From Norway

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As in many other places in Europe, Norway is lacking organization of and competence and resources in palliative care. We have only a few hospices, hospital palliative care units and few well-organized palliative care teams. Only a minority of patients with terminal disease obtains good palliative care. The debate on *euthanasia* does not make progress and it has little contact with the clinical setting. Until recently, very few health workers understood the concept of *palliative sedation* and its difference from euthanasia.

In the EAPC Task Force paper I feel it lacks a paragraph on 'How to protect palliative care teams, particularly the doctors'. This is crucial – doctors need help. They are working in an increasingly narrow professional space, where they are threatened by a more and more aggressive and demanding public, politicians, health authorities, journalists looking for sensational stories and doctors with differences of opinion, sometimes fundamentalists under the cover of being 'whistle blowers'. Common questions asked are: Was the dose of opioid given too high or too low? Did it hasten death? or Did it leave the patient suffering? or Was the patient really dying? Questions that can only be answered by the bedside physician together with his or her team. Palliative care teams are vulnerable in a situation where the field of palliative care still is in its infancy. Palliative care teams need greater *autonomy*. *Guidelines* and *definitions* are needed in the treatment of difficult pains to balance properly the need to give palliative sedation, perhaps with assistance from *clinical ethics committees*.

I have had a protracted personal experience of being under investigation as a doctor. In 1998 my closest medical colleague accused me of the euthanasia of 11 of my patients. The cases were investigated by the Norwegian National Board of Health and Welfare and the police and it was three and a half years before a final conclusion 'that the treatment given was good palliative care'. The case – 'Bærum-saken' – was continuously covered by the press, frequently with dramatic headings like 'This was Euthanasia'. In addition to bringing the debate on euthanasia back to life, 'Bærum-saken' resulted in Norwegian guidelines for palliative sedation. In Sweden there was a similar case in 1997 (the Kåltorp case) and in the UK the case of Dr Moor in 1999. Unfortunately, the 'protection of palliative care teams' will not be achieved by means of paragraph 4.10 of the Task Force paper.

In paragraph 4.6 therapy with so-called *mild sedation* should be more clearly distinguished from palliative sedation. I disagree with the statement 'it does not adversely affect the patient's conscious level or ability to communicate'. Sometimes sedation that is not palliative or terminal sedation may be deep enough to affect conscious level and ability to communicate, even if the patient is not in continuous sleep. Different degrees of sedation administered orally or parenterally are very common in palliative care. The word adversely sounds too negative in this context.

Statistics show that the great majority of Norwegian doctors are against euthanasia. However, 15% are in favour of euthanasia if the patient suffers a painful, incurable fatal disease. In 1993, 6% admitted that they had at least once hastened the death of their patient. An important goal for palliative care must be openness, honesty and competence. Unless protection and help is provided to doctors working with pain and intolerable suffering, doctors will leave this field of work.

Palliative medicine is not a *medical speciality* in Norway. To improve the competence and credibility of this area of medicine I hope the Task Force will suggest to all European countries that palliative medicine should become a medical speciality. This will bring greater insight into care of patients with advanced disease and will also improve the quality of the euthanasia debate.

The Task Force paper is helpful as it clarifies vague and misleading definitions. However, even if paragraphs 4.8 and 4.10 are important guidelines, they are too general and indicate little about how to really approach and solve the problems. For the time being I think that at least Norwegian political and health authorities need professional, international help and are ready to listen to advice from the EAPC.

To contribute more to a fruitful debate, I think the Task Force paper should be more provocative and take an unequivocal stance against the legalisation of euthanasia, i.e., it should be less neutral without being biased.

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