

On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A commentary

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One has to share some of Dr Craig's anxieties. We must strive for an accurate diagnosis for those who have not long to live or we cannot provide all possible help for them. But we know that hospice physicians create more routine investigations and a balance between over-investigation and neglect in the care of the dying is not easily achieved. I remember Dame Albertine Winner saying that a cup of tea is of much more use than a blood count in such cases.

Accurate diagnosis in hospice patients is usually straightforward. Admission should be preceded by careful clinical assessment and a full medical report. A hospice is no place for solving diagnostic problems, but so long as over ninety-five per cent of admissions are to do with disseminated and inoperable malignant disease, this presents few difficulties.

Even so, during my 15 years as medical director of a busy hospice occasionally humiliating lessons had to be learned; but these were more often cases of unexpected survival – the breast cancer patient whose skeletal abnormalities turned out to be due to Paget's Disease, for example – rather than errors associated with mismanagement and a premature death. I remember only one case of leukaemia, many years ago, that seemed to have had inadequate therapy. Our referral to a different specialist unit led to further treatment and the pleasure of seeing the patient's case demonstrated at a grand round several years later as 'a cure referred by the hospice'. That must be very rare.

Indeed hospice colleagues tell me that they still see more of enthusiastic over-treatment than of neglect. There are implications here for hospital training that sooner or later will need to be addressed and for hospice training too, as palliative care moves towards mainstream medicine. The fact that old age is the time for multiple pathologies as well as for dying means that the training of the hospice physician must have a generalist approach.

Key words

Nutrition; hydration; sedation; terminally ill; euthanasia; ethics.

If we take even half seriously the aspirations of the recent Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee paper, *Principles and Provision of Palliative Care* (1), the expertise in the symptom control of advanced cancer will not be enough. Some geriatric and rehabilitation skills will also be required, the management of advanced AIDS and Motor Neurone Disease, of secondary diagnoses such as renal failure or uncontrolled diabetes, all must be part of our stock in trade.

Palliative care is essentially a multi-disciplinary effort, and although the diffusion of hospice responsibilities will occur only slowly and with difficulty, analogous problems await our nursing colleagues for which they are not yet prepared.

If their patient has only a short time to live the problem of excessive dependence is irrelevant: but a disabled sufferer from, say, multiple sclerosis must be helped to cope with years of survival and patients encouraged to dress themselves even if it is exhausting and takes a long time. That would be cruel and unacceptable for the breathless lung cancer patient. It is difficult to combine these two different cultural attitudes on the same ward.

There are two tendencies to be observed in the present background to palliative care. First, the crudities of the 'contract culture' may threaten the survival of the costly hospice units. Second, if staffing levels are lowered and our responsibilities widened to take in the whole spectrum of incurable illness, the new specialty of palliative medicine will have its expertise dangerously diluted.

It may well be therefore that Dr Craig's points are not to be taken too seriously – yet: but they point the way to problems that will be with us for a long time to come and will not easily be resolved.

Dying is a social act. Usually even in the presence of grief, there should be little in the way of anger or resentment directed at the carers by those about to be bereaved so long as they are informed and involved as fully as possible in the management of the case. The health professionals need to be aware that every casual phrase, any inevitable difficulties, the minutest details, are likely to be recalled by the family to the end of their days – influencing attitudes and giving

comfort or distress for many years. This makes information and effective communication essential. Generally the process is both easy and rewarding.

But there are always exceptions and we need to be tactfully resistant to sacrificing the interests of our patient to the emotional distress of the relatives. An old man, transferred to a hospice after a hospital transfusion, was going gently downhill, but this caused sufficient distress to the son for him to demand: 'Can't you do more for my father? He's only ninety two'.

Such poor adjustment to dying can be found in all walks of life, although those who have a tough life in the city or on the farm quite often cope better than the doctor or the priest when they have to face the death of someone close. But everyone can feel excluded and ignored if all the measures that might prolong the process of dying are not deployed.

Sometimes patients come to a hospice seeking sanctuary from modern medicine, such as a respite from their chemotherapy. Others may be desperate to continue their chemotherapy for all that in their case it may be little more than a toxic or costly placebo. All doctors will therefore have to walk the tight-rope between over-treatment and neglect. The comfort of the patient must come first. Two common threats to the comfort of the dying are chest infections and dehydration, so perhaps they merit special mention.

Pneumonia was called, significantly enough in the last century, the old man's friend, for so often it put an end to suffering. Today in modern palliative care the chest infection in the incurably ill may be an intercurrent infection causing fever, cough, breathlessness so as to merit treatment under the heading of symptom-control. Alternatively it can be the beginning of the process of dying and not therefore to be officiously prolonged. Usually the difference is readily obvious, especially if colleagues and carers are involved in the assessment. The previously expressed opinions and wishes of the patient can be both helpful and relevant.

But rarely there will be doubt and here a delay of a day in the initiation of antibiotic treatment can

either make the desirability of energetic treatment clear or it can see the patient moving speedily towards death. Where there is still doubt, the patient should have the benefit of it.

Near the beginning of my career as a hospice physician, when patients' symptoms were well controlled and they were resting peacefully, as they moved nearer to death I would tend to reduce the dosage. This too often was associated with a restlessness as patients surfaced close to a reality with which they could no longer cope. The regime necessary to control distress was therefore maintained to the end. A comatose patient was much the lesser evil, yet despite encouraging nurses and carers to keep giving small frequent sips of water, dehydration could occur. Indeed, it sadly occurs far too frequently on medical and surgical wards far removed from the territory of palliative care.

In a hospice one is properly anxious to avoid either intravenous or subcutaneous infusions unless the needs are clear, for these can medicalise the process of dying, inhibit the limited mobility of the patient, and impede the involvement of the relatives. But in a sedated patient such infusions may be necessary to control discomfort or prevent infection. This is not often necessary and can be made even rarer by the overnight insertion of a slow drip of rectal tapwater when it has proved difficult to maintain adequate oral intake of fluids. This homely remedy still has a place, especially as dehydration can distress the more aware relatives and sour their relationships with the carer to what may seem a disproportionate degree.

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Reference

- (1) *The principles and provision of palliative care.* Joint report of the Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee. London: HMSO, 1992.