The diagnosis of dying

R Higgs

In the clear and comprehensive review of nutritional and fluid management for the dying by Lennard-Jones in the last issue of the JRCPL, one phrase shines out: 'The ethical situation is not that the patient is failing to drink and therefore will die, but that the patient is dying and therefore does not wish to drink'. Confronted by apparently difficult decisions at the end of life, we see by this light that some of our difficulties may be of our own making. We have just got our thinking back to front. Death continues to provide us with perplexities, increased if anything by technological progress. But concerned as we are to save or prolong life, we are in danger of starting from the wrong premise if we fail to ask 'is the patient dying?'. If this is so and is now inevitable, our task is to provide proper care for that process. To do otherwise is poor logic and bad medicine.

In the UK we may now be justifiably proud of some of the care in place: we have a well developed and humane hospice movement and comprehensive terminal care nursing, genuine attempts to respond to the needs of different cultures, concern (in the Royal College of Physicians as elsewhere) about a good death. But other things still elude us. When we are clear that a patient needs palliative care, the standards are in place – but only 12% or so of our people die in hospices. For the half of the population who die in hospitals, or the further quarter who die at home, much less can be said. Far too frequently reports still come, from patients and relatives in consulting rooms or friends over dinner tables, of aggressive treatments pursued too long, or practitioners caught unprepared or unavailable. Clinicians express perplexity about the same problems in a different way: how and when should we make the transition from curative to palliative treatment? We often find this change very hard. However clever we may be in making diagnoses in other areas of medicine, as clinicians we still find it difficult to make the diagnosis of dying.

It was not always thus. When doctors could do much less, their attentions were deployed more effectively at this point in the illness. At one of the most famous deaths of the nineteenth century, Nelson's physician described (in the third person) his response:

The Surgeon replied: 'My Lord, unhappily for our Country, nothing can be done for you,' and, having made this declaration, he was so much affected that he turned round and drew a few steps to conceal his emotions. His Lordship said, 'I know it...'.

With heroic action all about him at Trafalgar, that doctor could have been forgiven for making heroic attempts to save one of the most famous military leaders of the time. But he knew that events required something different: a man had to be informed about his impending death, and to be helped by such medical aid as was to hand to spend his remaining time as he wished, in as much peace as could be provided and with those around who mattered. It is time for twenty-first century physicians to reassess current practices and skills in this area, and relaunch those in danger of being forgotten. An influential and instructive report from a palliative care working party recently identified this process at the bedside as 'changing gear'. If we cannot easily make this change, our care may stall. Not only will clinicians remain confused, but patients will inevitably suffer.

Why should this change be so difficult to make? Of the possible answers, several stand out: the clinician may not think about the possibility and reality of the patient dying; may not make proper plans at the right point in the illness; may not be able to discuss dying; may not know what to do next in terminal care; or may be overwhelmed by the potential moral and legal complexities. We should examine these possibilities and look at what should be done in each case.

Bringing the question to mind: is the patient dying?

Much has been written about patients denying a lethal prognosis, but little about physicians doing so. However, most of us stay happy and hopeful by not thinking about death, and perhaps it is not surprising to catch ourselves and our medical colleagues using two distinct but related forms of avoidance behaviour. In one, we work as if it is our duty to fight death until the bitter end (and so see it as the ultimate failure). In the other, we allow the issue to remain unconsidered, so that events take their own course when at last our treatments are of no avail (and so it is in no sense our fault). Sadly, the challenge to such thinking sometimes occurs outside clinical work in physicians' own lives; perhaps in the first case when a close friend or relative becomes terminally ill, or in the second when bereaved relatives make a complaint. Thus, our initial corrective reminder is stark but unavoidable: managing the dying process is part of our job, whether this outcome is due to failed treatment or arises from circumstances we could not predict. We cannot claim, as specialists, that our expertise stops short of the final phase of a disease; or as generalists, that care for the dying is no longer generic. We are unlikely to be happy being cared for by such a physician, any more than we would be happy to learn that the pilot who had skillfully guided our package flight across
Continents could not actually land the plane. Although palliative care specialists are there to help us, they cannot tell us when our patients need the referral, nor can they cope, as things are, with more than the 15% or so of dying hospital patients whom they currently see. Making the assessment that the patient is dying and managing their overall care remains the potential job of every relevant clinician.

When should we ask ourselves the question and make plans?

The issue of whether the patient is dying should not just be raised in the patient's last hours. There are at least three key moments in any person's final illness that should alert the physician to think about the management of dying.

Diagnosis of a potentially lethal illness

The first is when a potentially lethal illness is diagnosed. We cannot treat a competent adult without consent, and consent implies information. The person must know what he/she is suffering from, what could be done about it and what may happen if this course is not followed. Except in rare and defined situations, modern health care implies openness. We should remind ourselves that there will be a small but significant group of patients for whom the treatment may be worse than the disease; even some for whom death may be a benefit. Some patients describe receiving confusing information, and we have given an account of the destructive effect of a clinician lying. Apart from the presumption of openness, the patient should be helped to understand the shape of future plans, the possibility of decisions being in their hands, and what sort of commitments the physician and his/her team are able to offer. (It is reasonable, although unusual, for a patient to refuse treatment; it is also reasonable for a patient to decide to seek help from someone else.) As part of this process, some advocate introducing the concept of advanced directives.

When treatment is of no avail

The second point at which physicians should think about a patient dying is when curative or stabilising treatment no longer produces effective results. Ultimately, only the patients can make the personal and painful cost/benefit assessment that this entails, but they cannot do so without medical help and guidance. For the therapeutic enthusiast, this is the point when a 'change in gear' may be difficult. Every therapeutic intervention used hitherto has to be reassessed. Side effects are no longer acceptable if the agent does not contribute to improving or maintaining the patient's quality of life. As doctors, we have been taught regularly about when and how to start treatments, but little about when and how to stop them. A good partnership, sensitive to the realities of the patient's feelings as well as to the particular stage of the disease, needs to be set up with the patient, family and therapeutic team to review aims and methods. Symptom control is paramount to reduce the chaos of a disease process that threatens the dignity, privacy and personal goals of the patient; issues such as dependency are of no concern. 'Depression' in the face of dying may be an inadequate description, but it too may need appropriate management.

The last days

How long it is before the third and final point is reached is usually hard to estimate. Doctors are often caught being too confident (and thus potentially destructive) in their predictions, and then missing the moment when it arrives. The signs that the patient's death is near may be subtle but discernible by those who have the will to look. The profoundly weak, bedridden, semi-comatose patient who refuses tablets and cannot take more than sips is within a few days of death. Patterns of breathing may obviously change. There may be a new gauntness, a hollowness in the facial features which the experienced will recognise. The patient may become withdrawn or unusually agitated, or may need to express new fears. Some patients articulate clearly to those who will listen that they are going to die. This is the time for the team to be faithful to what has been promised, and to do everything possible to enable a person to die their own death as privately as they might wish, in the presence of the people they love and who need to be with them. It is hard to see the open ward as the humane and respectful place for this important event to take place; this is a challenge for hospital management as well as for clinicians. Some patients indicate clearly a need to be on their own with their thoughts. Tolstoy had the gift to describe what such withdrawn dying might be like, but it is within everyone's compass to receive the clues on offer at the bedside and to respond appropriately. There are accounts of patients being peacefully 'given permission to die' by someone they are close to and trust.

Talking about dying

The fear of death or of the process of dying may lie unspoken in many consultations. Some patients express gratitude when a clinician carefully opens up the subject, or indicates that he/she is prepared to do so if it is required. Fears or fantasies of death are subjects which few can discuss within their own social circle. Can this discussion be harmful? The analogy with questions about suicide to the depressed is apposite: it would nowadays be considered bad practice not to do so. The anxieties clinicians might feel about suggesting something the patient had not thought of, or of a maladroit performance, are usually products of their own fears and lack of skill. The answer to the latter is, as with any skill, more practice with a good teacher. Time may be an important constraint at first, but not when the clinician is experienced. It is, as has been said, not a matter of length but of depth, and follow-up discussions are vital.
But both observation and intervention studies show we still have a long way to go.\textsuperscript{17}

**The practice of good terminal care**

Under pressure as most clinicians are, it is easy to let our skill and knowledge in this area slip, or to feel that someone specialising will know better and we can avoid worrying about it. There is no shortage of education, both in terms of general guidance and in specific discussion of individual symptom management, such as cachexia in malignancy.\textsuperscript{18} For fields other than cancer care, there are still challenges to be addressed by both specialist and generalist. Explaining to patients that we do not know something is acceptable; failing to educate ourselves, or to contact the appropriate expertise in order to inform or help them, is not.

**Moral and legal complexities but diagnostic clarity**

As technology progresses and society's expectations change, we may find ourselves challenged by decisions that enter unfamiliar territory or are contested. We cannot avoid the different perspectives of patients and relatives, nor of the different members of the therapeutic team. In a multicultural society of many faiths or none, there may be few routines which can be depended upon. But this complexity is precisely what provides us with the richness and depth to provide good solutions to individuals' real needs when they are dying.\textsuperscript{19} Not only must this be good medicine but also, in a broader context, the appropriate use of resources. But the gateway to such rich and satisfying practice is plain and simple. Without the right test, we cannot produce the right diagnosis. The test is, is the patient dying? The rest follows from there.

**References**

1 Lennard-Jones JE. Giving or withholding fluid and nutrients: ethical and legal aspects. \textit{J R Coll Physicians Lond} 1999;33:39–45.

2 Hospice Information Service/St Christopher's Hospice. \textit{Hospice facts and figures – place of death, hospice services 1977–1996: Fact sheet number 7}. London: Hospice Information Service, 1996.

3 Beatty W. The Battle of Trafalgar: the death of Lord Nelson. In: Lewis JE (ed). \textit{How it happened}. London: Robinson, 1998:186–9.

4 Working Party on Clinical Guidelines in Palliative Care. \textit{Changing gear – guidelines for managing the last days of life in adults}. London: National Council for Hospice and Specialist Palliative Care Services, 1997.

5 Maguire P, Faulkner A. Communicate with cancer patients: 2. Handling uncertainty, collusion and denial. \textit{Br Med J} 1988;297:972–4.

6 Ellershaw J, Foster A, Murphy D, Shea T, Overill S. Developing an integrated care pathway for the dying patient. \textit{Eur J Palliative Care} 1997;4:203–7.

7 Higgs R. Truth-telling. In: Kuhse H, Singer P (eds). \textit{A companion to bioethics}. Oxford: Blackwell, 1998:432–40.

8 Higgs R. Truth at the last – a case of obstructed death? \textit{J Med Ethics} 1982;8:152–6.

9 House of Lords Select Committee on Medical Ethics. \textit{Report} 1993–4. HL21-L.

10 Working Party on Clinical Guidelines in Palliative Care. \textit{Changing gear – guidelines for managing the last days of life in adults}. London: National Council for Hospice and Specialist Palliative Care Services, 1997:13–14.

11 Turner K, Chye R, Aggarwal G, Philip J, \textit{et al.} Dignity in dying: a preliminary study of patients in the last three days of life. \textit{J Palliat Care} 1996;12:7–13.

12 Morrison R. Depression and the desire to die. \textit{Br Med J} 1994;309:1088.

13 Ellershaw JE, Sutcliffe JM, Saunders CM. Dehydration and the dying patient. \textit{J Pain Symptom Manage} 1995;10:192–7.

14 Morita T, Ichiki T, Tsonoda J, Inoue S, Chihara S. A prospective study of the dying process in terminally ill cancer patients. \textit{Am J Hosp Palliative Care} 1998;7:217–22.

15 Tolstoy L. \textit{War and peace}. London: Penguin Books, 1982:1162–7.

16 Saunders S, cited in: Lamerton R. \textit{East End doc}. Cambridge: Lutterworth, 1986:11.

17 The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalised patients. \textit{J Am Med Assoc} 1995;274:1391–8.

18 Bruera E, Higginson I. \textit{Cachexia-anorexia in cancer patients}. Oxford: Oxford University Press, 1996.

19 Higgs R. Shaping our ends: the ethics of respect in a well led NHS. \textit{Br J Gen Pract} 1997;47:245–9.

Address for correspondence: Professor Roger Higgs, Department of General Practice and Primary Care, Guy's, King's and St Thomas' School of Medicine and Dentistry, Weston Education Centre, 10 Cutcombe Road, London SE5 9RJ. E-mail: roger.higgs@kcl.ac.uk.