innocent, defend the sick and to stand for truth? The RCP must never be neutral because to do so would be to undermine the very ethos of the College's Royal Charter.

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Editor – Thank you for finally bringing the Assisted Dying Bill for the Terminally Ill to the attention of members of the College (*Clin Med* November/December 2004, pp 534–40). It is disappointing that open discussion did not occur prior to the RCP's recent public statement to the House of Lords' Select Committee.

I was shocked and saddened to learn of my College's new position on euthanasia by reading press reports in October 2004.[1] To declare, on behalf of thousands of physicians, that we are neutral on this extremely important issue is a disgrace. If the RCP Committee on Ethical Issues in Medicine cannot come to a uniform opinion, it is also unlikely that the College membership would agree. To adopt a new position of neutrality surely requires a survey of all members to result in a 50:50 split?

It is not acceptable for the RCP to sidestep the importance of the doctor–patient relationship by declaring the Bill 'a matter for society as a whole'. It is not. If the Bill becomes law, doctors would be involved with the practical outworking of assisted dying. Society would not. The law must be a means of protecting vulnerable members of society, not destroying them.

As doctors, we are advocates for our patients. We must not allow this relationship of trust to be undermined by the suspicion that we may be angels of death. We must also stand up for the rights of the profession to maintain its integrity and hold to the Hippocratic tradition.

The GMC states that our role as doctors is 'to show respect for human life'.[2] We should care for and protect our patients as best we can. We can enable them to live valued lives within the constraints of illness. In terminal disease, this is achieved through high quality palliative care and interventions to address physical, psychological, social and spiritual concerns.

Our role as doctors is not to judge our patients lives as worthless and then to kill them at their request. I believe assisted suicide should remain illegal. Instead, resources should be directed to making good palliative care readily available to everyone who needs it.

References

1 http://news.bbc.co.uk/go/pr/fr//1/hi/health/3745714.stm
2 General Medical Council. *The duties of a doctor registered with the General Medical* Council. www.gmc-uk.org/standards/doad.htm

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Editor - I am writing to express my opposition to the views of Professor Tallis in his article supporting the Assisted Dying for the Terminally Ill Bill (*Clin Med* November/December 2004, pp 534–40). He asserts that there is a 'clinical need' for assisted dying. Killing (except for usual exceptions, eg just war) is morally wrong. Surveys into the wishes of the general public or doctors cannot make right something that is morally wrong; no such clinical need can therefore exist. I agree that autonomy is an important tenet of medical ethics but it does not stand supreme or in isolation. To be members of a society we have to limit our autonomy not only for our own benefit but for that of others; not legalising patient-assisted suicide (PAS)/euthanasia is another example of this. Legalisation of PAS/euthanasia would, I believe, be to the detriment of our society as a whole, damaging further the doctor–patient relationship and leading us as a society to continue to avoid, rather than confront, issues of dependence and suffering around death.

I believe that my role as a doctor in palliative care is not to judge my patients' lives as worthless and then to kill them, even at their request, but rather to cherish them and enable them to live their lives to the full as much as is possible. Even in the face of irremediable suffering, our role is to share their journey with them and not to terminate it. Practice in the Netherlands demonstrates that non-voluntary euthanasia and non-registered euthanasia both occur. No amount of regulation could prevent these or other abuses from occurring in the UK. In addition, legalisation of PAS/euthanasia could lead to fragmentation of palliative care services. Hospices are small places requiring unity of vision and purpose within the multidisciplinary team so that they can provide their unique atmosphere for care of the dying. Legalisation of PAS/euthanasia may lead to fracturing of these relationships as each hospice will have to decide whether or not to undertake assessment or provision of PAS/euthanasia. If the Bill is passed, it will also require allocation of already scarce resources and staffing in palliative care to implement a policy that will only be used by a minority of patients.

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The management of rare diseases

Editor – A meeting to discuss the management of rare diseases was held at the College on 5 October organised by the RCP and the National Institute for Clinical Excellence and sponsored by the drug firm, Genezyme. As an interested observer with 45 years experience in this field I must confess I was disappointed, not in what was said but in what was not said. I was left with the impression that the allocation of resources was more important than the care of the individual patient and that advances in therapy should be left to industry. The role of the individual researcher was not mentioned.

The development of drugs for orphan diseases can never be a commercially attractive proposition for a pharmaceutical company. Dr Shami suggested that the cost of development could be as much as £500 million. In a recent article in the *Lancet,* Trevor M Jones put the figure as high as $800 million.[1] Profits on this sort of expenditure can hardly be recouped on an orphan drug. Individual initiative is still required in this field.

Let me now turn to those aspects of the problem which were omitted from the meeting:

1 *The structure of rare disease clinics and their funding, and the relationship of the individual doctor to his patients.* This is a lifelong commitment for both doctor and patient; it is not satisfactory for the patient to be seen

by a different registrar on each attendance.

2 *The effect of the internal market.* A low budget district hospital will always be reluctant to refer a patient to a high cost specialist unit. I speak from experience. This problem must be overcome.

3 *The question of free prescriptions for patients with rare diseases.* The present list of those diseases which qualify is, to say the least, bizarre. I have raised this problem with every administration, either directly or through my MP, since the days of Harold Wilson, without success. If Italy can supply free prescriptions for such patients, surely the UK can too.

4 The malign influence of ethics committees on clinical research. Apparently, it now takes a 57-page questionnaire to be filled in, after reading the instruction booklet, to apply for permission to proceed. Any variation in the protocol, which may well be necessary once the work has started, has to be passed by 'a research manager'. I wonder what experience of clinical research these managers have; I only ask. I doubt if penicillamine (1955) or trientine (1969) would ever have been approved with the data available, at the time, on these compounds. I somehow avoided the ethics committee in 1984 when introducing tetrathiomolybdate. I doubt if having taken the compound myself for a week would have cut much ice with an ethics committee. In 1994 I wanted to try a new therapeutic approach for a patient with acaeruloplasminaemia but had to abandon the attempt. Hardly to the benefit of the patient.

I think these aspects of the management of rare diseases should have been discussed. They are extremely germane to various problems for both the doctor and patient and must be confronted.

Reference

1 Jones TM. Cheap at half the price? Book review. *Lancet* 2004;**364**:321.

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Influence of guidelines on CPR decisions

Editor – As a lawyer acting for the NHS, I was not surprised by the findings of Diggory *et al* in their 'Audit of clerking proforma' for cardiopulmonary resuscitation (CPR) decisions (*Clin Med* Sept/Oct 2004 pp 424–6). Their finding that the requirement to discuss a proposed Do Not Attempt Resuscitation (DNAR) order with the patient concerned was associated with a fall in DNAR orders accords with my own experience. Of the drop in the number of DNAR orders noted in Audit 5, I would like to know how many were due to patient discussions not taking place and how many to a demand by patients for CPR even where not advised? The article implies the former explanation. If so, how can the public distinguish between those clinicians who have correctly discerned an unacceptable risk to the health of their patient in having such a discussion, from those doctors who are simply too uncomfortable to broach such a difficult subject or, worse, believe they are beyond having to explain themselves?

Certainly, my interpretation of the BMA/Resuscitation Council/RCN 2001 guidelines differs significantly from that of Diggory *et al* on the question of prior consultation. One of the stated aims of the guidelines[1] is to promote transparent decision-making. The guidelines themselves go on to say that the emphasis on the individual's interests means that it is important that resuscitation is discussed sensitively with competent patients. This can help people to understand why treatment is given and why, in some circumstances, it may be unable to provide any benefit. There is a further paragraph in the guidelines directly on this point, which states that because the patient's own view on the level of burden or risk they consider acceptable carries considerable weight in deciding whether treatment is given, it follows that decisions about whether the likely benefits of successful CPR outweigh the burdens should be discussed with competent adults. This goes to the very heart of the decision-making process itself, casting doubt on whether the 'right' decision can ever be made for a competent patient without their involvement. The only exception to prior consultation mentioned in the guidelines is when a patient does not wish to have that discussion, ie the clinician is rebuffed on raising the issue. Surely a clinician must have an exceptionally good reason (relevant to *that* patient and not just a *category* of patient) for not even raising the issue in the first place?

The GMC's 2002 guidelines on *Withholding and withdrawal of life-prolonging treatments*,[2] to which the authors refer, are currently being reviewed by the Court of Appeal. Until that Court pronounces, I would suggest wider dissemination of the true success rates of CPR and more emphasis and research on the quality and not quantity of clinical decision-making in this difficult area.

References

1 The British Medical Association, the Resuscitation Council and the Royal College of Nursing. *Decisions relating to cardiopulmonary resuscitation.* A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, January 2002. (www.bma.org.uk/ap.nsf/Content/cardioresus)

2 General Medical Council. *Witholding and withdrawal of life prolonging treatments.* London: GMC, 2002.

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Editor – Diggory and colleagues (*Clin Med* Sept/Oct 2004 pp 424–6) have audited documentation of cardiopulmonary resuscitation (CPR) decisions, on the assumption that good documentation reflects high quality care. This is often true, but not invariably so. They have set their own standard for the audit, rather than choosing a standard derived from national guidelines. Their standard seems to be based on a belief that all patients must have a CPR decision documented at the time of hospital admission, even if this means ignoring some parts of national guidelines from professional bodies.[1] They have demonstrated that the modification of their policy to reflect these guidelines led to a fall in documentation, so conclude that the guidelines must be changed (or reinterpreted). An alternative conclusion could be that their standard should be changed, as it is not compatible with best practice.