

I don't think I thought about the futility of the situation until later. It was not until the next day that I was told that it wouldn't be appropriate for him to have a procedure like that again. I realised then that there had been an element of doubt about the value of such an intervention, but it was difficult for me to comprehend because the procedure had left my son feeling so much better. I do not know how I would have felt if the procedure had not gone well.

After the procedure, we were able to spend a happy weekend with him. He then became very drowsy but he was also settled. After several months of seeing him constantly in pain, it was such a relief to see him peaceful. We all agreed that he was so much more comfort-

able. Although he was unable to communicate, he did give us indications that he was aware that we were present. I do not know what my husband's innermost thoughts were during the course of the illness as we talked about only factual issues, but in the end I feel sure that he had come to terms with the imminent death.

Those last two weeks allowed us the opportunity to accept the situation and prepare ourselves as much as possible for his death. If he had died on that night, it would have been much more traumatic for us and his death would not have been so easy to come to terms with.

Competing interests: None declared.

A healthy view of dying

Julia Neuberger

Death is the one great certainty in life, yet Western society, and Western medicine in particular, seem unable to come to terms with this. Rabbi Julia Neuberger discusses how attitudes need to change

In his president's lecture for the King's Fund in June this year Richard Chartres, the bishop of London, drew attention to our society's inability to see life and health holistically (lecture available on the King's Fund website, www.kingsfund.org). He took us back to ancient Pergamon and its Temple of the Divine Healer, Aesculapius, and gave us an insight into that hospital: "In the Greek medical tradition, the fundamental recipe for healthy living was 'know thyself and be moderate in all things,' and this outlook was expressed in the regime followed in the hospital ... the temple must have been a tranquil and beautiful environment in which to recover, in an atmosphere that was a cross between Champneys and an Oxbridge college ... It was in the ruins of this place that I can remember contemplating the theme of healthy living and healthy dying."

The whole person was considered: mind, body, and spirit were as one. In the discussion that followed his lecture, a groundswell of feeling grew that, as a society, we are somehow not paying attention to the whole person in the care of dying patients and bereaved people, because of our strong Western medical model. Part by part, specialty by specialty, no integrated view can develop of the person and the culture from which he or she comes.

At the King's Fund, we had already been aware of a growing concern about this, from applications for grants from a variety of organisations. Some wanted to do work on "natural burials" and different kinds of funerals. Others wanted specialist palliative care services for people from various ethnic and religious minorities. Some wanted a well trained group of "sitters" for dying people, so that relatives could have some respite. Others wanted to explore palliative care for conditions other than cancer, motor neurone disease, and AIDS. Time and again, we were being asked for help. As part of our response, we published a short paper on psychosocial support for dying people last year, which received an enormous amount of attention.¹

Shortcomings in palliative care services

The degree of concern we have noted and the large number of grant applications we have received, plus the start of a campaign after Richard Chartres' lecture, suggest there is widespread unease with the Western medical approach to dying. Despite the huge advances made by the hospice movement and general advances in palliative care, in which Britain has undoubtedly taken a lead, the care available for terminally ill people is far from adequate, and far from satisfactory for a range of groups in our society—elderly people who do not have cancer, people with end stage renal failure, those with heart disease, those with Alzheimer's disease, black people, Muslims, Jews, Buddhists, Chinese, and so on. Meanwhile hospices worry increasingly about funding for the excellent work that they already do. Despite several national attempts to encourage primary care and hospital services to provide better care at the end of life,

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BMJ 2003;327:207-8



Seppuku—honourable Samurai death

services are patchy, depending too much on individual enthusiasts. There is no deeply rooted ethical base in medical practice about giving care when cure is no longer possible.²⁻⁴

Many conditions once thought terminal are now chronic—people live for decades with cancer, heart disease, and AIDS—and their treatment raises no questions because they are seen as fitting into a curative model rather than a care model. Once they are seen as terminal cases, however, things change. Services can be quite brilliant, and totally culturally appropriate—as I found with both my parents, when they were dying. Equally, and particularly for people with Alzheimer's disease living in nursing homes, palliative care can be virtually non-existent, and spiritual pain goes completely unrecognised.⁵

Exacerbating this inequality in service are the different views of different faiths and cultures on how hard one should strive to keep alive. Jews and Muslims, for instance, tend to argue for doing everything to keep people alive, life itself being seen as the most precious divine gift. Many Christian groups are less concerned with length of life than with last rites and final absolution. Chinese customs vary, and different minorities, apparently of the same group religion as the majority population, nevertheless have different views and customs that need to be respected. The experience is patchy, to say the least.⁶

This raises huge questions about our healthcare system. Do the views of the people who are dying take precedence over the views of the service providers? An autonomy model would suggest that they do, but, if there is no advance directive, can one be sure? And, if the study of different attitudes to death is not mandatory for all healthcare professionals, how can we be sure that some attitudes will be recognised, let alone respected? Add to that a potent fear of death among young healthcare providers, many of whom will not have seen someone die before they became a doctor or nurse and for whom death is not the norm, and we have a recipe for problems.

Time for a change in attitude

To quote Richard Chartres again: "Our failure to face our own fear of death is an important reason why we find it so difficult to help the dying and the bereaved . . . We try to gloss over the fact of death by using euphemisms and are protecting ourselves very often when we exclude children from funeral services or even the sight of dead bodies. Our hectic style of life



Antoine de Henin, Bishop of Ypres on his deathbed by Jean Bellegambe the younger (1560-1626)

Summary points

Insufficient attention is given to the whole person in the care provided for many dying patients

Psychosocial, or spiritual, support is essential

The curative model of care does not fit for chronic conditions that may eventually lead to death

Hospices have the right approach, but largely only for patients with cancer, AIDS, or motor neurone disease

We need to adopt a new approach to dying, striving for a good, and healthy, death

owes much to the suppressed fear of death and the unexamined notion that the faster we live, the more we shall get out of this short life . . . Hospices are places where we can experience and experiment with a different way of healthy living and healthy dying . . . medical intervention is subservient to exploring the potential in dying for health—health defined as the sustaining and development of a personal identity nourished by the resources and challenges of the environment and, most importantly, our multidimensional relationships.”

Yet we do not, and cannot, all die in hospices. Nor do all hospices succeed in providing this kind of healthy death. So some principles need to be established, as part of the value system of healthcare institutions. Among them needs to be a respect for varying cultural and religious attitudes, including a respect for secularism, which may require a different approach again. The desire of staff in hospices and palliative care teams to learn more about other faiths, and the need for textbooks about caring for dying people of many religions and ethnic groups, suggests a concern bubbling up from local communities and faith groups that is relatively new. Spirituality, most associated with death and dying, though often wrongly, has come back into fashion (some would say it never left).

Ilora Finlay argues that “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.”⁷ She is right. But that care needs to be multidimensional and generous, recognising the health that lies in dying well, and understanding that people differ in how they think about death and dying and that respect for those differences goes a long way to making people feel whole.

Competing interests: None declared.

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