Managing expectations

“Palliative care has come of age. In the last 12 months, there have been 90 references to palliative care in the UK Parliament. It is worth noting that palliative care has featured in several Bills as well as in questions and statements. The Bills include the NHS Community Care (Delayed Discharges) Bill, Patients’ Protection Bill, Regional Assemblies (Preparations) Bill and the Patient (Assisted Dying) Bill. What are the implications of all this awareness about palliative care? Recognition brings with it responsibilities; expectations are high and the price of failing those expectations may also be high.

Managing expectations is increasingly difficult in medicine. The article by John Tercier in this issue on the optimistic media portrayal of cardiopulmonary resuscitation is a good example of the way expectations are created through public exposure to a topic. Public expectations of palliative care now have to be met. Patients expect their symptoms to be controlled, and symptoms that are relatively trivial to the professional may be extremely distressing to the patient. Hiccups are one such example where patients complain about the pain of ceaseless hiccuping, yet the therapeutic options remain very much trial and error for each patient.

Specialist palliative care is now facing wide-ranging and complex medical conditions as patients are referred earlier in their disease. This gives us the opportunity to address patients’ problems with enough time to achieve some resolution of psychological difficulties and to make social arrangements and adjustments. But having this extra time does not mean that the services can act any more slowly; time is of the essence. When someone is dying, every day counts. Home adaptations must be put in place fast. The debate on motor neuron disease in the House of Lords highlighted the plight of patients who do not have everything in place when they need it. As one patient communicated to the All Party Parliamentary Group on Motor Neurone Disease, ‘It seemed as soon as I got what I needed, it was too late. I needed much more. The system seemed to be weeks behind my needs’.[1]

Mesothelioma awareness (see page 181) is not just confined to those in clinical care. As a Minister of Health, Hazel Blears spoke of research in palliative care in an answer she gave to the House of Commons on mesothelioma, saying, ‘There are two clinical trials looking into chemotherapy, surgery and palliative care to find out which combination of those treatments is the most effective’.[2]

So, research into the effectiveness of what we do in palliative care is very much in the public eye. The research basis of palliative care interventions needs to be focused, and centres of research excellence will emerge. The advent of cancer networks in the UK will allow smaller palliative care units to become increasingly involved in the teaching of undergraduates, in recruiting patients into trials and in the academic discussions that enliven the thinking of professionals. The future is very challenging, as the types of care delivered will be increasingly scrutinised.

Patient choice is emerging in the UK as a major driver of care

The proposed tariff pricing of services in the UK will bring the need for accurately and appropriately identifying the commissioning of services against a rigorous contract. All specialist services will probably be expected to provide 24/7 cover, with specialist advice available to those providing care in other venues, such as the patient’s own home or a nursing home. The specialist team will need to be completely up-to-date with managing common medical conditions, such as diabetes (see page 186), in the place of care chosen by the patient.

Patient choice is emerging in the UK as a major driver of care; palliative care services have promoted this concept and now must prove they deliver against a patient agenda. The debate on the Patient (Assisted Dying) Bill showed the high regard in which palliative care services in the UK are held. But such heights also bring huge challenges to deliver care that is ‘near perfect’ and some challenges will be harder than others to overcome.”

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References
1. Fairbrother A. Disabled Facilities Grants. All Party Parliamentary Group on Motor Neurone Disease, House of Commons, 9 July 2002.
2. www.parliament.the-stationery-office.co.uk/pa/cm200203/cmhansrd/cm030211/debtext/30211-01.htm