the consultation.

The investigators divided a group of students into a control group and a feedback group. Both groups were recorded on videotape whilst speaking with a patient. The feedback group then watched and discussed their recorded consultations with a tutor and were given advice on a handout. Both groups were again recorded whilst speaking with a patient.

Compared to the control group, the group that had received the feedback training:

- obtained three times more relevant and accurate information about the patient's presenting problem
- were given higher ratings by the patients.

The groups were followed up a few years later, after they had qualified.[15] Compared to the control group, the doctors who had received training when they were students were:

- more empathic and self-assured when speaking with patients
- more likely to:
  - notice verbal cues about the patient's problem
  - obtain precise information
  - use open questions
  - avoid needless repetition in the consultation.

Further studies have produced strong evidence that training can improve the quality of doctor–patient communication.[16,17]

Your learning

This book is intended to complement the experiences you have on your medical course, including formal clinical communication teaching and opportunities to practise in clinical settings. A useful framework for learning an experiential skill like clinical communication is this four-stage process:[18]

1. *Concrete experience:* doing something/having an experience, e.g. speaking with a patient to gather information.
2. *Reflective observation:* stepping back and reflecting on the experience, e.g. what went well, what would you like to improve?
3. *Abstract conceptualisation:* drawing out points you can apply to other situations, e.g. what skills or principles have been learned?
4. *Active experimentation:* trying out what has been learned, e.g. practising alternative ways of beginning the consultation.

Studies have shown that having the opportunity to practise, followed by receiving supportive and constructive feedback, is an effective way of developing clinical communication.[16,17] Having the opportunity to watch or listen to your own consultations again (for example, from a recording with a simulated patient) can also be a valuable and illuminating aid to learning.

Learning to communicate well with your patients, their families and your colleagues will continue throughout your career – it is lifelong learning. With an estimated average of over 2,000 consultations per doctor per year,[19] learning opportunities are abundant.

How to use this book

This book takes a practical approach to common topics in clinical communication. Throughout, you will find the following features that we hope will aid your learning.

Questions

These aim to encourage you to pause in your reading, to marshal your thoughts and to reflect on your own experiences.

Case examples

Examples of situations and conversations are given to illustrate the topics.

Key points

A list of summary points is given at the end of each chapter.

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Core skills in clinical communication

2

Margaret Lloyd, Robert Bor, Lorraine Noble

In Chapter 1 we saw the importance of effective and sensitive communication in health care. In this chapter, we are going to examine some of the core skills in more detail. But first we need to think about the doctor–patient relationship and how this affects doctor–patient communication.

The doctor–patient relationship

The doctor–patient relationship has changed over centuries and continues to evolve today.[1–3] Studies that have looked at recordings of consultations have found a variety of different styles of doctor–patient communication, which reflect the nature of the underlying doctor–patient relationship.[4–6] For example, consultation styles show differences in:

- the process of the consultation, e.g. how questions are asked, the amount of time each participant speaks during the consultation
- the content of the consultation, e.g. which types of topics are discussed, the language used to describe illness
- expectations of the role of the patient and doctor, e.g. who has responsibility for making decisions, who is perceived to have expertise (Table 2.1).

In what is now called the 'traditional biomedical approach' to the consultation, it was thought that the doctor's main focus was to interpret the patient's symptoms from the perspective of disease and pathology. Using this approach, the patient's perspective (including their concerns and understanding of illness) was not elicited, and patients were not expected to be involved in making decisions about their own treatment. However, evidence showed that many of the problems that patients had come to talk about were never

Table 2.1 Some examples of observed styles of doctor–patient communication

	Directive approach	Open, facilitative approach
Process	Doctor does most of the talking Mainly asks closed questions	Patient is encouraged to talk Doctor spends more time listening
Content	Focus on biomedical aspects of symptoms and disease	Considers the patient's experience of illness and goals for treatment
Roles of doctor and patient	Doctor as expert, gives advice Patient accepts advice	Patient makes requests Doctor provides information

discussed, and in half of consultations, patients and doctors did not agree on the problem which was to be followed up.[7,8]

These examples show two different approaches to the same consultation:

Case example 2.1 Different styles of communication

Mrs Fraser is 52 years old and works in an office. She has had a persistent cough and wheeze for the past 6 months. She has smoked a packet of cigarettes a day for 30 years. She is trying to stop smoking but is finding it difficult. She coughs mainly when she is at work and is worried that it is being made worse by the air conditioning in the office. She is afraid that she may have to leave her job, which she depends on to support herself and her three children.

Imagine that you are Mrs Fraser and you are about to see a doctor you have not met before.

Consultation style no. 1

Dr Eliot: *What seems to be the problem?*
Mrs Fraser: *I've had this cough, and I think it's getting worse. I've had to take time off work.*
Dr Eliot: *How long have you had the cough for?*
Mrs Fraser: *I've had it for 6 months.*
Dr Eliot: *Any other symptoms?*
Mrs Fraser: *I wheeze as well.*
Dr Eliot: *Do you smoke?*
Mrs Fraser: *Yes, I was smoking a packet a day, but I have been trying to stop. I have cut down.*
Dr Eliot: *Your symptoms are probably due to your smoking. I strongly advise you to stop smoking. Here's a leaflet. I'll arrange for you to have a chest X-ray and some other tests.*

Consultation style no. 2

Dr Eliot: *Could you tell me why you've come here today?*
Mrs Fraser: *I've had a cough, for about six months, and I also wheeze. I thought it was because of my smoking, and I have cut down. But the cough isn't getting better, and I've had to take time off work.*
Dr Eliot: *Is there anything else you'd like to tell me?*
Mrs Fraser: *I think the air conditioning at work might be making it worse. I've taken a lot of time off recently, and I don't want to lose my job.*
Dr Eliot: *What are you hoping I might be able to do for you today?*
Mrs Fraser: *Well, I would like some help to stop smoking completely, and anything that can help with the cough.*

Was there any difference between the two consultations in: (a) whether you felt that you were listened to? (b) whether you felt that you were working in partnership with the doctor?

Patient-centred communication

'Patient-centred' is defined as:

"Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."[9]

The goal of patient-centred communication is to help doctors provide care that:[10]

- is concordant with the person's values, needs and preferences, and
- enables the person to participate actively in decisions regarding their health and health care.

Evidence has shown that people who are more involved in discussions about their illness and decision-making about treatment are more satisfied with their care, more able to follow through with a treatment plan, less likely to regret the medical decisions made and have better health outcomes.[11,12]

The key features of a patient-centred consultation are:

- exploring the person's experience of illness
- eliciting the person's goals of care
- working in partnership to define the problems to be addressed and choosing a course of action.

Elements of a consultation which can facilitate this include:

- helping the patient to feel at ease at the outset
- using open questions
- active listening
- picking up and responding to verbal and non-verbal cues
- an empathic approach.

Patient-centred communication in different situations will be discussed in more detail throughout this book. This chapter will consider the core skills in communication which form the foundation of a patient-centred approach. But first, we will consider some other factors that affect communication in medical settings.

Factors that affect communication in medical settings

Imagine that you have some bad news to share with someone you know (e.g. you have to explain that a family member has a serious illness). Think about the factors that:

- *would help you to share the information*
- *would make it more difficult to share the information.*

Firstly, the setting or situation is clearly important – you are unlikely to want to have a conversation in a corridor or public place where you can be interrupted or overheard. Secondly, how you share the information will depend on the other person's perspective: what do they already know, how important is the news to them, how are they likely to react? Similarly, the sharing of information between patient and doctor can be influenced by factors that relate to the setting of the consultation, the perspectives of the participants and how the participants respond to each other.

People cope with illness in different ways depending upon their individual circumstances, life experience, social and cultural background, and expectations of care. Most people experience a degree of anxiety and apprehension when consulting a doctor. In particular, admission to hospital is a disturbing experience for most of us. Factors that contribute to our anxiety include an unfamiliar environment, loss of personal space, separation from family and friends, loss of independence and privacy, and uncertainty about what is wrong and what treatment might entail.

Other elements that have an influence are:

- what we understand about the problem; for example, how it was caused, whether it can be cured and its impact on our life
- the type of problem; for example, whether it is a minor problem, embarrassing or something we are afraid of
- expectations of the roles of a doctor and patient; for example, what each participant is anticipating from the other.

Your personal experience in having conversations with people who seem different to yourself (e.g. who are much older than you or from a very different background) or discussing certain topics (e.g. sex, bereavement, fears about illness) can affect how comfortable you are. Tiredness, preoccupation with other things, and your mood can all affect your communication with patients.

The setting of the consultation

Most consultations take place in a hospital ward, outpatient clinic or general practice surgery, and the setting itself can facilitate or hinder communication. For example, the sense of privacy: a patient in a hospital bed is unlikely to divulge personal or sensitive information knowing that the patient in the next bed can hear every word. Background noise and interruptions are another factor: imagine you are trying to have a serious conversation with a friend, and you are frequently interrupted by other people. Seating arrangements also affect the 'climate' of the conversation. In an outpatient clinic or general practice consulting room, there are often two chairs and a desk (Fig. 2.1).

Arrangement A, with the patient and doctor facing each other across a desk, is unlikely to make the patient feel at ease or facilitate discussion. The desk is a barrier and the conversation can feel like an interrogation.

Arrangements B and C are more informal and offer more flexibility for both parties, for example, in the distance between the seats. Seats too close together can feel threatening, but too far apart may convey a feeling that the doctor is not interested in the patient. This distance may change during a consultation, for example, the doctor might draw a chair closer to the patient when offering reassurance.

Speaking to a patient who is in a hospital bed deserves special consideration. Standing over a patient is likely to increase the person's feeling of vulnerability and sitting on the bed is likely to feel intrusive. Taking the time to find a chair can set the scene for a more comfortable conversation. Being on the same eye level as the person you are speaking to has a very powerful effect on how comfortable people feel in a conversation.

Some meetings between doctors and patients or relatives are spontaneous, or for some other reason start with both parties standing (e.g. meeting in a corridor, or outside a cubicle in the emergency department). This may be appropriate for a brief, factual update. But for any conversation that is more significant (e.g. explaining a diagnosis, making a treatment plan, breaking bad news), finding a quiet place to sit down enables both parties to give the matter their full attention without distractions. This is particularly important for any conversation when decisions are being made.

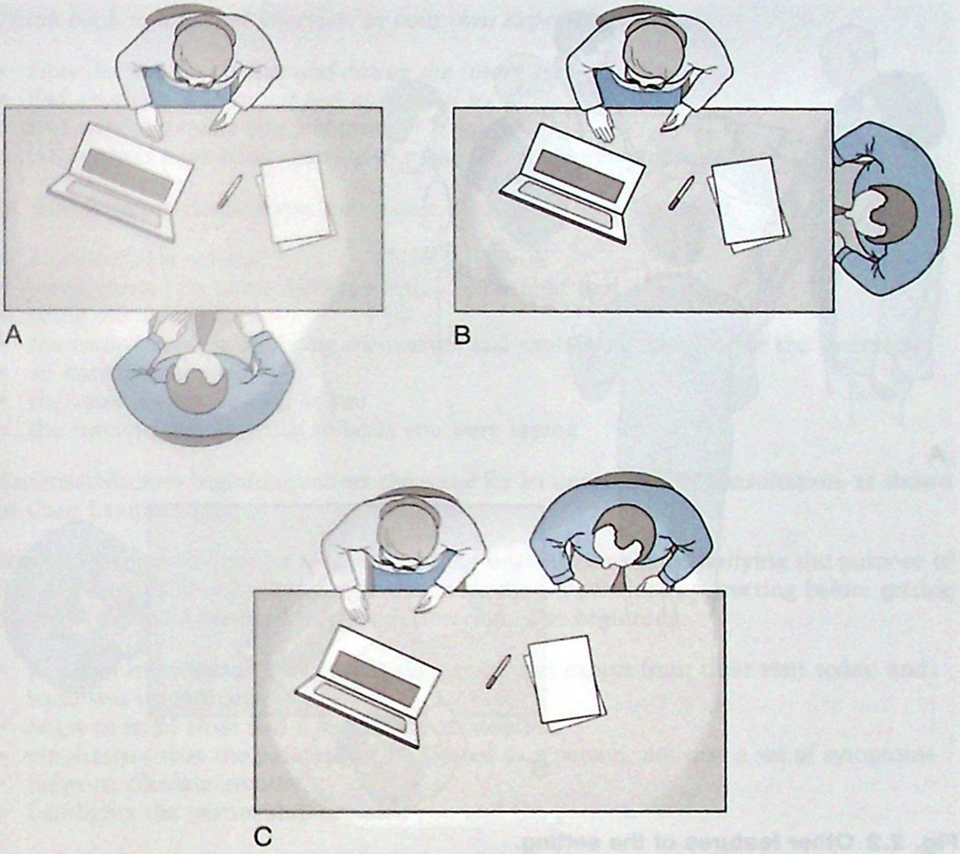

Fig. 2.1 **Alternative seating arrangements in an interview.**

Finally, consider two other features of the setting: the presence of other people and the presence of a computer (Fig. 2.2).

Imagine a situation where the doctor has test results to share with the patient. The patient has been very worried, as a relative with similar symptoms was found to have a very serious illness.

What do you think the effect of these might be on the patient:

- *The patient is in bed on the ward, and there are several other members of staff standing around the bed, as well as the doctor.*
- *The patient and doctor are sitting at the desk in the clinic room, but the doctor looks more at the computer than at the patient.*

Consider again the seating arrangements in Fig. 2.1. In which of these arrangements can the patient also see the computer screen? What effect might it have on the patient if the doctor is frequently looking at a screen that the patient cannot see?

The setting and the way in which we begin a conversation can have a profound effect on what follows.

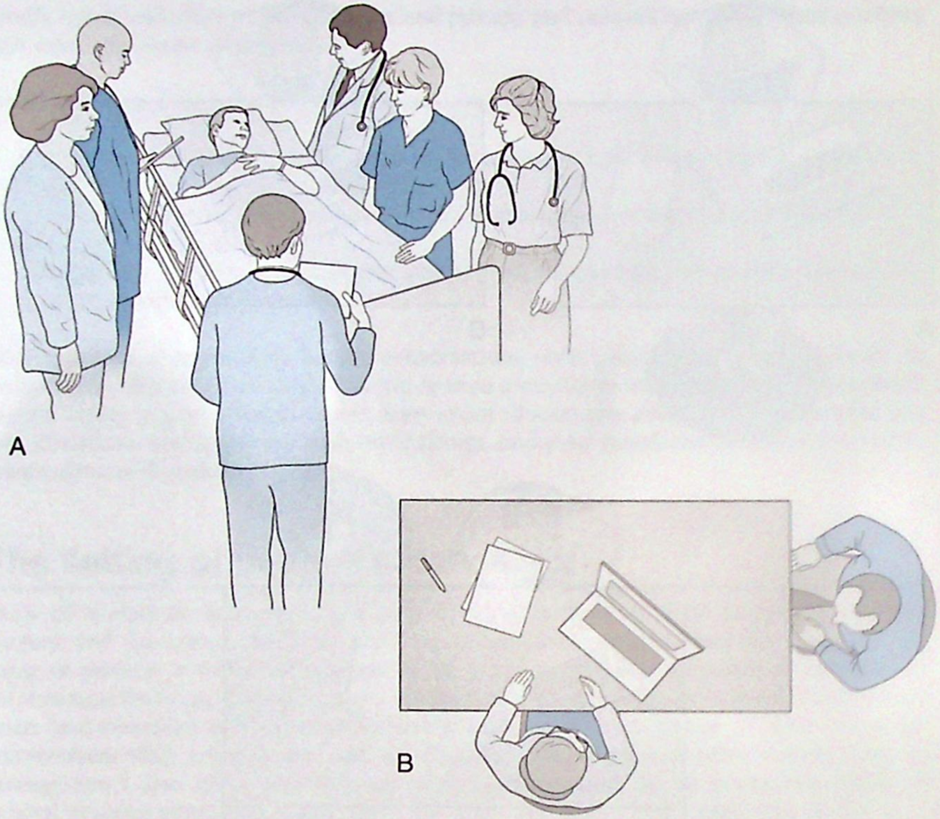

Fig. 2.2 **Other features of the setting.**

Beginning a consultation

"Introductions are about making a human connection between one human being who is suffering and vulnerable, and another human being who wishes to help. They begin therapeutic relationships and can instantly build trust in difficult circumstances."[13]

Case example 2.2 An unsuccessful beginning

Mrs Francis, a shop assistant aged 31, attended medical outpatients at her local hospital. Here is her story:

When I went into the room, which was big and bare, I felt lost. I didn't know where to sit, the doctor had his head down and was writing, the nurse was on the telephone and there were some medical students talking to each other. I waited around and wanted to run out the door. After what seemed like ages the doctor told me to sit down and asked what was wrong. I didn't know his name and I'm not sure that he knew mine. I'd been thinking about my problems and what I wanted to tell the doctor – but I forgot it all – he didn't seem very interested anyway. Hope I don't have to go again.

Think back to a formal interview in your own experience:

- *How did you feel before and during the interview?*
- *Did anything help to put you at ease? If so, what?*
- *Did anything make you feel uneasy? If so, what?*
- *What could have been changed to make you feel more comfortable?*

In describing what made you feel at ease, you might have included:

- a comfortable setting
- being greeted by name, perhaps with a handshake and a smile
- being offered a seat
- the interviewers introducing themselves and explaining the plan for the interview
- an easy first question
- the interviewers looking at you
- the interviewers listening to what you were saying.

An unsatisfactory beginning can set the scene for an unsatisfactory consultation, as shown in Case Example 2.2.

Beginning the consultation involves making introductions and clarifying the purpose of the meeting (Table 2.2). But the aim is more than a perfunctory greeting before getting down to the main business of the consultation. The beginning:

- provides information about what the person can expect from their visit today, and from you in particular
- helps to build trust and a supportive atmosphere
- emphasises that the patient will be treated as a person, not just a set of symptoms
- helps to alleviate anxiety
- highlights the partnership between you and the patient.

Models of the consultation, which are based on evidence about effective doctor–patient communication, emphasise the importance of this stage. For example, in the 'Four Habits Model', the doctor's first task is to *invest in the beginning* (Table 2.3). This includes three important elements: *creating rapport quickly, eliciting the patient's concerns, and planning the consultation with the patient.*[14]

The main part of the consultation

Remember the example of you having to share bad news with another person. You probably would expect the other person to:

- ask appropriate questions
- listen attentively and demonstrate interest
- help you to continue if you get stuck.

Questioning, listening and facilitating are three of the key skills that enable us to communicate effectively with others (see Table 2.2).

Asking questions

One of the most common reasons for a consultation is to gather information about the condition for which the person is seeking help. The aim is to obtain information which

Table 2.2 Key consultation skills

Beginning

- Greet the patient by name (e.g. 'Good morning, Mr Richardson') and shake hands, if it seems appropriate
- Offer the patient a seat or sit down at the same eye level
- Introduce yourself by name and role (e.g. 'I am Judy Williams, a medical student. I'm training to be a doctor. Dr Wells has asked me to speak to you.')
- Discuss the purpose of the conversation (e.g. 'I would like to find out about the problem which has brought you into hospital.')
- Say how much time is available (e.g. 'This will take about 20 minutes.')
- Explain what will happen next (e.g. 'I will go back to Dr Wells and explain what you have told me.')
- Explain note-taking (e.g. 'I'd like to take notes, so that I can remember what you have told me. Is that okay with you?')
- Check whether the patient agrees (e.g. 'Would that be okay?', 'Are you happy to speak to me?')
- Respect the patient's decision (e.g. 'Yes, of course, I can come back later when you are not so tired', 'Yes, we can talk for a shorter time if you only have a few minutes.')

The main part of the consultation

- Maintain a positive atmosphere, warm manner and good eye contact
- Use open questions at the beginning
- Listen carefully
- Be alert and responsive to verbal and non-verbal cues
- Encourage the patient both verbally ('Tell me more') and non-verbally (using posture and head nods)
- Use specific questions when appropriate
- Clarify what the patient has told you

Ending

- Summarise what the patient has told you, and ask if your summary is accurate
- Ask if the patient would like to add anything
- Explain what will happen next
- Thank the patient

Table 2.3 The four habits model[14]

- Invest in the beginning
- Elicit the patient's perspective
- Demonstrate empathy
- Invest in the end

is as accurate, complete and relevant as possible. The most obvious and direct way to gather information is to ask questions. However, studies of medical students and doctors have found a tendency to:

- ask too many questions
- ask questions quickly, without giving the patient enough time to respond
- ask questions that are too specific, long or complicated
- discourage the patient from explaining the problem in their own words
- ask questions in such a way that they may bias the answers given
- avoid asking questions about topics they feel are sensitive.

Studies have found that doctors who gather information most effectively:[15–18]

- start with an open question about why the patient has attended today
- listen, without interrupting, to the person's opening statement
- ask if there is anything else the patient would like to mention
- establish the person's perspective (e.g. goals, concerns, expectations and preferences)
- summarise the list of problems the person has mentioned
- explore each problem in turn
- ask open questions initially, then move to more specific questions to clarify details
- summarise periodically
- clarify any unfamiliar words, phrases or jargon used
- reflect back what the person has said to encourage further elaboration
- summarise information back to the person
- ask if the information in the summary is accurate and complete
- do a final check that nothing has been missed.

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As this list shows, gathering information effectively involves more than asking questions and involves several different skills which are used at different points during the consultation.

Open and closed questions

Open questions encourage the person to give full answers and explain the problem in their own words. They often start with *how, what* or *why*, but can also be phrased as indirect questions (e.g. *'Tell me more about that'*). Open questions are particularly helpful to establish the full range of problems that the patient would like to discuss at the outset of the consultation.

Closed questions limit the range of answers, for example, to simple 'yes' or 'no' (e.g. *'Does the pain wake you up at night?'*). These are helpful when focusing in on specific aspects, for example, when clarifying details. The two disadvantages of closed questions are:

1. you generally have to ask more of them to obtain the same amount of information, and
2. you can miss important information, as you only receive information on aspects you specifically ask about.

In particular, focusing in too quickly and asking a series of closed questions about the first symptom mentioned can lead to a large part of the consultation being taken up with a small part of the problem. The first symptom might not be the only – or the most important – problem the person has come to discuss. Sometimes people *build up* to mentioning the problem which is most worrying to them.

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Case example 2.3 Responses to open and closed questions

Mr Clark is an accountant aged 47 years. He comes to the emergency department after having an attack of chest pain. He is seen first by Dr Yates:

Dr Yates: *I see from your notes that you have had some chest pain. Do you still have the pain?*
Mr Clark: *No, not now.*
Dr Yates: *Was it tight or dull?*
Mr Clark: *It seemed a very dull pain.*
Dr Yates: *Did it go down your arm?*
Mr Clark: *No, I don't think so.*
Dr Yates: *Did it come on with exercise?*
Mr Clark: *No.*

Later, Mr Clark is seen by Dr Vale:

Dr Vale: *I understand that you have had pain in your chest. Can you tell me more about it?*
Mr Clark: *It came on when I was sitting at my desk. It was a funny dull pain that stayed in the middle of my chest. I've had it a few times recently.*
Dr Vale: *A few times?*
Mr Clark: *Yes, three or four times over the past month or so. I've been very busy at work, and it seems to come on towards the end of the day.*

Consider how efficient the two questioning styles are in gathering information about Mr Clark's problem.

Over the course of a consultation, a mix of questioning styles is generally helpful, often starting with open questions and moving on to more closed questions as needed to explore the problems in more detail. This is called the 'open to closed question cone'.

The approach to asking questions also depends on the setting and problem. For example, if a patient arrives in the emergency department with a painful arm after an accident, the doctor may fairly quickly move on to closed questions, to establish the location of the pain and whether the person can move their arm. A patient who is finding it embarrassing to talk about the problem might also feel more comfortable responding to a set of more specific questions, delivered in a 'this is all very routine' tone of voice. Being responsive to the impact of the style of questioning on the 'climate' of the conversation can help the flow of conversation.

Probing questions

Probing questions encourage a person to elaborate on a topic. Probing questions may be used to:

- Clarify: e.g. 'What do you mean by that?'
- Justify: e.g. 'What makes you think that?'
- Check accuracy: e.g. 'You take three tablets a day?'

Gathering information about a problem rarely involves asking a single, perfect question. Probing questions can help to explore different aspects of a problem or the person's experience of the situation.

Other questioning styles

Leading and complex questions tend to influence the person's responses and tend to be less effective in consultations to gather information. Leading questions encourage the person to give the answer that the interviewer expects – or wants. There are different types:

1. *Conversational*: often used in small talk (e.g. 'Aren't we having awful weather this year?'). This is not used to gather information, but as a social facilitator.
2. *Simple*: can be used to reflect back what someone has said (e.g. 'So you don't sleep well, do you?'), either to acknowledge information that has been given or to encourage the person to elaborate. But these questions can indicate that assumptions have been made (e.g. 'You've never had any pain like this before?', 'You never have sex without a condom, do you?'). These questions often act almost as rhetorical questions, to which patients may feel that the 'correct' response is simply to agree with the statement.
3. *Subtle*: where the wording of the question influences the respondent. For example, people were asked in a study 'Do you get headaches frequently and, if so, how often?' The average response was 2.2 headaches per week. When the question was changed slightly to 'Do you get headaches occasionally and, if so, how often?' the average response was 0.7 headaches per week – a significant difference.[19]

How could the question about headaches have been phrased to avoid influencing the answer?

People are often unaware that they are asking leading questions.

Complex questions encompass several questions in one. For example, 'Did you start vomiting yesterday or today, and have you had diarrhoea?' The chances are that only one part of the question will be answered. Speed of delivery and lack of eye contact – for example, when reading questions off a checklist – can also contribute to missing the person's cues about their real answers to these questions.

Listening

For patients, being listened to is one of the most important aspects of a consultation.[20,21] Listening is one of the most obvious components of the communication process, yet sometimes people find it difficult to receive the message the other person is trying to convey.

Imagine you are in another country and you need to ask for directions. You ask someone, who is willing to help, but you speak very little of the language.

What makes it easier or more difficult for you to remember the directions you are given?

Common barriers to effective listening are:

- too much information being delivered at once
- being preoccupied with something else (such as trying to remember to ask certain questions)
- the information not matching up with what you are expecting
- worrying about offending the other person (e.g. by interrupting their flow).

Listening involves not only receiving information, but also, and more importantly, being 'in tune' with the speaker and responding appropriately. This means being alert to cues that indicate what a person is trying to convey, whether it is exchanging facts, expressing a feeling or disclosing a concern. Deliberately and consciously concentrating on the other person in a conversation is called *active listening*.

Example 1: Mrs Hannawa has come to see her GP. When she comes into the room she doesn't smile. She looks tired, and not her usual self. When asked the reason for the visit, she replies briefly, saying that she wants to talk about her blood pressure tablets. The doctor is half listening. There have been problems with the surgery's computer system this morning and she is behind with her workload. As the patient arrives she is closing a document on the screen. Still looking at the monitor, she responds, 'Right, blood pressure tablets,' and calls up the patient's medication record.

Example 2: Mr Nuland has attended an outpatient clinic, as he has been having persistent stomach pains. The doctor asks if he has any other symptoms. Mr Nuland hesitates and says, 'No, not really'. He looks uncertain. The doctor decides to add to the previous question, to encourage him to say more: 'Or anything else that you've noticed…?'

The key features of active listening are:

- focusing on gathering information which is a complete, accurate and representative account of what *the patient has come to tell you*
- understanding the *implications for the patient* of what is being said
- responding to *verbal and non-verbal cues*
- demonstrating that you are *paying attention* and *trying to understand.*

Picking up cues

Cues are signals which can add to, modify, emphasise or sometimes even contradict what a person is saying. Sometimes they indicate a problem that a patient is not sure whether to mention or a particular concern.

Verbal cues

Case example 2.4 Picking up verbal cues

DR STONE: *Hello, Mrs Fine, please take a seat. How can I help today?*
MRS FINE: *I thought I'd come to see you, doctor, about my headaches.*
DR STONE: *Perhaps you could tell me more about these headaches.*
MRS FINE: *Well, they're really bad, and getting worse. They started soon after my mother died and now they're making me feel dizzy. I'm really worried.*
DR STONE: *Could you tell me why you are worried?*

Dr Stone has picked up one of the verbal cues, about Mrs Fine's worry, to start to explore the problem in more detail.

There are also para-verbal cues, which are characteristics of speech, such as tone, timing, emphasis on certain words, and vocalisation without words (such as 'mm-hmm' to indicate agreement). Again these can highlight what is important to the speaker.

Non-verbal cues

We reveal a lot of information about ourselves and our feelings in our body language – for example, our facial expressions, eye contact, gestures and posture – and other aspects, such as the way we dress.

Consider the effect on a conversation with a patient when a doctor:

- *fails to make eye contact at the beginning of the consultation*
- *spends most of the consultation looking at the medical notes or computer screen*
- *fidgets or taps their feet throughout*
- *has a facial expression that looks bored or disapproving.*

Whilst these seem to be very obvious cues, sometimes doctors and medical students focus on the information being exchanged *verbally* and 'tune out' to the signals that they are sending out *non-verbally*. Doctors, students and patients all express themselves through non-verbal cues. The combination of verbal and non-verbal cues can have a powerful effect on the patient's experience of the consultation.

Facilitation

Facilitation is an essential part of effective listening; the aim is to encourage the person to explain what they have come to say. Examples of *verbal* facilitation are:

"Please tell me more about that."
"Yes, I see – please continue."

Examples of *non-verbal* facilitation include leaning slightly towards the patient, maintaining eye contact and nodding your head at appropriate times. Vocalisations like 'mm-hmm' (which are called 'minimal encouragers') show that you would like the person to continue, without interrupting their flow.

Clarification

Asking a person to clarify what has been said can be done in several ways:

"Can you describe the pain in more detail?"
"What do you mean by 'dizziness'?"
"So you bought something from the chemist to help – what was that?"

Reflection

Reflecting back what a person has said shows that you are listening and encourages them to continue. This is helpful in many types of conversations with patients, and particularly when a person might be finding it difficult to go on because of their feelings.

"You said the tiredness started about a month ago."
"You've felt this way since your mother died."

Silence

Silent periods may make us feel uncomfortable, and there can be a temptation to rush in to fill the gap. However, silences give both participants in a conversation the time to reflect on what has been said. Pauses in a conversation help people to remember what they want to say, or what they want to ask. Taking a moment to take stock also helps in making the transition to the next stage of the conversation.

Empathy

"Realise, so far as you can, the mental state of the patient, enter into his feelings... Scan gently his faults. The kindly word, the cheerful greeting, the sympathetic look." Sir William Osler[22]

People generally want to feel listened to and understood. This is particularly important in medical settings: patients and their families are often anxious, there is often uncertainty and people may be facing difficult news or difficult decisions. When we talk about *empathy* in this context, we mean the doctor's ability to:

- accurately identify another person's feelings and experiences
- communicate that understanding back to the person.

This sometimes – but not always – involves thinking about how you would feel if you were in the other person's situation. For example, if you have experienced a bereavement or loss, this might give you an insight into how a recently bereaved patient is feeling. But it is not 'putting yourself into someone else's shoes' – you may never have experienced what the patient is feeling, or you may react differently if you were in the same situation. The aim is to appreciate what *the person* is feeling in *their situation*.

Some people find it easier to empathise than others, by virtue of their background, personality or previous experiences. However the ability to empathise with a patient is a key professional skill, which can be learned. It is a combination of good listening and a willingness to understand the experiences of another person.

Key skills are:

- fostering a supportive 'climate' in the consultation
- active listening
- responding to verbal and non-verbal cues
- exploring the patient's experience
- asking questions (e.g. about the patient's feelings or the impact of the situation on the patient)
- being aware of assumptions you might be making
- indicating your understanding and support, e.g.:

PATIENT: *I'd just gone through a very difficult divorce, then my father died suddenly from a heart attack.*
DOCTOR: *That must have been a distressing time for you.*

Empathy is a powerful therapeutic tool and is an important element in developing effective working relationships. Empathy is discussed in more detail in Chapter 4.

Touch

Touch is another powerful means of communication, that we use to express a whole range of emotions, including tenderness, love and anger. Within the context of the doctor–patient relationship, touch can convey concern and empathy, and it can have a therapeutic effect in itself. However, it can be misjudged and make people feel very uncomfortable.

When should touch be used in the doctor–patient encounter? There are no hard and fast rules. Shaking a patient's hand at the start of a consultation is often appropriate, but in some circumstances may feel too formal. Putting an arm around someone who is distressed can give comfort, or placing a hand on the arm of a patient who is having difficulty expressing their thoughts and emotions can convey empathy. But everyone has different preferences about touch, and what can feel reassuring to one person may feel very intrusive to another. Here are some general guidelines about touch with patients:

- Try to assess the patient's likely response to being touched. You can pick up clues from the way the patient relates their story, their posture and other aspects of body language.
- If you feel uncomfortable about touching patients, it is probably advisable not to do it – you are likely to communicate your anxiety to the patient.
- Consider social and cultural norms – in the UK, reassuring and comforting touch usually takes the form of a hand placed on an arm or shoulder, or taking someone's hand. The age, gender and cultural backgrounds of the doctor and patient can affect whether touch is likely to be appropriate or not.

If you do not feel that touch is appropriate, comfort, empathy and reassurance can be equally well conveyed by what you say, your posture, tone of voice and active listening.

Communication during the physical examination

What we have discussed so far about touch also applies to touch as a form of communication during a consultation. However, there are also some different issues concerned with touching during a physical examination. Patients are likely to feel very conscious of their vulnerability, for example, as they are sitting on a couch waiting to be examined. They may also feel embarrassed and anxious about what may be found. Some guidelines are:

- Respect the patient's sensitivity and modesty; only ask the patient to undress the parts of the body that are necessary; use a blanket to cover the patient when not examining the patient.
- Explain what you are going to do. Check whether the patient has any concerns about this.
- Use language which is clear and without jargon.
- Tell the patient what you are doing, and going to do, throughout.
- Give any instructions clearly and give the patient time to follow through.
- Be careful not to instil anxiety through your facial expressions, or by spending a long time on one part of the examination without explanation.
- Avoid causing discomfort if possible by watching the patient's expression and by letting the patient know how to respond, e.g. by saying 'Please tell me if I am hurting you'.

Signposting

Signposts on a road direct us towards our destination and keep us on the right track. Similarly, signposts in a conversation are statements that orient the person to what is happening next. These help both you and the patient to see the structure of the consultation and help to keep track of where you are.

Signposts are used at the beginning of a consultation:

"I would like to start with the problem that has brought you in today, and then I would like to find out more about your health in general."

Throughout a consultation:

"I would like to ask you a few more questions about..."
"It would help me to know more about the circumstances that bring on your chest pain."
"So no particular worries at home or at work. Can we go back to the headaches you mentioned?"
"I would like to examine you now, if that is alright?"

And towards the end of a consultation:

"That's all the questions I wanted to ask. Can I go over what you what you have told me?"

Summarising

Summarising periodically during a consultation, and at the end, serves several important functions:

- It allows you to check the accuracy and completeness of the information gathered by providing the patient with an opportunity to add anything that has been missed and correct any misunderstandings.
- It enables you and the patient to review what has been covered and consider what else needs to be explored.
- It is a form of reflection and hence can encourage a patient to say more.
- It can help you to 'keep on track'.
- It can be reassuring to the patient that you have listened carefully.
- It is an appropriate way to close most consultations. As a student, you will mainly be speaking with patients to gather information, but summarising is also helpful in other types of consultations, for example, when there has been a discussion about treatment options and decisions have been taken about the next steps.

Ending a consultation

Ending a consultation properly is satisfying for both participants. It is the point where the doctor and patient review what has been discussed and make a plan for the next stage of care (see Table 2.2). Key steps are:

- indicating that the conversation is drawing to a close (e.g. that you have covered all you need to)
- checking that the patient has nothing more to add
- summarising what the patient has told you, and checking that it is complete and accurate
- explaining what will happen next
- ending by thanking the patient.

Key points

- Key features of a patient-centred consultation are:
  - exploring the patient's experience of illness
  - eliciting the patient's goals of care
  - working in partnership with the patient.
- Core skills in communicating with patients are questioning, active listening and facilitating.
- Over the course of a consultation, a mix of questioning styles is generally helpful.
- Active listening is being alert to cues which indicate what a person is trying to convey.
- Empathy is an important element in understanding the patient's experience.

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3

Gathering information

Margaret Lloyd, Robert Bor, Lorraine Noble

People attending health care services bring to the doctor their:

- problems, often in the form of symptoms or complaints
- concerns about these
- expectations and hopes for treatment.

The consultation between the patient and doctor is the cornerstone of the problem-solving process, not just in exchanging information, but in establishing a working relationship. The doctor's role is to gain as accurate a picture as possible of the problems for which the person is seeking help (often called 'presenting problems'), whilst developing a supportive climate in which the patient feels cared for and confident in collaborating with the doctor going forwards.

How is this done? See Fig. 3.1.

1. Establish a rapport with the patient by 'investing in the beginning' (see Chapter 2). It is important that a person attending health care feels comfortable in telling their story, including their underlying concerns, as completely as possible.
2. Use a framework for gathering the information that forms part of 'the medical history', which will be discussed in this chapter.

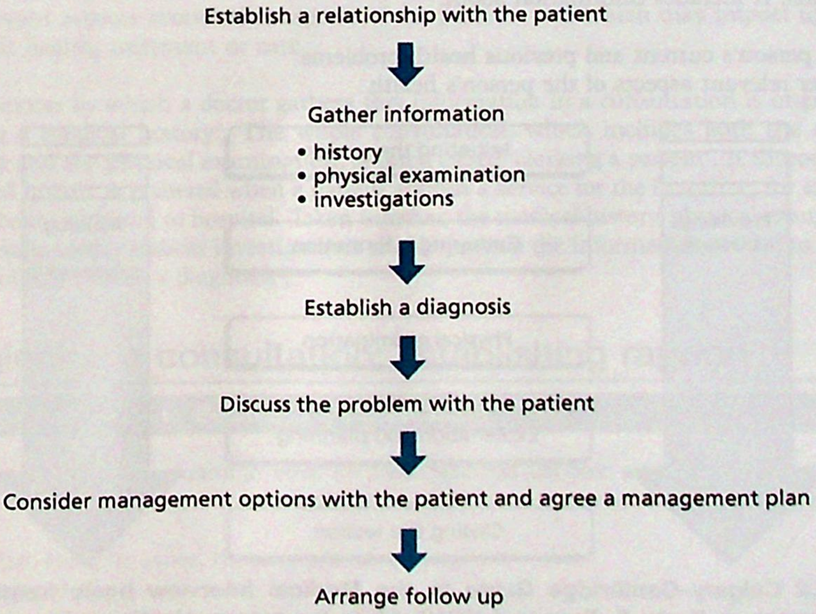


Fig. 3.1 Developing a management plan for a patient.

3. Use the information acquired during the consultation, the physical examination and any tests to identify the problem or make a shortlist of the possible diagnoses (this is called 'differential diagnosis'). This stage involves knowledge of clinical medicine and decision-making processes (called 'clinical reasoning') that develop with experience.
4. Share information with the patient about the problem and possible options for treating or managing the problem (see Chapter 5).
5. Discuss the possible options with the person and collaborate in making decisions (see Chapter 6).
6. Follow up on the progress of the plan that has been put into action.

An overview of the doctor–patient consultation

Jonathan Silverman and his colleagues designed the Cambridge–Calgary Guide to the Medical Interview, which gives an overview of a whole consultation.[1] The basic framework shows the chronological stages, from beginning the consultation, to gathering information, right through to closing the consultation (Fig. 3.2).

Simultaneously, there are two parallel strands, where the doctor focuses on building a relationship with the patient and providing a structure to the consultation, which both happen throughout the conversation. The expanded framework (Fig. 3.3) indicates some of the specific elements included in each stage. A more detailed version of the guide is available.[1,2]

In this chapter, we will consider the early stages of the consultation, focusing on a consultation with the purpose of gathering information to obtain a patient's 'medical history'.

The medical history

The medical history is a comprehensive description of a patient's health and health-related problems. It includes information about:

- the person's current and previous health problems
- other relevant aspects of the person's health

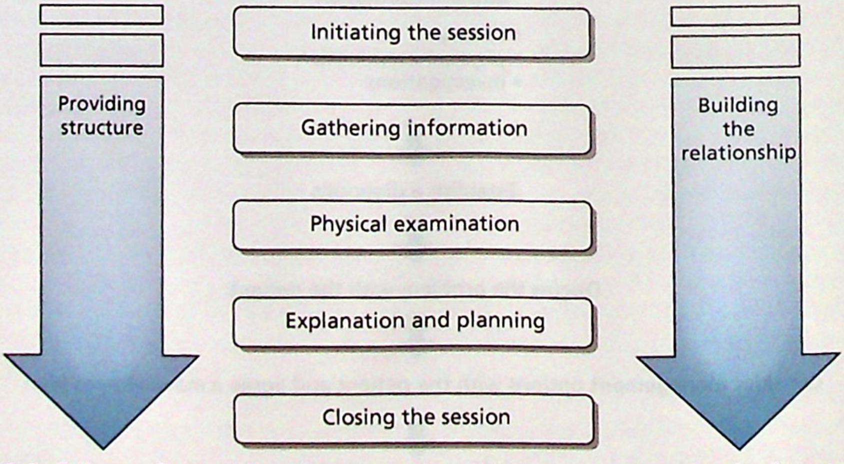


Fig. 3.2 Calgary–Cambridge Guide to the Medical Interview basic framework. © Silverman J, Kurtz S, Draper J (2013) *Skills for communicating with patients.*[1] Reproduced with the permission of the copyright holder.

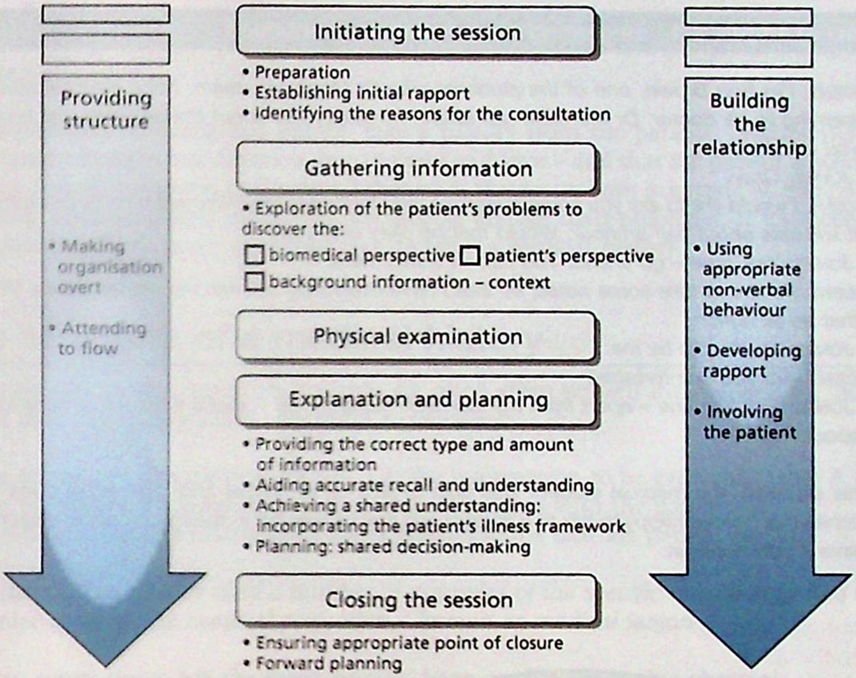


Fig. 3.3 Calgary–Cambridge Guide to the Medical Interview expanded framework. © Silverman J, Kurtz S, Draper J (2013) *Skills for communicating with patients.*[1] Reproduced with the permission of the copyright holder.

- current and previous medical treatment
- the person's perspective of the problem
- relevant aspects of the health of family members
- relevant aspects about other aspects of the person's life, which may impact upon their health, treatment or care.

The process by which a doctor gathers this information in a consultation is often called 'taking a medical history'. The whole consultation, which includes both the medical history and the physical examination, is often called 'clerking a patient'. A thorough and detailed history is gathered when a patient attends a service for the first time, for example, when being admitted to hospital. Taken together, the medical history, physical examination and results of any tests or investigations should provide the information needed to identify the problem ('make a diagnosis').

Beginning a consultation: establishing rapport

Case example 3.1 Beginning a consultation

A doctor has asked a student to 'clerk' Mr Jones, who has just been admitted into hospital from the emergency department. The student finds that Mr Jones is in a side room reading a newspaper.

STUDENT: *Hello, Mr Jones. I'm sorry to interrupt you.*
MR JONES: *Hello.*

Continued

Case example 3.1 Beginning a consultation—continued

STUDENT: *I'm Ben Brown, one of the students with Dr Morrison's team. I'm a medical student, learning to be doctor. Dr Morrison has asked me talk to you about the problem that brought you into hospital.*

MR JONES: *Okay.*

STUDENT: *I would like to ask you some questions, and I will pass the information on to Dr Morrison. It will take about half an hour. Would that be okay with you?*

MR JONES: *Yes, sure – go ahead. You can sit down there.*

STUDENT: *I'd like to take some notes, so that I have everything you tell me written down. Would that be all right?*

MR JONES: *That's fine by me.*

STUDENT: *Are you comfortable?*

MR JONES: *Yes, I'm fine – apart from my stomach though. I think that's what we're here to talk about.*

In this situation, the medical student was able to pick up on verbal and non-verbal cues from Mr Jones that he was happy to talk to a student and that he was not in too much pain or discomfort to have a conversation.

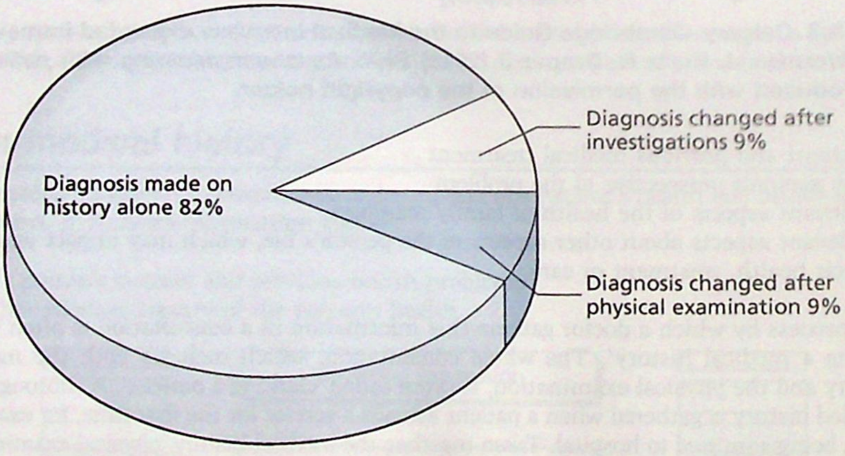


Fig. 3.4 Relative contribution of history, physical examination and investigations to final diagnosis.[4]

Gathering information for a medical history

"Listen to the patient. He is giving you the diagnosis." Attributed to William Osler.[3]

The importance of the conversation between the doctor and the patient in establishing a diagnosis has been confirmed in studies considering the relative contribution of the conversation, physical examination and subsequent tests and investigations. One study found that for 66 out of 80 patients, the correct diagnosis was made on the information gathered alone. For only 7 patients was the initial diagnosis changed after the physical examination and for a further 7 changed after the results of investigations were available (Fig. 3.4).[4]

These findings underline the importance of gathering information as accurately and efficiently as possible, using the skills outlined in Chapter 2. It is particularly important to *listen* attentively.

The somewhat old-fashioned phrase 'take a history from the patient' implies that the information flows in one direction, from patient to doctor – and that the patient is relatively passive. But we have seen in Chapter 2 that what the doctor does (e.g. style of questioning, listening, body language) influences how people divulge their problems. It has been said that doctors should learn to *receive*, not to *take*, a medical history.

The structure of a medical history

On beginning clinical training, students are often given written instructions on 'how to take a medical history'. It is important to consider:

- the content of the medical history, i.e. the information to be gathered (Table 3.1)
- the process of the consultation, i.e. communication with the patient
- to what extent the instructions foster consultations that are patient-centred.

This chapter has already used a number of examples of the specific terminology and turns of phrase used by the medical profession – known as medical jargon.

- *How many times has the word 'history' been used so far in this chapter?*
- *What do you think people who are not doctors understand by the term 'history'?*
- *One part of 'the history' is the 'drug history'. What do you think this comprises?*
- *What do you think the reaction would be from a patient if you said you wanted 'to ask about their drug history'?*

Initial information

This includes the person's full name and age, and any other relevant information (for example, that you and the patient did not speak the same language and the consultation was conducted via an interpreter).

Knowing the patient's name before the start of the consultation helps with greeting, but checking this information at the start is good practice. Note, however, that *'Are you John*

Table 3.1 The structure of a medical history

- Initial information
- Presenting complaint
- History of presenting complaint
- Ideas, concerns, expectations and goals
- Past medical, surgical and psychiatric history
- Drug history
- Allergies and adverse reactions
- Family history
- Social history
- Systems review
- Assessment of the patient's mental state

Eder?' is not in itself a greeting (it is checking a fact), but adding in a statement like *'Hello, Mr Eder, pleased to meet you'* completes the social aspect of the greeting. Ask if you are unsure of the pronunciation of a person's name. Taking the time to check a pronunciation is appreciated by patients and enables you to feel confident in using the person's name.

You might prefer that the patient refers to you using your first name, and some patients might be happy for you to use *their* first name. But this cannot be assumed – many adult patients, particularly older people, prefer the formality of being referred to by their title and surname. One solution is to start by using the person's title and surname and continue until told otherwise. Sometimes students are advised to check 'how the person wishes to be addressed', but this can lead to clunky questions like *'How would you like to be addressed?'* First names are generally used with younger patients (children and adolescents), but not necessarily with their parents.

Description of presenting problem

The problem that the patient has come to discuss with the doctor is called the 'presenting problem' or 'presenting complaint', and this can be:

- a symptom: something experienced by the patient, which can be physical or psychological (e.g. pain, feeling sad all the time)
- a sign: a physical indication of a problem (e.g. a breast lump, a limp)
- a combination of symptoms and/or signs.

The problem may be:

- new, in the sense of not having previously been discussed with a health professional
- an existing problem (for example, a long-term condition, sometimes known medically as a 'chronic' condition)
- related to an existing problem (e.g. new symptoms of dementia).

Bearing in mind that the most effective way to find out about a patient's problem is to:

- ask an open question, and
- listen without interrupting, until the patient has finished their opening statement

there are different ways of asking an open question. For example:

"Could you please tell me what problem has brought you to hospital?"
"Why have you come to see the doctor today?"

It is helpful to record the person's answer verbatim in the notes. Here are some examples from three patients:

Mr Alton: *(a teacher, aged 52) My bowels haven't been right for some time now, and I've had this pain in my stomach.*
Mrs Brown: *(a retired shop owner, aged 72) I've had trouble passing my water.*
Mr Dawes: *(an administrator, aged 47) I've had an attack of terrible pain in my chest, which is worrying me a lot.*

Sometimes a person will provide a diagnosis rather than a symptom: *'I have arthritis in my legs.'* When this happens, it is helpful to ask the person to elaborate on what they are experiencing, e.g. *'Could you tell me how that affects you?'*

Don't be put off if a diagnosis you have never heard of is mentioned:

PATIENT: *Well, I have Osler–Rendu–Weber syndrome.*
STUDENT: *I've just started and I'm afraid I haven't come across that condition yet – perhaps you could tell me what effect it has on you?*

People living with long-term conditions will have a very real understanding of the effects of symptoms and problems that you may only have read about, and learning from these experiences plays a valuable role in understanding the impact of these conditions.

People often voice concerns about what they have experienced:

MR DAWES: *I felt so awful that I thought I was going to die.*
STUDENT: *That must have been very frightening. Do you want to talk about it now or shall we go on, and talk about it later?*

Explicitly acknowledging a person's concerns or emotional reaction to the problem is an important part of showing that you are listening properly and *hearing* what the person is saying.

Next, ask the patient if he or she has *any other problems*. It is helpful to *identify* all the problems the person wishes to discuss with you before obtaining more detailed information:

STUDENT: *You've told me that it's painful when you pass urine. Before we discuss that further, could you tell me if you have any other problems?*
MRS BROWN: *Yes, I've been feeling a bit sick, and I've had back pain as well.*

It is helpful to make a list of all the problems the person mentions – physical, psychological and social – to be dealt with in turn. This helps you to organise the structure and pace of the consultation. It will also decrease the chance of a new problem – which can be the one that is worrying the patient most – being mentioned just as you are about to finish. Continuing to ask *'And is there anything else?'* until the person says *'No'* shows that you are willing to hear all the problems that the patient wishes to discuss.

Of course, sometimes people have problems that they have forgotten or may be reluctant to divulge at the start of the consultation. But as you proceed and build up a rapport, people find it easier to discuss their problems. Summarising periodically during a consultation, for example, after discussing each problem, can help. It provides the patient with an opportunity to add in anything else they wish to tell you, and for you to check that you have asked all the questions you wish to.

History of presenting problem

The aims of the history are to:

- obtain detailed information about the problem(s) for which the person is seeking help that is complete, accurate and relevant
- determine the effect the problem(s) on the patient's day-to-day life.

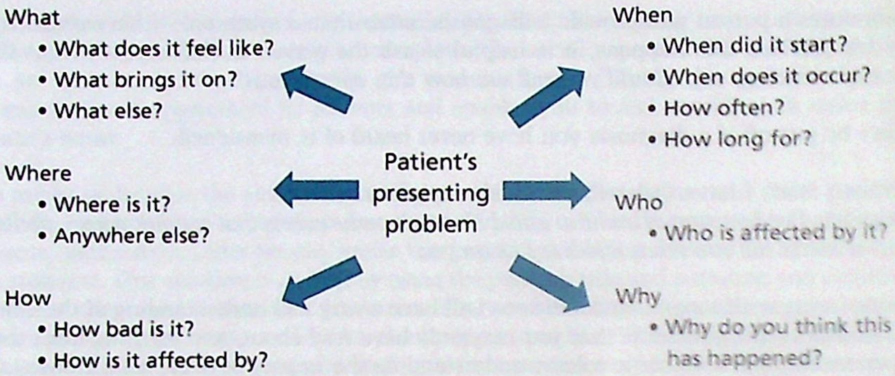


Fig. 3.5 History of the presenting problem.

To gather detailed information, often you will start by asking further open questions (Fig. 3.5). The exact nature of the questions will depend on the problem.

To consider this in more detail, we will look at the questions you might ask when a patient has come to the doctor with pain.

What is it like?

Symptoms vary in *quality*. For example, pain may be described as sharp, dull, tight, throbbing, constant or that it 'comes and goes'. This can be very important in identifying the diagnosis. For example, someone with pleurisy will usually mention chest pain that is sharp when breathing in, whereas someone who has had a heart attack will usually mention constant 'tight, gripping pain' in the chest.

What else?

Asking about other problems that the person has noticed (called 'associated symptoms' in the medical jargon) can provide essential information:

STUDENT: *When you had the pain in your chest, did you notice anything else at the same time?*

MR DAWES: *Yes, my heart was racing and I felt a bit out of breath.*

Where is it?

Establishing the *location* of the problem is particularly important. Asking the person to point exactly to the place on their body can provide more detail than words.

In some medical conditions, the pain *spreads* to another part of the body (called 'radiation' in the medical jargon). For example, a person with gallbladder disease may experience pain in the upper abdomen and in the right shoulder, and someone with a slipped disc may have back pain that spreads down their leg. Asking a person where they feel the pain is therefore important.

How bad is it?

You will want to know the *severity* of the problem, e.g. if pain is mild, moderate or severe. Of course, there is great variation in perception of and tolerance to pain, so it can be useful to ask the person to relate the severity of their present pain to a previous experience:

Mr Dawes: *The pain was pretty awful.*
Student: *Would you say it is the worst pain you have ever had?*
Mr Dawes: *Well, I had pain in my leg when I had sciatica, but this was far worse than that.*

How is it affected by...?

People sometimes find that there are 'modifying factors', which can either make the symptoms worse or better:

Student: *When you have the pain, is there anything that makes it better?*
Mr Alton: *It's better when I've passed wind or been to the toilet.*
Student: *Does what you eat affect it?*
Mr Alton: *I used to eat lots of vegetables and fruit, but I've cut that down and the pain seems to be a bit better.*
Student: *Do you ever take any medicine for the pain?*
Mr Alton: *No. I tried taking some painkillers for a few days, but that didn't seem to make any difference.*

When?

You will need to know about *timing:* when the pain began, how it started, its duration, how often it occurs and, if appropriate, how it ended. Sometimes it is helpful to ask the person to recall the first time the problem occurred and describe how it has developed since then. If there have been numerous episodes, ask the person to describe a typical one.

Student: *How long does the pain last?*
Mr Dawes: *Just a short while.*
Student: *Roughly how long is a short while?*
Mr Dawes: *Oh, less than half an hour.*
Student: *Less than half an hour.*
Mr Dawes: *About 20 minutes.*

It is important to establish the *context* in which the symptoms develop:

Student: *So you have pain in your abdomen, and problems with wind and trouble going to the toilet. Could you tell me about what you are usually doing when the pain comes on?*
Mr Alton: *I've been thinking about that. I never get this problem when I'm on holiday – it seems to happen mostly during the week when I'm busy at work.*

What effect does it have on the patient's quality of life?

You may have found out a lot about the impact of the problem on the person's life from the answers to your previous questions. It is also helpful to look specifically at the effect on the person's:

- mood
- relationships, particularly with a partner and close family
- job
- leisure and social life.

STUDENT: *I'm wondering what effect this has had on your life in general.*
MR ALTON: *I'm not sure what you're getting at, but I know I've felt a bit low at times.*
STUDENT: *A bit low? Can you tell me a bit more about what you mean by that?*
MR ALTON: *Well, I feel fed up when the pain comes just before we're going out and I have to sit on the toilet for ages and then we're late – my partner gets really cross.*
STUDENT: *Does that worry you?*
MR ALTON: *We've had our ups and downs – but not too bad, really. I think if it goes on like this it'll be a problem, because we've started to argue about it. If anything that makes it worse. I just want to go back to normal.*

Exploring the person's perspective: ideas, concerns, expectations and goals

Understanding what the problem means for the person is a key element in developing a collaborative working relationship. Establishing a shared understanding of the problem is a prerequisite for supporting the person in making decisions about care.

This includes asking what the person:

- thinks the problem might be caused by
- is worried about
- hopes the doctor/medical facility will be able to do
- hopes will be the end result.

Examples of questions are:

"Perhaps you could tell me what you think is causing your problem?"
"Is there anything that you are particularly worried about?"
"What are you hoping the doctor will be able to do today?"
"What are you hoping will happen?"
"What is most important to you?"

Past medical, surgical and psychiatric history

Information about the person's previous illnesses can help in understanding the current problem, and in considering the approach to treatment.

This includes information about the person's:

- previous general health
- previous illnesses
- admissions to hospital
- operations
- accidents and injuries
- pregnancies.

It is helpful to start by explaining what you intend to do (i.e. 'signposting'), and then go through the topics you need to cover:

STUDENT: *Now I'd like to ask you about any illnesses you've had in the past. Have you had any hospital treatment for anything?*

Mrs Brown: *Let me think, I had my appendix out when I was 15 or 16 and I had a really nasty chest infection when I was on holiday about 5 years ago. That's all.*

Student: *Have you had any other operations, apart from your appendix?*

Mrs Brown: *No, I haven't.*

Student: *And have you been in hospital at any other time?*

Mrs Brown: *Only when I had the two children.*

Student: *Were there any problems with your pregnancies?*

Mrs Brown: *No – never felt better!*

Student: *Could you tell me if you've had any accidents or injured yourself at any time?*

Mrs Brown: *Well, yes. I slipped on the ice and broke my leg about 10 years ago. Actually I was in hospital then.*

Student: *What sort of treatment did you have?*

Mrs Brown: *I had an operation – they said it was a nasty break. Seems okay now.*

Student: *Okay, so to recap what you've told me: you had your appendix out when you were about 15 or 16, and more recently, you broke your leg about 10 years ago, you had an operation for that, and you had a nasty chest infection about 5 years ago. You've had two children. Anything else you can remember, in terms of illnesses before now?*

Mrs Brown: *No, that's it.*

There are a number of conditions that you may want to specifically ask about at this stage. These will depend on circumstances, but may include conditions such as tuberculosis, rheumatic fever, diabetes and cancer.

You will notice that the student above used more closed or specific questions at this point, which is common – used judiciously – when screening for problems across a number of topics. The pace of the consultation and non-verbal communication is important in showing the patient that the topics are important and not being rushed through. The summary serves to check the information and to signal that the section is coming to a close.

Allergies and adverse reactions

Allergic reactions to substances (including food, insect stings, animal hair and pollen) and adverse reactions to medications are very common, but vary in degree. It is particularly important to check whether the person has any severe allergies which can cause an anaphylactic reaction, which can be fatal. One specific example is whether the person is allergic to penicillin.

Drug history

Medical professionals commonly use the term 'drugs', whereas members of the public are more likely to use terms such as 'medicine', 'medication', 'pills' and 'tablets'. The aim of the 'drug history' is to gather a comprehensive list of medicines being taken. It is also a good opportunity to ask about recreational drug use, if appropriate.

Include:

- all current medication prescribed by a doctor, including:
    - tablets
    - other types of medication, e.g. asthma inhalers, creams, adrenaline auto-injector

- all other medication the person is taking, including:
    - medicines that the person has bought over the counter
    - complementary, alternative and herbal remedies
- recreational drugs if used.

The aim is to gather specific, detailed information, including:

- how often the medication is taken
- dose
- side effects or other problems
- satisfaction with the medication.

For example:

STUDENT: *Now I'd like to ask you about any medicines you are taking. Have you been prescribed anything by a doctor?*
MR COX: *Well, tablets for, hypertension, the doctor called it. I didn't get on with them though, my legs swelled up.*
STUDENT: *Are you still taking them?*
MRS BROWN: *No, my friend at work said if I was tense, he recommended some tablets from the health food shop. I've been taking them for about three weeks.*
STUDENT: *Do you know what they are called?*
MRS BROWN: *Let me see if I've got some in my bag, and I can show you.*

Asking if the person has brought their medication with them, or a list, can be helpful if the person is unsure about names or doses.

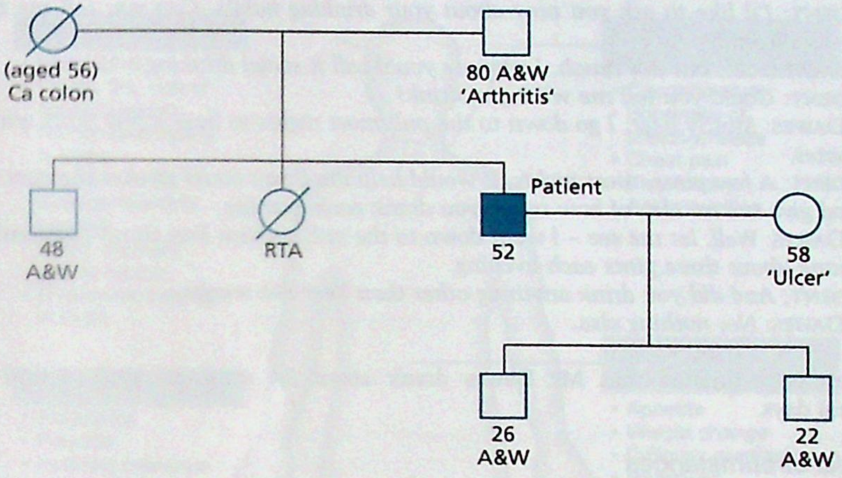
Family history

Gathering information about a person's *family's* health is important for two reasons. Firstly, the person may have a condition which is genetically determined. Secondly, the person's concerns about the problem may be related to the experience of other members of the family. For example, Mr Alton may be worried about his bowel symptoms because his father died from cancer of the colon. This is an important piece of information, partly because it will help you to understand why he might be particularly worried about cancer and also because he has an increased risk of developing cancer of the colon, which is, at least in part, genetically determined.

When gathering information for a family history ask about all first-degree relatives (parents, siblings, children): if they are living, and if not, the cause of death:

STUDENT: *I'm sorry to hear that your father died of cancer. How old was he when he died?*
MR ALTON: *He was 56, I think.*
STUDENT: *And your mother?*
MR ALTON: *Oh, she's well, apart from a bit of arthritis – she's 80.*

Towards the end, it can be helpful to ask if anyone in the family has had certain medical conditions, e.g. heart disease, high blood pressure, diabetes. You may wish to draw a medical family tree (Fig. 3.6).



Key: Ca = cancer; RTA = road traffic accident; A&W = alive and well

Fig. 3.6 **Family tree of Mr Alton.**

Social history

This part of the consultation focuses on other aspects relevant to the patient's health care, including:

- smoking
- alcohol consumption
- ability to complete daily tasks, such as self-care
- social circumstances, e.g. how work, family and caring responsibilities are affected by the illness
- current use of other health and social care services
- other legal issues.

Smoking

Ask if the person smokes, and if so, what do they smoke? How many per day, for how many years? If the person does not currently smoke, whether they smoked in the past and if so, for how long. The aim is to calculate the number of years the person has smoked the equivalent of a packet of 20 cigarettes per day (known as 'pack years').

Alcohol

Sometimes students are diffident about asking about alcohol, worrying about causing offence, but it is a standard part of a general health check or 'full clerking'. The aim is to determine the usual number of 'units' of alcohol the person consumes in one week, and whether this is spread over several days or concentrated (in 'single session' drinking). One unit is 8 grams of pure alcohol, which generally equates to about half a pint of beer, a small glass of wine (125 ml) or a small pub measure of spirits. Be aware that many beers and wines are stronger, and that measures (both in public establishments and home-poured) may be more generous.

STUDENT: *I'd like to ask you now about your drinking habits. Can you tell me if you drink alcohol?*

MR DAWES: *Yes, but not much. I suppose you'd call it social drinking.*

STUDENT: *Could you tell me what you drink?*

MR DAWES: *Mostly beer: I go down to the pub most nights to have a few pints with my mates.*

STUDENT: *A few pints, most nights. It would help me if you could go over the past week and give me an idea of how much you drank each evening.*

MR DAWES: *Well, let me see – I went down to the pub perhaps four times last week and drank about three pints each evening.*

STUDENT: *And did you drink anything other than beer last week?*

MR DAWES: *No, nothing else.*

It can be estimated that Mr Dawes drank about 24 units in total, spread over several days.

Social circumstances

This includes any relevant information about the patient's occupation, living conditions, family circumstances, dependents, and sources of support or stress. For example, an older person who lives alone in a flat which is only accessible by stairs may have difficulty if the treatment option is an operation resulting in a reduction in the person's mobility for a few weeks. A person's illness – and treatment – can have important effects on other people, which can cause both practical problems and stress for the patient.

Ability to complete daily tasks

This includes any difficulties the person has with the normal tasks needed to look after themselves (called 'activities of daily living') and problems with mobility. Important daily tasks include: preparing or eating food, washing and using the toilet, dressing and undressing, moving around and going out.

Current use of health and social care services

Ask about any other health services the person normally receives, such as visits by a district nurse, and any social care, such as visits by a carer or social worker.

Other legal issues

This includes, for example, if a person:

- has difficulties in making decisions about their own care (for example due to a mental health problem, dementia, or learning disability)
- has made an advance decision to refuse certain treatments
- has appointed a lasting power of attorney to make health care decisions on their behalf.

Systems review

This section of the consultation involves a series of questions related to each of the body systems. The purpose is to check for symptoms that the person may have forgotten or not considered significant (such as tiredness or unplanned weight loss). This is a very structured part of the consultation, comprising quite a lot of specific questions. To facilitate this:

- use an aide-mémoire: write down the body systems, with the symptoms and signs you will be asking about, and use it as a checklist during the consultation

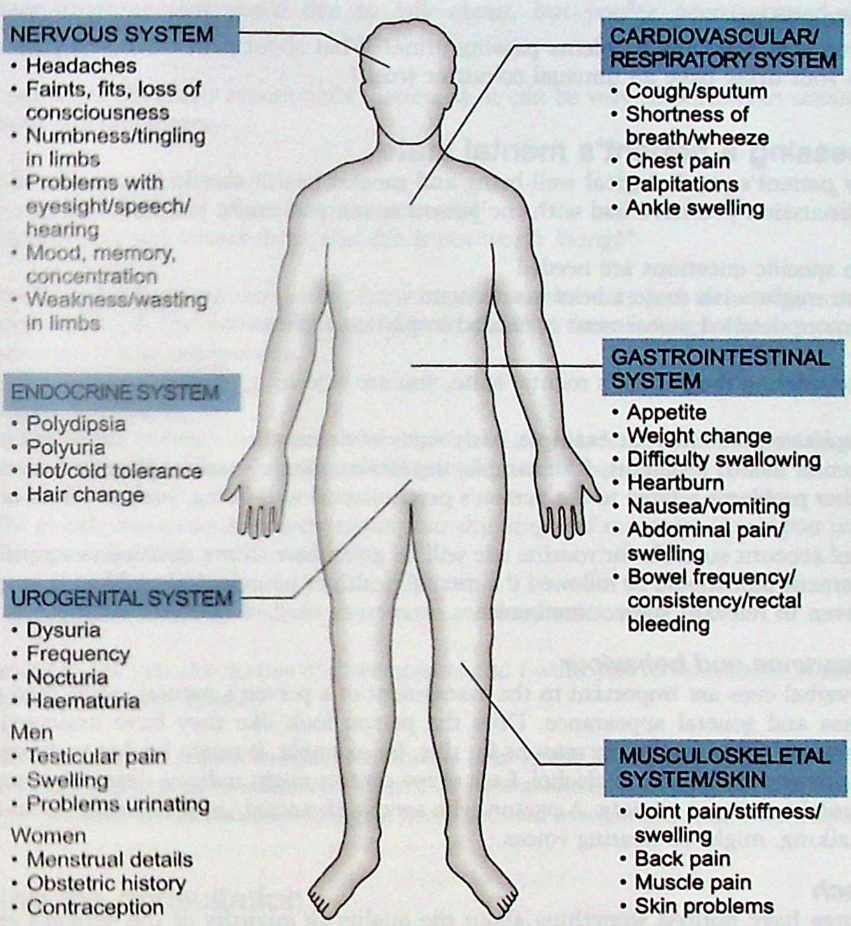


Fig. 3.7 **Systems review.**

- introduce this section of the consultation by saying something like: *'I'm now going to ask you a series of questions about common medical problems. This is to make sure we don't miss anything that may be important.'*

A common list of topics to be covered is shown in Fig. 3.7.

Examples of questions you might ask include the following:

Cardiovascular

Could you tell me if you have any trouble with your heart? What about chest pain? Noticing your heart pounding, or fluttering? Do your ankles ever swell?

Respiratory

Do you have any problem with your lungs, like feeling short of breath? Or coughing? Do you cough up sputum? What colour is it? Have you ever seen blood in it?

Genitourinary

Do you ever have any problems passing urine? What about pain when you pass urine? Does your urine have an unusual colour or smell?

Assessing a patient's mental state

Every patient's psychological well-being and mental health should be considered. From the discussion you have had with the person so far, you might feel that:

- no specific questions are needed
- you might wish to do a brief assessment
- a more detailed assessment is needed in particular areas.

By considering the patient's mental state, you are screening for any:

- cognitive problems, for example, early signs of dementia
- mental health problems, for example, depression, anxiety, schizophrenia
- other problems related to the person's psychological well-being, such as stress or grief.

A brief account suitable for routine use will be given here. More detailed descriptions of assessment that should be followed if a mental health or neurological problem is suspected are given in relevant subject textbooks.

Appearance and behaviour

Non-verbal cues are important in the assessment of a person's mental state. Take notice of dress and general appearance. Does the person look like they have neglected their appearance? There are many reasons for this, for example, it might be due to depression, dementia or dependence on alcohol. Lack of eye contact might indicate depression; restlessness might indicate anxiety. A person who seems distracted, as if listening to someone else talking, might be hearing voices.

Speech

You may have noticed something about the quality or quantity of the person's speech, which might indicate a psychological or neurological problem. For example, a person who is depressed may speak in a slow, flat tone; a person with mania may have a rapid, pressurised way of speaking.

Mood

During the consultation, you may have already gathered information about how the person feels generally, most of the time (called 'mood') or how they are feeling currently (called 'affect'). Does the person seem agitated, despondent, withdrawn, angry? To explore this further, you can ask general questions, such as:

"I'm wondering if you still enjoy life as much as you used to?"
"How have you reacted to the problems you've had?"
"Perhaps you can tell me if you've felt a bit down (stressed, anxious, excited) recently."

Thought content

The person may be experiencing thoughts or ideas that are troubling, but they might not share with you unless you specifically ask, e.g. delusions or thoughts about suicide. An appropriate first question could be:

"Could you tell me what's on your mind at present?"
"Has anything been particularly troubling you?"

"Is there anything that you'd like to talk about, but you've been worried about bringing up?"

If the person is obviously emotionally distressed, it can be very important to sensitively ask about suicidal intent:

"How do you see the future?"
"Have you had thoughts about harming yourself?"
"I wonder if you sometimes think that life is not worth living?"

People who have been contemplating harming themselves may feel too embarrassed or ashamed to broach the subject, but are able to disclose their feelings when questioned with sensitivity and compassion.[5]

Cognitive function

This refers to the person's awareness of the here-and-now ('orientation in time and place') and general mental functioning. An initial question could be:

"I'd like to ask you some questions about your thinking and memory. Could you tell me today's date and where you are now?"

Tests of cognitive function include short-term memory tests, e.g.:

"I'm going to tell you the names of three objects and I want you to remember them. The objects are fish, stars, house."

You can then ask the person to recall the objects later in the consultation. Another formal test is to ask the person to subtract 7 from 100 continuously. Carrying out a simple test like this can give an indication whether a more detailed assessment might be warranted.

Ending the consultation

By now you will be approaching the end of the consultation and should be familiar with the person's story and ready to write up your notes. As discussed in Chapter 2, the way in which you finish the interview is important.

What are the key steps in closing a consultation?

Writing up the medical history

There are some key differences between the conversation you have with a patient and how the information is written up (Table 3.2).

Writing up the notes enables you to organise the information and your thoughts. Notes are generally concise, and follow the order of the structure of the medical history (see Table 3.1). The beginning will include the date, time, location/service, patient's name (and identifying information, such as a hospital number), and your name and role. The ending will include a summary of the problems, a list of possible diagnoses ('differential diagnosis') and a suggested management plan (e.g. suggested further investigations or tests). If your notes are not being written in order to add to the person's medical record, avoid including any details that would allow anyone else to identify the patient, in case your notes are lost. For example, use the patient's initials rather than their full name.

Table 3.2 Differences between a consultation and the written notes

A face-to-face discussion with a patient to gather a medical history:

- Has a beginning (introductions, pleasantries, agreeing on an agenda)
- May include other topics (including small talk)
- Doesn't have to be strictly in order
- Is conducted in lay language (avoiding medical jargon)
- Includes 'signposts' to preface each section
- Sometimes includes a rationale for asking certain questions
- Enables you to establish the person's perspective and worries at various points
- **Helps to develop trust and an effective partnership**
- Requires different skills in responding to people in different settings and situations
- **Has an ending (summary, checking, thanks)**

A presented or written version for colleagues:

- Is given strictly in order
- Predominantly consists of medical jargon and abbreviations
- Includes differential diagnosis and a suggested management plan

Variations of the medical history

Becoming proficient in gathering information using the structure of a medical history takes time and practice. Regularly practising 'a full clerking' by running through the full list of topics – with patients with different problems, in different settings – helps to embed this as a fundamental skill. However, not all consultations to gather information are the same. For example, it would be inappropriate to spend time gathering information for a full medical history when a patient has just arrived in an emergency department with severe injuries after a road-traffic accident or with severe chest pain of sudden onset.

Similarly, in outpatient clinics and general practice, doctors are often selective in which aspects of the history to focus on. This reflects the way in which the doctor approaches the task of making a diagnosis and considering treatment options. Often, gathering all possible information from a patient (including the history, physical examination and investigations), and only then working out the diagnosis, is not the most efficient way to proceed in practice.

How then do doctors make a diagnosis? Studies have shown that doctors use their clinical knowledge and experience early on in the consultation to make a list of possible diagnoses. Some might be considered much more likely than others. Some can be ruled out very quickly. The doctor then seeks information that will either help to support, or reject, each potential diagnosis. This process of clinical reasoning (including 'hypothesis-testing' and 'pattern recognition') develops with experience.

However there are pitfalls – closing in too early on a suspected diagnosis may lead to important information being missed. For example, when questions are only being asked to *confirm* a particular diagnosis, and when information that is inconsistent with the diagnosis, or points towards another diagnosis, is ignored. The process of determining what information is needed and in how much detail is a key professional skill, which develops over time, with practice and experience.

Some practical hints

- Take every opportunity to speak to patients. There is no substitute for repeated practice with patients.
- Be realistic about how long a consultation will take, and agree upon this with a patient. You will speed up as you become more experienced.
- You are more likely to gather a good history if you use the skills outlined in Chapter 2:

  - Establish rapport.
  - Listen actively.
  - Ask mainly open questions in the early stages.
  - Pick up and respond to the person's verbal and non-verbal cues.
  - Facilitate or help if the patient gets stuck.
  - Summarise and check for accuracy.

- Make an aide-mémoire of the structure of the history to use during the conversation.
- Most people need to take notes as they are speaking with a patient. You may decide to make rough notes and to write them up later. Be aware of the effect of making notes on eye contact – don't give the impression that your notes are more important than what the patient is saying. It can help to say what you are writing as you write it down, which acts as a reflection or mini-summary, and then the note-taking becomes part of the conversation.

Presenting a patient's medical history

Formally presenting a medical history at a case conference or ward round is an invaluable part of learning how to communicate professionally with colleagues. Throughout your career, you will present the information from a medical history in many ways (in person, in written form, by phone) for a number of different reasons (e.g. to refer a patient to another doctor, to request certain investigations, to ask for advice from your senior colleagues, to hand over to other members of your team).

At first, it can seem daunting, but with practice will become one of your fundamental skills (Table 3.3).

Common concerns about meeting patients as a student

The patient refuses to see me

Most patients are happy to see students and often benefit from the time you spend with them: being listened to can be therapeutic in its own right. Plus many people wish to help in the training of future doctors. Sometimes, however, a patient may have told his or her story to several students and does not want to do it again, or may be feeling very unwell, or may be emotionally distressed (whether or not they show it). Respect the person's right not to speak with you and don't take it as a personal affront.

Table 3.3 Tips for presenting a patient's medical history

Preparation

- Obtain as much information as possible, i.e. the history, the findings of physical examination and results of investigations
- Write up the history using the standard structure
- Check whether you need to go back to the patient to clarify any points or ask for further information
- Read up in a textbook about the medical condition or possible conditions
- Identify the most important features you wish to emphasise
- Summarise details using headings and write them down (aide-mémoire)
- Think about possible questions you might be asked

Presentation

- Have your summary and the full written history with you
- Relax
- Speak clearly and fluently
- Look at your audience
- Be concise
- If you are asked a question and know the answer, express it confidently; if you are unsure or do not know, say so
- Be sensitive to the needs of the patient if he or she is present

Follow up

- If possible, go back to see your patient after the round to discuss any concerns he or she may have arising from anything that was discussed
- Reflect on the presentation: What did you do well? What could you have improved? What questions were you asked and what did you learn from this? Ask for honest and constructive feedback from your peers
- Consider how you might present the information if you were referring the patient to another doctor over the phone, or writing a letter back to the patient's general practitioner

I will forget what question to ask next

Gathering information from a patient involves more than asking questions. It is natural to feel anxious when there are gaps in the conversation, but silences are important for everyone to reflect on what has been discussed so far. Try telling a story to a friend, who is constantly interrupting you to ask questions, and see how quickly you lose the thread of the conversation. Summarising what the patient has told you so far can help.

The patient asks me a question about his or her condition

As a general rule, you should not answer questions that patients may ask you about their condition but suggest that they ask their doctor. Never be afraid to say:

"I don't know. As a student, I'm still learning. I don't want to give you any information that isn't correct. I can ask the doctor to discuss that with you."

Similarly off-hand remarks, like: 'Oh, I'm sure it's nothing to worry about' or 'I'm sure you'll be fine' or 'I expect the doctor will send you for tests at the hospital' may be taken as fact. The patient's concerns are an important part of the medical history and your supervising doctor will expect you to pass these on.

The patient tells me something in confidence

Confidentiality is an essential part of the patient–doctor relationship and has been enshrined in professional codes of practice since Hippocrates. Patients may feel that it is easier to talk to you as a student, particularly as you may be able to spend more time with them than some of the qualified staff. Occasionally, someone may want to give you information but will ask you to keep it confidential. This puts you in a difficult position. Some general guidelines are:

- It can help for patients to know that information is kept within the medical team and cannot be disclosed to others (e.g. the patient's family) without the patient's agreement. Only in very exceptional circumstances can a doctor break a patient's confidence when the patient has not agreed that information can be divulged. There is specific professional guidance about confidentiality.[6]
- Clarify whether the patient means that they only want you and the doctor to know, or whether they really do not want you to tell anyone else, including the doctor.
- As a student, never promise a patient confidentiality. As part of your introduction, say that you are going to pass on the information to the doctor. Do not say that 'everything you discuss will be confidential'.
- Explain that keeping information confidential (i.e. in the sense of you not telling anyone else, including the doctor) would put you in a difficult position. Sometimes people don't realise the full implications of the difference between a student and a doctor.
- Do not promise confidentiality in order to encourage a patient to disclose information.
- It can be helpful to explore why the person wants to keep the information confidential.
- If in doubt, discuss your predicament with a senior member of staff.

Having this conversation can help the person to decide for themselves what they prefer to do with the information.

The patient becomes emotional or starts crying

It is natural to feel anxious and embarrassed if a patient becomes tearful. Generally it is helpful to try to control your anxiety (it may be communicated to the patient), avoid rushing in to 'try to make it better' and simply give the person an opportunity to express the emotion. You can help by:

- listening
- showing empathy
- without having to be asked, putting a tissue into the patient's hand
- perhaps by touching the patient's arm or hand if this feels appropriate
- using reflective comments.

For example:

"I can see this is very upsetting for you."
"Would you like to tell me more about how you feel?"

Sitting with the patient for a time can be the most helpful and supportive approach.

Key points

- The doctor–patient consultation is the cornerstone of the process to identify the medical problem.
- Core skills to help gather information are using open questions, listening carefully, responding to verbal and non-verbal cues and adapting the consultation style to meet the needs of the situation and setting.
- Practising gathering information using the structure of a medical history helps to embed this as a fundamental skill.

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Discussing sensitive topics

Robert Bor, Margaret Lloyd, Lorraine Noble

4

Which topics are difficult to discuss?

So far, we have discussed gathering information with patients about medical problems, and often this means asking a series of routine questions in a fairly standard order. A person coming to visit the doctor will generally expect to discuss their current symptoms, for example, and other relevant aspects such as previous illnesses or the effects of the problem on their day-to-day life. However, some conversations are not so routine, as there are topics that people find more difficult or sensitive to discuss (Table 4.1). Many patients find it difficult, and at times extremely challenging, to seek help for these problems. It is important that if a patient has summoned the courage to seek help, that this help-seeking is validated and supported.

Topics may be difficult due to a number of reasons: embarrassment, shame, fear of being judged, fear of bad news, worry about not having the right words. In this chapter we will consider how to help people to discuss sensitive subjects, and then we will consider talking about sex as an example in more detail.

Broaching a sensitive topic

Consider a time when you had to discuss something sensitive with another person. This could be something to do with your health, your relationships, your work – any aspect of your life. Try to remember how you felt just before the conversation.

What was the subject and why was it sensitive to you?
How did you raise the subject in the conversation and how did you choose how you were going to broach it?
What response were you hoping for?

Table 4.1 Examples of topics that can be difficult to discuss

- Sex and sexual health
- Bereavement and death
- Serious and incurable illness
- Mental health
- Bowel and bladder function
- Obesity
- Physical appearance
- Termination of pregnancy
- Behaviours that can affect health (e.g. alcohol, recreational drugs)
- Addiction
- Violence and sexual abuse

Sometimes a person will raise a difficult subject directly:

STUDENT: *Why did you come to see the doctor today?*
MRS JENKINS: *I've been taking these tablets for depression for two months now, but it's not any better. I just can't see a reason to go on anymore.*

At other times, a topic will be alluded to indirectly. A person might be building up the courage to broach the topic or might be 'testing the waters' to see how the other person might react. In a consultation, a patient may offer a cue about a topic they wish to discuss, but proceed only if given 'permission' to elaborate:

STUDENT: *Have you had any other symptoms?*
MR FROOME: *No, not symptoms as such. Things just aren't the same really. You have to get on with it though.*
STUDENT: *'Things aren't the same'? Was there something you were worried about?*
MR FROOME: *Well I've not been able to, you know, with my wife.*
STUDENT: *You're having problems having sex?*
MR FROOME: *Yes. It just won't come up.*

In other situations, the doctor or student may feel that a sensitive topic needs to be broached:

STUDENT: *So you have bruises on both arms and on your face?*
MS LANDA: *Yes.*
STUDENT: *How did it happen?*
MS LANDA: *Well I had a bit of a to-do with my boyfriend, but it was my fault. He's a really good guy.*
STUDENT: *Can I ask whether he hurt you physically?*

You may be the first person that the patient has spoken to. People are often worried about the reaction to the disclosure. It can be helpful to acknowledge that a subject is sensitive and emphasise that the person is in control of the discussion, for example:

"I can see that this is difficult to talk about."
"Would you like to talk more about this today?"

When a sensitive subject is raised unexpectedly, it can momentarily throw your train of thought – but be aware that verbal or non-verbal signs of surprise might be misinterpreted as shock or even disapproval. Showing an immediate willingness to listen can be a helpful and supportive response, for example:

"Would you like to tell me more about that?"

Discussing a sensitive topic

The aim is to explore the person's experience of the situation, in particular:

- what has happened
- what effect has it had on the person
- what is the person hoping for.

Creating a supportive climate in which a difficult subject can be discussed relies on the core skills discussed in the previous chapters:

- building rapport early in the conversation
- actively listening
- asking open questions to encourage the person to tell their story
- responding with empathy.

Establishing the person's own perspective and reactions to the situation is the key to understanding their experience. When faced with a difficult situation, we all have our thoughts about how we might react, but the aim is to recognise the other person's feelings and experiences. Try to be aware of any assumptions that may be affecting your ability to explore the person's perspective.

MS NORTON: *The pregnancy test came back positive. We do really want this baby.*
STUDENT: *So this is a planned pregnancy?*
MS NORTON: *Yes.*
STUDENT: *How exciting! Is this your first baby?*
MS NORTON: *Well, I got pregnant about six years ago.*
STUDENT: *Oh, I didn't realise you already had a child.*
MS NORTON: *I don't – I had a termination. I hadn't realised how much I'd be thinking about it again.*

Being aware of what the situation means for the patient

There can be differences in your perspective of the situation and the patient's. For example, imagine that you are seeing a patient with a skin condition, where permanent pale patches develop on the face or hands (called vitiligo). The person naturally has pale skin, so the patches are not very visible, and you have seen patients whose condition is much more obvious. You may be inclined to reassure your patient that their condition is very mild in comparison with others. Although genuine, a response such as this might serve to trivialise the patient's experience or make them feel upset for having talked about it in the first place. 'Off-the-cuff' attempts at reassurance like this are most likely to happen when we feel lost for words, are under time pressure, or meeting a patient for the first time and are trying to form a positive bond with them.

As discussed in Chapter 2, empathy is the ability to accurately understand the person's feelings and experiences and reflect this understanding back to the person in a supportive way. The aim of empathic understanding is not just to acknowledge a person's emotions, however, but to identify the meaning of the situation for the person, to help both of you develop a deeper understanding (Table 4.2).

For example, consider an empathic response to this patient's statement:

"Since the acne has got much worse, I've felt that nothing has gone right. People don't like me. I don't like my work, and my relationship with my boyfriend has gone downhill. I don't like what I've become."

A low-level empathic response could be:

"It sounds as if, since your acne has got worse, that things haven't been going well for you."

Table 4.2 Empathic understanding

- Recognises the patient's feelings in response to their particular situation, which may be complex or ambivalent
- Goes beyond the recognition of obvious feelings to the level of emotions that are less clearly expressed
- Can help patients identify the meaning of an experience for themselves, about which they may initially be unaware

This reflects part of the patient's sentiment, but does not echo the magnitude of the problem the person is describing. A slightly more empathic response could be:

"So it seems that, since it's got worse, the acne has made you feel quite negative about things."

This conveys an understanding of the person's feelings, but again, limits the problem rather than attempting to understand the effect of the situation on the patient. An attempt to show a deeper understanding could be:

"From what you're saying, when the acne flares up, it affects many parts of your life at the same time. So it's not only that you don't like the way you look, but you don't like who you are."

People often worry about being judged when they describe a sensitive or difficult situation. A person may – quite accurately – surmise that you might well react in a different way if faced with the same set of circumstances. Similarly, at times you may find it difficult to understand the person's experience, either because it feels far removed from your own life experiences or because you cannot imagine making the same choices. It is important to recognise any barriers to empathy and be honest with yourself about these.

A useful concept is 'unconditional positive regard', which is an approach where you show that you care for the person and accept them as they are, without judgement (Table 4.3).[1]

MR DEAKIN: *I haven't been able to cut down. I went out every night last week, and I probably drank the same amount as the week before.*

STUDENT: *You planned to reduce your drinking, but that didn't happen?*

MR DEAKIN: *It seemed like a good idea when I came to the surgery, but what is there, if you can't spend time with your friends?*

STUDENT: *You feel you would be missing out on your social life?*

MR DEAKIN: *I can't stand going home. Susan doesn't have time for me anymore, and with the kids I can't get any peace. It's bedlam. She keeps telling me I should do more around the house and 'spend time with the kids'.*

STUDENT: *So you're finding it stressful at home, and spending more time out with your friends, which means you are drinking the same amount as you were. What's your take on the situation?*

MR DEAKIN: *I feel trapped, if I'm honest. I only drink this much when I'm really stressed.*

Talking about sex

Although it may seem easier to talk about sex in a genitourinary medicine clinic, medical problems in many settings can cause sexual problems that a patient may wish to discuss.

Table 4.3 Unconditional positive regard

- Involves expressing genuine care for the patient
- Does not evaluate the patient's thoughts, feelings or actions in comparison to how you feel you would cope in the same situation
- The attitude towards the patient is 'I accept you as you are' not 'I will accept you when...'
- Recognises the patient's right to have feelings (which may well differ from your own), though this does not necessarily mean that you would approve of all their behaviour

Table 4.4 Example assumptions and misconceptions about sexuality

- Old people don't have sex
- Gay men only have sex with men
- A married person couldn't have a sexually transmitted infection
- Young people under the legal age of consent don't have sex
- Everyone understands the basics of reproduction and contraception
- People know when they have a sexually transmitted infection
- The presence of sexual problems usually means that the person also has psychological problems
- When people have concerns about a sexual problem, they always raise them with the doctor
- Everyone understands the medical terms doctors use when describing sexual activities and genitalia
- You can tell a person's sexual orientation by his or her appearance

In addition, in many instances patients go to the doctor to discuss a sexual problem, but during the consultation become inhibited and fail to raise their concerns. It is important that doctors and medical students working in a wide range of settings are able to convey to the patient that they are not embarrassed to talk about sexual problems, whether these:

- are the reason for seeking medical care or
- stem from another problem.

Barriers to open communication about sexual problems include stereotypes and unchallenged assumptions about people's lifestyles and behaviour (Table 4.4). Assumptions can prevent information being gathered about important issues.

Gender differences and cultural rules may further complicate the doctor-patient relationship where sexual problems need to be discussed. Some female patients may feel uncomfortable discussing intimate issues with a male doctor or student (and vice versa), particularly if they are worried that they may then have to be examined. Most patients feel both vulnerable and self-conscious being physically examined.

Our personal attitudes towards sexual practices and lifestyle may influence how sexual problems are discussed with patients. Verbal and non-verbal behaviour can communicate indifference to, acceptance or rejection of sexual practices. Subtle hints about the clinician's personal values can influence patients in deciding whether to disclose or withhold their worries.

When to talk about sex

Gathering information about sex and sexual health may be required in the following situations.

Where a person arrives with a problem that is likely to be sexually related

A patient may state at the outset that the problem relates to sex, e.g. request for contraception, pain on having intercourse. Certain symptoms, such as a genital discharge, would also prompt gathering information to obtain a sexual history.

When a person has a problem that may lead to sexual difficulties

Medical problems, both physical and psychological, frequently have implications for a person's relationships and sexual activity. Problems with sexual function, such as impotence, can result from diabetes, infertility, alcohol dependence and grief, to name but a few. A person with an existing medical problem, like HIV, may worry about disclosing their status to a partner when starting a new relationship.

When medical treatment can lead to sexual difficulties

Certain treatments, including medications and operations, can cause problems with libido (sexual desire) and sexual function.

At different stages of life

People who seek advice on sexual health may be: having sex for the first time, wishing to avoid pregnancy, wanting to start a family, starting a new relationship after separating from a long-term partner, going through the menopause, and so on.

Gathering information for a sexual history

When a person has come to discuss a sexual problem, it is obvious that it is necessary to gather information for a 'sexual history'. But when the main problem that the person has come to discuss is not a sexual problem, there can be a dilemma as to whether it is appropriate to broach the subject. The advantages and disadvantages of asking patients about sexual health matters are set out in Table 4.5.

There is a difference between asking a patient whether he or she has any sexual or relationship problems whilst gathering information for a general medical history and gathering information for a detailed sexual history. As part of a general medical history, a starting point could be to ask if the person has any worries about their sexual health.

The setting

The setting in which the consultation takes place directly influences what can be achieved. An open ward which offers little privacy to the patient, an unfamiliar outpatient clinic or a busy general practice surgery, can affect how comfortable the patient is in having the conversation. Ensuring that the environment in which the consultation takes place:

Table 4.5 Advantages and disadvantages of asking about sexual problems

Advantages

- It shows that sexual problems are within the normal range of problems discussed with the doctor
- Patients may feel more comfortable about mentioning sexual problems in future consultations
- It can be an opportunity for health promotion

Difficulties

- It may be embarrassing for the patient and doctor
- The person may feel that his or her lifestyle is being judged
- The person may begin to worry about something that was not previously a problem

- is private (the conversation cannot be overheard)
- feels welcoming
- is free of interruptions

are all important in creating a supportive climate for the conversation.

Confidentiality

People are often worried about who else may be privy to the information they provide during the consultation. There are very specific rules about confidentiality, particularly in sexual health clinics.[2] It is helpful to reiterate to patients the relevant policy about confidentiality.

Start with the presenting problem

As usual when gathering information for a medical history, start with the problem the person has come to talk about, and then progress to more sensitive areas later on in the conversation. At the end of a discussion about other problems, a general question might be:

"Apart from this problem, is there anything else you would like to discuss with me?"
"Is there anything about a relationship or a sexual matter that you wanted to talk about?"

Be purposeful

Where it is important to open the discussion, it is helpful to be purposeful and direct. For example:

"Do you mind if I ask you some questions about your sexual relationships?"

Both verbal and non-verbal cues are helpful in demonstrating that you are comfortable in discussing topics related to sex and sexual health. These include:

- maintaining a normal amount of eye contact
- asking questions clearly

- using the same tone of voice as for questions about other topics
- having a clear structure and a set of routine questions.

Being clear about what information you need, and why you need it, is critical for you to feel confident in asking questions, and in providing a rationale for why you are asking the questions. Considering the wording of your questions in advance of a conversation with a patient enables you to ask questions fluently. Undue hesitation, when obviously struggling to find the words to express a question, can be interpreted as embarrassment or an indication that you do not really want to discuss the topic. That said, being purposeful does not mean rushing through the discussion.

Consider language

People vary in their preferred terms for describing parts of the anatomy and sexual activities. The aim is to be clear, and this involves striking a balance between:

- medical terms, which may be precise, but poorly understood
- colloquial language, which may be understood but might be seen as unprofessional or offensive.

Consider which terms you are comfortable using, and ask colleagues in different specialities and settings which words they use. When speaking with patients, and observing consultations on clinical attachments, see what reaction different words and phrases have in helping a patient to feel comfortable and facilitating the flow of conversation. Preferred words and phrases for sensitive subjects may differ, depending on the patient's background and age, for example. Generally it is helpful to use more neutral terms, for example 'having sex' rather than 'making love'.

People also vary in the way they prefer to describe themselves and their relationships. For example, consider the terms 'homosexual', 'gay' and 'men having sex with men' – terminology used within a culture changes over time, but the aim in taking a sexual history is not to 'put labels' on people. The aim is to gather specific information in order to understand a person's relationships and any risks to their sexual health. Try to be vigilant to any 'unconscious biases' you may have, in terms of making assumptions about people's relationships or sexual activities based on stereotypes or your own cultural upbringing. Also be aware that people who self-identify as gay, lesbian, bisexual or transgender may have experienced discrimination and negative attitudes, even in their contact with health care services, and that the language that you use is particularly important in demonstrating empathy and a commitment to providing high quality care.

Gather information about relationships

Initial questions do not presume the gender of a partner or the nature of the person's relationships, for example:

"Do you have a regular partner?"
"How many other partners have you had?"
"When did you last have a sexual contact?"

Follow-on questions can add detail to the information already gathered:

"Was this with a man or a woman, or both?"
"Have you previously had a sexual relationship with a man or woman?"

The implications of a sexual problem for the patient's personal relationships should also be addressed, for example:

"So your girlfriend does not know you have this discharge from your penis?"

Gather information about sexual activities

In order to establish the implications for the person's health, it is important to clarify details, for example, to establish whether the person may be at risk of sexually transmitted infections or an unwanted pregnancy. It sometimes helps to formulate questions by:

- reflecting back the patient's own words
- listing sexual activities.

"You say you had sex. Can I check with you, does that mean you had oral sex … vaginal sex … anal sex?"

Clarify any terms that are unfamiliar:

"I haven't heard that expression before: 'slamming Tina'. Can you please explain to me what it means?"

The way questions are framed can help a patient to feel more comfortable and less likely to feel judged. For example:

"So apart from your regular girlfriend and the girl you met at the weekend, have you had sex with anyone else recently?"

rather than

"Have you cheated on your girlfriend with anyone else?"

Gather further information to provide a comprehensive sexual history

Addressing the main problem is one aspect of gathering information for a history. For a more comprehensive sexual history, information might include the following:

- nature of previous sexual activities
- methods of contraception and barrier protection methods
- previous sexually transmitted infections, including relevant factors, such as travel away from home, use of alcohol or drugs
- previous pregnancies, miscarriages and terminations
- age of first sexual experience
- sexual abuse
- psychological problems
- psychosexual problems (e.g. erection, ejaculation, loss of sexual desire, pain during intercourse)
- cultural and religious rules and practices.

More detailed information on gathering information about a sexual history is given in:

- *2013 UK national guideline for consultations requiring sexual history taking*[2]
- *A guide to taking a sexual history*[3]

Case example 4.1 A married man worried he might have contracted HIV

Mr Jones, aged 32, had had sex while on a business trip 3 years ago and now he is worried about AIDS.

Mr Jones: *I've had night sweats and diarrhoea.*
Student: *For how long?*
Mr Jones: *Both of them, for the past week.*
Student: *Have you noticed any other problems?*
Mr Jones: *I can't sleep I'm so worried.*
Student: *I'd like to ask you a few more questions. Are you in a relationship with anyone?*
Mr Jones: *I've been married for 10 years. My wife doesn't know I'm here.*
Student: *Do you and your wife have a sexual relationship?*
Mr Jones: *Of sorts. It hasn't been very good since we had our last child 4 years ago. There's never been anyone else except the prostitute on that trip.*
Student: *I need to check with you whether you have sex with your wife.*
Mr Jones: *Occasionally.*
Student: *Do you use any form of contraception?*
Mr Jones: *She's on the pill and we also use condoms. She finds sex a bit messy!*
Student: *Is there any other way in which anything could be passed on to her during sex?*
Mr Jones: *I don't think so; she doesn't like oral sex.*
Student: *What sort of sex did you have with the prostitute?*
Mr Jones: *Intercourse. We used a condom. But I can't remember if it broke – I'd been drinking.*
Student: *Was this anal or vaginal intercourse?*
Mr Jones: *No, just 'straight'.*
Student: *Did you notice any symptoms in the few days after you had intercourse?*
Mr Jones: *Mmm, such as?*
Student: *Maybe a discharge from your penis? Any sores? Itching?*
Mr Jones: *Not that I remember. There's nothing like that now, anyway.*
Student: *Have you had a test for HIV before, or any tests for any other sexually transmitted infections?*
Mr Jones: *No.*

Key points

- Supporting a person in talking about a difficult topic involves:
  - helping a person to broach the subject
  - showing a willingness to listen
  - responding with empathy.
- Being aware of what the situation means to the patient is key to an effective discussion.
- Discussing sexual health is important in with many patients, in many settings, at different times in people's lives.
- Being clear about the information needed and being prepared to ask specific questions helps in discussing sexual topics, as well as other difficult and sensitive topics.

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5

Sharing information

Lorraine Noble, Margaret Lloyd, Robert Bor

The information obtained from the medical history, physical examination and investigations will enable a diagnosis to be made for most patients and a management plan to be devised for all patients.

The importance of sharing information with patients has been highlighted by the General Medical Council in the UK in their duties of a doctor:[1]

- *You must give patients the information they want or need to know in a way they can understand.*
- *You must work in partnership with patients, sharing with them the information they will need to make decisions about their care.*

The NHS Patient Experience Framework notes that people need to have information on their:[2]

- clinical status
- progress
- prognosis
- processes of care

in order to facilitate:

- patient autonomy
- self-care
- health promotion.

In addition, the NHS National Quality Board has highlighted elements of a good experience of care (Table 5.1).[3]

The way in which information is shared with patients has been shown to have a profound effect on several outcomes of care, including people's:[4–7]

- satisfaction with care from the doctor
- ability to understand and recall information about the problem and the management plan
- involvement in, and satisfaction with, decisions about treatment
- level of anxiety and stress
- ability to follow through the treatment plan in the long term
- use of health care services (e.g. time spent in hospital, need for pain-relieving medication).

Table 5.1 What is a good experience of care?[3]

All users of health services should be able to say:

- I am involved as an active partner in my care
- I am treated as an individual – my needs, values and preferences are respected
- The people providing my care recognise that I am the expert on me
- I have access to the information I need, which is presented in a way that is right for me
- Communication is tailored to me and is delivered with care and compassion
- I have the opportunity and time to ask questions and have a conversation about my care, treatment and support
- I have access to the support I need, including emotional and practical support

Surveys of patients have found that communication of information has been improving over time, but there are still shortfalls in whether patients:[8]

- always receive an answer they can understand from the doctor, when asking important questions
- are involved as much as they want to be in decisions about care and treatment
- receive a complete explanation of what will be done during an operation or procedure
- are given information about what they should and should not do on leaving hospital
- have a discussion about any further health or social care services they might need
- receive enough emotional support during a stay in hospital.

In addition, more than one in five patients in hospital felt that doctors talked in front of them as if they weren't there.[8]

Preparing to share information

Imagine you are a doctor looking after Mr Roy:

Mr Roy is a 50-year-old man. He reports a 2-month history of heartburn, with occasional chest pain, which is worse after meals, particularly after his evening meal. He has a past medical history of a stomach ulcer, 10 years ago. Investigations including endoscopy examination has confirmed a diagnosis of hiatus hernia. Recommended management: lifestyle changes to dietary habits, weight loss, and medication (PPI).

Do you feel that you are ready to go and speak to Mr Roy?

What might you do in advance of the consultation?

Sharing information with patients about their condition and treatment options is an important part of the process of care. This consultation may be the only opportunity you have to discuss this with the patient. If you are asked to give a presentation, you would normally prepare your material in advance. Similarly it is helpful to make a plan for the consultation before meeting with the patient.

1. Clarify in your own mind the information you plan to share

Having accurate and comprehensive knowledge of the medical condition and possible treatment options is a prerequisite to providing an explanation to another person. What are the key points that you wish to cover? How long will the consultation be and how will you allocate the time?

2. Consider what the person already knows

You may have already had a conversation with the patient about what the problem might be or a colleague may have written about what they have discussed with the patient in the medical notes. If you know the person's starting point and any concerns they have mentioned previously, you can build on this. However, you might have no information about what the person already knows or is worried about.

3. Think about questions you might be asked

People often want to know:

- How did the problem come about?
- What is causing the symptoms?
- Is it serious?
- Will it get better on its own?
- How long does the treatment last?
- What effect is this going to have on my day-to-day life?

4. Translate medical jargon

Without using any medical jargon, can you explain what a 'hiatus hernia' is?

During medical training, students become immersed in a language which is not shared by the majority of the population. A particular feature of this socialisation process is that the jargon is given first, followed by an explanation of what it means, as in: *'In today's lecture, we are going to cover Hiatus Hernia. This is when part of the stomach squeezes through an opening...'* Unfortunately this is not the most helpful way to provide information to someone who has only very occasional brushes with medical jargon. The principle:

"given before new"[9]

succinctly describes a more effective way to provide information, which is to:

- start with what the person already knows
- build on this when providing new information.

To focus the mind on avoiding jargon when preparing for a consultation, one strategy is to consider how you might explain the condition and/or treatment in question to someone who is much younger, for example:

Instead of Mr Roy, imagine that your patient is Sam Roy, a 12-year-old boy. How would you explain the condition to Sam?

This is likely to reduce any temptation to use words such as 'diaphragm' and 'oesophagus' in the explanation. Consider whether any visual props, such as a picture or an anatomical model might help. When you meet Mr Roy, you may discover that he is a science teacher, or has recently arrived in the country with English as a second language, so it is worth having in mind some flexibility in how you might word your explanation.

The importance of avoiding jargon *whilst you are explaining the problem* cannot be overstated. People are often worried about what might be wrong, and anxiety makes it more difficult for the brain to process and recall information – which is exacerbated by being given difficult material to absorb. Plus, whilst the person is trying to decode jargon, other aspects of the explanation can be missed. Keeping messages concise and simple at the outset provides a firm foundation – which subsequent discussion can build upon.

In addition to *explaining* the situation, however, there is the task of *naming* the situation. It is helpful for patients to know the medical names of:

- the condition
- procedures
- treatments.

This can help the person in seeking further information, or recognising words which are used by other health professionals at different points in their care. Generally, it is most effective to *name* the problem or treatment after the explanation has provided a framework to help the person understand the problem. For example:

"The difficulty you've been having with breathing, and the chest infections you've been getting, are due to a problem with your lungs. Your airways are narrowed, which has been reducing the flow of air in and out of your lungs. We call this chronic obstructive pulmonary disease, or COPD for short."

"So because your thyroid gland isn't making enough of this hormone, thyroxine, the recommended treatment is a medication. This simply replaces the hormone your body isn't making. You take it as a tablet every day. It's called levothyroxine."

Sharing information during the consultation

In a similar way to a consultation in which you are gathering information, it is helpful to have a structure to follow during a consultation in which you are primarily sharing information (Table 5.2).

1. Clarify the purpose of the meeting today

After the introduction, beginning with a recap of the key points about what has happened so far helps to orient the discussion.

DR SMITH: *So to recap, you came in because of the heartburn you've been having, and you had an endoscope examination down your throat.*

MR ROY: *Yes.*

DR SMITH: *I can tell you what we've found, and we can talk about how we can try and get rid of these symptoms.*

MR ROY: *Okay, sounds good.*

Table 5.2 Steps in sharing information during a consultation

- Introduce yourself and clarify the purpose of the meeting today
- Check the person's understanding of the situation/condition
  - Establish any particular queries or concerns
- Explain the diagnosis in a way the person will understand
  - *Chunk* information into sections
  - *Check* understanding after each section
- Check the person's understanding of the explanation
- Find out the person's concerns and address these
- Explain the treatment or management options in a way the person will understand
  - *Chunk* information into sections
  - *Check* understanding after each section
- Check the person's understanding of the explanation
- Find out the person's concerns and address these
- Summarise and agree an immediate plan

2. Check the person's understanding of the condition

The aim is to establish what the person already knows, or suspects, and any particular worries or concerns they might have. Some example questions are:

"Has anyone told you anything so far about what might be wrong?"
"Do you have any questions for me right now?"
"Is there anything you are particularly worried about?"

Phrases to avoid are those which use the heading of this section, e.g. particularly 'Can you tell me what you understand about your condition?' or blunt questions like 'What do you think is wrong with you?'

DR SMITH: *I was wondering if you'd had any thoughts yourself, about what might be wrong, or anything you're worried about?*

MR ROY: *Well, because I had an ulcer a while ago I was wondering if it's come back. I have a friend who was very ill from a burst ulcer.*

3. Explain the diagnosis in a way the person will understand

In doing this, it is important to:

- give the most important information first
- use short words and short sentences
- avoid medical jargon as part of the explanation
- give medical names where needed (e.g. diagnosis, procedures, treatment) – and offer to write these down
- be specific – vague information only increases anxiety.

Dr Smith: *None of the tests you've had has found a stomach ulcer: it hasn't come back. But the tests did show what the problem is. The heartburn, and the chest pain you've had occasionally, are due to acid from your stomach coming up into your gullet. It irritates it. Let me show you on this picture… Here's your stomach, with the acid in it to digest your food. There's a valve, there, which stops the acid going up there. But this bit has poked through, so the valve isn't working properly and the acid is coming up. We call this a hiatus hernia. Have you ever heard of that before?*

Mr Roy: *I've heard the name. I think my grandmother had one, but I haven't much of a clue, really.*

Dr Smith: *Does that make sense so far?*

Mr Roy: *Yes. So why's it worse after meals?*

Dr Smith: *Because that's when your stomach makes the most acid.*

Mr Roy: *Right.*

Dr Smith: *So that's when the acid is irritating your gullet and causing you pain.*

Mr Roy: *Right, that's causing the pain.*

4. Check the person's understanding and address any concerns

At the end of a section, it is helpful to take stock before moving on to the next topic.

Dr Smith: *So I want to check that you're happy with all that, before we go on to talk about what we can do about this. Would you like me to go over anything?*

Mr Roy: *No, it all makes sense.*

Dr Smith: *Any questions for me at this point?*

Mr Roy: *I can't afford to take time off work. You're not going to tell me I need an operation or anything?*

Dr Smith: *No, I'm not.*

5. Explain treatment or management options in a way the person will understand

Consider this explanation:

Dr Smith: *Now, I'm going to explain how we can try to get rid of your symptoms. I think it would help if you were able to lose a bit of weight. Your BMI is higher than it should be for a man of your age, which is probably making the problem worse. You will be less likely to get the pain if you can eat smaller meals regularly. For example, instead of one large meal at night, I suggest you eat a good breakfast (such as cereal or toast), perhaps a light lunch, such as sandwiches, and then have your evening meal, which should be smaller than usual. Certain foods and drinks will make your symptoms worse. You should cut down on coffee and alcohol. I suggest that you sleep on three pillows because then the acid in your stomach is less likely to come up into your gullet than when you lie flat. Lastly, I'm going to give you some tablets that will stop your stomach producing acid; you should take one each morning.*

If you are in Mr Roy's position:

- Is the advice relevant to your situation?
- Would you be able to remember all the advice?
- Do you think you will follow through with all the suggestions?
- Are you satisfied with the advice?

Here is some more information about Mr Roy:

I work as a long distance lorry driver. I often drive up to Scotland and back, and the days are long, particularly when the traffic is unpredictable. I usually try to get on the road as soon as I get up, to beat the worst of the morning's traffic. I'm mainly sitting down all day. I tend to eat at the service stations where the trucks go. I don't drink coffee – I'd be weeing all day. I don't drink alcohol – I've never liked it, and I couldn't risk it because of my job. After a long day my favourite meal is a curry. I don't like taking tablets, but I will if it will stop this heartburn. It's been waking me up at night.

Information is generally easier to digest when given in smaller chunks. 'Signposts' are helpful to provide a structure.

DR SMITH: *Dealing with this problem is really about getting your stomach acid under control. One of the things we can do is look at what you eat and when you eat it. Another thing is to think about some medication. That's in the short term, things we can do right now. And we can look at the longer term as well.*

MR ROY: *Okay.*

DR SMITH: *So there are several things you can do. Would it help to go through them one at a time?*

MR ROY: *Yes, sure.*

DR SMITH: *Starting with what you eat and drink. What you eat and drink – and when – affects how much stomach acid you produce.*

6. Check the person's understanding and address any concerns

Towards the end of the consultation, the aim is to consolidate what you have discussed and check that the information meets the patient's needs.

DR SMITH: *Perhaps you could tell me what you feel about that.*

MR ROY: *Well, I'm pleased I don't need an operation. I'll need to think about the food and drink, to see if I can get things that are not so irritating to my stomach on the road.*

DR SMITH: *I can give you some more information about foods that are less likely to make your stomach produce a lot of acid.*

MR ROY: *And I can take the tablets – they don't have any side effects do they? I've got to keep my wits about me when I'm driving.*

7. Summarise and agree an immediate plan

The summary in this type of consultation is less detailed than in a consultation where you have been gathering information. The aim is to clarify what has been agreed. This will normally include:

- actions you have agreed to do (e.g. arrange for the person to have some tests)
- actions the patient has agreed to do (e.g. try out the plan for a month)
- next steps (e.g. when the patient should book in a follow-up appointment)
- 'safety netting' – any reasons why the patient might want to seek further help quickly and not wait for the follow-up appointment.

The way you do this is flexible: sometimes you might want to give a 'bullet-point' summary, at other times you might want to ask the patient about what they plan to do as a result of the discussion you have had together. This section is sometimes misinterpreted as an opportunity for the doctor to simply repeat any advice they have given again. This is not the purpose of this section. There is plenty of evidence showing that there is a difference between advice that is *given* and what subsequently *happens*.[10] The aim is to check what has been *agreed* – in particular what the patient is taking away from the discussion and intends to follow through.

DR SMITH: *Shall we go over the plan?*
MR ROY: *Yes.*
DR SMITH: *I'll do the prescription. And you're going to…*
MR ROY: *Look at what I'm eating, sleep on three pillows. I think the losing weight is a bit trickier, to be honest, but I'll think about it.*
DR SMITH: *Let's see how you are getting on after a month or so. If the chest pain gets worse, or is different…*
MR ROY: *Oh yes, of course… if it's a different sort of chest pain I'd better come and see you sooner.*
DR SMITH: *Have we covered everything?*
MR ROY: *Yes, that's fine.*

Discussing uncertainty and risk

Medical care does not always have a certain outcome. Uncertainty about the course of a medical condition or the effects of treatment is a fundamental part of the reality of health care. Uncertainty is, however, unsettling and frustrating for many of us. When we have health problems, we hope that professionals know exactly what is wrong and can provide a definitive cure. Similarly, doctors much prefer to be able to say: '*This treatment will definitely cure the problem*' rather than '*I can offer this treatment – but I can't say whether or not it will work*' or '*Your health might be affected in the long term, but we just don't know.*' Doctors often have to discuss uncertainties with patients, and so it is worth pointing out the emotional effect – the sense of dissatisfaction – experienced by both the patient and doctor during these conversations.

There are different types of uncertainty, for example:

- something that could be known, by seeking more information, e.g. a test to determine whether or not a lump is cancer
- something that cannot be known, e.g. how long before the person's dementia becomes so severe they cannot recognise family members.

Being aware of which type of uncertainty is being discussed is important in helping you to decide how to respond. Is there something *practical* you can do, or do you need to respond to the *emotions* raised by the situation? For example:

> *"From what you have told me, I'm not sure what the diagnosis is. I would like to refer you to a specialist."*
> *"Unfortunately I don't know, for you, whether the condition will be stable for some time, or whether it will get worse very quickly. I'm sorry – I know that is not what you wanted to hear."*

Doctors increasingly have to discuss likelihoods of certain outcomes, as part of discussions to help the patient make a decision about treatment. Often these likelihoods are called risks. A risk is normally defined as the likelihood of an adverse event, for example, the chance that a person who smokes will develop lung cancer, or the chance that a person having an operation will have a complication. Providing information about risks enables a person to make an informed choice about a course of action. If a person knows that a treatment has a high chance of success, and a low risk of complications, this generally makes it a more attractive option than a different treatment, which has a low chance of success and a high risk of complications. If the only treatment available, however, has a low chance of success and a high risk of complications, the person can still weigh up whether or not it is worth the risk. This might depend on how unbearable their current symptoms are, for example.

When making a decision when there is a risk, a person might consider:

- *Frequency* – how likely is an event? For example, would you take a daily medication that is likely to cause disturbed sleep once a month? What if it is likely to cause disturbed sleep several times a week?
- *Severity* – what is the impact of the event? For example, would you have an operation on your dominant hand that is likely to cause a temporary tingling sensation, for about a week? What about a temporary numbness, for about a week?
- *Individual circumstances* – what are the implications for the individual in their particular context? For example, imagine that you are a woman who has had long-term pain in your pelvis, and one of the treatment options is an operation to remove your womb (hysterectomy). What might determine whether this is a treatment you would consider?

Discussing risk is often difficult, because the decisions that result from the information are not straightforward. It can help to provide a structure to the conversation which acknowledges that the discussion involves uncertainty and that the person may need more time to come to a decision (Table 5.3).

Research considering how to discuss risk effectively has produced a number of recommendations (Table 5.4).[11,12] It is clear that simply using verbal descriptors (such as 'very common', 'common' and 'rare') is problematic, as people hold very different views about what such terms mean.[13] The way numerical information is presented can also influence the perception of risk, particularly if it is presented along with an opinion (e.g. *'the success rate is excellent – the operation is successful for 7 out of 10 people, and only 6 out of 10 people experience long-term complications').* The aim is to provide information which is clear and unbiased, so that the person is sufficiently informed to make the decision that is right for them (more in Chapter 6), and not left bewildered by an overload of complex information.

Table 5.3 Steps in conversations to discuss risks

- Establish what the patient already knows and is concerned about
- Agree the agenda
- Tailor the information to the individual ('you')
- Present information in an understandable format
- Acknowledge the uncertainty
- Acknowledge the person's disappointment that there is no definite, positive outcome
- Be aware of the person's needs for information and for emotional care
- Provide information in stages; don't overload
- Encourage time to deliberate before the decision

Table 5.4 Strategies for discussing risk

- Be careful about using words without qualification (e.g. 'often', 'rarely')
- Use numbers in the form of natural frequencies, not percentages (e.g. '3 in every 10 people', not '30%')
- Use small denominators where possible (e.g. '4 out of 10 people', not '40 out of 100 people')
- Give absolute risks, rather than relative risks (e.g. 'the risk is one in a million with treatment A, and two in a million with treatment B', not 'the risk is twice as big with treatment B')
- Be aware of positive and negative framing (e.g. compare: 'the treatment is very effective – 80% of people recover' with 'the treatment is not very successful – 20% of people don't recover')
- Supplement the verbal explanation with other media, e.g. pictures or diagrams

Written information

A number of studies have shown that it is helpful for people to have supplementary information in addition to the face-to-face consultation. This can be in the form of leaflets, copies of letters, resources from the internet, written or audio recordings of a consultation or online access to medical notes.[14-16] Such material can supplement the verbal explanation and provide the information in a form that the person can go back to over time. Evidence shows that supplementary information, presented in an appropriate form, enhances patients' understanding and recall.

Written information for patients should:[17]

- be easy to read – use short words and sentences
- use plain language and everyday words
- use the active rather than the passive voice, i.e. 'we think' instead of 'it is thought'
- ideally provide tailored, rather than general information
- include information about issues affecting people's quality of life and day-to-day living
- understand and meet the needs of users.

Key points

- The way in which information is shared with patients has a profound effect on a person's experience of care, and ability to remember and use the information discussed.
- Key elements are making a plan before the consultation and focusing on sharing information in a way that is understandable and meets the needs of the individual patient.
- Discussing risk and uncertainty involves attention to the patient's informational and emotional needs.
- Supplementary information can help people to understand and remember information discussed in a consultation.

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Shared decision making

6

Lorraine Noble

"The patient, or person receiving care, should be at the heart of decision-making."[1]

In this chapter, we will consider:

- *the processes involved in shared decision making*
- *ways of increasing the effectiveness of consultations to support patients in making health care decisions.*

Jess Bishop is a 25-year-old woman. She is pregnant for the first time, in her 15th week of pregnancy. As part of her antenatal care, she has had a blood test. She has been told that the baby 'has a high risk of Down's syndrome'. She is being offered a test called amniocentesis.

- What do you think is Jess's initial reaction?
- What might she want from the consultation?
- What do you think would help her in making a decision?

Some medical decisions are easy to make – take for example, a situation in which:

- there is only one treatment option
- a cure is guaranteed
- the treatment is easy to take and works quickly
- the person will feel a definite benefit (e.g. resolution of symptoms)
- there are no risks from taking the treatment.

How likely would you be to take a treatment under these circumstances? Most people are likely to follow through a treatment plan when the benefits so clearly outweigh any risks. We could describe this as an 'overwhelmingly positive' treatment option. But many decisions are not so clear-cut. Consider how you would react if you had a medical condition and you were told that the treatment being recommended:

- has a 50% chance of a cure, but a 15% chance of a serious complication
- will almost certainly cure the condition, but will involve weekly visits to the hospital for two years, plus additional time every day 'self-managing'.

In these circumstances, people tend to weigh up whether:

- the condition is sufficiently serious or disruptive to everyday life to warrant following the plan through
- the outcome will be significantly better having taken treatment

Table 6.1 Questions to consider in a decision-making consultation

- What is the patient expecting from today's consultation?
- What does the patient know about the medical condition?
- What are the patient's priorities and goals?
- What does the patient know about the available options?
- Does the patient have any initial preferences?
- What questions and concerns does the patient have?
- What is most important to the patient?
- What support does the patient need to make a decision?

- the costs (e.g. time, effort, disruption to daily life, risks to health) are not excessive
- the balance of benefits and costs favours taking treatment.

This may seem counter-intuitive – surely patients follow medical advice and take prescribed treatments as recommended by their doctor? There is considerable evidence that adherence to medical advice often falls far short of what doctors might expect. Adherence is affected by people's perceptions of risk to their health, perceived benefits and costs of taking treatment, and communication with the doctor.[2–4]

This tendency to weigh up of a number of factors can make decision making sound like a simple process of weighing up the pros and cons and making a 'logical' choice. However, many decisions in health care have an emotional component. Patients may feel:

- frightened of the condition and/or the treatment
- uncomfortable making decisions in an unfamiliar context (medical setting)
- frustrated if there is no 'overwhelmingly positive' option
- disappointed that the doctor cannot simply deliver a cure.

In the previous example, the patient is being offered a screening test, which involves a risk to the pregnancy. The patient will have to weigh up the options, as each offers a different benefit/risk profile. Some questions the doctor might be thinking about when planning this consultation are shown in Table 6.1. If you were the doctor about to have a consultation with this patient, consider what information you would need and how you would approach the consultation.

Patient autonomy in decision making

Central to this discussion is the concept of patient autonomy: the right of people to make decisions about their own health care. It is important to consider how decision making in medical care has changed over time, to show the range of approaches which have been used (Table 6.2).

Historically, doctors' services were available only to those who could pay. These were often wealthy customers, who shopped around and requested the treatments they wanted, resulting in a 'consumerist' approach to medical care.[5] As medicine developed into a regulated profession, doctors were perceived as having the knowledge, experience and status to make decisions about patient care. In this version of the doctor–patient

Table 6.2 Historical development of medical decision making

Model	Role of patient	Role of doctor
Consumerist	Requests and pays for treatment	Provides requested treatment
Doctor as expert	Complies with prescribed treatment	Chooses treatment Provides information and advice
Informed consent	Understands risks Agrees to treatment Complies with prescribed treatment	Chooses treatment Provides information and advice Explains risks
Shared decision making	Provides information about priorities and goals Chooses preferred treatment	Provides information about treatment options, benefits and risks Supports decision making

relationship, the patient was expected to be relatively passive, their role confined to following ('complying with') the prescribed management plan. However, patients reported undergoing procedures or treatments to which they had not agreed and about which they had been inadequately informed. The concept of 'consent' was introduced to ensure that the doctor had obtained agreement from the patient, for example, before taking blood or conducting a pelvic examination. This was elaborated into 'informed consent', a medico-legal concept introduced to ensure that patients had been made aware of the risks of treatment, particularly with regard to the potential complications of an operation.

Consider the phrases 'consenting the patient' and 'getting informed consent'. Do you feel these imply that the patient has an active or passive role in making decisions about their health care?

The notion that both doctors and patients are experts in their own fields[6] and the increasing expectation that people have the right to make decisions about health care[7,8] led to a more collaborative model of decision making, which is commonly known as shared decision making.

What is shared decision making?

Shared decision making can be defined as *helping a person develop an informed preference*.[9] It is the process by which doctors and patients work together to:[10]

- clarify goals
- share information about options and preferred outcomes
- reach mutual agreement on the best course of action.

This approach assumes that both patients and doctors have expertise to bring to the table (Fig. 6.1). In this model, the patient makes the decision about the course of action, having been provided with:

- information
- support to make the decision.

Components of shared decision making are shown in Table 6.3.

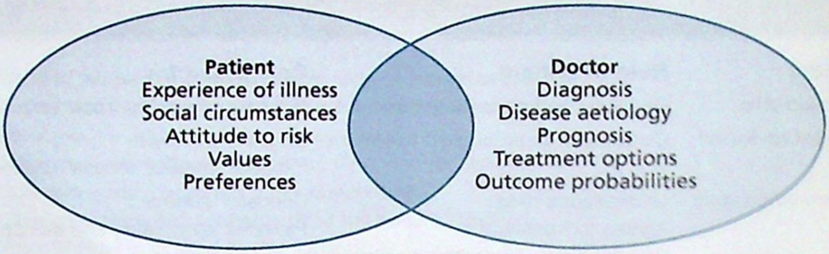


Fig. 6.1 Patients' and doctors' areas of expertise[10]**.**

Table 6.3 Essential components of shared decision making[10]

- Providing the patient with reliable, balanced, evidence-based information on:
  - treatment, care or support options
  - expected outcomes
  - uncertainties
- Decision-support counselling with a doctor to clarify options and preferences
- A system for recording, communicating and implementing the patient's health preferences

When is shared decision making used?

Patients have the right to make decisions about undertaking any medical intervention or procedure. This applies to decisions about:

- treatment and management strategies
- screening and prevention
- investigations and tests.

Some of these conversations can be quite brief. For example:

Doctor: *So you've been feeling tired quite a lot of the time, although you are sleeping normally.*
Patient: *Yes.*
Doctor: *And there's nothing else?*
Patient: *No. It's not that I'm worried, I'm just tired of feeling tired all the time, if that makes sense.*
Doctor: *It might be anaemia – where you don't have enough iron in your blood. I'd like you to have a blood test. Would that be okay?*
Patient: *Yes, no problem.*

Other conversations require more involved discussion. These can include:

- 'preference-sensitive decisions' – situations where there is more than one treatment option, but there is no 'overwhelmingly correct' option (this is also known as 'clinical equipoise')
- situations where the outcome is uncertain, for example, the likelihood of success is unknown, or there is a possibility of harm resulting from the treatment.

Case example 6.1 Treating knee pain

Mr Jones has osteoarthritis in both knees, which causes pain and stiffness on most days. This has been going on for nearly a year. At work he has had to alter his schedule to accommodate his reduced mobility. He attends his general practice surgery and is provided with information about two treatment options:

- a course of physiotherapy, to stretch the muscles and reduce stiffness
- an operation, which may involve knee replacement.

Mr Jones is told that both treatments are likely to reduce his pain and stiffness, although a definite cure cannot be guaranteed in either case. Surgery is more likely to resolve the problem completely, but there are some risks associated with having an operation. Physiotherapy is less likely to resolve the problem completely, although it does not incur the risks of surgery. Both treatments would require Mr Jones to take time off work, although this would be in a single block for the operation or smaller amounts over a longer period for physiotherapy.

This is an example of a 'preference-sensitive' decision, where there is no 'overwhelmingly correct' decision, and the outcome is uncertain. In this situation, the 'right decision' for Mr Jones depends on his individual needs and goals. What matters most to Mr Jones may be choosing the option which:

- has the highest likelihood of resolving the problem, or
- has the lowest risk, or
- causes the least disruption to his work.

Other people with the same condition as Mr Jones and faced with the same options, may make the same decision or a different decision, depending on their individual circumstances.

We join the conversation just after Dr Hassim has explained the treatment options:

Dr Hassim: *So those are the two options.*
Mr Jones: *Right.*
Dr Hassim: *What do you think about that?*
Mr Jones: *So neither of them will definitely work. Definitely take away the pain and get my knees back to normal.*
Dr Hassim: *No...*
Mr Jones: *But an operation is more likely to.*
Dr Hassim: *Yes.*
Mr Jones: *But it's an operation, and there are risks.*
Dr Hassim: *Yes. I can give you more information about both of them, that you can take away with you. To help you think about it.*
Mr Jones: *I was hoping there would just be one thing, you know, to deal with it once and for all. With no downside.*
Dr Hassim: *Yes, I'm sorry I can't offer that. But there are these two choices. I've had patients before, who have either had an operation or physiotherapy, and they have been pleased with the result.*
Mr Jones: *It's not the easiest decision to make.*
Dr Hassim: *If I were to ask you, what matters most to you, what would you say?*

Continued

Case example 6.1 Treating knee pain—continued

Mr Jones: *Whatever is most likely to work. And it will be a lot easier to do it all in one go, with my work, even if the recovery takes a while. Because of the way we're allocated to projects in my job.*

Dr Hassim: *Right.*

Mr Jones: *I'll take the information though. Discuss it with my wife. At the end of the day it's arthritis, isn't it? It's not going to get better by itself. I have to do something.*

Dr Hassim: *Do you want to come back when you've had a chance to think about it? If you've got any questions, feel free to write them down for when you come back.*

Table 6.4 Core skills for shared decision making[11]

- Listen to patients, take account of their views, and respond honestly to their questions
- Give patients the information they want or need to know in a way they can understand
- Work in partnership with patients, sharing with them the information they will need to make decisions about their care, including:
    - their condition, its likely progression and the options for treatment, including associated risks and uncertainties
    - the progress of their care, and your role and responsibilities within the team
- Respect patients' right to reach decisions with you about their treatment and care

In the last chapter we saw the importance of the way in which information is shared with a patient. Having provided information about the treatment options, the doctor supported the patient to make a decision by:

- encouraging the patient to reflect on the available choices
- acknowledging the patient's wish for a single, definitive, risk-free treatment
- exploring *what matters most* to the patient
- offering written information to take away
- offering to answer further questions
- encouraging the patient to take time to make the decision
- and in addition, by *avoiding:*
    - overloading the patient with information
    - rushing the patient
    - trying to make the decision for the patient.

Some core skills for consultations to support shared decision making are given in Table 6.4.[11]

Preparing for a decision-making consultation

Imagine you are a doctor looking after Mrs Susan Bygraves.

Mrs Bygraves has breast cancer. In her situation, there are two treatment options, both surgical: either lumpectomy with radiotherapy or mastectomy. She has attended with her husband to discuss treatment.

How will you prepare for the consultation?

If you look back at the framework for sharing information from Chapter 5, you may also find it helpful to:

1. Clarify in your own mind the information you wish to share.
   - Are you clear about which topics you need to discuss in this consultation?
   - Do you have the relevant information you need about the treatment options?
   - Are there other resources and support that you can offer?
2. Consider what the person already knows.
   - Have you met the patient and her husband before?
   - What is written in the notes?
   - What do you know about what information has been discussed?
   - Are you aware of any particular concerns or questions that the patient has expressed?
3. Think about questions you might be asked.
   - What questions might the patient and her husband arrive with?
   - What concerns and questions have patients and relatives raised with you previously in similar consultations?
   - What expectations and hopes might the patient and her husband have?
4. Translate medical jargon.
   - How much medical jargon is given in the scenario and in your notes about the information you are planning to discuss?
   - What might be the emotional impact of some of the terms you might use?
   - How will you discuss the options in a way that is clear and understandable?

Supporting decision making during the consultation

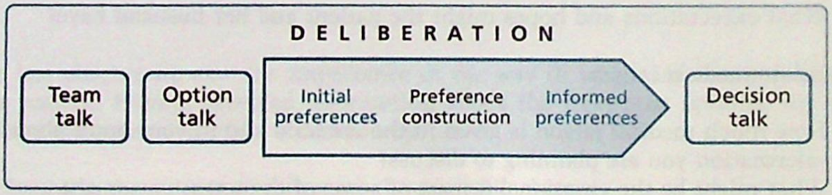
There are generally three phases in a consultation to support decision making (Table 6.5). These stages have been described as team talk, option talk and decision talk (Fig. 6.2).[12]

1. The beginning: identifying the decision

It may seem obvious that the aim of the consultation is to make a decision about treatment, but in practice:

Table 6.5 Steps in a shared decision making consultation

1. The beginning: identify the decision
   - Signpost that there is a decision to be made
   - Support the person in articulating:
     - their current understanding of the condition/situation and treatment/test options
     - what they hope to achieve (preferred outcome) from the treatment/test
   - Emphasise partnership and support
2. Sharing information: discuss options
   - Explain the treatment, test or management options
     - options available
     - potential benefits
     - potential harms
     - uncertainties
3. Discuss the decision: establish the patient's informed preference
   - Support the person in articulating:
     - their individual priorities/needs (*'what matters most'*)
     - their own concepts of benefit and harm
     - their preferences
     - readiness to make a decision



Team talk: Explain the intention to collaborate and support deliberation
Option talk: Compare alternatives
Decision talk: Elicit preferences and integrate into subsequent actions

Fig. 6.2 Collaboration talk model for shared decision making.[12] Figure, copyright Glyn Elwyn 2015, used with permission.

- the patient may not know the reason for the consultation
- the colleague who saw the patient last might not have explained the stage of care that has been reached
- the patient may be expecting more tests or investigations to clarify the diagnosis.

As with any consultation, *clarifying the purpose of the meeting today* is one of the most important tasks.

Mrs Bygraves is meeting with the specialist, Dr Ansari:

Dr Ansari: *So you saw my colleague Dr Hassim yesterday…*
Mrs Bygraves: *Yes.*
Dr Ansari: *And she told you about the cancer.*
Mrs Bygraves: *Yes. It was a shock.*
Dr Ansari: *Yes, I'm sorry.*
Mrs Bygraves: *But she was very positive.*
Dr Ansari: *Right.*
Mrs Bygraves: *And she said you'd see us today.*
Dr Ansari: *Did she say what you would be here to talk about?*
Mrs Bygraves: *Not really.*
Dr Ansari: *I'd like to talk about treatment.*
Mrs Bygraves: *Right.*
Dr Ansari: *There is treatment that we can offer.*
Mrs Bygraves: *Okay.*
Dr Ansari: *I'd like to tell you about it…*
Mrs Bygraves: *Yes.*
Dr Ansari: *What we can do, what we hope to achieve with treatment…*
Mrs Bygraves: *Mm-hmm.*
Dr Ansari: *So we can make a decision, together.*
Mrs Bygraves: *Right. A decision.*
Dr Ansari: *Yes. There are two options.*
Mrs Bygraves: *Okay.*
Dr Ansari: *I'd like to tell you about the options, so you have all the information you need to choose the one that's right for you.*
Mrs Bygraves: *Okay.*
Dr Ansari: *I know it's been a shock.*
Mrs Bygraves: *My head's spinning half the time, but my husband is here to ask the questions.*
Dr Ansari: *Ask all the questions you want. I want you to be happy with the plan.*

In this consultation the doctor had not met the patient and her husband before, and was aware that the patient may feel overwhelmed by a new diagnosis of cancer. In this early segment, the doctor focused on:

- developing initial rapport
- clarifying the purpose of the consultation
- explaining the key 'headline' of the content (that there are two treatment options, that the plan is to make a decision)
- signalling the patient's role in decision making
- ensuring that the patient feels supported
- showing that the consultation will proceed at a manageable pace.

2. Sharing information: discuss options

The second stage of the consultation focuses on ensuring that the patient has reliable, evidence-based information about the available options, presented in a clear and understandable way. This includes information about what the options are and what they involve in practical terms, comparing the options in terms of benefit and harm, and discussing any uncertainties.

The way in which information is presented is critical in ensuring that the person is able to understand and make use of the information when making a decision. A simple, face-to-face, verbal explanation is the standard approach for straightforward information, although many people find visual aids, such as pictures, diagrams or use of physical props very helpful. Patients also may find a slower pace helpful when the information is unfamiliar or complex, or when feeling frightened or upset. Where the discussion involves more than one option, or the patient needs to weigh up potential risks and benefits, a more structured approach can be useful. This could involve using a diagram or other visual representation, such as an icon array.[13] Another method involves presenting information about the treatment, test or management options in a table, so that the patient can compare the options side by side.[14]

For example, to help Mrs Bygraves with the decision about her breast cancer treatment, a written leaflet could be used to provide information (Table 6.6).

Providing written information, which is used during the consultation, can help the patient to recall the conversation afterwards, which can in turn help the patient in involving family members and in private deliberation. Interventions to support patients in making decisions also use written information and other resources in a more flexible manner, for example providing information and support to formulate questions in advance of the consultation. These interventions, known as 'decision aids':[15,16]

- explicitly state the decision to be made
- provide evidence-based information about options, benefits, harms, and uncertainties
- help patients clarify the values that are important in making the decision (for example, maximising survival time or quality of life).

Imagine you are the doctor meeting with Jess Bishop, from the example earlier, and discussing the option of testing for Down's syndrome.

Table 6.6 Information that might be included in a leaflet

Topic	Example
Overview of treatment	An operation, where there are two options: (a) lump removal, conserving the breast; and (b) removal of the breast
Aim of the treatment	Whether a cure is possible What 'remission' means
Which option is best for long-term survival	Whether there is a difference between the treatments What is meant by 'long-term survival'
Which option is best for preventing a recurrence of cancer	Whether there is a difference between the treatments What is the likelihood of the cancer returning
What other treatments might be needed	Chemotherapy, radiotherapy, hormone treatments
Treatment risks	Common, serious and significant side effects
Quality of life	The effect of the treatments on the person's ability to have a normal day-to-day life

Doctor: *So your options are: one, not having a test for Down's syndrome.*

Patient: *Right.*

Doctor: *We know that there is an increased risk that your baby has Down's syndrome, but we won't know if your baby has Down's syndrome until the baby is born.*

Patient: *Okay.*

Doctor: *You will still be offered all the usual tests to check your health and the health of your baby throughout your pregnancy.*

Patient: *Okay.*

Doctor: *The second option is having a test for Down's syndrome.*

Patient: *Right.*

Doctor: *This involves taking a sample of the fluid your baby is sitting in, see in this picture, through a needle in your abdomen, here.*

Patient: *Okay. Through a needle.*

Doctor: *That is sent to the laboratory, and it will tell us whether your baby has Down's syndrome.*

Patient: *Right, so that would give us an answer.*

Doctor: *Yes. It has a risk, though. About one out of a hundred women having this test will miscarry, and lose the baby.*

Patient: *Is that more likely if the baby has Down's?*

Doctor: *No, it's because of the procedure. It's the same risk whether or not the baby has Down's.*

Patient: *Right.*

Doctor: *Whichever option you choose, if your baby does have Down's syndrome, we won't know how much your baby is affected by Down's before your baby is born.*

Patient: *It's just whether there is Down's or not.*

Doctor: *That's right. I can give you more information, about both the options, and about Down's syndrome.*

Patient: *Yes, that would help.*

Doctor: *And we can also talk through what are the things that are important to you, that can help you making a decision.*

Patient: *Okay.*

Doctor: *You don't have to make the decision today.*

Patient: *No.*

Doctor: *Would you like to ask me any questions?*

3. Discuss the decision: establish the patient's informed preference

Having shared information, the final phase of the consultation is to support the patient in making the decision which is right for them (see Table 6.5).

In the previous example, what is most important to the patient might be:

- knowing for certain whether or not her baby has Down's syndrome
- choosing the option with the least risk to the pregnancy
- coming to a decision together with her partner.

People have different approaches to making decisions, and this can depend on what the decision is, and how high the stakes are.[17–19] For example, sometimes people like to compare the 'pros and cons' systematically for all the options. At other times people make decisions very quickly, based on a 'gut feeling' or as a result of one particular aspect being most important (known as 'one reason' decision making). Decisions about medical care, like other decisions people make, are rarely based on a cold analysis of facts, but are influenced by individual perceptions of risk, fear of loss and other emotions. A person's support network, personal circumstances and health literacy also affect decision making. For example, a patient:

- may prefer the option of hospital treatment, but chooses a community-delivered intervention due to caring or childcare responsibilities
- might choose to have another round of chemotherapy (despite not wanting to go through the side effects again), because she knows her family would like her to live as long as possible
- might look for clues as to the doctor's preference if the decision appears to be complicated.

Going back to the example from earlier, where Mrs Bygraves is making a decision about her treatment for breast cancer, the doctor wishes to gauge the patient's preference:

DR ANSARI: *What are your thoughts on the two options?*
MRS BYGRAVES: *I'd like the one that is most likely to get rid of the cancer for good.*
DR ANSARI: *Right.*
MRS BYGRAVES: *But you say that, in my situation, they are both the same.*
DR ANSARI: *Yes. So on that basis, you can choose either one. With that in mind, what else is most important to you?*
MRS BYGRAVES: *I want to do the most that I can.*
DR ANSARI: *Okay.*
MRS BYGRAVES: *I feel that taking the whole breast away does that better than taking out a lump.*
DR ANSARI: *Right.*
MRS BYGRAVES: *I know that might not be rational – you've told me there's no difference.*
DR ANSARI: *No.*
MRS BYGRAVES: *But out of all the things you've told me, that's the thing that stands out most. I want to do the most I can to get rid of this.*
DR ANSARI: *That's what you want to do.*
MRS BYGRAVES: *Yes.*
DR ANSARI: *So that would be removing the whole breast.*
MRS BYGRAVES: *Well, I don't want to do either. But that's the best I can do. I want to tell my daughters I've done everything I can.*

Sometimes very short questionnaires are used to help patients to reflect on whether they are ready to make a decision (Table 6.7).[20,21]

Table 6.7 Example scale to check readiness to make a decision

SURE[21]

- Do you feel sure about the choice for you?
- Do you know the benefits and risks of each option?
- Are you clear about which benefits and risks matter most to you?
- Do you have enough support and advice to make a choice?

The importance of support

Most people want to be actively involved in making decisions about their own health care. People are more likely to defer to the clinician when the illness is very serious or it is a 'high stakes' decision, particularly where there is a likelihood of a significant loss. Uncertainty and fear reduce people's confidence in making their own decision in an unfamiliar setting.

Case example 6.2 A surprise decision

Mr John Crowley went to his general practice, due to a persistent cough over the past month. It had started like any other cold, but was not getting any better. His doctor asked a number of questions and asked him to breathe into a tube. Mr Crowley reported no other symptoms and his doctor did not seem too worried. He suggested that Mr Crowley have a blood test and a chest X-ray, to check that everything was fine. The doctor told Mr Crowley that the X-ray was 'not definitive' and that he would like to send him to a specialist for more tests. Mr Crowley duly attended the hospital and had a scan and a tube into his lungs to take a sample. He is now meeting with the specialist, Dr O'Donaghue:

DR O'DONAGHUE: *Nice to meet you. You've had a lot of tests.*
MR CROWLEY: *Yes.*
DR O'DONAGHUE: *We've found you have lung cancer.*
MR CROWLEY: *What?*
DR O'DONAGHUE: *Non–small-cell lung cancer.*
MR CROWLEY: *Non…*
DR O'DONAGHUE: *It's not advanced.*
MR CROWLEY: *Okay.*
DR O'DONAGHUE: *We need to talk about treatment. There are options for you to choose from.*
MR CROWLEY: *Oh. Options?*
DR O'DONAGHUE: *We could do active monitoring, or radiotherapy, or surgery, perhaps with or without chemotherapy. I can tell you more about the treatment options.*
MR CROWLEY: *Oh.*
DR O'DONAGHUE: *But it's your choice. I can only give you the information.*
MR CROWLEY: *If you were me, what would you choose, doctor?*

In this situation, the doctor:

- informed the patient that he had cancer
- named the treatment options
- made it clear that it was the patient's choice.

However, the doctor failed to:

- establish a working relationship with the patient
- prepare the patient to receive bad news
- address the emotional impact of a frightening diagnosis
- provide information in a way that could be properly understood
- support the patient in making the decision which was best for him.

Providing support is integral to any consultation where a patient is making a decision about medical care. It is important that patients do not feel 'abandoned' to make sense of the factual information they have been given, or to feel that they have to make a decision unaided. Attention to the emotional needs of the patient is particularly important when there is no 'good option' that meets the goals of the patient. Many patients value the opinion and experience of the doctor, and may ask for a recommendation. That said, a patient might not choose the option that you would choose under the same circumstances. Adults who have the ability to make their own decisions ('capacity') may choose a different treatment, or refuse treatment completely.[8] However, the development of a partnership between the doctor and patient is critical in providing support:

> *"For a relationship between doctor and patient to be effective, it should be a partnership based on openness, trust and good communication. Each person has a role to play in making decisions about treatment or care."*[8]

Key points

- People make decisions about health care based on perceptions of risk, perceived benefits and costs of the intervention, and personal values.
- Patients and doctors have their own areas of expertise which they bring to a consultation.
- Key elements of a decision-making consultation are:

    - signposting that there is a decision to be made
    - sharing evidence-based information
    - discussing what matters most to the patient.

- Support is integral to consultations in which patients are making decisions about their care.

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7

Breaking bad news

Robert Bor, Margaret Lloyd, Lorraine Noble

Breaking bad news is an inevitable part of medical practice and it is one of the most challenging aspects. Most of us worry about our ability to communicate sensitive and sometimes distressing news to others. Evidence indicates that what and how people are told affects their trust in their medical practitioner as well as how they cope and adjust in the future.[1]

The increased openness in the relationship between doctors and patients makes it important to focus attention on how to share bad news in such a way that it is:[1]

- *understandable*
- *personalised*
- *accurate*
- *complete*

to ensure that the patient's informational needs are met.

In addition, the patient's needs for emotional support need to be addressed, which involves:[1]

- *empathy*
- *cue recognition.*

As with any consultation in which information is shared with a patient, ensuring that the person receives the right amount of information, that meets their needs, at the right time is critical. Being aware of patient cues about what information is wanted and at what pace is key to this. Approaches which fail to do this, such as providing information in a blunt and abrupt manner, or circling evasively around the topic, have been observed in practice. Another problem is doctors' reluctance to broach a subject before the patient asks, although patients often wait for a subject to be broached by the doctor as the cue to begin the discussion. As we have already seen with other types of consultations in earlier chapters, having a clear structure for a consultation and being aware of effective (and ineffective) approaches helps to navigate these situations and prepare patients and relatives for what may be ahead. This chapter considers what bad news consists of, why it is often difficult to break bad news and how to share bad news. This approach can be adapted for different settings, with different patients and in relation to a range of issues.

What is bad news?

What would you consider bad news in your life? Finding out that you had failed an exam? Hearing that a relative or someone close to you was ill or had died? Being refused a bank loan? Think of an example when you received bad news. How was the bad news given *to you? Directly, in a roundabout way, in a letter or over the phone? What was your first reaction? How did you cope? Did you feel differently about the news 3 hours later? The next day? Could the news have been given to you differently, or in a way that softened the blow?*

All bad news situations involve a *serious loss* of some kind. The death of a patient or diagnosis of serious illness, a worsening medical condition or disability are usually considered bad news. Some doctors would add having to explain to a patient that there is no bed available in the hospital, that the patient's medical notes have been misplaced or that an operation has had to be cancelled. Conventionally, the concept pertains to situations where there is:

- a feeling of no hope
- threat to an individual's mental or physical well-being
- risk of upsetting an established lifestyle
- a message which implies the person has fewer choices in life.

Whilst we will often agree on situations which represent prototypical bad news, there are differences between individuals on what constitutes bad news in their own situation, as well as how people cope with the news. Partly this depends on what people are expecting. Some people, when diagnosed with a terminal illness, cope with the news, yet for others, conditions or treatments regarded by doctors as relatively minor or routine can be distressing and interpreted as bad news. Whether news is perceived as either 'good' or 'bad' depends on people's beliefs, value judgements and emotions.

There are many situations in which doctors might preface information with 'I am sorry to tell you that...', or 'I am pleased to tell you...', illustrating how value and meaning are attached to information from the outset. Such preconceptions about what is 'good' or 'bad' news are based on personal and professional experience. However, in some cases, these preconceptions may not be congruent with the other person's reactions. A patient with back pain who is given so-called 'good' news that there is no evidence of a serious problem may be devastated that there is still no diagnosis – and consequently no definitive cure. Conversely, if a person has been worried about their symptoms for some time, the confirmation of a diagnosis may be – although not exactly welcome – tinged with some relief, enabling the person to move to the next stage and start making practical decisions.

Bad news is, therefore, a relative concept, and depends on the patient's interpretation of information and reaction to it. Whenever a person feels that their future will be adversely affected, then it can be considered bad news. Usually, we can predict what will be viewed as bad news, but not with complete certainty. Trying to avoid making assumptions about a person's feelings and responses is an important step in the process. Instead, paying attention to the person's needs and emotions is critical.

What is difficult about sharing bad news?

There are personal, professional and social reasons why breaking bad news may be difficult (Table 7.1). Training in medicine emphasises treatment, healing and the reduction of suffering. Serious illness, a deterioration in a patient's condition, disability or death all confront us with the limitations of modern medicine. In some situations, doctors may feel responsible for inflicting emotional pain or suffering on patients and their family. Bad news often implies the loss of well-being, youth, hope, health and relationships. It marks a transition in life for patients and their family that may be either premature,

Table 7.1 Why is it difficult to give bad news?

- The 'messenger' fears being blamed
- Not knowing how best to do it
- Personal experience of loss
- Reluctance to upset the patient
- Fear of upsetting the patient's existing family roles or structure
- Not knowing the patient and their sources of support
- Fearing the patient's emotional reaction
- Uncertainty as to what may happen next
- Not having answers to some questions
- Lack of clarity about one's own role as a health care provider

unwelcome, or both. The news ushers in new family roles: a partner may become a carer or a widow, a generation may end, and the family structure may change. For the patient who is unwell, there is the 'sick role' and the associated social stigma. People may be concerned about whom, within their family and social circle, they wish to share the information with. Many people may fear disfigurement, physical pain, and loneliness, as well as worries about emotional, social and financial well-being.

Doctors and other health care professionals themselves are not immune to the experience of personal loss. A recent experience of loss or illness can make it difficult to break bad news and provide support. It may also be difficult to anticipate how a patient or relative might react, and this unpredictability may cause a doctor to be wary of sharing difficult news. Some doctors worry that their own emotional reactions – such as wanting to cry – might make them appear unprofessional in the eyes of the patient. Sometimes doctors fear extreme reactions from patients, such as emotional distress, anger or suicidal thoughts. Other reasons for a wariness to share bad news may be more subtle. Bad news may spell the end of a close professional relationship with a patient, and the personal loss may be difficult to face.

A fear of 'doing it wrong', or giving incorrect information, can also cause reluctance. Differences in preferred approaches among colleagues within a team can cause difficulties in responding openly to the patient's concerns and fears. Medical students sometimes report that patients ask them to confirm the diagnosis because the medical and nursing staff have not openly discussed it with them. This creates a dilemma for the student, who may be privy to important information but not have the authority to talk about it with the patient. Involvement of qualified staff in the team is critical in such situations.

Preparing to break bad news

Before meeting with the patient or relatives, it is important to consider how and with whom, information will be shared.

To whom should bad news be given?

Studies have consistently found that the majority of patients wish to – and expect to – be given the bad news by the doctor. The duty to share the information that the patient wants and needs to know applies to 'bad' news in the same way as to any other information about diagnosis, prognosis and treatment. In the past, information was often withheld on the basis of 'protecting the patient' or 'because it would hurt the patient to know'. But without the information needed to engage in decision making about treatment, patient autonomy is compromised. Similarly, providing information first to the relatives of an adult patient breaches both patient confidentiality and autonomy. In reality, patients who were not told were often aware of the bad news, 'leaked out' by the behaviour of others around them – such as the sudden avoidance of eye contact, touch, and straight answers to questions. The stress of 'keeping secrets' and colluding in a 'conspiracy of silence' inevitably reduced the ability of family members to support each other at a difficult time.

Nonetheless, considering who will be present in the consultation is important. Patients often appreciate the presence and support of family members when there is bad news to be discussed. Sometimes it is possible to plan this, for example, by suggesting that a patient brings someone along to the scheduled appointment where test results will be given. Where the news is unexpected, and the patient either has no one with them or perhaps a large number of family members, it is equally important to consider what the patient would prefer with regard to this particular conversation. This can be actively managed. For example:

"Mr Boonen, I can see that you have a lot of visitors today. Would it be possible to have a moment with you in private? Thanks… The test results have come back, and it is very important that I discuss this with you. It is not the news we were hoping for. Would you like someone to be here with you while we talk about this?"

There are some very specific situations in which you may need to consider whether to give bad news to the patient. For example, if a patient has a significantly diminished capability to understand and remember information (reduced 'mental capacity'), which can be the result of a serious physical or mental illness. When treating a child, one usually confers with the parent or guardian before breaking bad news. These are decisions carefully made with the involvement of the wider team and there is specific professional guidance about situations in which information may or may not be withheld from a patient.[2–4]

Who should break bad news?

Often a patient has seen several different doctors or health care professionals as part of their journey towards this point. A patient who has had tests in a hospital may still expect his or her general practitioner to reveal the results, and may be surprised when given the news by a hospital doctor. Sharing bad news usually requires time, so it may be inappropriate for someone to do this late in the day when tired at the end of a shift. On the other hand, a doctor at the end of a working day may judge that they have a better relationship with the patient than a freshly briefed colleague who has not met the patient before. Whenever possible, if the news is related to a predictable event (such as test results coming back) it is helpful to have a conversation with the patient in advance about who will discuss the results and where, so that the patient can plan to have an accompanying person with them. Sometimes, however, the unpredictable nature of health care makes this impossible, and you find yourself as the doctor on the spot having to break unexpected news, or perhaps having to re-explain bad news that was given briefly to the patient by a colleague. Even if you do not feel optimally equipped, it is poor practice to delegate the task to a colleague because you do not feel like confronting the patient yourself. You may not have answers to all the questions the patient might ask even if you feel fully prepared, and people generally understand that you might need to obtain more information or consult with other colleagues.

Personal preparation

It takes time to give bad news properly, to answer questions, and to instil confidence and support at a difficult time for the patient. For this reason, it is not usually appropriate to break bad news in the middle of a busy clinic or during a ward round. As with any consultation where news is being shared, it is helpful to consider what the person needs to know, and whether you have all the information you need, before seeing the patient. You might consider the following questions:

- Is the patient expecting bad news? What does the patient already know so far?
- What information do I have to give? How can I explain this in an understandable way?
- What questions might the patient ask? How will I respond to questions I don't have the answers to?
- Have I got sufficient time to spend with the patient? Can someone else look after my bleep for a while?
- What will happen immediately after this consultation? Who else in the team needs to be involved?
- Are there any 'what if …' questions I should prepare myself for? (e.g. 'What if he wants to discharge himself from hospital?'; 'What if she gets angry with me?')

Pause, think and pre-empt difficulties before seeing the patient. In sharing bad news, more difficulties arise from not thinking clearly about what you are doing and how best to achieve it than from not having answers to some of the patient's questions.

Be aware in your preparation that you would naturally like to provide certainty, and a guarantee of a good outcome, and that you may well be able to offer neither. It is not a failure if the patient or their family members become upset. Your aim is to support your patient and their family members at this difficult time, not to stop them from feeling the emotions that are caused by this situation. Be aware that you may also feel emotional, or feel your heart pounding, but don't worry about becoming tearful. Your patient will have enough to occupy their thoughts and emotions. There is no need to feel self-conscious – focus on your patient. Be mindful, though, of anything you might do in an attempt to assuage your own emotions, such as wanting to say the information as quickly as possible. It is normal to feel anxious, upset and uncomfortable when breaking bad news.

The physical setting

The ideal setting is a private room that is reasonably comfortable, free from interruptions, and has a calm ambience. Of course, such a setting is not always possible, and bad news may be shared in open wards, semi-private rooms, emergency department cubicles and patients' homes. In these settings, do what you can to ensure privacy and comfort, for example, curtain drawn around a bed or a 'do not disturb' sign can signal a need for uninterrupted time. Manage potential sources of distraction (e.g. telephone, television and radio).

Your physical position in relation to the patient, and maintaining a similar eye level, are both very important in creating a supportive climate. Being seated conveys that you intend to stay and that the meeting will not be rushed.

There are some obvious things to avoid:

- Don't give bad news at the end of a physical examination while the patient is still undressed.
- Don't give bad news in corridors or over the telephone (if this can be avoided).

- Don't pace around, keep looking out of the window or become distracted by activities nearby.
- Don't be distracted by props (e.g. fumbling through clinical notes, or fixing drips) whilst talking to the patient.

It takes very little time to actively manage the environment to arrange a more conducive setting:

PATIENT'S RELATIVE: *Doctor, is there any news about my father, John Leff?*
DOCTOR: *I was just coming to see you. Are you Mr Leff's daughter, Miriam?*
PATIENT'S RELATIVE: *Yes that's right. I've been waiting for an hour and no one's told me anything. Is he all right?*
DOCTOR: *Let's not speak in the corridor. There's a room here that we can talk in. Is there anyone else here with you?*

Sharing bad news

It is always a matter of judgement as to how to approach a situation; however, there is a particular sequence that is helpful to follow when breaking bad news (Table 7.2).

Table 7.2 The process of sharing bad news

Find out what the patient already knows and what they expect (or want) from this consultation
↓
Give an indication that there is bad news coming
↓
Give information in small chunks and check understanding
↓
Use clear words and phrases
↓
Focus on the key points
↓
Explain the implications of the news
↓
Give the patient time to digest
↓
Solicit and respond to questions
↓
Provide appropriate reassurance
↓
Consider the patient's readiness to make any decisions
↓
Be responsive to cues about ending the consultation
↓
Make an immediate plan

also helps in constantly checking what the person is taking from the information. It also enables the person to ask questions as they arise, rather than trying to save them up for a gap and forgetting until after the conversation has ended.

Whatever you tell the patient, it is essential that you do it slowly, or at least at the pace dictated by the patient. Conversation can become more formal when giving bad news. If asked by a relative whether a patient had survived an operation, it would be unusual to reply with a simple 'no' and walk away. Instead, one might say:

"Your uncle was very unwell before the operation. We did the best we could, but I'm afraid that was not enough. He never regained consciousness. I'm sorry to tell you he died shortly after the operation."

Be mindful of how good intentions, aiming to 'soften the blow', can distort the information you convey:

Mrs Shah has an aggressive cancer. The last treatment has failed and the condition is now terminal. Your consultant has told you that she does not expect Mrs Shah to live for more than a month. Mrs Shah has attended with her husband, and you are explaining the situation to them.

MR SHAH: *So there is nothing more you can do.*
MRS SHAH: *How long, doctor?*
DR COLE: *It's difficult to say – it's different for everyone. I can't give you a definite time frame. It could be months.*

Afterwards you overhear Mrs Shah and her husband discussing with their son over the phone how he should come and visit with his family in a couple of months' time.

Use clear words and phrases

Using clear and understandable language is vital when sharing difficult information. Using euphemisms or jargon can cause confusion and additional anxiety, as well as indicating to the patient that the doctor is uncomfortable discussing the topic. We all find it difficult to concentrate when we are worried or upset, and need simpler messages to ensure understanding. Terms such as 'cancer', 'died', 'we can't cure it' and 'not long to live', however difficult to say, provide a clarity that 'carcinoma', 'lesion', 'malignancy', 'not curative', and 'we lost him' cannot provide. Being particularly aware of jargon words and turns of phrase that are used routinely in your normal conversations (with colleagues) is critical. Words such as 'palliative' and 'remission', for example, are poorly understood. 'Passed away' tends to be appropriate only for expected deaths.

Focus on the key points

Communication is about the 'bigger picture' as much as the detail. Consider the key pieces of information you would like the patient to have by the end of the conversation, for example, that it is cancer, that it is serious and that it cannot be cured. In terms of providing a structure to the conversation, these could be considered as three 'chunks' of information. Whilst you will want to provide more detail in your explanation, be aware of:

- how much detail the person wants and can take in at this point
- the balance between sharing information and providing time for the person to digest it
- the questions that the patient will want to ask.

Many people who have been given very difficult information by a doctor have said that when the key piece of bad news is given (e.g. the word 'cancer'), their mind seems to 'switch off' and they can no longer hear what the doctor is saying. So whilst the information-giver's natural inclination is often to provide more information – for example, if there is something positive they want to add – it is simply not being heard. Leaving a pause is essential.

Outlining the 'big picture' enables the person to have an overview of the territory. In much the same way as a book is organised, with a title, table of contents and chapters, when a person has the overall structure, they can choose which areas to focus on in greater depth. This does not need to happen all at once. For example:

"I have some important information to give you today, about what we've found and about some options for treatment. We don't have to make a decision about treatment today."

"We talked last time about the two main options for treatment. Could you let me know your thoughts so far? I can go over anything again that you want to. Then perhaps we could make a plan."

Explain the implications of the news

You may be more confident in discussing medical details, such as practical aspects of treatment, diagnostic staging of cancer, or side effects of chemotherapy. However, from the patient's point of view, other questions may be more pressing, such as the implications for their ability to work, plan for the future, or make family decisions. Acknowledging the wider issues, and providing a safe space for a patient to raise these, is the first step. It does not mean that you will be able to provide answers or solutions to all the issues, nor does it assume that these are your decisions to make.

DR MEYER: *What that means is that it is likely to get worse over the next few months.*
MRS FINLEY: *I was going to go abroad to work for six months.*
DR MEYER: *Well it can be unpredictable, and I can't say for sure. If it does get worse for you, the symptoms will be much stronger than they are now.*
MRS FINLEY: *That would be a problem. I'm only just coping as it is. So it's a risk.*
DR MEYER: *Yes.*
MRS FINLEY: *I hadn't realised it would affect my work. I'll have to think about that.*

Give the patient time to digest

In these conversations, people need time to even begin to digest the information, although it often takes longer for the news to really sink in. This is only the start of the process. Not over-filling the consultation with information can help – as can consciously allowing space between each 'chunk' and towards the end for consolidation. Be aware of cues which indicate that a person has reached the limit of the information they can digest in this conversation.

DR CARROLL: *I've given you a lot of information today.*
MR WESTON: *I just wasn't expecting this.*
DR CARROLL: *We could talk a bit more about treatment, or would you prefer to leave that for another day?*
MR WESTON: *I don't think I could take it in now, if I'm honest.*

Solicit and respond to questions

Checking for questions at the end of each 'chunk' of information is a good general rule of thumb. Even if a patient does not have a question for you at the moment, it signals your willingness to answer any queries which may arise. Generally it is helpful to respond to direct questions with a direct answer. Note that sometimes questions are asked indirectly – the person may be cautious about raising a topic, but provide a cue that this is an area they would like to go into.

MR WATERS: *I know I need to have the operation. The missus won't like it but we've not got a whole lot of choice.*
DR CICERO: *What do you mean?*
MR WATERS: *We were thinking of having another baby. I guess that's not on the cards anymore.*

Be aware that patients expect doctors to raise certain topics without having to ask – and because a patient has not asked a question, it does not mean that they do not want to know. Asking a person if there is anything they want to know is a reasonable question. Sometimes guidance on breaking bad news suggests a more complex route – such as asking the person whether they are 'the sort of person' who wants to know everything, as a means of obtaining the patient's 'permission' to divulge information. However, as a general enquiry this can be confusing or even more worrying to the patient. If you are unsure about whether to raise a subject, such as how long a person is likely to live, it can be raised gently, for example:

"There is more information I can give you about what will happen in the future. Would you like to talk about that now?"

Provide appropriate reassurance

Information and reassurance need to be honest and realistic. Often the inherent uncertainties mean that you will not able to provide the definite answers that a person may hope for. Your clinical knowledge and experience will also affect your confidence. So it is important to balance a sense of hope – which is important to many patients – with an awareness of what you can, and cannot, provide.

MRS DAVIS: *Will I be cured or do I have to be treated for life?*
DR BECK: *I hope that things will get better after this course of treatment. I can't say whether you'll be cured. We will need to keep a close eye on things and probably repeat this course of treatment.*

There are some aspects that you may be more likely to be able to provide reassurance about, for example, that the team at the hospital is very good, or that pain relief is taken very seriously. Some aspects of reassurance are more about conveying that you understand the difficult situation the patient is facing, and that you and your colleagues are committed to providing the best care you can. Providing emotional support, and showing empathy and compassion, are critical. Sometimes simply sitting in silence can be supportive and reassuring.

DR FRYER: *The results suggest that it's not just an 'ordinary' lump.*
MRS BLACK: *This sounds like bad news.*
DR FRYER: *I was hoping to be able to reassure you. But the test on the lump found that the cells weren't normal.*

MRS BLACK: *That doesn't sound good.*
DR FRYER: *No. It is cancer.*
MRS BLACK: *We all know what that means....*
DR FRYER: *I realise this is a shock.*

Warmth and caring can be conveyed throughout the consultation. The way in which you introduce the topic of bad news will influence, to some degree, how the patient responds. It is sometimes helpful to use prefaces such as:

"I was wondering whether you had ever thought what it would mean if this infection does not clear up as quickly as last time?"

A little gentle self-deprecation can also encourage the patient to talk more freely, for example:

"You may think that some of my questions are a bit odd, but I can't help wondering whether..."

Showing patients that you are not afraid to discuss their concerns, no matter what these may be, is an important way of showing empathy. Eliciting feelings and concerns is an important part of this, for example:

DR SEEDAT: *What is your main concern now that I have told you what may happen?*
MR THOMAS: *Being in pain. And not being able to look after myself.*
DR SEEDAT: *Right. Let's discuss both of these.*

Be aware that patients and relatives can show any sort of emotional response, or none at all. People who are not expecting bad news may simply be stunned, with the full emotional impact not coming until much later. Also sometimes people prefer not to become visibly upset in front of doctors. Denial and anger are also possible emotional reactions, and reminding oneself that these arise as a result of extreme distress can be very helpful.

Saying *'I'm sorry'* is an accepted way of showing empathy and compassion. Avoid negating the sentiment by qualifying with 'but', e.g. *'I'm sorry, but we've done the best we can.'* Also avoid *'I'm sorry to have to be the one to tell you'* as this shows more concern for your own emotional needs than the patient's.

Consider the patient's readiness to make any decisions

Sometimes patients will have been expecting (or half-expecting) bad news, and may have thought about some of the options, and be ready to proceed with making some practical plans. Most patients, for whom the news is a devastating and unexpected shock, may not feel ready to make decisions immediately after the news is broken. Being swept up in making immediate arrangements for treatment may leave patients feeling that they simply have to agree to the plan being laid out, increasing a sense of helplessness and loss of control.

In order to make an informed decision, people generally need time to take the information in. Consider what options are available to facilitate this, for example, could you come back and see the patient later, after their family has visited or they have spoken to someone close to them on the phone? Where the process of care in a setting makes this difficult, immediate plans can be revisited, for example:

"I know you will probably want more time to think about this. If I put in a request for you to be referred to this unit today, it will still be a while before you get the appointment through, but it gets you into the system without any delays. How do you feel about that? Perhaps you could come back in a couple of days, when you've had time to think it over and talk with your family?"

Be responsive to cues about ending the consultation

Communication is a dynamic process. Whilst you may have a list of information you were hoping to cover, this may be too much for some patients in one sitting. Be mindful of when someone has reached the point where they have had enough and need to stop. For very sudden and very significant news, for example, such as breaking the news of a relative's death, there may be very little in the way of 'content' in comparison to what you were expecting to discuss. A relative may not be ready, for example, to ask many questions or be given detailed information. By picking up on these cues, you may feel it would be more helpful to draw the consultation to a close and agree to come back later. There is little point in continuing to provide information that the person is unable to take in.

Make an immediate plan

Even if the person is not ready to make any decisions, having a simple concrete plan is essential in ending a consultation, and can help, in a very small way, to show that the situation can move forward. For example:

"I will organise the tests we talked about. When you've had the test, can you come back here, and we can speak again?"

Be clear about how the patient can contact you. It can help to reiterate your name and write any contact information (including your name) on a piece of paper.

It can be surprisingly difficult to end a consultation when you have shared bad news. You are likely to want to stay to comfort the patient, even when you know you have to attend to other patients. Patients need time to themselves after being given bad news. It can help to take your leave by offering *one* of the following options, such as:

- asking if the patient/relative has someone that they want to be phoned, or
- if they would like some time to collect their thoughts (perhaps offering a cup of tea), or
- if they would like someone to sit with them.

It is important not to overload the patient at this point. When people have been given shocking news, they often report that their train of thought is derailed and their head is spinning with implications. In this state, people can be unable to make even small decisions. Consequently it can help to phrase these offers as rhetorical questions, for example: *'Shall I ask the nurse to sit with you?'* to convey *'I'll go and ask the nurse to sit with you'*.

Case example 7.1 Breaking the news of breast cancer

Mrs Ball noticed a lump in her breast and spent several weeks worrying about it. She initially felt too frightened to tell her husband or doctor, but eventually went to her general practitioner when she started to lose weight and had difficulty sleeping. The tests showed cancer, and she had surgical removal of the lump. She is now having a consultation with the doctor, with her husband present.

Consider how this case illustrates elements of sharing bad news, such as conveying sympathy, being practical, being circumspect, being open about the prognosis and working together with the patient to consider management.

MRS BALL: *It's all my fault. If I'd come earlier, it wouldn't have turned out this way.*

DR DAY: *The fact that you came and you have had treatment is important.*

MR BALL: *My wife always blames herself. If only she had told me earlier. It really upsets me that you worried about this all on your own. Will she get better, doctor?*

DR DAY: *From the tests we have carried out, we're confident that we were able to remove the tumour from the breast. We will need to find out now if it has spread to anywhere else. If it has, it will depend on where it has spread to and what damage it has already caused. Do you have any questions for me at this point?*

MR BALL: *I'd like to be optimistic, but this time I'm very worried.*

DR DAY: *What is your main worry?*

MR BALL: *That I'll lose my wife (cries, the couple embrace).*

DR DAY (TO MRS BALL): *There is a chance that we haven't removed all the cancer. Are there any immediate decisions you have to make?*

MRS BALL (CRYING): *I was going to start working again in the next few months and one of the children is going to university later on this year.*

DR DAY: *How do you see your illness affecting these?*

MRS BALL: *We'll have to put everything on hold until we know where all this is going to. But I don't want my daughter staying home to look after me.*

DR DAY: *Have you thought about how you are going to tell your children?*

MR BALL: *We will be completely open with them both. Can we still expect my wife to come home soon?*

DR DAY: *Yes, that hasn't changed. It is important to keep an open mind about decisions until we have more information from the tests. I realise it must be stressful for you both not yet having a clear idea of how things will turn out.*

Feedback and handover to colleagues

It is good practice to inform colleagues about the meeting with the patient, summarise what has been explained to the patient and others, and note any particular preferences or concerns that the patient has mentioned that your colleagues may need to know about. This helps others caring for the patient to know where the patient's starting point might be for the next consultation. However, be aware that some, or all of the information, might need to be recapped, and the patient may have new queries or concerns. Consulting with colleagues can also be helpful in providing you with professional support and exploring ideas about how best to care for the patient throughout the process, as they have contact with different teams.

'What to do if…'

As a student in training, contemplating breaking bad news can be daunting. This is realistic: doctors with experience of breaking bad news report that it is one of their most challenging tasks. Trepidation can lead to fears about what might happen, in particular extreme reactions from the recipient of bad news, such as 'What do I do if a patient cries, or becomes angry, or violent?' It is nearly impossible to predict how a patient or relative will react to bad news, even if they are well known to you. It is important, however, to act in a supportive and professional manner. Whatever advice may be appropriate to the specific situation, acting in a way that is congruent with your own feelings and within the limits of professional conduct is a good guide. For example, if you are uncomfortable holding a patient's hand while he cries, do not do so; it will probably come across as contrived and awkward.

What if the patient cries?

Showing support to the patient who becomes upset usually takes the form of pausing in the consultation, and also handing the patient a tissue you have taken from the box. The patient will give you a cue as to whether to continue or to wait a moment. Although some doctors advocate touch (for example, on the shoulder or arm), if this does not feel natural, it can feel intrusive. Sometimes a patient may hold your hand when you put a tissue into their hand. Touch can indicate that you are not 'afraid' of the diagnosis (patients diagnosed with serious conditions such as cancer have reported that people are less likely to touch them). It is usually inappropriate, however, to hug or kiss a patient.

Patients often want the consultation to continue, and may expect you to continue even before they have finished crying. Acknowledging the emotion is important, for example:

"I can see this is upsetting. Would you like me to continue, or do you need a moment?"

Trying to minimise or stop the person's emotion – even with good intentions – shows a lack of empathy and compassion. For example, *'Don't worry about this for now'* or *'Actually, it could be a lot worse'*.

How would you react if a close friend shared some bad news with you and started to cry? What do you think the friend might expect of you? How would you know what to do?

What if the patient becomes angry or violent?

Think about a situation where you might get into an argument with a stranger. What is likely to inflame the situation and possibly lead to violence?

There are different types of anger. One is an immediate negative reaction to being given some shocking news, fuelled by a combination of wishing to deny the reality and hoping that the doctors have been incompetent and got the results wrong. It is a natural human reaction to want to blame *someone* when something very bad has happened that is perceived as truly unfair. It is one way for us to feel that we have more control over our lives. Calmly acknowledging the emotion, and the distress from which it arises, is important, for example:

"I can see that you are angry about this. I can assure you that I wish these results were wrong too. I'm sorry that they are not."

Remaining calm, polite, helpful and respectful when confronted with someone who is angry is the most effective approach. Remembering that it is not you personally who is the target of the anger, but the situation, can help.

That said, there are other forms of anger. These include when the person is shouting at you, when you feel threatened or when the person makes a personal attack (e.g. says something derogatory about you). If the anger has escalated, it can be helpful to show empathy whilst making the boundaries clear. For example, you might say, in a polite, apologetic, yet firm way:

"I realise that you weren't expecting to hear this. I'm sorry about the news. Unfortunately I can't have a discussion with you when you are shouting at me."

If this does not result in a rapid de-escalation, you may wish to terminate the consultation:

"I'm sorry you feel that way. I will ask my colleague to see you out. Let's discuss this another time."

If at any point you feel that you are at risk of physical threat, or you feel verbally abused, it may not be appropriate to signal an end to the consultation, if you feel it might inflame the situation further. In this case, you may wish to simply leave the room, and seek immediate assistance from colleagues.

Many patients and relatives are mortified that they have lost their temper, and will wish to apologise later.

Key points

- The way bad news is shared affects how people cope and adjust.
- Whilst there are some circumstances which most people would agree represent bad news, there are differences in people's perceptions of and reactions to bad news.
- Breaking bad news involves the same elements of communication as other situations where information is shared with patients and relatives.
- Sharing bad news requires time, a setting free from distractions or interruptions, active listening, empathy, and humility to say that you may not have the answers to certain questions.

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8

Communication with a patient's family

Robert Bor, Margaret Lloyd, Lorraine Noble

Students are taught in medical school to think of the human body as a set of interrelated systems; change in one system can result in changes in another. For example, if you are late for an examination you will start to feel stressed and you will speed up your journey. As you walk faster and your leg muscles work harder, your heart rate will increase, your breathing will become more rapid and you will begin to sweat. When you realise you are going to make it on time, you will feel relief, your breathing will slow down and you will notice your heart starting to return to a normal rate. Similarly, a person's health problems have an impact on other systems that the person inhabits, of which the family is probably the most significant.

In the traditional 'biomedical' model of diagnosis and treatment, learners are taught to look for problems inside the person and then to target treatment exclusively at the relevant bodily system. However, we also know that an individual's social and physical environment play an important role in the development of health problems and a person's response to them. For example, young people are more likely to take up smoking if their parents or other household family members smoke.[1] For many people, illness affects many aspects of their lives, and the lives of others in their family.

Chris Porter is a married mother of two school-age children who runs a small business from her home. One day she finds a lump in her breast, and investigations find an aggressive form of breast cancer. She embarks on an intensive treatment programme, which is time-consuming and exhausting. She asks her sister to help with taking the children to school, and her husband asks his employer for reduced working hours so he can help out more. The doctors are unable to predict whether the treatment will be successful, and the family faces an uncertain future. Think for a moment about the ways in which Mrs Porter's illness is affecting her life, and those of her husband, her children, and her wider family.

It is helpful to consider the different ways in which those closest to the patient can provide support (Fig. 8.1).

At times of ill health, we look to others for support and may depend more on our close family and friends. Support is not only concerned with practical problems, such as helping the patient get to and from the clinic or ensuring that children are picked up from school. It also entails emotional support and comfort at a time when people are feeling worried and fatigued. Studies have shown that social support can act as a buffer to psychological distress. There is also evidence that our bodies undergo physiological changes at stressful times, with the immune system being especially affected. Social support, therefore, can have an impact on both a person's physical and psychological health. Encouraging the patient to draw support from others can be

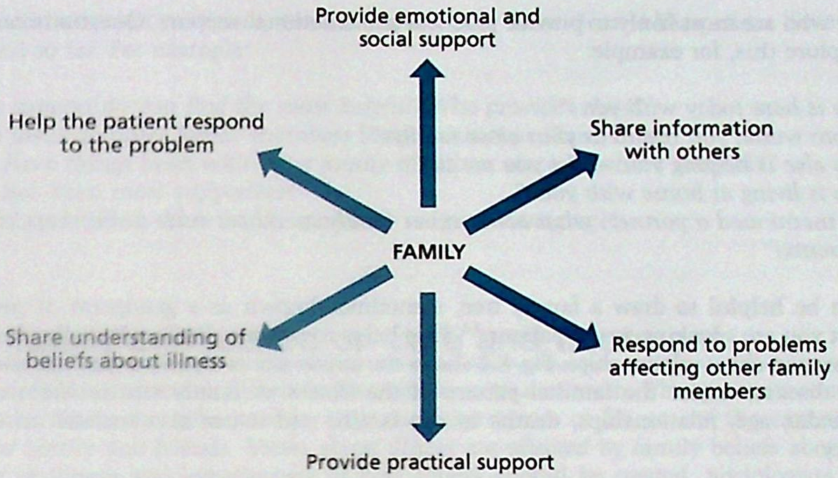


Fig. 8.1 How the family can help in diagnosis, treatment and care.

helped by talking about the family and asking questions about who the patient regards as close family.

It is important to note, also, that sometimes the people closest to the patient are not family members, and it is the patient's right to choose whom they wish to involve in their care. The wording of the General Medical Council guidance acknowledges that those supporting the patient may or may not be family members:[2]

> *"You must be considerate to those close to the patient and be sensitive and responsive in giving them information and support."*

Initial observations

Before you start the conversation, you can consider whether the patient is being supported by others:

- Is the patient alone or is anyone with the patient?
- Has one relative come along, or are there several family members?
- Has the patient been visited by anyone on the ward?
- Has the patient received cards or has someone brought in personal items (e.g. toothbrush, hairbrush)?
- Does the patient converse with others on the ward?

Of course, this information does not reveal whether the person prefers to draw on others for support or copes better without; that can only be explored by talking to the patient.

Identifying family members

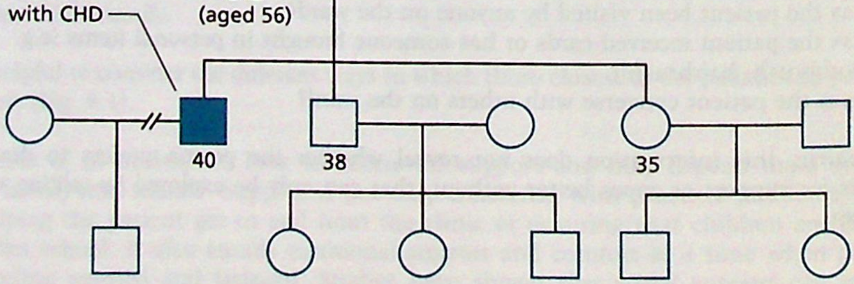
Although factual information may be needed about the patient's family to complete the background history, it is also important to ask about family and friends in order to identify those who are most likely to provide practical and emotional support. Questions can help to explore this, for example:

"Who is here today with you?"
"Whom would you regard as your close family?"
"Who else is helping you whilst you are ill?"
"Who is living at home with you?"
"You mentioned a partner; what about other family members such as brothers, sisters, parents?"

It can be helpful to draw a family tree, sometimes known as a genogram or pedigree whilst you are speaking to the patient.[3,4] This helps to organise and graphically represent information about relationships. Fig. 8.2 shows the family tree of a patient who has coronary heart disease; notice the familial pattern of the illness. A family tree includes details on gender, age, relationships, deaths in the family, and it can also include an illness history.

Having gathered details about the family, it can be helpful to explore the patient's views on the quality of these relationships. For example:

"How often do you see (or have contact with) your daughter/son?"
"Is there anyone who could help you with the shopping?"
"You mentioned your sister; is there any reason you would not ask your brother to help?"
"Who is most worried about you?"
"Is there anyone who ought to know you are here today?"



Key: CHD = coronary heart disease, RTA = road traffic accident

Fig. 8.2 A patient's family tree.

As the conversation continues, you can explore how those close to the patient have been involved so far. For example:

"What support do you find the most helpful? Who provides this?"
"What ideas do other family members have about your illness?"
"How have things been with other family members since you have been ill?"
"Who has been most supportive?"
"How do you think other family members see you managing?"

The family's influence on care and treatment

A person who experiences ill health does not do so in a vacuum. That person's concerns about the illness are influenced by their own experiences of illness and the experiences of their family and friends. Views about illness are affected by family beliefs about the nature of illness and expectations of how illness should be treated. Sociologists have written about the 'sick role' in regard to a patient's relationships with professional carers and with relatives. In the 'sick role', a person has 'rights' (for example, exemption from normal social roles) and 'responsibilities' (for example, to try to get better). We become more dependent on others when we are ill, and this can alter normal family relationships. For example, there can be role reversal, where a daughter or son assumes a caring role over a parent. Relatives who are healthy can also suffer as a result of illness in the family. For example, the brother of a boy with a serious illness may play truant, shoplift or wet the bed when his brother is admitted to hospital. The husband of a patient with cancer may be unable to sleep for months due to worry. Psychological distress can manifest in a number of different ways, depending on the age and role of the family member.

Relationships in every family, no matter how rigid they may appear, are dynamic and complex. At times of illness, in particular, each person's capacity to adapt is tested in response to new demands. This is why family relationships are often more tense and uncertain at these times.

Asking questions about:

- how people are coping
- what problems are being experienced
- family views about illness and treatment

can help you to understand the patient's situation better, and can in itself be supportive, by acknowledging the effects of illness on the family. For example:

"Has anyone else in the family suffered from a similar problem?"
"Have there been any changes in family relationships since your illness?"
"Who finds it most difficult to cope?"
"What ideas do your family members have about this illness?"
"How has your family coped with serious illness (or death) in the past?"
"Whose views about health and treatment are most influential in your family?"

Medical students and doctors sometimes worry about asking questions which might reveal problems in a patient's social circle, for example if a family member is finding it difficult to cope. However, patients and their families appreciate being asked and being listened to, and do not expect the medical team to solve these problems. That said, discussion about family circumstances may bring to light needs that could be addressed by other services, such as support for carers.

Working with couples

The close nature of a couple's relationship can be profoundly affected by illness. This is influenced by a number of factors, including:

- the nature of the illness (e.g. long term, progressively worsening, life threatening)
- specific effects of the condition or treatment (e.g. mobility problems, sexual dysfunction)
- whether the onset was sudden or gradual, and the extent to which the couple could prepare for it
- the existing quality of their relationship
- previous personal and family experience of coping with illness
- the role of the person in the relationship (e.g. primary bread-winner)
- whether the illness is infectious
- existing roles of each person in the family network, and the relationship between the couple and the wider family
- availability of support from other relatives or carers
- the developmental stage of the couple (e.g. newlyweds or a long-standing couple growing old together)
- the psychological resilience of each individual.

When illness strikes a couple relationship, the effect may be either to destabilise the relationship or to create an even closer bond between partners. Sometimes it has the effect of doing both, although greater closeness is often preceded by a period of uncertainty and instability, both of which are normal. These fluctuating states occur as a result of feelings such as fear, anticipation of loss, fear of abandonment, anger, or loneliness. Partners may also sometimes have expectations of one another that are not met, giving rise to feelings of resentment. Added to the disruption of routine and the re-allocation of tasks that often occurs as a result of illness, it is not surprising that tensions often rise when one's partner becomes unwell. The stress can appear in different ways, depending on the couple. For example, the patient may become more quiet and withdrawn in a consultation with the doctor, whilst their partner asks more questions and challenges decisions.

It is all too easy for the medical student or doctor to feel caught in the middle of these relationship dynamics and feel 'pulled' to side with one or the other partner. For obvious reasons, this should be resisted. Gentle and sensitive questions can be used to explore the perspectives of the patient and their partner, for example:

"Your husband seemed to be very stressed when he visited you today. Is something the matter?"
"So you've been incontinent for the past year. How has that affected things at home?"
"In a sense you've switched roles, and you stay at home whilst your partner goes out to work. How has that affected your relationship?"
"Your partner seemed very concerned about that. What do you think?"
"I can see that that might put a strain on a relationship. How are you both coping?"

Confidentiality

Adult patients have the right for information to be kept confidential within the medical team, and not shared with their family members. Nonetheless, many patients expect their families to be involved in their care and kept informed as a matter of course. In order to ensure that the patient's wishes are adhered to and to avoid misunderstandings, guidance about sharing information with those close to the patient notes that the doctor should *find out from the patient what information they wish to be shared, with whom and under what circumstances.*[5] This is best established early on during an episode of care, and is an ongoing process. For example, a patient may agree that relatives can be given a general status update but not test results.

On admission to hospital, a patient is usually asked to provide details of a contact in case of an emergency, often referred to as 'next of kin'. Although this is often taken to mean the closest family blood relative or partner, a patient can specify anyone close to them to be their 'next of kin'. The term carries no legal implications in the UK, and family members who are next of kin do not have the right to be given information or to be involved in decisions about the patient's care. This can seem counter-intuitive to relatives who are not familiar with the medical rules about confidentiality. Professional guidance details the rules about sharing information with relatives under specific circumstances, for example, if the patient lacks the mental capacity to make decisions for themselves, if the patient is a child (under the age of 18), or in the event of a patient's death.[5,6]

Asking questions to clarify the patient's wishes is helpful to ensure that the correct balance is struck between maintaining confidentiality and sharing information that the patient wants to be shared, for example:

"Sometimes relatives phone the ward for information. Would you like us to provide information over the phone? Whom would you like us to share information with? What information would you like us to share?"
"Would you like us to phone your son/daughter after the operation to let them know how it went?"
"If something were to happen to you, whom would you like us to contact?"
"Would you like me to explain the results to your husband when he comes in?"

If you are contacted by relatives who you do not know, and you have no prior instructions from the patient about whom information may be shared with:

- What are your responsibilities regarding confidentiality?
- What would you say to the relative?

Secrets

Coping with illness can be an extremely stressful experience for patients and their relatives. Societal taboos about talking about serious illness, certain infectious illnesses, mental health problems and death are still widespread.[7,8] With good intentions, therefore, sometimes the patient or their relatives wish to protect each other from difficult news.

Asking future-oriented and hypothetical questions is a non-confrontational strategy that can help some patients to consider ideas they might otherwise fear to address. Sometimes relatives wish to protect the patient, and may request that information about test results

Case example 8.1 A patient who is reluctant to tell his wife about possible testicular cancer

Mr Potts, aged 52, saw his GP because he had been having pain in one testicle and had recently noticed a lump. He also reported a persistent cough and occasional episodes of lower back pain. The doctor was concerned and suggested an urgent referral for further tests.

DR CHURCH: *Is there anyone that could go with you on the day?*
MR POTTS: *My wife, but I can't tell her about this.*
DR CHURCH: *You haven't told her about the lump and the pain?*
MR POTTS: *No, her father died of cancer. I don't want to worry her if I don't need to.*
DR CHURCH: *If she knew that you had come here today, what do you think she would say?*
MR POTTS: *She'd be so worried. Maybe I can tell her I'm going up north for a few days to see my brother while I get all the tests done.*
DR CHURCH: *What do you think would most worry her?*
MR POTTS: *Losing me as well, I expect.*
DR CHURCH: *If you were in her shoes, would you want to know?*
MR POTTS: *Yes, I suppose so.*
DR CHURCH: *So what do you want to do?*
MR POTTS: *Can you tell her, doctor? I've been awake all night wondering how I'm going to break it to her.*
DR CHURCH: *Yes, I can. Can you come back at the end of the surgery today? We can go over any questions you both have.*

is given to them first, or that information is withheld from the patient. It is important to understand the intention of the relative to protect the patient from upsetting information or the burden of having to make decisions. Nevertheless, the doctor's responsibility is to the patient, and patients have a right to be given information about their health and be involved in decision making. Whilst these may seem at times to be incompatible goals, having a conversation which addresses the underlying worries of the relative can help in providing reassurance that both the patient and the relatives will be supported.

Responding to concerns and fears

Each family member will respond to a relative's illness differently, depending on roles in the family. Some family members find it easier to provide practical support, whereas for others it is emotional support. Some family members are repelled by illness and either visit infrequently or prefer to enquire about the patient's condition over the phone. By way of contrast, some families organise a 24-hour vigil and take it in turns to be with the patient at all times. Most children's hospitals and paediatric wards make provision for parents to stay overnight with their child. When relatives are anxious, they will naturally seek out a doctor to obtain information about diagnosis and the likely prognosis, among other issues. Difficulties can arise when:

- Relatives approach 'junior' members of the team, such as junior doctors or medical students. This happens especially when senior doctors have not provided a clear account of the illness, prognosis and treatment. Junior doctors may not have the knowledge or experience to provide a clear answer, and medical students are not in a position to provide information. In both cases, the individual approached will need to show understanding of the relative's need for information, and agree a plan for the relative and patient, to have a conversation with someone who has the capability to provide the information that is required. Acknowledging the relative's concern and distress is key.

- Relatives seek out the opinions of different health professionals caring for the patient in a drive to 'get to the truth', or solicit a word of hope in a seemingly hopeless situation. In a situation of uncertainty, where the outlook is not good, it can be tempting to present the most optimistic view and offer reassurance about the outcome. The balance between offering hope and sharing your honest assessment of the facts as you see them is one of the most difficult tasks of a doctor. In these situations, taking time to acknowledge the relative's emotions and the impact of the illness on them can be as important as repeating factual information.
- The patient and relatives have different opinions about what is the most appropriate action to take. This may be either to do with which treatment option to choose, or other longer term actions (such as whether the patient returns to live in their own home or goes into residential care). Whilst these differences may reflect the different priorities of patients and relatives, they also reflect the different fears and concerns that relatives have compared to patients. Whilst adult patients have the right to choose the course of action they wish to take, excluding the views of those close to them can lead to important information being left out of the decision-making process. Taking the time to have a conversation where the views of the patient and the relatives are explored, and the reasons behind these are discussed, can enable a more comprehensive discussion of the issues in advance of decision making.

Key points for communicating with a patient's family

The following strategies can help in having effective conversations with patients and their families:

1. Find out who the relatives are at the outset, ask for their names and relationship to the patient.
2. Involve family members in the conversation. Ensure that family members are given time to share information, raise concerns and ask questions.
3. Acknowledge the support that the family members provide.
4. Ask for the family members' perspectives.
5. If part of the consultation is with the patient alone, whenever possible, find a space where family members can wait.
6. Ask the patient who in the family can be given what information.
7. Identify a key worker (e.g. a nurse or doctor) whom family members can contact, if needed. For example, agree how family members will be contacted if the patient's health deteriorates.
8. Share information firstly with the patient, and check whether you have the patient's permission to discuss it with others.
9. When in doubt, tell the relatives to ask the patient if you are not sure you have the patient's permission to discuss something with them.
10. Write up a summary in the notes of important discussions with relatives so that your colleagues know what has been discussed and with whom.
11. If the patient is very unwell, encourage relatives to make frequent, but short visits.
12. Do not examine the patient (unless a child) in front of relatives.

13. Do not carry out procedures (such as taking blood) in front of relatives. Ask them to leave the room.
14. Do not discuss family issues in ward rounds or any other settings where you might be overheard.

Key points

- Illness not only has an impact on individuals, but also affects family members and others close to the patient.
- Family members often provide practical and emotional support, so it is important to address their personal concerns and their role in care giving.
- Drawing a family tree provides a graphic representation of relationships and clues to patterns of illness among generations.
- Asking patients about what information they wish to be shared with family members helps to avoid misunderstandings.
- Exploring the perspectives of family members can enable a comprehensive discussion of issues in advance of decision making.

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Communicating with children and young people

9

Zack Eleftheriadou, Lorraine Noble, Robert Bor

Children are not miniature adults. (General Medical Council[1])

Although children and young people may suffer similar medical problems to those of adults, caring for minors in the clinical setting is, of necessity, different in certain respects. Working with younger patients offers rewards as well as challenges.

Think how you would explain human reproduction to a 4-year-old, a 7-year-old, an 11-year-old and a 14-year-old child. Try this with a friend or another student. Do you think you sound childish? Overly scientific and complex? Patronising? Would you talk, draw, or use puppets or dolls? Think about:

- *What assumptions do you make about what the child already knows?*
- *What questions would you ask to check the child's level of understanding and knowledge of terms for parts of the body?*
- *Do you feel embarrassed discussing this topic?*
- *What questions do you expect the child to ask?*

What to consider when communicating with children and young people

Understanding developmental stages from infancy to adulthood is important in making decisions about how to pitch the level of a consultation. Think about the changes that a child undergoes in their understanding of the world, ability to express themselves, sense of time, and understanding of illness or death, for example.

It is important not to talk down to children. If communication is pitched at an age level younger than the child, that child may feel that they are not being taken seriously. Being addressed appropriately makes children feel reassured that they will be understood and respected. This can determine how comfortable they feel about sharing questions and fears. Likewise, children are more likely to take an interest in their treatment and to trust the medical staff, if they feel involved and have some control in the medical encounter. The doctor might say:

"Let's see, what do you think we should do to get rid of this?"

Actively involving the child demonstrates that their opinion is valued, which can set the tone for this and future encounters. Strategies for enhancing communication with young patients are given in Table 9.1.

Table 9.1 Enhancing communication with child patients

- Be at the same physical level when talking to or examining the child
- Establish rapport and gain the child's confidence before touching or examining a child
- Learn the child's terminology for his or her concerns and parts of the anatomy
- Use simple language
- Use photo albums of procedures that can children can view before a procedure with the relevant health professional
- Check understanding by asking the child to repeat what you have said, or demonstrate using a doll or teddy bear
- Engage the help of a parent or guardian, especially when examining a child
- Explain procedures before you do them, in terms of what the child can expect
- Keep talking; a calm voice is reassuring, even if a child is obviously upset
- Carry out procedures promptly, to prevent prolonged anxiety
- Avoid relying on bribery in return for having a procedure or taking treatment
- Avoid making promises you can't keep (e.g. 'this won't hurt'), but be honest and give praise and reassurance
- Ensure the child is never alone in an unfamiliar setting or with unfamiliar people
- Avoid encouraging the child to 'be good'; allow the child to cry or show distress

Even babies and very young children can pick up subtle cues about the feelings of parents and medical staff. For example, a toddler may, through their behaviour, express the anxiety that the adults in the room are feeling, and may start to play loudly with toys when the conversation turns to a topic that the mother is worried about. Young children are also more aware of what adults are discussing than they appear to be, even if they look distracted playing with toys. Asking the child afterwards can result in an impressively accurate summary of the main points from the consultation, for example, that they are very poorly, that mummy and daddy are very worried, and that they will need to spend a long time in hospital. Children can express their understanding of the situation – and the impact on the family – in a variety of different ways.

It can help to remember that every consultation involving a child or young person is a triadic consultation (doctor–parent–young patient) rather than a dyadic consultation (doctor–parent) where there also happens to be a smaller person in the room.

In any consultation where there is an infant, younger or older child or adolescent, it is important to consider their involvement in the consultation. This can include:

- In what ways do you involve the young patient in the consultation, appropriate to their needs and stage of development?
- What information does the young patient need?
- How will the young patient be involved in making decisions and following through a treatment plan?

Communication with young patients at different ages

How a young patient can be included in a consultation depends on their age and developmental stage, as well as the child's individual personality. For example:

Infants

Have their own personality and preferences, and the most effective way of learning about these is to interact, e.g. make eye contact, lean towards the baby at a safe enough distance and speak to the baby in a calm, gentle manner. Non-verbal communication, being at the same eye level as the patient, and showing an interest in what they are interested in are all basic building blocks of communication with very young patients.

Babies and toddlers can show their feelings in a variety of ways, and can pick up on and reflect feelings within the room (including those of the doctor). Young patients are also aware of whether their primary caregiver (usually the mother) is feeling relaxed or anxious, for example, about a physical examination of the child or a procedure.

Young children

Will have some words to explain how they are feeling, although they may find it easier to express themselves through play rather than through conversation alone. If parents have been asked to bring a favourite toy to the consultation, for example, this can help to establish rapport with the child, gather information and explain medical procedures. Engaging the child in play with their favourite toy or soft toy can help in opening a line of communication which is centred on a familiar and safe object. For example:

"Shall we have a look at teddy's tummy and find out where it hurts?"
"What would teddy need to make him feel better?"
"Show panda how wide you can open your mouth."

Drawing is also helpful as a means of communication, as children can use it to provide information and express their feelings in different ways. Children can draw their families, for example, and sometimes surprise parents by including members of the family who have died, and whom parents have tried not talk about in front of the child for fear of upsetting them. This can help to illuminate the child's understanding of who is important in their family and social circle, and role of family members who have died or who no longer live in the family home.

Drawing and role play with dolls or other toys can also help children to show what they understand about illness and treatment, for example, that the hero is in the castle and there is a big battle going on outside. Having a conversation with a child using play as a backdrop can help a conversation flow more naturally. For example, if a child is quiet for a time in response to a question, the silence feels less awkward than if the doctor and child are sitting looking at each other across a desk.

As well as helping communication, having toys and drawing materials available gives the child something to occupy themselves during what may be experienced as long, boring and occasionally frightening visits to the clinic or hospital.

Older children

Are more likely to be obviously actively involved in the consultation, and there is a balance to be struck in using language which is pitched at an adult level and a level which includes the child. Whilst this might seem to be a dilemma, discussing a problem at a level a child can understand can improve the clarity of an explanation (for example, by focusing the mind on avoiding medical jargon). It can also be reassuring to parents to have the problem and treatment broken down into simpler terms, particularly at times of anxiety, and repetition of information is often appreciated. As an additional benefit, using language that a child can understand and actively involving the child in the discussion can help parents in talking about the problem and treatment with the child when they are back at home. Children have views and preferences about treatment (for example, they may wish to avoid a treatment that their peers have talked about in the playground), so helping the child to be involved in their care and addressing their concerns can improve a child's sense of control.

Adolescents

May find that adults sometimes treat them as if they are adults, but at other times as if they are much younger children. Adolescence itself is a complex developmental stage, in terms of an individual's social, emotional, behavioural, physical and sexual maturity, which develop at different rates. Adults may be unsure about how to pitch explanations, and how to involve the young person in decisions. Likewise, the adolescent patient may sometimes want to have independence and make their own decisions, and at other times may simply want to be looked after. How families cope with the transition of the child becoming an adult varies from family to family, and it is often a moving target, with changes happening at bewildering speed for all concerned. Differences of opinion about treatment decisions, for example, may reflect differences of opinion about other aspects of the family's life which are happening outside the consultation. The need for patients and family members to feel supported, however, remains a constant.

It is also worth highlighting that older children and young people will often have access to online resources, including social media, and will be using these to do their own research on topics that they want to know more about.

The physical environment

Adults take for granted that our physical environment is built in proportion with ourselves and not children. Look around you wherever you happen to be now; if you were half or a third your size, what would become an obstacle?

- *Could you still reach the door handle?*
- *Could you sit down by yourself on a chair, or would you need to be lifted up?*
- *Could you sit at a table and still put your elbows on it?*
- *Could you get up or down stairs on your own?*
- *Could you leave where you are now without help from an adult?*

Obviously it is not possible to create a totally child-oriented environment in all settings, but think about being a general practitioner or working in a hospital. What would you want to do to make sure young patients felt more welcome and comfortable where you work?

Research exploring the experiences of children and young people in hospital settings has found that the physical environment has a strong influence on whether young patients feel:[2]

- welcome
- comfortable
- a sense of control

- able to maintain a positive frame of mind
- a sense of privacy
- able to move about independently.

Access to a well-equipped play area and toys in the waiting room, for example, can show that the environment is child-oriented. Children find it comforting to see brightly coloured walls, play materials and furniture (e.g. small tables and chairs) that are in scale with their size. Some children's hospitals name wards after animals and ensure that door handles and other objects are at a level that can be easily reached by most children. For older children, age-appropriate aesthetics, artwork and activities create a familiar environment.

In hospitals, having spaces that can be personalised with toys or personal possessions provides a place of normality to counter the unfamiliarity of other hospital spaces with their hard clinical surfaces and scientific equipment. It also creates a welcoming environment for friends and family members, which can reduce the anxiety of the young patient's peers when they come to visit.

The consulting room

Like the waiting room and the overall environment of the healthcare setting, ensuring that the consulting room is child-oriented can provide reassurance to young patients that the strange environment is actually a safe place. How child-oriented the space is often depends on the nature of the service being provided. Even small adaptations can help, for example, a poster on the wall of a popular children's film, computer game or music idol can provide a familiar image and act as a talking point.

Children and young people need privacy just as much as adults, particularly when being examined; for example, having the curtains drawn or the door shut.

The doctor's appearance

The dress and appearance of doctors can help a child to feel comfortable in hospital. Some doctors who regularly care for children have multi-coloured stethoscopes, wear fun badges on their lapels and carry a small, fluffy toy in their pocket in case a child needs to be distracted or cheered up. Many prefer to wear more casual clothes, rather than hospital uniforms (such as scrubs) wherever possible, in order to create a more relaxed and friendly impression. That said, young patients and their families need to be clear about who assorted staff members are, and their roles.

What other aspects of a hospital or clinic setting might be unsettling for a child or young person? How could you address these?

Who should be present

Parents have an important role in preparing the young patient for clinic or hospital visits, sharing information with the patient and supporting the patient through their illness. Ideally, both parents should come to the consultation in order to create a family atmosphere. Even if one parent cannot attend, the invitation should always be extended to both. Providing support to the young patient's family helps the family to be better able to provide support themselves to the young patient.

Introductions

The key to effective conversations with children and adolescents is to be flexible in talking with young patients at different stages of development. A warm and friendly introduction is always appreciated, as is patience in building rapport. Some children and adolescents build up trust slowly, for a variety of reasons. Some young patients will be affected by the strangeness of being in a healthcare environment. Others will be naturally shy. Others may have expectations of what will happen when they visit the doctor; for example, a worry that the doctor will touch their very sore tummy and cause more pain.

Judge how comfortable the child feels by the way the child walks into the consulting room. For example, does the child stride in front of the parents or refuse to leave mother's side? This might be the child's characteristic way of meeting new people or the child may be anxious about the unfamiliar setting.

Asking about hobbies and interests before addressing medical problems can help to break the ice and show that you are interested in engaging the young patient in the discussion. Being aware of aspects of popular culture that are relevant to certain age groups can help in triggering a conversation at particular points, for example, when washing your hands and preparing to examine the patient.

The beginning of the consultation is also the first opportunity to assess the child's progress against developmental milestones. The child's behaviour and responses to you can provide information about whether the child appears to be within the range of normal development or whether there are any indications of a developmental delay.

Gathering information

Children of all ages appreciate being involved in a consultation, in a way which is age-appropriate. Depending on the age of the child, questions may be directed more to the parent, more to the young patient, or a combination of the two. Be aware that young children have to work with the vocabulary they have available, for example, they may say that their leg 'feels bad' but might not be able to say whether it is a dull ache, shooting pain or pins and needles, or how often it occurs. For example:

STUDENT: *This leg feels bad, does it?*
CHILD: *This one. Naughty leg.*
STUDENT: *If you touch it, do you go 'Ouch!'?*
CHILD: *No, it's inside bad.*
STUDENT: *Like 'Ow, this is sore!' or…?*
CHILD: *Sometimes.*
STUDENT: *What about right now? If your leg was talking to you, what would it say?*
CHILD: *That's silly! Talking leg!*
STUDENT: *Yeah, that would be really silly.*
CHILD: *It would say 'Owwwwwwwww'.*

Being patient in asking questions is important, as children are often very aware of the emotional tone in the room and are able to sense whether they are giving the 'right answers'. Young patients may not separate out 'physical' and 'psychological' symptoms in the way that adults do. For example, children may describe or express pain as tiredness or being in a bad mood.

All young patients are normally seen in the presence of a parent or guardian, although it may be appropriate for at least a part of the consultation to be conducted without the adult who has accompanied the child. For example:

- An adolescent patient may be particularly embarrassed to talk about aspects of the problem in front of a parent.
- A child may have questions or concerns that they are afraid to discuss in front of a parent because they know the parent gets upset.
- You may have concerns about whether there is some form of abuse within the family (for example, physical or sexual abuse of the child, or domestic abuse).

Having a routine for the consultation where the parent or guardian is asked to step out for a short time can help in normalising this as part of the standard procedure. It can sometimes be helpful to have a chaperone, such as a nurse, present in the room.

Gathering information from infants tends to be through non-vocal means. Observing and interacting with a baby can provide a lot of information, such as how the baby responds to other people (e.g. smiling, eye gaze), clues as to the baby's temperament, and how it soothes itself (e.g. thumb-sucking or crying for mother). During this time, parents are likely to voice their own concerns about the baby or about their general abilities as parents. For example:

STUDENT: *Look at that smile! That's a nice smile!*
PARENT: *She's happy most of the time, but in the evenings she just howls.*
STUDENT: *What happens in the evenings?*
PARENT: *She starts to cry, like she's in pain, and it goes on for about half an hour. I just walk around with her.*
STUDENT: *I see you smiling at me! Every evening?*
PARENT: *Pretty much. I don't know what I'm doing differently. My first baby never did anything like that.*
STUDENT: *Is it something you're worried about?*
PARENT: *I rang my mum, who said it was 'just colic', but she's just so distressed when it happens.*

Examining a young patient

Before being examined, all patients appreciate:

- reassurance
- information about what is going to happen
- clear instructions on what to do
- information on what to expect (e.g. whether it will be painful).

Approaching the examination of young patients is no different, albeit that the form that reassurance and information take will depend on the developmental stage of the child. It is helpful to engage the support of the parent when examining a child. Parents who are anxious about examinations or procedures can convey that anxiety effectively to the young patient. It is helpful to consider the needs of both the child and the parent when providing information and reassurance.

Choices can be made available where possible; for example, if the child shows independence from his or her parents, the child can be asked if they want to be examined on the examination table or on their mother's lap. Young children may prefer to stay on the parent's lap. A commentary from the doctor which is reassuring and acknowledges the child's perspective shows that this is a routine and safe part of the process. For example:

"You don't want to move away from mummy? That's fine. So are you all nice and comfortable? Good. Let's take a look at that ear."

Responding to a young patient's feelings

The hospital environment can cause anxiety in children, and their behaviour may regress to that of a much younger child. For example, a child may become more clingy or start wetting the bed again. Anxiety is quite normal, but by addressing the child's feelings (for example, of fear, loss, abandonment or becoming disabled), medical staff can help maintain the child's self-esteem and prevent some behavioural problems becoming the norm. Sometimes, this involves responding to something that you sense the child is trying to communicate but has not verbalised clearly.

STUDENT: *You look a bit sad today.*
CHILD: *Mummy was a bit cross.*
STUDENT: *Oh. Why's that?*
CHILD: *I wet the bed again. Mummy said I'm too old for it.*
STUDENT: *It's a bit different here than at home.*
CHILD: *At home Mummy reads to me at bedtime.*
STUDENT: *Should we ask her to read to you when she comes in? It might not be bedtime.*
CHILD: *Yeah.*

Children may blame themselves for an illness, believing that it is a punishment for bad behaviour or being a bad person. Children can believe this so strongly that their behaviour deteriorates, because they feel that they deserve to be punished. This view can be reinforced by the exhortation by adults to 'be good and you will get better'. Young patients can feel that it is their fault if they do not get better, and feel guilty and unhappy. Explicit reassurance that sickness is not the result of naughtiness and that they are not responsible for the illness can be a great relief to young patients. For example:

"This is something that happens to other children too, not just to you, so you mustn't feel it's your fault. I've seen lots of other children who have asthma just like you."

Children like to feel in control and that they have acquired new skills regarding their illness. For example, a child might learn to detect some warning signals and in turn inform the parents. Children who are chronically ill can be repeatedly told how well they are coping and that they can still fight the illness.

Young patients need to have the opportunity to explore their feelings and ask questions about medical procedures. It can be useful to show photos or videos of procedures that the children view together with the relevant professional beforehand. This provides information for the children and reassurance that other children have been through a similar experience.

Even when the procedures are over, the child can be encouraged to articulate or play out some aspects of medical procedures or treatment that have made a particular impression. This provides the opportunity for the child to tell others (such as parents) what it felt like, and to mentally 'file' the experience as one that was successfully navigated. After each medical procedure, the child can be complimented, congratulated or encouraged, before being prepared for the next stage. This explicit reassurance helps to address the emotional impact of the illness and the experience of undergoing treatment. Children may not necessarily have an outlet for these feelings, unlike adults, who could ring a friend or talk to family, friends or workmates.

Involving young patients in decisions

Parents and doctors often naturally want to shield younger patients from information that may be distressing or decisions that may be difficult. Nonetheless, young patients have their own perspective about their illness and treatment.

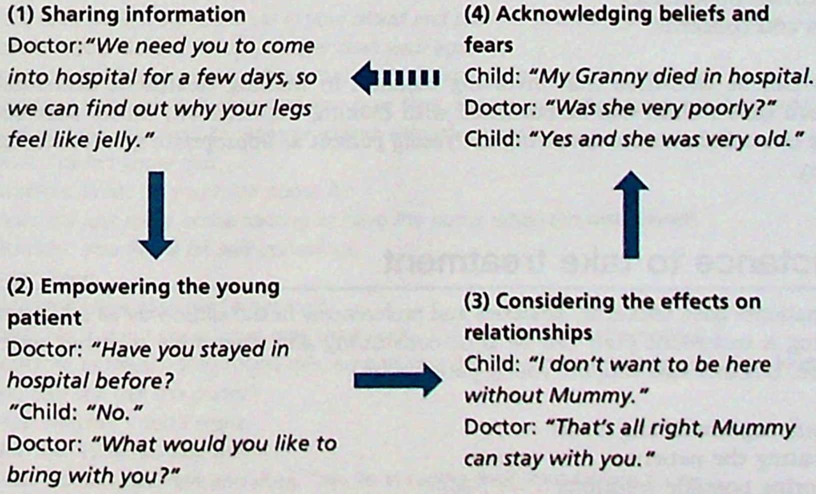
Jane is a 9-year-old patient with kidney disease. Today the doctor is meeting the family to discuss the option of one of her parents donating a kidney. Prior to the consultation, this is what each of them is thinking:

Doctor: *I want to be reassuring but also be clear about the risks.*
Mother: *I just want her to have a kidney. I hope one of us is a good match.*
Father: *I want to know how long a donated kidney will last.*
Jane: *I don't want Mum or Dad to give me a kidney if it's going to make them sick like me.*

If you were the doctor, how would you approach this conversation?

Discussing management with young patients involves several elements, as shown in Fig. 9.1:

- sharing information about the condition and treatment
- empowering the young patient to have a sense of control



(1) Sharing information
Doctor:*"We need you to come into hospital for a few days, so we can find out why your legs feel like jelly."*

(2) Empowering the young patient
Doctor: *"Have you stayed in hospital before?*
"Child: *"No."*
Doctor: *"What would you like to bring with you?"*

(3) Considering the effects on relationships
Child: *"I don't want to be here without Mummy."*
Doctor: *"That's all right, Mummy can stay with you."*

(4) Acknowledging beliefs and fears
Child: *"My Granny died in hospital."*
Doctor: *"Was she very poorly?"*
Child: *"Yes and she was very old."*

Fig. 9.1 Elements of communication with a child patient.

- considering the effects on relationships
- acknowledging the young patient's beliefs and fears.

Even very young patients often have opinions, preferences and worries about treatment. The General Medical Council recommends that doctors should:[1]

- involve children and young people in discussions about their care
- be honest and open with them and their parents, whilst respecting confidentiality
- listen to and respect their views about their health, and respond to their concerns and preferences
- explain things using language or other forms of communication they can understand
- give them opportunities to ask questions and answer them honestly
- have open and truthful discussions
- give young patients the same time and respect as given to adult patients
- involve children and young people as much as possible in decisions about their care, even when they are not able to make decisions on their own.

There is also guidance on how to determine whether a young patient is able to make decisions for themselves, confidentiality, child protection and sexual health advice.[1]

Exploring the perspectives of the patient and those close to them forms the basis of supporting patients and their families in making decisions that are best suited to their individual needs. This discussion will necessarily depend on the age and maturity of the child, as well as the nature of the medical condition and treatment options.

When decisions are more complex, for example, if there is more than one treatment option, if the proposed treatment involves risks, or if the outcome is uncertain, this may involve exploring:

- what the patient and their family hope to achieve
- what matters most to the patient and their family
- treatment preferences
- fears and concerns.

Parents can be reassured that involving children in making treatment decisions does not mean that a child will be burdened with making the decision, rather that decision making is a collaboration, involving the young patient as appropriate given their age and maturity.

Reluctance to take treatment

Young patients have concerns, anxieties and preferences, in the same way as adult patients. Following a treatment plan can be time-consuming and disruptive to other aspects of daily life. Doctors can support young patients by:

- identifying conflicting needs
- educating the patient
- exploring possible solutions
- encouraging the patient to feel in control of their treatment.

Knowing that their child is not taking treatment as recommended can be immensely stressful for parents, and the resulting battle for control can be distressing for all concerned. Parents may be baffled by their child's behaviour and the child may feel that they are not being listened to. The doctor's task is a delicate one because the boundaries need to be flexible. This means taking into account different individuals and circumstances; for example, whether a child is not taking tablets as a means of demonstrating their independence, or whether an adolescent patient who is taking risks (such as having unprotected sex) is placing a greater priority on their social needs than their health needs.

Case example 9.1 Young patient with anaemia who is reluctant to take treatment

George, a Greek-Cypriot boy in his early teens, has thalassaemia major, a type of anaemia found in Mediterranean populations. He needs regular blood transfusions, as a result of which his body builds up excess iron. To get rid of the iron, he needs continuous infusion of a medication via a pump 5 days a week. He does not mind the transfusions or hospital visits because he meets other young people with thalassaemia, but in the last few weeks he has begun to resent having to use the pump, and during his routine check his iron level was found to be high. Worried about the result, his parents brought him to the hospital. The doctor reviewed the results with George and his parents in the room. The parents expressed their concerns and their desire for a solution, but George was silent throughout. The doctor suggested that she talk to George on his own for a few minutes.

Dr Norton: *So your iron level has gone up, and I can see your parents are really worried.*

George: *Yeah, I know.*

Dr Norton: *Are you having problems with the treatment?*

George: *I'm just so sick of it.*

Dr Norton: *Which bit of it?*

George: *The transfusions are okay. It's the pump.*

Dr Norton: *Do you know what the pump is for?*

George: *To 'reduce the iron in my blood'.*

Dr Norton: *Do you know what happens if your iron goes up?*

George: *Not really.*

Dr Norton: *If we keep the iron down, we expect you to develop normally. If there's too much iron, over time, it can build up in your blood and prevent you from growing properly. This can result in you looking much younger than your age.*

George: *Yeah, I've seen people like that at the hospital – it's really frightening!*

Dr Norton: *If there's a build-up of iron over time, then your body organs can be damaged as well and this can lead to other problems with your health.*

George: *I didn't know that.*

Dr Norton: *What do you think about it?*

George: *It's just really embarrassing to have the pump when I'm with friends.*

Dr Norton: *You feel a bit self-conscious.*

George: *Yeah.*

Dr Norton: *Have they said anything?*

George: *No, I don't know what they think really. I've never really talked about it.*

Dr Norton: *Is there a way round this, so that you don't feel embarrassed with your friends but you can still use the pump?*

George: *Maybe. I don't know.*

Dr Norton: *What do you think?*

George: *I could ask Pete and Joel. They're in having their transfusions today.*

The example shows that when George has time alone with the doctor, he can express his concerns without being worried about being immediately overruled. The doctor acknowledges his concerns, giving him the facts and acknowledging that George has competing needs. Helping the young person to solve problems, in this case by identifying that there are two goals that are important to George (being healthy and having a normal social life) is the first step in a process of negotiation. Engaging the young person in finding a solution that they feel is workable not only supports the treatment plan, but helps educate the young person about how to work through problems caused by their illness. A definite solution might not be agreed by the end of a single consultation, particularly when long-term behavioural changes are needed (which are challenging for all patients, whatever their age). Sometimes a trial period of a suggested potential solution can be agreed, and the young patient may have inspiration in the meantime and find a better solution, which they have ownership of.

Separation, isolation and chronic illness

Some medical procedures require a child to be separated from family, friends and a familiar environment. A child undergoing treatments for cancer, or chronic or infectious diseases may need to spend long periods in hospital or off school. Furthermore, changes to mobility or physical appearance can seriously disrupt a young patient's normal routines and relationships.

Young patients can be helped if there is consistency in their routine and in the staff who care for them. They can become upset if a favourite doctor leaves. Keeping children and young people informed about the staff members caring for them, and any staffing changes, can help in providing a sense of order in an unfamiliar setting.

Children who are hospitalised can adapt to the strange environment more easily if there is continuity in their usual routines and they are able to bring in favourite objects and toys from home. Some hospitals have teachers who visit and bring schoolwork, which has the added benefit of enabling young patients to feel a sense of achievement and progress at a time when their body has let them down. Helping a child to feel a sense of control over their environment can be achieved in a number of ways, for example:

- Provide a range of activities and let the child choose from these.
- Mark and celebrate events, e.g. birthdays, end of term.
- Encourage regular contact with friends and family, e.g. over the phone.
- Encourage frequent visits (even if they are short).
- Help the child personalise their space, with photos, toys and favourite objects.
- Spend time with the child, even when there are no medical procedures to carry out.
- Encourage the child to make a chart and mark off the days until leaving hospital.
- Give realistic hope.

Young patients who need to follow a treatment plan at home for longer periods (or perhaps indefinitely) can gain a sense of achievement and control from being involved in self-management. Education on the rationale and skills required will depend on the age of the child and the treatment regime. For example:

DR SMITH: *So this involves injecting insulin every day, about four times a day.*
PARENT: *So at least one of those will be when she's at school. I'll have to go into school to do it.*

CHILD: *No, I'll do it myself.*
PARENT: *No, it's too important.*
DR SMITH: *You will have to learn how to do it for yourself in the long run. It takes some practice though, and you might not want to do it all the time.*
PARENT: *Can we both learn how to do it? Then I know I can always do it.*
CHILD: *OK. I want to do it though.*

The worry of having a sick child can be very distressing for parents. Strategies to help parents help care for a sick child are given in Table 9.2.

Breaking bad news to young patients

Whatever difficulties exist in breaking bad news to adults, they are compounded when caring for children. For parents, bad news will shatter their hopes and dreams about the child's future. A shortened lifespan, chronic illness, disability or death of a child give rise to feelings of shock, disbelief, anger, guilt and blame. Even though the child may adjust relatively quickly to limitations resulting from illness or injury, the parents' distress and the reactions of others may continue to cause upset within the family.

For parents, the painful emotions and reactions can arise from:

- fear of loss
- loss of expected developmental milestones
- worry about the child's quality of life

Table 9.2 Helping parents care for their sick child

- Invite both parents to see the doctor for consultations where diagnosis and treatment are being discussed
- Acknowledge their expertise as parents
- Be honest and clear
- Jointly decide on the best time to tell the child about a hospital visit, hospitalisation or treatment
- Involve only a few other staff so the parents do not feel overwhelmed by professionals
- Share medical information at a pace parents can cope with
- Name the disorder, describe the treatment plan and expected prognosis and possible implications on the family, schooling, etc.
- Do not assume the parents know about the illness; they may only have hearsay or second-hand information
- It may be helpful to give parents written information, online resources and names of parent support groups
- Be available to see parents on a regular basis, even if only for brief periods
- Act as facilitator to the parents and child adapting to the illness, especially long-term illness
- Discuss the importance of being honest with the child and support parents in providing explanations to the child
- Parents of a dying child usually want to know how long the child will live and under what conditions the child will die. This information will help them to plan the remaining time and express their feelings
- Allow time for questions, concerns and opinions

Table 9.3 Breaking bad news to children

1. Adapt the explanation to the child's age, developmental stage and level of understanding
2. Discuss with parents who should tell and what to tell
3. Try to learn what the child knows about illness and death. Ask about previous experiences in the family or among pets
4. Be direct and honest. Avoid euphemisms. Do not give false reassurance and do not lie
5. Share information in the presence of parents. Check what the child has understood
6. Check what meaning the child attaches to explanations so as to avoid misunderstandings and unnecessary anxiety
7. Play and drawings can help a child to understand disability and loss and express their feelings
8. Attend to the needs and concerns of parents and siblings, who are sometimes more distressed than the child
9. Accept that a bad temper and tantrums are normal reactions in a severely ill child
10. Emphasise what the child will be able to do, thereby giving realistic hope

- a sense of guilt
- feeling deprived of an expected future.

The doctor and parents can work together to decide how to tell the young patient the bad news and exactly what to say. Note, however, that children can have a different view of the future compared to adults and may be more matter-of-fact about some news which is very upsetting to parents. Children are often more aware of bad news which is discussed within families than parents may realise; for example, they may be told information by an older sibling or even by a friend at school (when parents have been discussing the illness with other adults). Children who find out unexpectedly about their illness can feel angry and cheated, or can feel that they must keep the secret as their parents would be upset if they mentioned it. When secrets are kept, children may fill the gap by worrying that they have deserved the illness by 'being bad' or by finding information out from other sources.

Some elements of breaking bad news to children are given in Table 9.3. The conversation with either the child or parents should cover:

- basic information about the illness or disability
- consequences of the information
- the effect on the family
- beliefs about how the medical problem arose
- concerns
- the plan for care and ongoing support.

At times of extreme stress, family members may blame themselves for somehow 'causing' the illness, and it can be helpful to encourage family members, including the young patient, to express their feelings of self-blame or guilt. This provides the opportunity to give explicit reassurance.

DR SMITH: *What do you think, now I've told you that?*

CHILD: *My friend Joe said you get better if you try really hard. Maybe I didn't try hard enough.*

Dr Smith: *I think you've been trying really hard, but that's not how it works. Sometimes the treatment doesn't make this go away. It's about how the medicine works, not about what you do.*

When the news is very difficult, there can be a wish to 'soften the blow' by using euphemisms, for example, by saying that a child will 'go to sleep' rather than 'die'. Although well-intentioned, this can cause more problems, for example, the child may become afraid of going to sleep at night or afraid of their parents going to sleep. Likewise, this can also cause fear and confusion among siblings.

Guidance on supporting families when a young patient has a life-limiting illness suggests that professionals:[3]

- are sensitive, honest and realistic
- give reassurance when appropriate
- discuss any uncertainties about the condition and treatment.

Key points

- Communication with young patients depends on their age, maturity and the nature of the medical condition and treatment options.
- The physical environment and rapport between the doctor and child are important.
- Young patients appreciate being involved in the consultation and talked to at a level which is appropriate to their needs.
- Children and young people have their own perspective about illness, including concerns, which can be very different to those of adults.
- Young patients benefit from feeling involved in decisions and feeling a sense of control.

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10

Communicating with people from different cultural backgrounds

Zack Eleftheriadou, Lorraine Noble

Culture is defined as:

"a socially transmitted pattern of shared meanings by which people communicate, perpetuate and develop knowledge and attitudes about life. An individual's cultural identity may be based on heritage as well as individual circumstances and personal choice and is a dynamic entity."[1]

Culture is a social construct and a sense of identity which can be determined by a multitude of factors, including where you were brought up, what language you speak, your religion/spiritual beliefs, education, sexuality and age, amongst many others.

'Cultural background' is often taken to mean a person's nationality and/or ethnic identity. However, it is a broader construct. Culture can be defined as ideas, values, beliefs, customs and behaviours, which are based on a person's upbringing and personal experiences. Cultural differences are further highlighted by language, physical appearance, dress, gender issues, family relationships and attitudes to illness, amongst other factors.[2]

This chapter will focus on how cross-cultural differences between doctors and patients can affect communication, focusing on situations where there are differences between the doctor and patient in ethnic group or country of origin. However, it must be acknowledged that culture has many sub-parts, including religion, gender, class and education, all of which can have an important influence on the conversation.

When do we notice cultural differences?

Generally, people are unlikely to notice 'culture' when having conversations with people with whom they feel they share the same culture. Within the same cultural group, there is an expectation of a shared worldview, common values, and accepted norms about appropriate social behaviour. However, it is always crucial to remember that a cultural group is not homogeneous. For example, when people indicate their 'ethnic group' when filling out hospital paperwork, it gives us little information about a person's individual outlook or behaviours. A more helpful way of looking at it is to think about an interaction of:

- the person
- within a particular family system
- within a sub-cultural or religious group
- within the broader society in which they have been brought up.

All of these layers might contribute towards the person's individual values, beliefs and behaviours.

Imagine that you have been invited to a wedding of a friend. When you arrive at the venue, you see that there is no one else that you know among the guests. Nonetheless, you are confident that you know where to sit, what to do at what time, and what format the wedding will take. You settle down and look forward to seeing your friend arrive.

Now imagine that you have been invited to the wedding of a friend from a very different cultural background to yourself, perhaps also in a different language. When you arrive, the format is not what you are used to. You suddenly realise that you are not sure where to go and what is expected of you as a guest. The language barrier makes you feel even more isolated. You look around, and decide to copy the behaviour of other guests, but you are uncomfortably aware that you do not know what might be regarded as inappropriate behaviour. You feel unsettled and a bit foolish.

Consider how perceptions of culture might affect communication in these situations:

- Mr Thomas Hermitage is a retired army brigadier, who is in hospital with a chest infection. A young Asian woman in hospital scrubs comes into the room and says brightly, *'Hi Tom, how are we today?'* Mr Hermitage replies, *'Good morning miss. When am I going to see the doctor?'* The young woman frowns slightly. This was not the response she was expecting from her patient.
- Mrs Adenegan has had a routine health screen by the practice nurse. The nurse has spoken to the doctor and explained that Mrs Adenegan has recently arrived in the UK. When the doctor goes to speak to the patient, he says in a voice which is slower and louder than normal, *'You will need to go to the hospital for some tests. Tests. Today. At the hospital.'* He points at his watch. Mrs Adenegan looks at him, slightly puzzled and wondering why the doctor is speaking to her in this manner.

Communicating across cultural groups in the doctor–patient consultation can pose different pressures from those encountered when working with people from the same cultural group. A review of the literature found:

"consistent evidence that race, ethnicity and language have substantial influence on the quality of the doctor–patient relationship. Minority patients, especially those not proficient in English, are less likely to engender an empathic response from physicians, establish rapport with physicians, receive sufficient information, and be encouraged to participate in medical decision making."[3]

Patients who come from a different country *and* a different culture find themselves not only in a new and unfamiliar social environment, but also in an unfamiliar health care environment. Both primary and secondary care services may represent a different set of cultural values and expectations. Facing illness in a foreign environment and away from friends and family can make the whole experience extremely alienating, especially when no one speaks the same language.

Imagine that you are on holiday in a different country, and you have fallen ill. You know you need to see a doctor, and you go to the nearest health care centre. You walk into an unfamiliar building. All the signs are in another language. Your grasp of the language is sufficient for normal 'tourist' activities, but you can't describe your illness or understand medical questions. How would you feel? What would you do?

Cross-cultural encounters can be difficult for doctors, patients and their families. Consider the following case:

Case example 10.1 Mrs Jawad, attending an outpatient clinic

Mrs Jawad arrived at the hospital with her husband, and the nurse called her in to see the doctor. Her husband got up to go with her, but the nurse told him this was not necessary. Mr Jawad looked angry and insisted on going in to the consultation with his wife. The doctor overheard the fractious exchange between the nurse and Mr Jawad. With the couple sitting down in the clinic room, the doctor began the consultation. Mrs Jawad looked worried and Mr Jawad looked irritated.

Consider what each of the participants in this example is feeling about the communication that has taken place so far.

The role of culture in the doctor–patient relationship

As we saw in Chapter 2, in any consultation the aim is to provide patient-centred care by:

- establishing the person's values, needs and preferences
- enabling the person to participate actively in decisions about their care.

The key elements to facilitate this process in the context of potential cultural differences are:

- **to be curious and ask questions:** checking and clarifying enable you to feel confident that you haven't made any incorrect assumptions
- **to listen:** picking up on cues about what is important to the patient is particularly important if you feel that there is a difference in expectations
- **to invest in developing the relationship:** taking time to establish rapport, showing an interest in the person and actively seeking to understand the person's perspective are the cornerstones of effective communication.

Consider the many events, procedures and routines in medical care that are likely to be new or different for a patient. Now consider which of these might especially provoke anxiety.

When cultural issues arise in health care, it is important that members of staff feel comfortable listening to the person's perspective and discussing their concerns. When doctors are comfortable asking questions, patients are more comfortable and willing to answer, even if the topics are considered private or difficult to discuss. If people feel listened to and validated, they are less anxious and more confident in making decisions about their care.

There may be cultural differences between the doctor and the patient in:

- beliefs about the body and how it works
- beliefs about health, illness and treatment

- perception of the roles of the doctor and patient
- expectations of medical care
- the social acceptability of expressing emotions
- perceptions of gender roles
- expectations of the involvement of others in the patient's social circle
- the social acceptability of challenging or expressing disagreement with those perceived to be in authority
- expectations and preferences about decision making.

For example, in some cultures, there is a greater expectation that family members and sometimes community leaders are involved in making decisions about treatment. In other cultures, it is expected that the doctor makes the decisions, and that it is socially inappropriate to ask questions or disagree with the doctor. The patient may have come from a culture where it is customary for information to be given to the patient's family first, particularly if it is bad news, and for the family to decide whether or not to share information with the patient. Parents or elders may be considered the most important members of their society and there may be clear cultural rules regarding expectations of how older people should be addressed by those younger than them.

These differences in social rules can create confusion in expectations of what will happen during the consultation. Identifying that there *are* differences in expectations and being prepared to discuss these differences, are the first steps in developing an effective working relationship with a patient that meets their cultural needs. Some strategies for enhancing cross-cultural communication are given in Table 10.1.

Exploring a person's preferences

Whilst people's expectations and values are often related to their cultural background, individuals make their own choices and it is important not to make assumptions that are so fixed that we expect all patients from a particular culture to think or behave in the same way. We might assume, for example, that all Bengali women expect to be spoken to through their husbands or another male relative. Although this may be true for some Bengali women, there are others who hold different views.

If cross-cultural information needs to be brought into the consultation, the doctor has to be specific on what information they need and why it might be helpful to know. For

Table 10.1 Enhancing cross-cultural communication with patients

- Be aware of your own values
- Learn about the cultural background of your patients
- Learn which cultural differences might affect decision making about treatment
- Show patients that you are curious about and respectful of their culture
- Find out if there are similarities in ideas and expectations and build on them whenever possible
- Be open-minded about cultural practices unfamiliar to you
- Openly discuss any differences between expectations and what you are able to deliver
- Explain that you will try to give the best medical care possible, although you are not an expert on their culture

example, in a consultancy with a pregnant woman a doctor will need to find out about their blood type, as there are blood conditions, such as thalassaemia, which mainly affects Mediterranean, South Asian, Southeast Asian and Middle Eastern groups. Similarly, a doctor can ask the patient to clarify his or her cultural practices if they are relevant to the consultation (e.g. *'Are there any foods that you don't eat because of your culture?'*). This way of questioning treats the patient as an individual, by not making assumptions about cultural practices, but also gathers information when it is required.

Individuals from all cultures adopt some cultural ideas and reject others, so it is misleading to assume that all behaviour will be determined by a person's culture. For instance, although they share some basic ideas, the Muslim Chinese, Chinese Buddhists and the modern Chinese differ significantly in their attitudes to how the body of a deceased person should be treated. Having an awareness of cultural practices – and variations – can be very helpful when preparing to have respectful conversations with patients and their families, particularly at difficult times.

Culture is a social construct, and so boundaries are not clearly marked. When meeting someone for the first time, therefore, it is difficult to make assumptions about what a person might expect or want from medical treatment, simply based on factors such as the person's country of origin, appearance or religious beliefs. Furthermore, the boundaries of what constitutes culture can change over time, and *'individuals/groups may not behave in ways that are predictable, or in congruence to their culture.'*[4]

In the example of Mr and Mrs Jawad, the doctor could explore the patient's preferences about being accompanied by her husband:

DOCTOR: *Hello, Mrs Jawad? And your husband, Mr Jawad? Hello. Would you both like to join me, or is your husband happy to wait outside?*

MRS JAWAD: *My husband must come with me so that he can explain to me what I have to do. I mustn't be left on my own – it is my husband who has brought me here.*

In this case, Mrs Jawad's verbal and non-verbal responses indicated that she very clearly expected her husband to be present during the consultation and that she felt that this was supportive.

Perceptions of illness, care and treatment

Each culture has different views about acceptable and effective forms of medical treatment and health care.[5] All patients will have some notion of how they became ill and what care and treatment they need. As in every consultation, it is helpful to try to establish what the person's ideas are early on in the consultation. Later misunderstandings can be caused by not asking about cultural beliefs that are relevant to the person's understanding of illness and preferences about treatment.

Both across cultures and within cultures, people have different beliefs about how illness is caused. For example, a patient who had travelled to Europe from Africa was shocked when found to be HIV-positive because he thought it was only a 'white person's disease'. He felt that his illness was God's punishment and consequently did not see any reason for treatment if it was God's will that he should die. In this case, the doctor might find it hard to reconcile the patient's perspective with his or her own culture's approach to this illness and expectations regarding care. Exploring the person's beliefs and preferences, in a respectful manner, is fundamental to developing an effective working relationship. As in any consultation, feeling listened to is one of the most crucial aspects of the conversation.

Developing a collaborative approach enables the patient and the doctor to share information about their perspectives of the problem and preferred responses to it. The doctor can share information about the options for care and support, rather than challenging the patient's beliefs, and discuss how the patient could best be supported within this medical framework. Sharing information between the doctor and patient about treatment options, risks, benefits and preferences forms the foundation of any decision-making conversation, whether or not cross-cultural issues are present.

It can also be helpful to consider whether there are any members of staff within the team who are from the same culture or whether there are any culture-specific support groups who may be able to provide additional support, as patients who have travelled to a new country may not have access to their usual support network.

Language

Language can be foremost among misunderstandings in cross-cultural communication. Even when the patient is familiar with the language of the majority culture, there are nuances, metaphors, idiomatic expressions and non-verbal cues that can cause misunderstanding or confusion for non-fluent speakers. Misunderstanding can threaten the doctor–patient relationship and also have serious implications for the patient's care.

Consider the basic bodily function of going to the toilet. Think of as many different expressions for this as you can. These may be formal, colloquial, or regional, for example. How many of these expressions do you think a person who has come from a country with a different native language would understand?

Now consider the feeling of sadness. What different expressions are used for this? If a patient came into a consultation and mentioned one of these, what would you infer about the reasons for this feeling and therefore what might be an appropriate management plan? Would it be different for the different expressions? How many ways of expressing a feeling of sadness do you know in any other language?

It is vital not to use words or phrases which are embedded in a cultural context and cannot be understood without this knowledge. It can help to pace the questions, to ensure that the underlying meaning is clear and that the patient is following the language. Trying to speak in a second language at a time of fear or anxiety can be more difficult, both in terms of understanding what the other person is saying, and in producing a response. Asking if the patient wants to bring someone else along to the consultation can help the person to feel supported, both linguistically and emotionally.

Working with interpreters

Where there is a language barrier, interpreters can play an essential role in facilitating the health care consultation. The linguistic match of the interpreter and the person has to be done carefully; for example, the two parties may share a language but they may differ in terms of their religious or political beliefs (which is particularly sensitive for refugees). Other cultural issues such as perceptions about gender and age may affect the consultation. For example, a female patient may find it difficult to discuss her pregnancy in front of a male or an elder. Ensuring that the patient is comfortable with the interpreter is key to the success of the conversation.

Trained interpreters are professional and clear about their role, and are able to act as a bridge between the doctor and the patient. The aim is to facilitate the relationship between the patient and the doctor, rather than developing their own connection with the patient. Their role can remain professional by not engaging in direct contact outside the consultation or outside the doctor's presence and being clear about their duties (for example, not filling out forms for the patient but if necessary directing the person to the appropriate person to help).

Trained health care interpreters understand that their role is to translate 'word for word' directly, without adding words, meanings, interpretations or opinions. If the interpreter encounters a concept or belief that does not directly translate, there may be room to explain its cultural meaning, but that has to be made explicit to the patient. For example, an interpreter may say *'I had to stop because the doctor did not understand what that means, perhaps we can say it in a different way.'* An important aspect of the interpreter's role is to ensure that what the patient and doctor are saying to each other is not being edited in any way. Otherwise, the patient may feel excluded and worried that things are being said about them that they do not comprehend, or that the interpreter is involved in decision making.

Suggestions for good practice in working with interpreters are given in Table 10.2.[6]

Table 10.2 Good practice when working with interpreters*

Before the consultation

- Allow enough time for the consultation (book a double appointment)
- Check that the interpreter and patient speak the same language and dialect
- Ensure that the interpreter understands the rules of confidentiality
- Ask the interpreter to say, word for word, what you say to the patient, and likewise what the patient says to you
- Ask the interpreter to ask for clarification if you use any medical terminology that is not clear or if the patient expresses a concept that is difficult to translate
- Ask the interpreter how to pronounce the patient's name correctly

During the consultation

- Ask the interpreter to introduce themselves and explain their role
- Be aware of how anxious the patient might be, and focus on creating a relaxed and supportive atmosphere from the outset
- Look at the patient, not at the interpreter
- Address questions and any information to the patient, not to the interpreter
- Be particularly aware of using non-verbal communication to show that you are listening and understanding in what the patient is saying
- Be patient – conversations always take longer via an interpreter
- Be mindful of inadvertently using any medical jargon
- Towards the end of the consultation, check that the patient is confident about the immediate action plan

*Adapted from *Valuing Diversity*.[6]

Working with lay interpreters

Sometimes patients arrive with a family member or someone else from their social circle who has come along to interpret. The patient may have specifically chosen the person to accompany them, but sometimes the patient may not have had a choice (for example, if it is determined by who speaks good English and is available to attend the appointment). Family members and other lay interpreters are unlikely to have had training in interpreting in medical consultations, so it can be helpful to briefly discuss some ground rules.

Firstly, finding out who has accompanied the patient and their role is helpful in understanding how the person is supporting the patient, what information they may be able to add, and how the situation has affected them.

Mrs Nowak has arrived at her appointment today with a man accompanying her to interpret. Consider how it might affect the consultation if the man is:

- *her husband*
- *a neighbour who speaks both languages*
- *a cousin who has been asked to help out*
- *her grown-up son who is living with her as a full-time carer.*

How might the consultation be affected by the presence of a lay interpreter if she wishes to discuss a sensitive or embarrassing problem?

It is important to discuss how the interpreter can best help in the conversation, for example, by explaining the importance of relaying questions and answers 'word for word', between the doctor and the patient without editing. For example:

"First of all, I would like to find out from Mrs Nowak herself about what has been happening. Please can you translate what I say exactly, when I ask a question, and tell me exactly, word for word, what she says back. Please don't shorten it or add any other information. I will try to keep my questions short."

Confidentiality is obviously a difficult issue, as the conversation may involve the patient having to disclose information that they would not normally share with the person who has accompanied them. Being explicit with the interpreter about the importance of keeping the information confidential within the consultation is essential. There may be some aspects of the discussion that might be worth keeping back until another consultation where a professional interpreting service is available. For non-urgent problems, it may be possible for the patient to come back later the same day. For example:

"Mrs Nowak, I think it would help if we had another consultation, to discuss the problem more fully. If we arrange that now, we can book in an interpreter."

Ensuring that the interpreter has the opportunity to explain their perspective is often very important to those accompanying the patient, who have a 'dual role' as a translator and a concerned family member. Asking about this depends on the role of the individual. For example:

"Can I ask how this has affected you as well, Mr Nowak?"
"Is there anything else you would like to add, from your perspective?"

Table 10.3 Issues to be aware of when working with interpreters

- The discussion may focus on 'surface' facts, with less depth of understanding of the patient's situation
- Cultural differences in expectations may not be explored
- The presence of another person in the room may affect the development of rapport and a working relationship
- Some words, phrases and concepts can be difficult to translate
- The patient may feel inhibited about discussing emotions or the impact of the illness

When working with lay interpreters or family members

- Confidentiality may be compromised
- The patient may withhold information, for example, due to embarrassment or stigma
- The patient may feel a lack of control
- When children are engaged as interpreters, they may be exposed to information and decisions inappropriate to their age and relationship to the patient
- The patient may feel less fully involved in decision making

Signposting to the patient that you would like to ask the interpreter some questions, and asking the patient's permission for this, signals that your central focus is still the patient. When a doctor and interpreter are having a conversation that the patient is not party to, it can feel very alienating and the patient can feel a loss of control.

"Mrs Nowak, I would like to ask your husband some questions about how this situation has been affecting him. Is that alright with you?"

It is helpful to continue to include the patient, for example, by asking the family member to summarise to the patient what they have been discussing with the doctor.

Some issues to be aware of when conducting consultations through interpreters, whether professional or lay interpreters, are given in Table 10.3.

Working with an audio-only interpretation service

Sometimes in health care services, it is not possible to ensure that a professional interpreter is physically present in a consultation. Over-the-phone professional interpreting services are increasingly being used. As with other forms of interpretation, it is important to ensure that:

- the interpreter is clear about the ground rules of how to translate information shared between the doctor and patient
- the patient understands that the information remains confidential, regardless of the communication channel used for interpretation.

How might the conversation between the doctor and patient be different if the interpreter is either: (a) present in the room, or (b) being relayed over a speakerphone?

When no interpreter is available

There are times in health care when the unexpected happens or unusual circumstances arise. A general practitioner is called to an urgent home visit for an isolated patient. An injured patient is brought in to the emergency department by passers-by. A patient arrives for an appointment, and it becomes apparent that they speak very little English. The doctor may have to make some decisions quickly, for example about whether the patient needs immediate medical care. As well as requesting an urgent interpretation service, taking the time to speak with the patient and make one's own assessment of what communication is possible is essential.

For example, the doctor can consider:

- What is already known about the patient's problem, e.g. from other sources, from seeing the patient?
- How does the patient respond to an initial introduction and open questions?
- Would it help if the doctor or patient used gestures or physical props (e.g. pointing to a part of the body, miming coughing or vomiting, pointing to a clock or a calendar)?
- What symptoms does the patient seem to be trying to convey, and do any of these indicate 'red flag' symptoms that suggest a serious or life-threatening problem requiring immediate treatment?
- Would asking questions about everyday aspects of the patient's life (such as family, or work) give a better picture of the patient's command of the language than discussing medical topics?
- Would non-verbal communication to show empathy and reassurance reduce the patient's anxiety and enables the person to use more of the language?
- At the end of the conversation, what information is the doctor confident about and what questions remain?
- On the basis of the information gathered, what are the appropriate next steps?
- If possible, have a follow-up meeting after the emergency has passed in order to check that there is a shared understanding of the problem, treatment and plans for future care.

Providing written material

At times, published material can be useful for patients to have in their own language, but these leaflets do not replace face-to-face consultations. Leaflets and websites are often a way for patients to read further or to absorb information in a less pressurised setting or without the presence of relatives. However, it is important to check that the patient is able to use the information, for example, by checking that the person is able to read and which language they prefer to read.

Communication strategies for discussing cross-cultural issues

The setting

Think back to your first week at medical school. What was it like finding your way around? How did it feel spending all your time with people you didn't know? What was it like knowing that others were in the same situation as you?

The unfamiliar atmosphere and people in medical settings can make patients more anxious. It is important that conversations are not conducted in a public place. Patients will have their own expectations about their treatment, depending on the setting;

for example, a hospital admission raises different expectations from those associated with treatment in a general practice surgery. Patients need clear information about any planned procedures or treatment, in order to make informed decisions about their care.

Introductions

Naming

Getting the patient's name right provides reassurance and helps to set the tone of the conversation. This includes checking the pronunciation of any names that are unfamiliar to you. It can also be helpful to check which is the patient's first name and surname, as the order can be different in some East Asian cultures.

"You are Mr…? Is that how you pronounce it?"

Ensuring that the patient's full name (correctly spelled) is properly documented in the medical notes is an important element of providing safe care. At times, patients (particularly the younger generation) may make their names or surnames more westernized so they are easier to say. It can be helpful to ask if the patient has a first name or surname which is different from the one they are known by. Be aware that the surnames of other family members (e.g. spouses) may be different.

Patients may expect to be addressed by their title and surname as a matter of course. In some cultures, elders may expect to be addressed formally as a sign of respect. Note that pronouns may be used differently. For example, in Bengali there is no gender differentiation for common nouns and pronouns, so you may find that 'he' and 'she' are used interchangeably.

Involving those accompanying the patient

It is always helpful to ask who has come with the patient today and their relationship to the patient. Find out if the patient wishes to be accompanied during the consultation. As with any consultation in which family members are present, it may be appropriate to ask them to step out for a time, to have a one-to-one conversation with the patient. During this time, it can be helpful to ensure that the patient really is comfortable with the presence of their family members, rather than feeling an obligation due to cultural factors. Sometimes patients may feel inhibited about disagreeing with the opinion of a family member whilst they are present in the consultation.

It can help to explore the role of those accompanying the patient. For example, in the case study, Mr Jawad felt it was his duty, as head of the household, to be with his wife in order to explain her problem to the doctor and be directly informed about her condition. Whilst Mrs Jawad was happy with this, the doctor in this situation still has a duty to ensure that the care which is provided meets the needs of the patient, for example, that the patient understands her condition and is fully involved in decisions about care.

Gathering information

As with any consultation, it is helpful to orient the patient with an explanation of the process, for example, that you would first like to find out about the problem that the person has come with, and then you would like to ask some more questions about their health. Be aware that in some cultures, there is an expectation that communication will be more indirect, avoiding the direct question-and-answer method characteristic of some Western cultures.[7] Some patients from other countries may expect to be asked details about their family first and may find it strange that the doctor wants to begin discussing the illness immediately. Conversely, some patients will not readily disclose information about their family.

Basic biographical information usually gives clues to further questions that should be asked about the patient's cultural background.

"Would you please tell me where you were born?"
"I hadn't realised that you are fasting. Can you tell me more about that and how long that lasts?"
"Is there anything you think I should know about your culture that might affect your stay in hospital?"

It is important only to ask about cultural issues when relevant. However, being comfortable asking about cultural issues when required is essential for gathering the information to best understand the patient's situation within their cultural context.

Explore the person's ideas about illness and treatment

People from all cultures have ideas about the cause of their illness and expectations and preferences regarding treatment. Exploring these can provide insight into the patient's problem (Table 10.4).[8]

Table 10.4 Exploring the person's perception of illness, care and treatment

Topic	Example questions
Explore individual views of the illness, care and treatment	Can you describe to me how you have been feeling? What do you think is the cause of your illness? Is there anything in particular you are worried about? What type of treatment do you think would help?
The patient's experience of illness	Could you show me where you feel the illness? What has been different since you have been ill? When did you realise you were ill? How has it affected your day-to-day life? Are there things you can't do because of your illness?
Perception of control	What have you done since you found out you were ill? Have you tried anything to make it better?
The views of relatives	What do you think is the reason your relative has not been well?
Cultural ideas about illness	How do people from your culture view people who have cancer/AIDS? How would this be treated normally in your culture?

Exploring cross-cultural issues

You might find that the patient holds the same or differing views to your own, in relation to:

- spiritual beliefs and practices
- beliefs and values arising from your family, social and cultural background
- beliefs about health, illness and treatment.

For example, it may be difficult to understand why a patient wants relatives to be present at all consultations, as in Western cultures there is generally more emphasis on individual autonomy and privacy. In all consultations, exploring the patient's perspective of what is helpful to them is a key element in developing an effective working relationship.

Involve relatives

There may be times when it is helpful to consult the relatives of a patient to obtain more information about the family's practices in the management of the person's illness. However, it is also important to clarify these with individual patients as their preferences may not be made explicit due to cultural hierarchies. For example, a Muslim woman grieving for her husband may find it hard to express her feelings in front of her older brother-in-law or parents-in-law.

When a patient has died, relatives need to be consulted on culturally appropriate practices. For example, in Judaism, the deceased person must be buried as soon as possible, usually within 24 hours, and mutilation of the body is not allowed unless there is a legal requirement for a post-mortem. For Hindus, the dying patient is usually read passages from the Holy Book, and once the person has died the body must be left uncovered. The rituals surrounding death are emotive ones for the relatives. Making decisions without consulting relatives could be viewed as disrespectful or offensive.

Consult colleagues

Sometimes it may be necessary to consult colleagues in order to find the most effective way of bridging cross-cultural differences and medical practices. Colleagues from the same cultural background as the patient may be particularly helpful in suggesting ways to ensure that the patient feels supported, as well as, for example, providing the presence of someone who speaks the patient's language. As always, however, it is important to confirm that this is acceptable rather than assume that the staff member and patient share significant cultural or religious values.

Support from other social networks

Often there are useful resources available to people from different cultures, such as counselling services, centres for particular cultural groups and sources of other culturally specific information. Networks or community support may be the most helpful for patients and their family. For many countries the biomedical model is not the most prominent healing system, and patients may seek the support of traditional faith healers or herbalists. Members of some religious groups may want to consult a minister of religion to perform religious rites. Finding out about how patients and their families use additional resources can be very helpful in understanding how a patient is supported through their illness.

Case example 10.2 Refugee family seeking advice regarding their son's health

This family has been in the UK for a period of less than a year. Shortly after arriving they had a baby boy, Hussein, who is now nearly a year old. They have two older girls and had longed for a boy. As he was born shortly after they left their home country, they have always been concerned about his health. Their health visitor has voiced some concerns regarding the baby's development. Since she is one of the few people they have regular contact with, they have become confused and distressed about her comments, but the father does not feel in a position to discuss these matters with her.

This is a common example as it demonstrates how often doctors' consulting rooms can become the only arena for cross-cultural differences regarding health care to be addressed.

DOCTOR: *Tell me about your concerns for the baby.*
FATHER: *I am sure he is fine. We just came to you for advice.*
DOCTOR: *What advice can I help with?*
FATHER: *The nurse was worried about the baby's not growing normally.*
DOCTOR: *I am wondering if you have the same concerns as your health visitor does for the baby?*
FATHER: *Maybe our baby is different in some way.*

The father hesitates and when asked to be specific, turns to the mother for more information. The mother understands most of the exchange and replies to the question, but responds in their native language and the father interprets for the doctor.

FATHER: *The nurse felt that he was not moving enough and about his diet. I think he is fine and he's just a quiet boy.*

In this case much of the confusion was due to cultural factors and different expectations about development. The father was particularly anxious that the health visitor was implying that his son had some type of brain damage.

The doctor decided it would be useful to assess the baby properly, but to do so at a time when an interpreter would be present. Even though the father's English was good enough, some words were used differently and there was scope for misunderstanding. The father also did not seem to understand fully the term 'health visitor' or what her role involved compared to a doctor's role, which was another source of anxiety and required clarification.

The health visitor's main concern was that the baby was not as mobile as he ought to be for his age, and that he was not exploring enough or being 'allowed to become independent'. Furthermore, she was concerned that the mother breast-fed him but provided no other supplements.

In many cultures it is the mother who determines the infant's physical and exploration space. This aspect is largely culturally defined, even as far as what is considered a safe distance to move away from others.[9] The mother did not attend any playgroups and was rather cautious after their experiences in their home country, fearing that something might happen to the baby (this emerged much later in the discussion).

In this case there are many learning points, taking into account the perspectives of the whole family and the health professionals. For example, in this case, the mother knew the child best

Continued

Case example 10.2 Refugee family seeking advice regarding their son's health—continued

and speaking to her through an interpreter was helpful. With the father left with the role of narrator and interpreter, it was difficult for the doctor to assess the baby's development and address the concerns. The father, mother and health visitor all had different concerns.

Additionally, when there are cross-cultural differences, it is useful for the health professionals involved to consider how cultural factors (and other factors, such as trauma, in the case of refugees) may play a role. In the case of Hussein's family, the usual anxieties about having a new baby were exacerbated by having to leave their home country and being new arrivals in an unfamiliar country.

After this consultation, the examination and assessment of the baby were carried out and were found to be normal. The family were able to discuss alternatives to the child's diet and physical needs, finding a way to provide what was necessary for his continued normal development and, at the same time, respecting their cultural preferences and beliefs. The mother was happy to continue breast-feeding once a day and providing the baby with additional solid food during the day.

Another consideration when working with refugee patients is that laws are in constant flux as to what treatment they are entitled to receive and at which point of their immigration process. This again provides a sensitive issue for families at a time of physical ill health and uncertainty for medical staff regarding the extent and follow-up possibilities in terms of treatment. Having open and sensitive discussions about this is an additional aspect that may be needed in these consultations.

Key points

- Heightened awareness of cultural issues can help doctors and patients to achieve a shared understanding of the medical issue in a cultural context and can improve the therapeutic relationship.
- Working with interpreters requires active management by the doctor to ensure that patients feel confident in the consultation and information is shared effectively.
- Doctors can facilitate communication in cross-cultural conversations by being curious, listening and investing in the relationship.

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11

Diversity in communication

Lorraine Noble

We have seen in previous chapters that there are communication strategies to improve the effectiveness of doctor–patient conversations, where:

- the patient feels listened to and cared for
- information is exchanged in order to achieve a shared understanding of the problem and possible solutions
- difficult or sensitive topics are broached with compassion and empathy
- the patient is supported in making decisions about treatment
- the patient is treated with respect and dignity.

We have discussed approaches which can help the doctor to achieve this, in their role as the 'host' of the consultation, for example by:

- using a structure for the consultation (like the Calgary–Cambridge)[1]
- focusing on core elements of communication, such as listening, questioning, facilitating and empathising
- considering the needs and perspective of the patient in their particular situation (for example, when breaking bad news to someone who is not expecting it or discussing an operation with a young patient).

These core elements of a consultation are evidence-based and help both the doctor and the patient to feel confident that their aims for the meeting will be achieved. Sometimes, however, there is an assumption that 'communication skills' teaching implies that the same set of rules applies in every consultation. For example, that:

- 'it is always good to have long silences' (even if these clearly feel uncomfortable for the participants)
- 'you should always do ICE' (i.e. ask the patient about their ideas, concerns and expectations, in a formulaic way, at a point in the consultation defined by the doctor)
- 'more is always better' (for example, repeatedly asking a patient if they understand or how they feel).

Yet all communication – which includes 'clinical communication' between doctors and patients – is a dynamic process, depending on:

- the personalities involved
- the participants' mood and emotions
- each person's expectations and goals
- trust and rapport
- the assumptions that participants make about each other
- preferred conversational styles.

Dr Spanou is starting her afternoon clinic, seeing patients who have been referred for chest pain. In the waiting room are:

- *Mrs Smith, who is pleased that her doctor has referred her to be checked out, but is not expecting anything to be seriously wrong. She is very busy at work and keen to get back promptly this afternoon.*
- *Mr Patel, who is worried that he might have a heart attack. Coming to the hospital has made him more anxious, and he can feel his heart pounding, his palms getting sweaty and his mouth getting dry.*
- *Mr Jones, who is quietly seething. Somehow his general practice and the hospital failed to communicate, and there was a mix-up with his appointment, twice. Plus he has had a difficult journey to the hospital today as the trains were cancelled.*
- *Ms Naidoo, who is hoping that she is in the right place. She speaks little English and her sister, who was coming with her to translate, has pulled out at the last minute. She has not been to a hospital in this country before.*

Although the medical problem may be the same for all these people, how might the consultations be different? Would you expect the doctor to behave in exactly the same way with each of these patients? If not, how might the doctor's communicative behaviour differ with each of these patients?

Diversity in communication is often taken to mean communicating with patients who have a different ethnicity or cultural background to the doctor. Rather, diversity refers to the individual differences among people which are the result of many different influences. Some examples of these influences are listed in Table 11.1. Think about those influences in your own case. How might they affect your style of communicating?

Effective communication adjusts to the needs of the individuals and situation. Thus it is necessarily responsive and adaptable. It is not an indefinable 'art' where there are no rules and 'no right or wrong way to do it', nor is it simply following a fixed protocol in the same way for every patient.

Table 11.1 Some examples of influences on diversity

- Age
- Nationality
- Physical abilities/impairment
- Socio-economic status
- Life experiences
- Language
- Gender
- Education
- Ethnic or cultural background
- Sexual orientation
- Religious beliefs
- Communicative abilities
- Family background
- Learning abilities/difficulties
- Perspective, beliefs, expectations

This chapter will consider some examples of consultations where a doctor's communicative style can help to facilitate an effective consultation in response to different needs of the patient and situation. It is not intended to be comprehensive. The aim is to consider some different situations a doctor may encounter to illustrate the diversity of situations and communication approaches which can help to build good working relationships with patients.

Communicating with people who have a learning disability

People who have significant cognitive deficits are often treated differently in health care settings. For example, one review of studies found that patients with intellectual disability in hospital experienced:[2]

- lack of care
- poor or no communication
- discriminatory attitudes
- failure to treat pain
- failure to provide assistance to enable the person to go to the toilet or eat a meal
- denial of diagnostic procedures and treatments.

Furthermore, patients reported:

- fear of not knowing what to expect
- fear of an unfamiliar situation and environment
- general fear of doctors, nurses and medical procedures.

Imagine that you are Ashley Conway, 20 years old. You have Down's syndrome. Your general practitioner has referred you to hospital due to a persistent digestive problem which is causing you pain and diarrhoea. Your older brother has offered to come to the hospital with you as he works nearby and you are going to have lunch with him afterwards. In everyday life, you sometimes struggle to express yourself, although you know what you want to say. If people are patient it helps. You are aware that people often react to you based on the way you look, even before you have started a conversation.

On arrival at the hospital, as you go to check-in, the receptionist speaks to your brother, not to you. Another member of staff asks your brother 'Can Ashley come this way?' and you are shown into the consultation room. You both sit down. The doctor looks at both of you and says to your brother 'So, Ashley's had a problem with pain and diarrhoea?' Your brother replies 'You'd better ask Ashley, I don't really know.' The doctor looks at you and says, in a louder tone, 'Problems with poo?'

How confident are you that you will be listened to, and that your problem will be resolved?

Learning difficulties and disabilities take a variety of forms, and vary in severity from mild to severe impairment. As in Ashley's case, physical appearance can sometimes have an undue influence on the assumptions made by others about the person's:

- communicative ability
- autonomy
- ability to make health care decisions.

Table 11.2 Strategies for enhancing communication with a person with a learning disability (adapted from General Medical Council,[6] Mencap[7])

- Find a quiet room without distractions
- Take your time and allow more time for the consultation
- Talk directly to the patient
- Ask the patient for permission to involve the family member or carer in the consultation
- Tell the patient and family member or carer what is going to happen in the consultation
- Use facial expressions, gestures, drawing and pictures
- Ask open questions
- Reflect back to check that you understand what the person is saying
- Be vigilant for medical jargon or complex language
- If a physical examination is needed, be careful to explain what this involves and ensure the patient has agreed to the examination
- Give patients and carers information in advance where possible
- Use written aids such as a health passport and information designed for people who have learning disabilities (such as easyread[8] or a 'communication jargon buster'[9])

As with any consultation, it is difficult to make any assessment of the patient's perspective and ability to engage in decision making without beginning a conversation and listening to the person. Personal accounts of care experienced by people with learning disabilities highlight the importance of being treated with respect and being afforded the same opportunities as any other adult patient.[3]

Professional guidance in the UK requires doctors to presume that every adult patient has the mental 'capacity' to make decisions about their own care, unless it is clear that, having been given all the appropriate help and support, the person cannot understand, retain or use the information, or communicate their wishes.[4]

The following key elements of a conversation with a patient with a learning disability have been suggested:[5]

- Treat the person with respect.
- Acknowledge the person's feelings.
- Consider what reasonable adjustments might be made (e.g. allow extra time, hold the meeting at a time and place of the person's choosing).
- Share information in a way that helps understanding (e.g. using pictures) and check understanding.
- Ensure that carers are involved appropriately.

Strategies to help in communicating with a person with a learning disability are given in Table 11.2.[6–9]

Communicating with transgender patients

Sharon Morris is a medical student on attachment in General Practice, meeting patients who have agreed to speak with her prior to their appointment with the doctor. The next patient is Luke Rand, a 37-year-old patient listed as 'female' in the notes Sharon has been *given. Luke last attended one month ago. The notes are brief, but state that Luke was concerned about tenderness in the left breast, which the doctor noted was 'likely to be cyclical breast pain'. How might Sharon approach this consultation, in terms of:*

- *preparing for the consultation*
- *opening the consultation and establishing rapport*
- *prioritising which areas to cover*
- *asking questions*
- *being respectful towards the patient's needs?*

Transgender (or trans) refers to a person who feels that their gender identity does not match the sex they were assigned at birth. People who are transgender may:

- wear clothes and use a name which matches the gender they identify with
- change their bodies by medical and surgical means to be congruent with their preferred gender
- adopt their preferred gender identity in all areas of their life, or in only some areas of their life, or they may not disclose their transgender status to anyone.

People who are transgender report experiencing discrimination, harassment, misunderstanding and humiliation in day-to-day life and in health care encounters.[10–12] These include health care staff refusing to perform examinations or procedures, using the pronoun 'it' to refer to the person and persistently referring to the patient according to their birth-assigned sex. Consider the effect of some of these behaviours on the professional-patient relationship.

Some strategies to help improve communication between medical staff and transgender patients include:[10,13]

- training doctors in the specific health care needs of transgender patients and their experiences of health care
- improving the environment and procedures in health care settings (for example, registering a person's preferred name and gender)
- greeting the patient without making assumptions (e.g. by avoiding pronouns and titles if unsure about the patient's preferred gender identity)
- politely clarifying when needed (e.g. 'What name would you like me to use?')
- avoiding asking questions out of curiosity (e.g. about the person's genital status or sexual orientation) which are not relevant to this episode of care
- apologising if you make a mistake and say the wrong thing
- maintaining confidentiality; only disclosing the patient's transgender status to those who require it for the patient's care
- fostering an inclusive and supportive environment in the workplace.

This is the first part of the conversation between the medical student and the patient.

STUDENT: *Hello, are you Luke Rand?*
PATIENT: *Yes, I'm Luke.*
STUDENT: *Hello. My name is Sharon Morris, I'm a medical student. Is it okay if I ask you some questions before you see the doctor today?*
PATIENT: *Yes, that's fine. What do you want to ask?*
STUDENT: *I wanted to find out why you've come to see the doctor today and then I'll pass the information on to the doctor before she sees you. Would that be all right?*
PATIENT: *Yes, sure.*

STUDENT: *Do you mind if I take some notes?*
PATIENT: *No, that's fine.*
STUDENT: *Can I ask why you've come in today?*
PATIENT: *About two months now, I've had pain, here.*
STUDENT: *Pain, there, on the left? Is that in your breast?*
PATIENT: *Yes.*
STUDENT: *One side, both sides?*
PATIENT: *Just one.*
STUDENT: *How would you describe it? Is it painful? Tender?*
PATIENT: *Sore. Sometimes it feels like it's burning, and occasionally I get real stabs of pain.*
STUDENT: *So sore, burning, sometimes stabbing pain. About two months?*
PATIENT: *Yes. I came here about a month ago, and the doctor I saw that day said 'it's normal mastalgia, that women often get'.*
STUDENT: *Mm-hmm.*
PATIENT: *He wasn't that interested. He didn't examine me.*
STUDENT: *You weren't examined.*
PATIENT: *No, I felt he wanted to get me out of here as quickly as possible.*
STUDENT: *What made you think that?*
PATIENT: *I see it all the time. People shut down, don't want to know. This doctor is okay though. I know she'll listen.*
STUDENT: *What are you hoping for today?*
PATIENT: *I am worried and I want to be examined.*
STUDENT: *Is there anything in particular you are worried about?*
PATIENT: *I don't know, it could be serious.*
STUDENT: *By serious, you mean...?*
PATIENT: *My grandmother had breast cancer. She died when she was 40.*
STUDENT: *Would you like to discuss that with the doctor?*
PATIENT: *Yes.*
STUDENT: *Was there anything else you wanted to talk about with the doctor today?*
PATIENT: *No, it's just this.*
STUDENT: *Can I go over what you've told me so far?*

Think about:

- Which aspects of the conversation might have helped the student to establish a rapport with the patient?
- To what extent do you feel that the patient being transgender was important to the conversation? In which parts was it relevant or not relevant to the discussion?
- Would you have done or said anything differently, if you had been the student?
- If you were continuing the conversation, what would you discuss next?
- If you had been the patient, would you have been satisfied with this conversation so far?

The core skill of listening to the patient helped the student in the example above to focus on what the patient had come to discuss, without the consultation being dominated by the patient's transgender status. This can help in avoiding a phenomenon called 'diagnostic overshadowing' where a doctor focuses so much on one aspect of the patient that assumptions are made about the cause of the problem without the problem being properly explored – for example, the assumption that Luke's presenting problem was likely to be related to his transgender status.

Communicating with older patients

At what point does a person become 'old'? 65? 50? Over 80? Consider some of the terms used to refer to older adults: elderly, geriatric, senior citizen, mature, old age pensioner, old lady. What are the connotations of these terms? In medicine, the term 'elderly primigravida' is used to refer to patients having their first pregnancy over the age of 35, which often comes as a shock to the patients in question.

Older adults face a number of challenges to their health, including an increased likelihood of:

- sensory deficits, such as hearing or visual loss
- serious and long-term conditions
- multiple conditions requiring simultaneous treatment
- physical and social isolation.

Dr Broughton is conducting his afternoon clinic in general practice, with appointments scheduled at regular ten-minute intervals. His next patient is Mrs Walton, a 70-year-old widow who has rheumatoid arthritis, glaucoma and hearing loss, for which she wears a hearing aid. She recently had a chest infection which resulted in a brief hospitalisation. When she is called in, she walks slowly into the room, and shuffles tentatively towards the chair.

How do you think Dr Broughton will approach this consultation? What communication strategies might be particularly helpful?

This is the beginning of the exchange between Dr Broughton and Mrs Walton:

DOCTOR: *Hello, Lucy, come and sit down.*
PATIENT: *Oh, er, right, Doctor, thank you.*
DOCTOR: *Lucy, I can see that you've recovered well from your chest infection. It's important to keep warm at this time of year.*
PATIENT: *Yes.*
DOCTOR: *Your walking's not so good today, is it? Your rheumatoid is playing up again. It might be time to review your medication. When was the last time you went for a check-up at the hospital?*
PATIENT: *Oh, I'm not sure...*
DOCTOR: *No, no, it's okay, we can check on that. So what's brought you in today?*
PATIENT: *Well...*
DOCTOR: *And your glaucoma, yes, we'd better review that as well.*

In this example, Dr Broughton was unaware of how he had:

- rushed to cover a number of topics, partly because the patient had taken longer than expected to sit down, and partly because he was worried about the number of medical problems she might wish to discuss
- greeted the patient with inappropriate informality (she had expected to be referred to as Mrs Walton)
- made assumptions about the purpose of the consultation, by focusing on existing medical problems
- shown less respect for the patient's perspective than he usually does (with his younger adult patients), by not taking the time to listen to why she had attended.

How might the following affect the assumptions people make about whether an older adult can actively participate in their own health care:

- the patient's physical appearance?
- the presence of relatives or carers in the consultation?
- evidence of sensory loss?

Some strategies for enhancing communication with older patients are given in Table 11.3 and tips for communicating with patients with hearing loss are given in Table 11.4.[14,15]

Table 11.3 Strategies for enhancing communication with older patients (adapted from Robinson et al[14])

- Allow extra time to ensure that the patient does not feel rushed
- Provide a quiet setting without distractions (e.g. minimise background noise)
- Sit face-to-face (which can improve lip reading)
- Speak slowly, clearly and at an appropriate volume (depending on hearing loss)
- Focus on one topic at a time
- Take the time to ensure that the patient's information needs are met
- Simplify and write down advice
- Provide written information in large, easy-to-read print

Table 11.4 Strategies for enhancing communication with patients with hearing loss (adapted from Action on Hearing Loss[15])

- Be aware that even if a person is wearing a hearing aid, they may also find it helpful to lip read
- Face the person directly, on the same level and in good light
- Ensure you have the person's attention before you begin speaking
- Do not talk whilst turned away (e.g. facing a computer or washing your hands)
- Speak clearly and distinctly, but not too slowly
- Do not shout or exaggerate mouth movements
- Use simple sentences
- Keep your hands away from your mouth
- Avoid interrupting the patient
- Be alert to non-verbal cues

Case example 11.1 Memory problems

Donald Stewart is an 86-year-old retired accountant. He lives at home with his wife, and they have two grown-up children. Over the past few months he has become increasingly forgetful and at times seems confused about where he is. On two occasions he has become disoriented and distressed when his wife left him for a few minutes in a familiar shopping centre. She has also noticed that at times he seems uncharacteristically irritable but afterwards has no memory of this. He has attended his general practice surgery with his wife and they explain the situation.

Continued

Case example 11.1 Memory problems—continued

Doctor: *So you forget to lock the back door, more often than not? And you've left the gas ring on all evening, a few times?*

Mr Stewart: *The problem is, I don't know when I've done something or not. I just don't remember.*

Mrs Stewart: *I'm really worried, I almost have to follow him around, checking what he's done.*

Doctor: *And you say he's become quite snappy on occasion?*

Mrs Stewart: *Yes, he'll just, almost shout at me, I mean, I've just come in the room, and it's like I've done something dreadful.*

Mr Stewart: *I don't remember any of it, I don't know what's happening.*

Doctor: *What are you worried about, Mr Stewart?*

The doctor involves both the patient and his wife in the consultation, having checked that the patient is happy with this. This is particularly helpful in this situation, where the patient's relative is able to provide a corroborative history. However, the doctor is careful to bring the focus back to the patient at key points in the consultation. In this instance, for example, the doctor is beginning to broach the topic of a potential diagnosis.

Mr Stewart: *I know what this means.*

Mrs Stewart: *He thinks he's going senile. We both do.*

Doctor: *What do you mean, when you say you 'know what this means'?*

Mr Stewart: *It's that Alzheimer's, isn't it?*

Doctor: *I am worried about what you've been describing.*

Mr Stewart: *So what do we do?*

Doctor: *There are some more things we need to do today here, and I'd like to refer you to the memory clinic.*

Mr Stewart: *We were afraid of this.*

Doctor: *I know you're worried. We're here to support both of you.*

Mr Stewart: *What happens next?*

Having a conversation about a feared diagnosis is a careful balancing act. In this case the doctor:

- was aware that Mr and Mrs Stewart were worried about a potential diagnosis of dementia
- was keen to put a plan in place to further investigate the problem
- wanted to respond to Mr and Mrs Stewart's concerns honestly
- was thinking about the need to support the Stewarts in living with this condition in the long term.

In due course, this doctor (or a specialist) may need to share the information confirming the diagnosis of dementia. Some principles of sharing a diagnosis of dementia, based on the experiences of people living with the disease, are shown in Table 11.5.[16] Using these principles, and the framework of breaking bad news from Chapter 7, consider how you would conduct a consultation to break the news to Mr Stewart and his wife.

Diagnoses which affect a person's psychological health are often particularly difficult for patients and relatives due to the profound effect of the condition on the person's personality, relationships and sense of themselves as a person. In the case of dementia, people affected by the condition worry about being able to make decisions in the long term, losing their 'personhood' and the impact of the condition on their loved ones. Being aware of the experiences of people living with a condition such as dementia can help in preparing to care for patients.

Table 11.5 Principles for a dignified diagnosis (adapted from Alzheimer's Association[16])

- Talk to me, the person with dementia, directly; tell me first, not my relatives
- Tell the truth; be honest about what you don't know
- Test early, so I can have an accurate diagnosis as soon as possible
- Take my concerns about memory seriously, regardless of my age (Alzheimer's disease is not a normal part of ageing)
- Deliver the diagnosis in plain, but sensitive, language
- Co-ordinate with other care providers
- Explain the purpose of different tests and what you hope to learn from them
- Give me the opportunity to ask questions
- Give me tools for living with the disease; provide information about treatments, resources and support
- Work with the me on a plan for living a quality life
- Recognise that I am an individual and the way I experience this disease is unique
- Alzheimer's is a journey, not a destination; please continue to be my advocate not just for my medical care but my quality of life

Key points

- Diversity refers to the individual differences among people that are the result of many different influences.
- Effective communication is adaptable and responsive to the needs of the patient and situation.
- The core skills of listening, empathy and treating the person with respect and dignity are fundamental to all consultations.

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Communicating about medical error

12

Margaret Lloyd, Robert Bor, Lorraine Noble

"To err is human."[1]

We all make mistakes. Alexander Pope expressed this three hundred years ago in his Essay on Criticism, which also recognises the difficulty of responding to mistakes and their consequences. Some mistakes are trivial, with no significant consequences or which pass unnoticed. Some have serious consequences and may threaten the lives of patients. They may lead to complaints from patients or lawsuits against the doctors involved.

How should we react to our own mistakes and those of others? How should doctors respond when patients and families complain about the treatment they have received? The way we communicate in such situations is vitally important and may greatly affect the outcome.

Making mistakes in everyday life

Admitting our mistakes is difficult. Yet recognising when we have made a mistake and reflecting on why it happened often provide an excellent learning opportunity. Before considering errors in medical practice, we need to think about how we deal with the mistakes we make in everyday life.

First of all, think about a mistake you made recently in your daily life, for example, something you said or did that was hurtful to someone else. Was there an identifiable cause? How did you feel? What did you do? What did you say to the other person?

Depending on the nature of the mistake you might have:

- passed it off as 'one of those things' and done nothing more about it
- felt very guilty
- blamed it rightly or wrongly on someone or something else
- admitted your mistake and apologised to the other person
- tried to analyse why you made the mistake – was it something you did wrong or was it a consequence of some other problem?
- reflected on your analysis and resolved to avoid making the same mistake again.

Now think about an occasion when you were affected by someone else's mistake. What did you expect of them? Go over the above list again. How did you react to their mistake?

There is no doubt that it is often difficult to admit that we have made a mistake and it often takes courage to acknowledge it to ourselves and to the other person. Here is an example in a medical setting to think about.

You are on a ward round with your consultant who is known to be demanding and expects high standards from students and colleagues. The consultant will be signing off your report card later today. She asks you to present the patient who was admitted the previous night with a myocardial infarction. You have spoken to and examined the patient but realise during the ward round that you have forgotten to measure his blood pressure, which is a key aspect of the examination. The consultant asks you: 'What was the patient's blood pressure on admission?' What would you say? What are the elements you would include in your response and why?

Mistakes in medical practice

Studies have shown that a significant number of patients suffer harm as a result of medical management whilst receiving health care. For example, data from the UK and USA have indicated that incidents where a patient is harmed by medical care are common across a range of health care services.[2–4] One estimate from the UK found that in hospitals alone, events in which harm was caused to patients by medical care (adverse events) occurred at the rate of 1 in 10 hospital admissions, or at a rate in excess of 850,000 per year.[2] In the USA, it has been estimated that 210,000 to 400,000 premature deaths a year occur as a result of preventable harm.[4] This is not harm that results from the natural course of a patient's illness, or known side effects of treatment.

How often do doctors make mistakes? In a questionnaire survey, junior doctors were asked about the frequency with which they made mistakes.[5] The authors of the report classified mistakes into three categories:

- Minor mistakes, defined as actions that did not result in the patient suffering pain or discomfort – but corrective action should have been taken.
- Moderate mistakes, which resulted in the patient suffering pain, discomfort or temporary or permanent disability, but which had not put the patient's life in danger.
- Major mistakes, which resulted in a patient's death or the patient's life having been in danger.

Of the doctors who responded, 77% said that they had made a minor mistake during the previous month, 24% had made a moderate mistake during the previous 2 months and 16% reported having made a major mistake during the previous year. Despite evidence that mistakes are common in medical care, it remains a difficult subject for medical professionals to discuss, with patients and with colleagues.

Causes of medical mistakes

Mistakes in medical care are rarely the fault of one person. Consider the following case and think about the factors that contributed to the mistake.

Case example 12.1 A fatal mistake

Robin Smith, aged 17 years, was admitted to hospital to receive chemotherapy for leukaemia. Dr Jones, a junior doctor, was asked to perform a lumbar puncture and inject the chemotherapy (known as intrathecal administration). He felt tired and anxious but was relieved when he carried out the lumbar puncture successfully. He reached for the vial from the trolley and injected it easily. Shortly afterwards Robin had a convulsion and it became apparent something had gone very wrong. Dr Jones looked at the vial carefully; it said 'for intravenous injection only'. Robin was taken to intensive care but died later that day.

There are a number of possible contributing factors to this error that had such disastrous consequences. The key mistake was that Dr Jones did not check the contents of the vial or the route of administration before injecting it into the patient's spine. Why might this have happened?

There are a number of possible reasons, including:

- Dr Jones was inexperienced in conducting this procedure.
- He made an assumption that the correct vial had been put on the trolley.
- He expects medication to be beneficial to the patient, not harmful.
- The vials of medication for intravenous or intrathecal administration looked very similar.

Some of these reasons might relate to failures of communication, for example:

- Dr Jones did not check with the nurse that the medication was correct for this procedure.
- The nurse who put the medication on the trolley assumed Dr Jones would check it before administration.
- Several of Robin's medications were delivered by the hospital pharmacy at the same time and no one checked that the medications for intravenous and intrathecal administration had been separated out.

What implications does this have for the management and prevention of medical errors? It is usually inappropriate to blame one person. Errors are often multi-factorial and invariably involve aspects of how tasks within the health care system are organised and carried out. Health care is complex and risks to patient safety abound. The emphasis is on managing that risk: firstly, by looking carefully at procedures to identify potential risks and addressing them, and secondly, by learning from errors that occur by analysing adverse events and 'near misses'. For example, repeated deaths worldwide due to the errors in administering a medication called vincristine led to national guidance in several countries on the safe administration of intrathecal chemotherapy.

Now consider that you are the doctor who made this mistake, and that you have to explain to Robin's parents what has happened.

- How would you prepare for the consultation?
- What would you say?
- What will Robin's parents want to know?
- How do you expect Robin's parents will react?
- What are the next steps following this consultation?

What should you do when you have made a mistake?

Doctors in the UK have a duty to be open and honest with patients when something goes wrong with care which causes the patient harm or distress.[6] This is known as the professional duty of candour. This includes:

- telling the patient (or where appropriate, their family member or carer) when something has gone wrong
- apologising
- offering an appropriate remedy or support to put matters right
- explaining fully the short- and long-term effects of what has happened.

Health professionals often feel a sense of failure and shame when they have made an error. It is understandable that disclosing an error is a difficult task. As with most difficult tasks in medicine, however, many doctors have faced this situation previously, and lessons have been learned about effective or less effective ways of discussing it with patients and their families.

Some of the key elements of supporting a patient or their family when things have gone wrong include:[7]

- promptly acknowledging the incident
- taking the patient's and family's concerns seriously
- responding with compassion and understanding
- providing an explanation which is truthful, timely and clear
- avoiding medical jargon in explanations
- providing a sincere and meaningful apology
- designating a single point of contact for the patient or family
- treating patients and their families with respect and consideration at all times.

Studies of what patients (and their families) want when there has been a medical error highlight the value placed on honesty, a clear explanation, and an acknowledgement of the emotional effect of being told that there has been a mistake.[8] (Table 12.1) Perhaps unsurprisingly, clarity of language is important to patients, for example, being told that there has been a 'mistake' or an 'error' (rather than an 'adverse event' or 'complication').

Consider what you would do in the following example:

Case example 12.2 Admitting your mistake to a patient

You have to take a sample of blood from Mr Thomas, who has severe rheumatoid arthritis. You have great trouble getting the blood from one of the veins in his forearm and he complains of pain. You put the blood into the bottle and are about to send it to the laboratory when you realise that you have used the wrong bottle. The blood test is important and you return to Mr Thomas to take another sample. What would you say to him? Consider:

- how you will explain your error
- what else you might need to discuss with Mr Thomas
- what might be Mr Thomas' point of view in this situation.

After any instance where you have made a mistake in a medical setting, it is critical to honestly consider how it happened and what you can learn from it, in addition to following your organisation's procedures for reporting adverse incidents and near misses.

Some strategies to consider when you have made a mistake are given in Table 12.2.

Table 12.1 What patients want when you have made a mistake

- Honesty
- An apology
- An explanation of what happened, and why
- A plan to redress any harm that has resulted from the error
- An explanation of what steps are being taken to ensure the same error does not happen again (to the patient or anyone else)
- Empathy
- Reassurance that their care will be unaffected

Table 12.2 What to do if you make a mistake

Do:

- Be honest – admit it to yourself and tell a senior colleague
- Be prepared to discuss it with the patient
- Listen to the patient's or relative's concerns and show that you are listening
- Apologise – this is not necessarily an admission of guilt
- Make a record in the patient's notes – a factual statement of what happened
- Analyse with the help of others why the error occurred
- Seek help if you feel burdened by what has happened

Don't:

- Become defensive
- Criticise others
- Speculate when you do not have the full facts
- Expect the patient or their family to 'move on' after a single conversation
- Avoid or treat the patient or family differently afterwards
- Try to 'go it alone' by not involving any of your colleagues

Saying sorry

When a mistake has been made, in medicine as in any other aspect of life, the single, most important response that people want is an apology. Yet traditionally, doctors have been anxious about apologising, on the basis that it might 'admit liability' for the error. This has resulted in legislation, in many countries, which protects the doctor's right to apologise to a patient without this being taken as an admission of medico-legal liability for an error (these are known as 'apology laws'). The importance of an apology in acknowledging the damage to the doctor–patient relationship, and helping to repair that relationship, has been recognised:

> *"It is both natural and desirable for clinicians who have provided treatment which produces an adverse result, for whatever reason, to sympathise with the patient or the patient's relatives; to express sorrow or regret at the outcome; and to apologise for shortcomings in treatment. It is most important to patients that they or their relatives receive a meaningful apology."*[9]

The wording of an apology is important. Think how much more sincere an apology sounds if the words *'I'm sorry'* are included, compared to, for example, *'I regret'*. An apology has many functions. It shows:

- empathy and concern
- that you appreciate the impact of the situation on the person
- that you are taking responsibility for dealing with the situation – even if the error was not yours.

Patients and their families report that poorly handled responses when an error has been made can have a more destructive effect on their trust in doctors than the error itself. In particular, a lack of apology, the failure of any one person to take responsibility for dealing with the situation, and defensive or vague responses increase frustration, anger and fears about future care.

The accepted form of an apology may vary across countries and cultures. In the UK the use of the phrase 'I'm sorry' is so ubiquitous in everyday life that its absence in a difficult situation, such as disclosing a medical error, is a glaring omission. The use of the specific wording *'I'm sorry'* also shows care and concern for another person in a way that other forms of apologising do not.[10]

Example phrases to use when apologising:

- I'm sorry that this has happened
- I made a mistake
- I apologise
- I am looking into how this happened
- I gave you too much medication

Example phrases to avoid when apologising:[11]

- I'm sorry, but...
- I was negligent/I am liable
- I think it was the night shift who made the error
- I apologise for whatever it was that happened
- If I did anything wrong, I'm sorry

Recording errors

It is essential to make a record of what has happened in the patient's notes, which is:

- accurate and clear
- free of ambiguous abbreviations

- legible
- dated, with your name in capital letters, and signed.

This includes details about the error, and notes about any explanation or apology given to the patient (or family members). Entries to the patient's notes must be contemporaneous – records must not be retrospectively edited or amended.

Consequences of medical errors

In Case examples 12.1 and 12.2 the consequences of the mistakes that were made were very different. In the first one, Robin Smith died as a result of the error. In the second, Mr Thomas suffered discomfort (having to give a second blood sample) but no long-lasting effects.

This illustrates the range of consequences of medical mistakes for patients. The responses of patients or their relatives also range from accepting an explanation and taking it no further to making a formal complaint or taking legal action against the doctor and hospital.

Complaints

Have you ever made a complaint? Think about a situation where you complained, for example, in a shop or restaurant or to a company or organisation.

- *What were you complaining about?*
- *What did you hope to achieve by making the complaint?*
- *Did you feel listened to?*
- *Were you satisfied with the response?*
- *What features of the response you received affected how satisfied you were?*
- *Did you feel the matter was resolved by the end?*

The number of complaints by patients is increasing. For example, the health service in the UK receives written complaints at the rate of just under 4,000 per week.[12] This increase is a reflection of patients' increasing expectations of health care professionals and the increasing culture of consumerism within the health service. Complaints about the attitudes of staff and poor communication of information are among the top causes of complaints.[12] Some examples of poor communication that may lead to complaints are shown in Table 12.3.

Table 12.3 Examples of communication problems that may lead to patients complaining

- Inadequate information about their medical condition or treatment
- Feeling ignored, not listened to or not taken seriously
- Procedures or treatment had been conducted without the patient's permission
- Perceptions of having been treated in an insensitive manner
- Lack of care about maintaining a patient's privacy and dignity
- Feeling discriminated against (e.g. due to age, gender or ethnicity)
- Difficulty in arranging appointments
- Lack of information about discharge planning

Case example 12.3 A visit to the antenatal clinic

Mrs Jones has attended for an antenatal appointment, scheduled at 9.00 a.m. She has arrived early and is first in the waiting room. She checks in with the receptionist. Over the next hour, the waiting room fills up and one by one, patients are called through by members of staff. Mrs Jones is worried that she has been forgotten and speaks to the receptionist again, who tells her to wait. By 10.20 a.m. Mrs Jones is concerned that she will not make it to work in time for a meeting at noon. She asks the receptionist again, who again tells her to wait: *'You will be seen'*. A little while later, a member of staff comes into the waiting room. Without introduction, she asks Mrs Jones whether she has had anything to eat or drink this morning, because she has to be tested for diabetes. Mrs Jones was expecting some blood tests, but had not been told anything else. The member of staff is clearly annoyed when Mrs Jones says that she had breakfast and that she was expecting to be back at work by noon. Having had some blood taken, Mrs Jones is ushered into another room. Another member of staff, again without introducing herself, checks Mrs Jones' due date and asks her to lie down on the couch for an examination. Whilst Mrs Jones is still lying down, abdomen uncovered, the staff member says *'Your baby is breach, you'll have to have a Caesarean'*. Mrs Jones is devastated. She feels frightened and unsupported.

Thinking about Mrs Jones' example:

- Do you think she complained about the care she received?
- If so, what do you think she said in her complaint?
- If not, why do you think she didn't complain? Do you think she should have?

A patient may initially be dissatisfied about one aspect of the care received, which is then compounded by poor communication. Whilst people are often very forgiving of the practical difficulties inherent in a busy and complex health care service, patients who feel that they are being treated dismissively are more likely to escalate the problem into a formal complaint. Whilst patients or relatives often complain because they are frustrated or angry at how they have been treated, a common underlying motive is to prevent the same thing from happening to someone else.

Responding to complaints

Investigation of complaints should be seen as an opportunity to improve the quality of service provided to patients. Moreover, the early and sympathetic handling of a patient's complaint is less likely to leave the person feeling aggrieved and feeling that they have to resort to legal action to resolve the problem.

Guidance on responding to people who wish to make a complaint suggests the following steps:[13]

- Check how the person would like to be addressed (e.g. Mr, Mrs, Ms or by their first name).
- If the person has phoned, offer to call them back or arrange a face-to-face meeting.
- Ask the person how they would like to be kept informed about how their complaint is being dealt with.

Table 12.4 What to do if a patient or relative wishes to make a complaint

Do:

- Be sympathetic
- Listen carefully
- Gather full details
- Keep good notes
- Ask what the patient or relative hopes will be the outcome
- Summarise back to the patient or relative what they have told you
- Apologise
- Provide details of how the patient or relative can make a written complaint if they wish to
- Explain to the patient or relative what the next steps are and when they can expect a response
- Ensure that the patient or relative has relevant contact details
- Seek advice from a senior member of staff
- Follow the local complaints procedure

Don't:

- Avoid the complainant
- Get angry or defensive
- Try to provide an explanation or justification before the patient or relative has finished explaining their complaint
- Speculate about what might have happened
- Try to cover up – always be honest about what happened
- Tamper with the notes
- Criticise colleagues

- Ensure the person is aware that they can request an advocate to support them, particularly in the first meeting.
- Systematically go through the reasons for the complaint.
- Ask the person what they would like to happen as a result of the complaint.
- Agree a plan of action, including when and how the person will hear back.

Whilst it is often difficult to hear that a patient is unhappy with the care that you or a colleague have provided, resolving to use it as an opportunity to learn something that will improve your practice can help to reframe a difficult and unpleasant experience for all concerned into a positive event. Some strategies to consider when responding to a person who wishes to make a complaint are given in Table 12.4.

Health care services usually have local (and/or national) procedures in place for handling complaints, both in terms of responding to the complainant and in helping the organisation to learn from the feedback. Being familiar with these procedures can help you to reassure the patient that they will be listened to and taken seriously, and that something practical will happen as a result of the complaint. For example, some departments have regular meetings to review markers of service quality, including any feedback or complaints received, which ensures that action is taken at a departmental, or hospital, level as needed.

Preventing complaints

There is evidence that developing and maintaining good communication skills decreases the likelihood of a doctor receiving a complaint. For example, a study in Canada showed a link between the communication skills scores of doctors in an examination they took soon after graduation and the number of subsequent complaints made against them, with doctors rated as having better communication subsequently receiving fewer complaints from patients.[14]

Litigation

Unfortunately it is becoming more common for patients to take legal action against doctors. This is distressing for the patient and stressful for all those involved in the patient's care. A study in the UK found that patients and relatives took legal action after an incident because they wanted to:[15]

- know why and how the injury had happened
- prevent a similar injury to other patients
- see staff disciplined and held to account
- gain compensation.

Very often the decision to take legal action after an incident is strongly influenced by the way in which the incident is handled by staff. The patients and relatives interviewed in the study described above complained that they had not been given an adequate explanation of what had occurred, there had been no apology and they were often treated as if they were 'neurotic'.

Once again, the way in which a doctor communicates with the patient is important. A study in the USA found that 1% of hospital patients had suffered significant injury due to medical negligence, but that less than 2% of these had brought a malpractice claim against the doctor involved.[16] The authors compared the communication skills of the doctors who had claims against them with those who had no claims. They found that the 'no-claims doctors' used:

- more humour in the consultation
- more facilitation statements like, 'What do you think the problem is?' and 'Go on …'
- 'signposts' to let the patient know what the doctor was going to do, for example: 'I would like to ask a few questions about your work' or 'I would like to examine your back'.

The implication was that doctors' routine consultation style differed, and that doctors who communicated more effectively on a day-to-day basis were less likely to be sued.

Other studies have found a relationship between other aspects of communication, such as tone of voice used by surgeons, and the doctor's history of being sued.[17] The conclusion from evidence gathered from clinical practice and research studies is that developing good communication skills improves patient care and also reduces the chance of litigation.

Key points

- Doctors do make mistakes in clinical practice and patients have a right to know about any errors in their care.
- Mistakes can be compounded by poor communication.
- When there has been an error, people expect an apology, a clear explanation of what happened and steps taken to prevent the same error happening again.
- When mistakes happen, communicating sensitively and effectively with patients, their relatives and with colleagues helps all those involved to deal with the situation.
- How doctors communicate with patients and their relatives influences their decision about making a complaint or taking legal action.

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Clinical Communication Skills for Medicine is an essential guide to the core skills for effective patient-centred communication. In the twenty years since this book was first published the teaching of these skills has developed and evolved. Today's doctors fully appreciate the importance of communicating successfully and sensitively with people receiving health care and those close to them.

This practical guide to developing communication skills will be of value to students throughout their careers. The order of the chapters reflects this development, from core skills to those required to respond effectively and compassionately in challenging situations. The text includes case examples, guidelines and opportunities to encourage the reader to stop and think.

The contents of the book cover:

- The fundamental elements of clinical communication, including skills for effectively gathering and sharing information, discussing sensitive topics, and breaking bad news.
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