

EDITORIALS

Dying with dignity

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Over the last 30 years much has been written about the way people die, and in the UK, as in most of the rest of the world, much has changed. It is no longer acceptable for pain to be unrelieved and for suffering to be ignored. Spiritual pain is a recognised major component of distress, as is emotional turmoil when the reality of death is faced. The role of palliative care as a specialty is therefore not in doubt. All the medical schools in the UK teach palliative medicine in the curriculum, and postgraduate training has developed apace. The Diploma in Palliative Medicine from the University of Wales College of Medicine alone has had over 700 course graduates from around the world since 1990.

But what is really happening in inpatient units across the UK? Much is spoken about patient-centred care and patient choice, but some of this is lip service and may be fooling the professionals and those commissioning services. The pressures to meet targets has created a service that risks responding to demand more than need, and whose staff are demoralised, working defensively to protocols and fearful of doing the right thing for a patient if it does not conform to established systems.

The hospice movement was founded out of an overwhelming desire by many to try to meet the needs of dying patients with compassion. Those who had lost relatives were acutely aware that constant unrelieved pain was exhausting and humiliating, and tortured both the patient and the relatives who looked on with love and helpless despair. Now hospices are mainstream; they are part of the parlance of the country and, by and large, are no longer feared by patients and professionals. They were set up as havens of care for those with unusual needs, where rules were broken for the sake of patients' and relatives' needs, which were paramount. Some hospices with an obvious religious foundation unwittingly alienated some in need, and thereby denied them care. But this has changed and has given way to a more secular approach to care and an awareness of differing cultural needs. Hospital support teams sprung up to disseminate the principles of palliative care, to provide advice and spread compassionate practice.

In parallel, the delivery of healthcare has changed. Recognition of the need for confidentiality has made the ward round of the consultant-and-entourage a thing of the past; delicate details are not discussed at

full volume in the midst of the ward. Attempts are made to preserve confidentiality, but discussions at the patient's bedside in the ward when the doctor does come round, or when nursing handover occurs, can often disclose embarrassing personal details, such as bowel or bladder dysfunction, which others can overhear. Wards are usually not single bays, with soundproofing in-between: curtains around a bed are a token screen rather than a real shield affording complete privacy.

So dying with dignity has a long way to go. The hospitals in which patients find themselves as they approach their last days or hours are sometimes overcrowded, with shared wards without facilities for relatives to stay overnight, to have food and drinks, and to walk around away from the bedside for a short break, without leaving the hospital. The pressure on beds is such that no sooner has someone died than the bed is needed for another patient. Continuity of care is lacking, as the hours worked and the systems in place mean that one team may have admitted the patient, but they are unlikely to see the patient again. Likewise junior doctors often do not follow the patients they admit, or they may be rotated to another firm. Thus it is only the hard-pressed consultant who can provide some sort of long-term continuity of care for the most vulnerable of all patients – those approaching death.

So is death with dignity possible? If, as Cicely Saunders put it, 'dignity is having a sense of personal worth', then our dignity is inherently dependent on the way we are treated by others. Respect for our needs is not encapsulated by any care plan on the ward; respect is shown in the staff's whole attitude and their attention to the minutiae that might affect the patient. For those whose pet is the most loved being in the world, why not let the pet visit in hospital? The infection risk should be compared to the stream of visitors and bed-to-bed transmission of infection in hospital; it warrants studying.

This picture of hospital care may seem gloomy, but things are only a little better in the community. General practitioners have opted into large rotas, so almost none now provide the family of the dying patient with their home or mobile number to be contacted when 'off duty'. District nurses may provide some sort of continuity on a day-to-day basis, but out-of-hours district nursing is not universally available. Home care teams of specialist nurses have in the

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past often run out-of-hours services, but few do now. Specialist nurses should provide a high level of expertise, but they are only available during office hours. So again it is only the on-call consultant in palliative medicine in the area who may provide any sort of continuity in care, but s/he cannot possibly cover the whole caseload of many specialist nurses and GPs. Some areas now have established out-of-hours communication pathways for information to be handed on, so that long waits and seemingly endless retelling of the same story are avoided, but such systems are not yet in place everywhere. All too often, the family of the ordinary dying patient is left to phone NHS direct and have a house call from a pleasant and well-trained young doctor they have never seen before, who knows little about them and who will not be able to visit again the next day to reassess the situation.

And in all this, scant attention, if any, is given to the children or grandchildren of those who are dying. For a child, the loss of someone they love will mould their attitudes for life. Too many prisons contain those who were abused or were unsupported in bereavement, whose anger erupted inappropriately at a society that failed to hear their distress and failed to support them when they were in greatest need. The child about to be bereaved needs to know what is happening, why things are or are not being done, what will happen to him or her, and what the risks are of

others they love dying prematurely. The child also needs to be able to ask about what has happened, about the disposal of the body and all the other myriad questions that will spring in and out of his or her mind. The child needs to be included in the normal grieving processes of the family that is left; only then can grief be resolved.

It is hardly surprising, then, that the patient wants to have some control in the system; hardly surprising that the only thing the frightened person can call for is for the ability to ask someone to end his or her life when it is all too much, when the fear of indignity and anonymity is too great a humiliation to bear. However, if the needs of the dying are properly met, such discussions will be obsolete.

All those who profess to provide good care must look at the dying and the quality of care they are given. Just as perinatal mortality is a marker of nutrition and public health as well as of perinatal services, the care of our dying is an indicator that reflects the overall quality of our care and compassion.

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Mbarara University (Uganda) and University of Bristol Chair of Medicine

Applications are invited for this new post within the Department of Medicine at Mbarara University of Science and Technology, South West Uganda. The prime role of this appointment is to provide leadership in the academic development of the Department of Medicine – both with respect to excellence in teaching and the building of a research culture. The University of Bristol is closely involved in the development of the teaching and research programmes, and it is anticipated that the incumbent will be offered a Visiting Professorship at Bristol. Applicants should have considerable experience of clinical teaching and have the administrative skills to run a small but enthusiastic department. Applicants will be expected to commit a minimum of two years to this appointment.

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