

# 1 Introduction

This book is about healthcare ethics relevant to speech and language therapists. In it we aim not just to deal with the dramas and dilemmas which tend to characterise thinking on ethics – the ‘Should I do A or B?’ ethics – but also to delve into the subtleties of attempting to understand people with communication disorders well enough to represent them, of managing interactions in a way that affirms and empowers people, and of making fair decisions about resource allocation.

The primary aim of the book is for debate into ethical issues to be stimulated within the profession of speech and language therapy, prompted by description of various clinical scenarios. Equally importantly, the book is concerned with highlighting the need to consider ethical issues in all aspects of our clinical practice. While we will need to invoke a number of concepts from moral philosophy, the book is primarily about clinical work and the ethical issues experienced by clinicians. It is written by two clinicians with an interest in the relationship between healthcare and ethics.

Ethics is basically about people and how they relate to each other. So rather than starting with discussion of exact definitions of ethics, different approaches to healthcare ethics or the relationship between ethics and, say, law, we are instead going to consider some examples of the impact of ethical issues on therapists and therapeutic interactions. We start with a speech and language therapist, Alison, who is mulling over a problem in the small hours – a familiar experience for people working in healthcare.

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The basic problem is that if I ask her, she might say no. On the one hand Rebecca’s mum hasn’t said I *can’t* pass information to the rest of the team. On the other hand, she doesn’t actually know I know anything about Rebecca’s dad. I think Rebecca would have a much better chance of settling into school if they knew her father was in jail. What was it Rebecca had said? ‘He did a bank.’ From a preschool child! It sounded like he was violent towards his family before he went to jail as well. It might help the school to understand why Rebecca was so timid and not quite ready for the classroom. But she has to go to school next year and this is the only school in town. I want her to have a good first year; her future depends on it.

## 2 ■ Ethics in speech and language therapy

Alison rarely lost sleep over her work, but this case was worrying her. She almost wished little Rebecca hadn't told her about her father. Alison had been seeing Rebecca for blocks of therapy on and off for most of the year. Rebecca had been so timid and with such delayed speech and language at the start of the year that she hardly said a thing. But as the year passed and her communication skills progressed, Rebecca had warmed to Alison and started to tell her more and more about preschool, her friends, pets and siblings. One day when her mother was unable to join in the session because of a medical appointment, Rebecca told Alison about her father. She was quite tearful and said she hoped he wouldn't be coming home for Christmas.

Now Alison was worrying about whether to pass on this information. The team's psychologist was due to assess Rebecca the following week to provide a report to the local school about Rebecca's school-readiness and support needs. Rebecca's mother had not said 'no' to sharing that information, but Alison felt that it might make the difference between success and failure for Rebecca in her first year of school.

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The dilemma at the heart of this scenario is typical of a traditional view of ethics – Alison has a choice of X or Y and she must choose one of them. Basically, she is faced with the option to divulge the information (and risk damaging the relationship with the mother) or not to divulge the information (and risk undermining the contribution of the psychologist to Rebecca's future and potentially risk aspects of Rebecca's future itself). There are various more subtle options – for example, Alison could attempt to negotiate the release of information with the mother – but at its heart the decision is 'to divulge or not to divulge'.

The focus on dilemmas, we argue, constrains understanding of ethical practice. We would like to illustrate a wider perspective by standing back temporarily from the world of speech and language therapy. In their research paper entitled 'Saying no to the staff', Finlay, Antaki and Walton (2008) describe in detail what at first sight appear to be a fairly routine set of interactions in a home for people with intellectual disability. The residents have high support needs and most have only a small number of intelligible words at their disposal. The authors provide a context for the article by highlighting the fact that care staff have to negotiate a course between two potentially contradictory obligations. The first is the obligation to respect the preferences and decisions of the residents (and, by implication, to find some way of establishing what these preferences and decisions are). The second, seemingly more mundane obligation is to monitor residents' weight regularly as part of general health screening. The article describes in detail the interactions between care staff and Matthew, who is known to be averse to stepping onto the scales to be weighed, but who expresses himself primarily via nonverbal vocalisation. The analysis of attempts by a member of staff to persuade Matthew to step onto the scales (while somehow respecting his preference not to) illustrates the subtlety of approach that is required.

An initial request (or perhaps invitation) by the member of staff – Jill – is worded as 'Dy'wanna get weighed?', to which Matthew responds with a vocalisation that is interpreted as a refusal. Jill then issues a second invitation ('Dy'wanna nother go?')

and then, following a second refusal, a third ('Shall we get weighed?'). The authors analyse the wording of Jill's contributions and her selection of particular phrases from a potentially large set of eligible phrases. They describe the second invitation as a 'no-blame formulation' in that the reference to 'another go' – even though there hasn't really been a first one – serves to absolve Matthew of blame for his inaction. They also highlight the collective phrasing of the third attempt as signalling a task that Jill and Matthew are to accomplish together. In fact, after various contributions to the interaction from other staff, Matthew wins this particular battle of wills and leaves the room without being weighed.

The linguistic sensitivity with which these negotiations are undertaken should be entirely familiar to clinicians working in the field of communication disorder. What the authors illustrate in particular is the link between the words that make their way to the conversational surface and the ethical issues lying much deeper, in this case active respect for Matthew's choice and the contradictory obligation to care for his health needs. The following extract, worth quoting in full, illustrates what important work is going on in these interactions:

*Choice and control are issues that arise in the way people talk to each other, in which utterances are taken up and which are ignored, in how and what options are offered, in how preferences are expressed, how information is presented, how spaces are opened up for people to express preference and how spaces are shut down. (Finlay et al., 2008, p. 56)*

The authors stress the importance of being able to express such preferences for people with communication difficulties, who may have limited opportunities to exercise control over other aspects of their lives.

In the circumstances described above it is unlikely that Jill would be seen as facing an ethical dilemma in her choice of words, yet there are serious ethical considerations involved. Language here *is* the surface manifestation of ethics. We explore this view further in a second scenario.

This example is from my (RB) clinical practice. Although it seems like a relatively minor incident, it has stayed with me for over 20 years. I was in my fourth year of clinical practice, my first as a specialist in neurology. I was feeling rather pleased with myself. Specialist status meant – surely had to mean – that I had particular expertise and could therefore contribute more. I felt established, useful and important, a pleasing combination.

Although I had been involved in the assessment and management of people with motor neurone disease (MND) on acute hospital wards, I had worked with only one man from the time of his diagnosis to his death. I had tried to help him make the most of a communication aid, given rather inexpert advice on managing his increasing difficulty with swallowing (this being before dysphagia management came of age) and visited him in the hospice. For most of this time I had worried about being asked questions I couldn't answer, but I had also found it a moving and positive experience.

I was now working with my second person with MND. Mrs Davies had known of her diagnosis for almost a year and was becoming increasingly restricted to the

house, not because of her mobility but because of the difficulty in making herself understood. I had introduced the possibility of trying a communication aid and she had reluctantly agreed at least to look at it.

I collected a potentially suitable electronic aid and drove out to Mrs Davies's house on a stuffy summer's afternoon. Her daughter had not been able to come to this appointment but had said she was happy for it to go ahead. Mrs Davies opened the front door and led me into the front room. It was oppressively hot and the quietness outside seemed to make the situation quite tense. We exchanged a couple of phrases about the weather and then I found myself asking how her speech had been, thinking as I said it, 'I *know* how her speech must have been. I can hear it.' Still, this was my job; this was what I was getting paid to ask for detail about. And then, seemingly equally as inadvertently, I asked, 'Have you had any problems with your swallowing yet?' She gave a long, drawn out, dysarthric wail and, almost out of breath, half-whispered, 'Please don't say *yet*.'

I found myself simultaneously registering the clarity of her articulation and realising the momentous implications of such a short and apparently innocuous word. Mrs Davies was inconsolable for the next 10 minutes and the communication aid had clearly become an irrelevance. Eventually she succeeded in gathering herself and offered me a cup of tea. We managed a few minutes of superficial, calming conversation and then both agreed that the session would be better reconvened for another day. I headed out to the car feeling flat and a bit helpless. I imagined Mrs Davies sitting in her room looking at the blank television for a while.

This event clearly does not constitute an ethical dilemma. I did not ponder whether one course of action would be better than another. In fact the question left my head so quickly there would not have been time to contemplate it anyway. It would be a harsh judge who would interpret this interaction in terms of 'unethical conduct'. It was not even possible to say with any certainty that it was a 'bad thing' in itself – Mrs Davies might in some way have gained some benefit from the catharsis. And yet, in this context and at this time, the word 'yet' had caused her acute psychological distress and I felt that I had caused that distress by being thoughtless. And that was exactly the point – I had not necessarily chosen the wrong phrase but I had not considered the implications of the phrase that I did use.

Thinking about it afterwards, I was struck by the thought that there is an ethical dimension to the choice of single words, phrases, intonations. They have implications for their recipients, often acutely sensitised by the vulnerability of their circumstances. I felt sad and I am quite sure Mrs Davies felt despondent. It is not always possible, or even desirable, to avoid saying things that make people sad, but in this case the use of the word 'yet' was insensitive and I could have broached the subject in a way that was less distressing.

Like the interactions described in Finlay et al.'s residential home article, this last clinical scenario is a long way from what could be termed a dilemma. Nor does it feel like an entirely 'clinical' issue. It involves, at its heart, the effects of an action that happens to be speech.

Speech acts are a well-known phenomenon in the study of pragmatics and they are thus familiar territory (at least in a theoretical sense) for speech and language

therapists (SLTs). Savulescu, Foddy and Rogers (2006), writing in the *Journal of Medical Ethics*, make the important link between speech acts and ethical theory in relation to the words we choose in talking to people who are dealing with a health problem of one sort or another: 'When we say something to a person who is suffering, we perform a speech act that can have significant impact on their wellbeing. It is morally important why we say what we say' (p. 8).

This focus on the subtleties of language should not be taken to imply that ethical dilemmas do not occur in speech and language therapy. Although as a profession we do not tend to deal with what are variously called 'neon' ethics (Braunack-Mayer, 2001), 'science fiction' ethics (Cribb & Duncan, 2002) and even 'gee-whizz' ethics (Fulford et al., 2002) – the headline news, life-and-death, sometimes legally mediated decisions that make their way into public consciousness – we are certainly faced with choices about the best way to act. Indeed, many of the later scenarios in the book incorporate decisions to be pondered by SLTs. But focusing on ethical dilemmas distracts attention from the fact that healthcare is fundamentally an ethical business. As Parker and Dickenson (2001) put it, 'the danger of this concentration on crises is that it creates the impression that medicine and healthcare is otherwise unproblematic' (p. 125). We would go further and say that ethics is not just about problems but also about attitudes and the underlying direction of health work.

The situations involving Alison, the residential home staff and Mrs Davies serve to illustrate different aspects of healthcare ethics to which we return later in the book. We now step back temporarily from the direct focus on people attempting to negotiate an ethically positive route through their daily work to consider some of the ethical landscape in the background.

### **What is ethics?**

Ethics is often equated with decisions of high moral magnitude and associated with weighty concepts of right and wrong or good and evil. The relevance of ethics to the daily experience of working in healthcare is not always easy to perceive. A definition proposed by Seedhouse (1998) highlights this daily relevance. He refers to ethics as 'a process of deliberation about how best to act in the presence of other lives' (p. 47). This definition may better characterise our thoughts on the way to work, or indeed, as many people will have experienced, in the middle of a sleepless night: how are we going to help X achieve something? how are we going to guide Y away from doing something else? which should we do first?

### **Why is ethics important?**

Many writers have highlighted the centrality of health to our lives. To quote Seedhouse (2002a) again, 'all health care practice takes place in the ethical realm' (p. 253). However, to a large extent this sound moral foundation to healthcare is taken for granted. During training as health professionals we devote large

amounts of our time and effort to the assimilation of theoretical and technical knowledge together with professional and clinical skills. Relatively speaking, we devote only very small amounts of time and effort to consideration of the huge ethical implications of what we are learning to do. The knowledge and skills we learn in training (and develop throughout our careers) are what Sim (1997) terms the *means* of providing healthcare. They form the focus of much of our thinking and discussion as health professionals. Ethics, on the other hand, provides a way of thinking about the proper '*ends*' of healthcare (Sim, 1997) – the whole point of all that time spent learning and refining the means. It may be the case that in their broadest sense the ultimate ends of healthcare remain relatively stable, i.e. the optimisation of everyone's health potential, but the subgoals shift as society develops and courses of action influence each other, such that decisions over what to do and how to act have to be taken within a dynamic, shifting ethical environment. And of course the major contribution to the dynamic, shifting ethical environment that constitutes healthcare comes from people – service users, carers, clinical staff, domestic staff, managers and many more. This is a fundamentally human endeavour, bursting with other people's lives.

The development of new technologies and approaches to healthcare often serves to alert the public to questions about whether such technologies *should* be put into practice simply because they *can* be. Medical issues most commonly perform this alerting function, but related questions can be asked of all aspects of healthcare. Does this therapy programme actually work? Is it an approach my client prefers? Will it benefit my client? Is it worth a try even if we don't know whether it works? Is it cost effective for my employer? Who should receive the therapy? Who could we be seeing instead? What impact does my instigation of this therapy have on service delivery by my colleagues? It is easy to conceptualise these questions as purely clinical in nature, involving clinical decision making, but it is fundamentally impossible to take a clinical decision that does not have ethical implications one way or another.

We can illustrate this point with an example from a recent teaching discussion (RB) of ethics in cleft lip and palate, during which a student raised the issue of how, and particularly *when*, to bring to the notice of parents a suspicion that their child might have some further serious condition as well as the cleft. Another student then queried whether this was an ethical issue or a clinical one. The clinical considerations to this question loom large. You would want to be sure of your clinical ground but not want to delay any opportunity for more detailed assessment and intervention. You would need to consider the clinical roles within your team and judge who should follow up your clinical hunch. Importantly, though, your handy textbook on clinical decision making in cleft palate may not address this issue at all – since it is a byproduct of the central clinical issue – and it is especially unlikely to deal with the sense of conflicting obligations you feel to the child, the parents and your team. You don't want to give them the wrong information, but you might have to put them through some anxiety in order to find out one way or another. The clinical and ethical aspects of this situation represent two sides of the same coin.

There is also a sense in which, as we shall see in the following section, recognition of the importance of ethics is of particular significance in the field of communication disorder. Communication is one of the most sensitive expressions of 'acting in the presence of other lives', and the essence of our work as SLTs is about helping people who have a specific difficulty in affecting others' lives through communication and giving expression to how they want others to act in the presence of their own lives. SLTs spend their working lives in psychologically intimate relationships with people who are at some sort of disadvantage in their dealings with others.

We now consider the recent expansion in literature on the subject of healthcare ethics and the extent to which this literature is applicable to speech and language therapy or informs its practice.

### Healthcare ethics literature

Ethics in medicine (usually termed either medical ethics or bioethics) has now reached sufficient critical mass to be considered a discipline in its own right, as evidenced by the proliferation of journals dedicated to the subject, such as the *Journal of Medical Ethics*, *Cambridge Quarterly of Healthcare Ethics* and *Journal of Clinical Ethics*. Related fields have also made a start in this direction, for example the journal *Nursing Ethics*.

Clearly, there are areas of medicine and medical ethics that are not essentially relevant to speech and language therapy practice. Most SLTs will have no professional involvement in decisions about termination of pregnancy, except perhaps where their clients are having to ponder the decision themselves. Other hot topics in medical care, such as genetic testing and disclosure of information on transmissible diseases, are outside the areas where SLTs generally practise. On the other hand, many of the insights provided by the general debates in medical ethics are relevant to speech and language therapy.

On a theoretical level, for example, recent articles in the *Journal of Medical Ethics* (Freeman, 2006; Sokol, 2006) have lamented the unhelpful distance between (medical) ethicists and (medical) practitioners. Sokol (2006) refers to 'abstruse theorising and ignorance of practical medicine' (p. 1226) on the part of ethicists, and Freeman (2006) says that although ethical theory may provide some guidance, it does not provide sufficient help in individual cases. While speech and language therapy is rarely, if ever, specifically subject to the pronouncements of moral philosophers, there is certainly a parallel gap between ethical theory and speech and language therapy practice. Faced with the issue of client confidentiality at the opening of this chapter, Alison is unlikely to turn to one of the major medical ethics textbooks to prompt her thinking, much less to Aristotle or John Stuart Mill. This is an issue to which we return later when discussing ethical decision making.

On a more concrete level, the medical ethics literature features regular debate on, for instance, rationing of services, something with which all healthcare professionals are familiar. Browne and Browne (2007) discuss ways in which clinicians sometimes violate practice guidelines (i.e. bend the rules) so that their

patients can derive a benefit they might otherwise be denied (because, for example, they do not fit predefined criteria for access to treatment). They further differentiate between *offensive* violations, where most people stick to the rules and the clinician in question wants to secure an advantage for a patient, and *defensive* violations, where other people may well be breaking the rules and the clinician follows suit so as not to *disadvantage* a patient. The article may have originated in medicine, but it is not too difficult to imagine circumstances in speech and language therapy where the concepts would be relevant.

Given (a) the volume of medical ethics material available and (b) the fact that there is at least some overlap between medical ethics and the world of speech and language therapy, anyone who has read this far might be forgiven for wondering why we need to consider ethics in speech and language therapy separately. The answer, of course, is that speech and language therapy is special. Just as there are issues that arise in medical ethics but not speech and language therapy, the reverse, i.e. ethical issues that arise in speech and language therapy but not in medicine, is consistently if perhaps less transparently true.

Speech and language therapy is fundamentally about people's ability to communicate. Despite the growth of work in dysphagia, it is still communication that defines us as a profession and it is our body of knowledge concerning communication disorder that differentiates us from other professions. Seedhouse's (1998) 'how best to act in the presence of other lives' might justifiably be paraphrased by SLTs as how best to *interact* in the presence of other lives.

A paper by Malloy et al. (2006) includes a potentially revealing comment on doctors' perceptions of communication disorder. The authors explore a model of moral intensity originally conceived by Thomas Jones (1991) as a way of delineating factors which might make an ethical dilemma more intense. One of the factors identified is proximity, defined as the relative physical, social or psychological closeness between decision-maker and patient. The authors exemplify this construct as follows: 'A physician who is able to communicate verbally with a patient will have a greater sense of proximity than will a physician attending to a patient with severe cognitive impairment and inability to communicate verbally' (Malloy et al., 2006, p. 286). It is likely that anyone – SLT or physician – who has experienced the intense interactions that can occur with people whose communication is severely restricted might take issue with the somewhat unidimensional view expressed in this statement. At the very least, it suggests that it is not enough for the speech and language therapy profession to rely on the field of medical ethics for exploration of the ethical issues arising from communication disorder. An alternative perspective can be found in a study of dementia care by Brannelly (2006) in which observers noted consistency of what was termed 'social regard' by practitioners (care staff, social workers, etc.) interacting with people with dementia. This consistency was not necessarily a positive thing in its own right since some of the practitioners consistently approached people with dementia with social regard and others consistently did not. The important factor is that this consistency was applied 'regardless of [the person with dementia's] ability or communicative capacity' (Brannelly, 2006, p. 203).

Disruption of people's ability to communicate thoughts and feelings takes us deep into people's lives and presents us as therapists with the responsibility of handling a world of ethical subtleties in a sensitive way. It also highlights the possibility of viewing communication as a basic human right alongside health, food and shelter (Horner Catt, 2000) (an issue we return to in Chapter 8). A few examples by way of illustration:

- An intellectually disabled man has always expressed a fear of illness and is now terminally ill. Someone needs to assess the extent to which he can understand what is going to happen to him and to balance his right to know with his capacity for dealing with and communicating distress.
- The family of a five-year-old girl who has had repair of a unilateral cleft lip and palate is offered a series of speech and language therapy appointments. They attend one but then stop responding to contact. The girl is at a critical point in her emotional and social development and yet the family appears to have made an autonomous decision not to attend for therapy. How far can the SLT pursue this? Is it really the SLT's decision? Is the only course of action to wait until she reaches adulthood? And then do what?
- Demands on funding mean that a Stroke Group needs to be closed down, as a result of which an aphasic woman, whose husband has recently died, finds her access to social interaction all but curtailed. Her language problems make it difficult for her to make use of standard services or to meet people without help, and the Stroke Group has until now provided the only regular time when the skill of the therapist and the supportive enthusiasm of the other participants made communication less effortful than it generally is. Her language is not likely to improve and other clients have more obviously pressing needs.

The therapy relationship between clients and SLTs often develops over significant periods of time, with many hours spent together in highly charged interactions. Picture a 13-year-old stutterer – bullied at school, sullen and resentful – in her first session with a speech and language therapist who her mother has finally persuaded her to see. She is probably hoping for a rapid, responsibility-free cure – anything less and she would have been right not to listen to her mother all along. For the therapist the first job is to establish some sort of relationship that can be prolonged. But prolonged to where? Improvement? Control? Awareness? Acceptance? Despair? The therapist might be persuading the girl to engage in therapy only for her to experience the crushing realisation that this speech pattern is never going to disappear completely. On the other hand, the SLT might see someone developing into a self-confident and competent young woman who is so free of the pressures of dysfluency that both of them have difficulty recalling the person she once was.

And just below the surface of the desire for a cure lie other unspoken hopes: of being able to talk to someone about what it's like; of being able to talk to someone who knows something about the subject; of dealing with someone who will be honest with you but who can judge the best time to give difficult information; of

having someone on your side, someone who will fight your corner, someone who will get you out of the mire at school; of working with someone who will put themselves out for you.

This combination of a communication disorder and the relationships involved in trying to manage it is unique. As such, it raises unique ethical issues requiring dedicated (in both senses of the word) discussion.

Another reason to conclude that speech and language therapy requires its own literature on clinical ethics is that even where the issues discussed in medical ethics journals overlap with speech and language therapy, the discussion itself takes place, in effect, out of sight of the profession. Theoretically we could all browse medical ethics books and journals and interpret what we find there for our own purposes. Realistically it is going to be a very determined SLT who takes time away from clinical work to check out medical ethics literature on the off-chance that something will resonate with speech and language therapy practice.

It is important to acknowledge that this book is a contribution to a small but growing literature on ethics in speech and language therapy. By way of example there are Irwin, Pannbacker, Powell and Vekovius's *Ethics for Speech-Language Pathologists and Audiologists* (2007); a special issue of *Seminars in Speech and Language* (2003, 24[4]); Hersh's work on discharge in aphasia (Hersh, 2002, 2003) (to which we return in Chapter 5); various discussions of the ethical aspects of dysphagia, particularly non-oral feeding (Landes, 1999; Sharp & Bryant, 2003; Sharp & Genesen, 1996); and Kenny, Lincoln and Balandin's (2007) recent speech and language therapy incursion into the *Journal of Medical Ethics*. In addition, more closely centred within speech and language therapy professional circles there have been a number of discussions on websites and/or articles in professional publications. Other examples include the *ASHA Leader Online*, part of the website of the American Speech-Language-Hearing Association (ASHA), which features short discussions and statements on ethical topics (e.g. statements on cultural competence [ASHA, 2005]) and client abandonment [ASHA, 2008b]), and the professional bulletin of Speech Pathology Australia (*ACQuiring Knowledge in Speech, Language and Hearing* or 'ACQ'), which also has occasional articles on ethics (e.g. R. Cross, Leitão & McAllister, 2008).

This might look like a fair amount of discussion on the subject of ethics when gathered into one paragraph. However, given the breadth of clinical practice and the number of professionals and service users involved worldwide, the material is actually spread pretty thin and is dissipated across various forums, some more widely accessible than others (the *ASHA Leader Online*, for example, is open to public view). From our point of view the profession currently needs as much in the way of ethics debate as it can get.

### **Morality, values, law and ethics**

Having established that ethics in speech and language therapy is worthy of discussion, we now introduce some concepts associated with ethics. The relationships

between concepts such as morality, law and ethics are described in detail by various authors (e.g. Hendrick, 2000; Sim, 1997), and we do not intend to add detailed discussion here. However, a brief overview is warranted in the interests of starting from a reasonably firm conceptual foundation.

### ***Ethics and morality***

For SLTs considering whether to divulge possibly confidential information to a colleague, the relationship between the philosophical concepts of ethics and morality may seem to be of little interest and certainly of no practical use for the task at hand. This, largely, is the line followed in this book, in part because various authors on healthcare ethics describe the two concepts, in some senses at least, as effectively interchangeable (Horner Catt, 2000; Malloy et al., 2006). This does not mean to say, however, that distinctions are not drawn between the two concepts. In fact, these same authors highlight possible distinctions: Horner Catt (2000) refers to a delineation between social good in general (morality) and individual good (ethics), and Malloy et al. (2006) (following Aristotle) describe morals as ‘universal concepts that transcend cultural variation and practice’ and ethics as ‘principles particular to context’ (p. 286). Likewise, Sim (1997) states that while there is no real difference between ‘ethical’ and ‘moral’ in some uses of the terms, there is a sense in which ethical is taken to refer to a ‘specific code of moral behaviour associated with a particular professional role’ (p. 12). So one interpretation is that the relationship between ethics and morality can be conceptualised as the former being a systematisation of the latter. Indeed, Colicutt McGrath (2007) describes ethics as the systematic study of moral values, in the course of which those values are translated into standards and rules of personal and cultural practices.

From our perspective, it is important to establish that although ethical standards and rules might arise from the systematic study of morality (and in their turn give rise to statements or codes of ethics), we would not want to equate ethics with rules or codes. This point is relevant to some of the commentaries later in the book, because in some formulations (e.g. Downie & Macnaughton, 2007) the concept of (professional) ethics is largely interpreted in terms of its regulatory function. Moreover, in some parts of the world (notably the USA) the term ‘ethics’ relates primarily to rules (of conduct) and codes (of ethics), leaving wider areas of debate to come under the heading of ‘morality’.

For us, and for our view of the daily practice of speech and language therapy, ethics and morality *are* functionally interchangeable, relating as they do to ‘choices large and small that impact others – sometimes to enhance others’ lives and sometimes to harm them’ (Horner Catt, 2000, p. 138), though Horner Catt herself applies this phrase only to morality. As we discuss in Chapter 2, a wider view of ethics has significant implications in terms of recognising the limitations of codes of ethics for addressing the issues that arise in clinical practice, some of which are described in the scenarios.

**Ethics and law**

Although there are laws covering a huge variety of behaviours – for example, the UK has a 1969 law prohibiting the tattooing of people under 18 (other than by a medical practitioner) regardless of parental consent – it is also not difficult to imagine situations in professional work about which the law would have little or nothing to say. The decision (outlined above) to stop running a Stroke Group, for example, is very unlikely to be the subject of legal debate. The fact that the decision has ethical implications, on the other hand – whether it is the right or wrong thing to do in the light of other service needs – is less debatable, though this may not make the decision itself any clearer.

It is, of course, the case that a variety of laws *are* entirely relevant to SLTs in their work, such as laws concerned with the rights of children and with anti-discrimination legislation. A key point here, as outlined by Sim (1997), is that the law works in terms of minimum standards below which behaviour should not fall. This is not to say that everyone agrees on the ethical rightness or wrongness of the area *below* the minimum legal standard. In other words, some people may think that a law is not ethically acceptable. Above these minimum standards there is significant scope for ethically good or bad decision making. We will take another example from my (RB) early – I'd like to plead inexperience – clinical practice, when I was working with a patient with dysphonia who had had nasendoscopy recommended by the Ear, Nose and Throat surgeon. She was, perhaps not surprisingly, somewhat averse to the idea of having a tube inserted up her nose and I took to persuading her of the benefits, unwittingly painting myself into a corner at the same time. The crucial point in the discussion came when I claimed that the procedure was 'not that bad', which prompted her to ask whether I had experienced it. If I said 'No', my claims would dissolve; a pause would be equivalent to an admission that I hadn't but that I was possibly contemplating some claim to the contrary; 'Yes' would be lying but might persuade her to undergo the procedure. These were the only alternatives that presented themselves in the very short space of thinking time. Perhaps some variant of 'No, but I've talked to people who have' would have offered another alternative, though at the time that would not have been strictly true either. At the risk of alienating the book's readers before we've really started, I must report that I said 'Yes', and she had the nasendoscopy done, as did I shortly afterwards in an effort to assuage my guilt. As far as I am aware I did not contravene any law (though I'll reiterate the plea of inexperience just in case), but I have had a number of debates since then with students as to whether this was an unethical action on my part. The outcome for the patient was fundamentally positive but the 'ends justifies the means' approach, although legal, seems to teeter dangerously close to the top of a slippery ethical slope and I certainly did not feel comfortable with it at the time.

### ***Ethics and values***

Cutting across ethical concepts of good, bad, right and wrong and, more importantly, the deliberation of how to act in the presence of other lives are the various things that people value and that have to be considered in making ethical decisions. For example, we might place value on a friendship, an heirloom, trade unions, honesty, the fact that the shop down the road sells pomegranates, etc. The list of our values is unlikely to be an exact match for those of even the people closest to us, let alone all the people with whom we come into contact in our working lives.

Some of these values are more clearly relevant to our interactions with other people's lives than others. So my valuing of the availability of pomegranates might be ethically neutral for most other people (though the question of how they arrive in my local shop may not). My valuing of trade unions, on the other hand, may come into direct conflict with the views of a patient whose company is in almost permanent dispute with its workforce. Taking this one step further, we could ask whether, in my interaction with this patient, I am ethically obliged to help her communicate anti-union sentiments, should that be her stated wish. Moreover, it is not inconceivable that some areas of therapy, such as voice work with transsexual clients, might present significant challenges in relation to the values espoused by some therapists.

### **Structure of the book**

Having discussed the importance of ethics to speech and language therapy, in Chapter 2 we look at resources such as codes of ethics and ethical decision-making frameworks and consider their role in ethical practice. The central six chapters (3–8) are based on specific areas of clinical practice: dysphagia; intellectual and sensory impairments; acquired communication disorders; paediatric speech and language disorders; degenerative conditions in ageing; and, finally, service provision and management. The selected areas cover many of the major areas in speech and language therapy, and we hope that the issues raised will be relevant outside their area of origin. Each of the six chapters has a similar structure, incorporating two clinical scenarios (written by us), two commentaries on each of the scenarios (written by people who are not us) and a discussion section.

For the commentaries we have invited leading SLTs from a wide range of countries (Australia, Canada, Malaysia, New Zealand, South Africa, the UK and the USA) to bring their experience to bear on the issues raised by the scenarios. The commentators were asked not to use the 'language of ethics' (e.g. beneficence, veracity) but to discuss in plain language why they felt the scenarios presented challenging issues. The commentators have tackled the task in different ways, and by and large we have chosen not to interfere with this. In some cases our

discussion has picked up issues highlighted by both commentators and in others we have pulled out issues that were not the focus of either of the commentators' efforts. Guidance to the commentators also included a request not to include many references, in order to facilitate focus on the topic under discussion itself. In some instances the approach taken by an individual commentator meant that inclusion of a larger number of references was deemed appropriate. In Chapter 9 we draw together the common themes across the various clinical and management areas covered in the previous chapters. We also attempt to look into the near future and anticipate the ethical issues that will be raised by new developments in speech and language therapy provision.

A list of the areas not covered in the book might turn out to be longer than the book itself, but we should note some of the absences made unavoidable by limitations of space. In terms of client groups, we were unable to include scenarios specifically based on dysfluency, voice, cleft palate, neonatal feeding or mental health, to name but a few, and we recognise that all these areas of clinical practice have the potential to present significant ethical challenges. Our hope is that the issues that are discussed in relation to our scenarios translate to other client groups. We also decided not to include the ethics of research in relation to speech and language therapy. Although there have been steady increases over the last few years in both the importance attached to research and the number of clinicians involved in it, the profile of clinical ethics seemed to us to be in greater need of development at present. This reflects a sentiment expressed, by way of example, in the UK Royal College of Speech and Language Therapists' (RCSLT) *Communicating Quality 3*: 'With the advent of clinical governance, health professionals are being increasingly called upon to examine the ethics that lie behind all practice decisions' (RCSLT, 2006, p. 15).

Finally, we inevitably need to acknowledge that not everyone will agree with everything written in the book. Although we have not set out to provide prescriptive solutions to the situations described in the scenarios, various viewpoints and courses of action are offered by the commentators and by us. That these may not meet with universal agreement reflects the essence of the subject matter of the book. As Malec (1993) says in a discussion of ethical approaches to (brain injury) rehabilitation, 'a fundamentally shared value in a pluralistic society is that many values need not be shared' (p. 384). Beauchamp and Childress (2009) put this even more strongly, saying, 'we regard disunity, conflict, and moral ambiguity as pervasive features of the moral life' (p. 374). Despite this acknowledgement, it is important that discussion of ethical issues should not serve to make situations even less comprehensible than before the discussion. To quote Peter Carey in his novel *Theft: A Love Story* (2006), 'There is so much fog around the moral high ground' (p. 155). We hope that our discussions render the fog somewhat less impenetrable.