

Help the Hospices

SUBMISSION ON THE ASSISTED DYING FOR THE TERMINALLY ILL BILL

Introduction

1. Help the Hospices supports hospices in the UK through grant-aid; education; training; information and advice. It is the national voice for the 188 adults' and children's hospices run by local charities (known as "independent" hospices). These provide 72% of UK specialist inpatient palliative care, as well as many community and day care services.

Methodology

2. In his memorandum of 22nd October 2003 Lord Joffé requested that a Select Committee give consideration to seven key issues. Help the Hospices focussed its consultation around those aspects that staff in independent hospices are, through experience, uniquely well qualified to address:

- i. Whether palliative care can in all cases provide the care that will enable terminally ill patients to die with dignity, and free of unnecessary suffering.
- ii. Whether the safeguards in the Bill, intended to protect vulnerable members of society, are adequate.
- iii. The effect on patients, health staff and the families of patients were the Bill to become law.
- iv. The different views within the professions involved in providing palliative care.

3. Using convenience and purposive sampling, Help the Hospices consulted 69 specialist palliative care staff via interviews and regional focus groups (Scotland, Wales, South East of England and North of England). The interviews were conducted at the outset of the consultation to inform research design and supply qualitative data. Many staff attending focus groups elicited colleagues' views and presented these on their behalf.

4. The focus group sample included 10 specialist palliative care physicians, 34 specialist nursing staff including community nurse specialists, 2 physiotherapists, 1 occupational therapist, 5 social workers, 6 chaplains, 1 volunteer, 1 counsellor and 2 management professionals drawn from 29 independent hospices. About half of staff in the sample currently occupy leadership roles: of this fraction 3 were chief executives or equivalent, 11 were directors of services (clinical, medical or nursing) and the remainder were multi-disciplinary team leaders or team leaders in their specialty.

5. Focus groups used a modified nominal group technique. Participants identified all likely opinions of those working in and using hospices. Respondents subsequently recorded their own views in writing. It was thus possible to survey the totality of views and also to permit minority opinions to be expressed in confidence without fear of conflict.

6. Within the timeframe set by the Committee, it was not possible to elicit hospice users' views.

7. It is emphasised that focus groups were not scientifically selected but, of necessity, consisted of hospice staff able to attend. Help the Hospices is confident it has captured

the range of views held by hospice staff and some indication of their prevalence. However, the frequency with which views are held across independent hospices cannot reliably be extrapolated from these data. In order to discourage undue weight being placed upon frequency indicators, data are reported below using approximate fractions rather than percentages.

Hospice values and euthanasia

8. The independent hospice movement pioneered specialist palliative care and continues to lead its development. Respondents emphasised hospice care's holistic principles: respecting the physical, emotional, and spiritual needs of whole persons. They also emphasised respect for autonomy. However, consideration of patient needs alongside respect for autonomy generated differing assessments of the impact of euthanasia on the exercise of autonomy (see below).

Approaches to moral reasoning

9. About one half of respondents cited Christian belief as relevant to their view on euthanasia.

10. Many respondents urged attention to the moral distinction between factual and normative propositions. Regarding euthanasia as morally wrong, they argued that the extent to which palliative care could relieve suffering was not relevant to the moral status of euthanasia.

11. Those indicating support for the introduction of euthanasia cited respect for autonomy as a foundational rationale and/or indicated they believed euthanasia to be right by reason of unbearable suffering.

12. Respondents differentiated between moral and ethical beliefs. About one half indicated they believed euthanasia to be morally wrong, with the remainder indicating it was either not a moral issue or morally right. However, two thirds of respondents indicated they believed it unethical for health care professionals to provide assistance to die. One third of respondents indicated they would treat assisting death as an ethical obligation.

Respecting autonomy

13. For some respondents, respecting autonomy in the context of holistic care entailed accepting euthanasia. They reasoned that where patients concluded that euthanasia was in their best interests, they were entitled to seek others' assistance to die.

14. For other respondents, respecting autonomy in caring for the terminally ill entailed rejecting euthanasia. They viewed autonomy as context-dependent, arguing that some decisions are meaningful only if social structures facilitate their implementation. They reasoned that introducing euthanasia would change the landscape of palliative care in ways that denied patients resources and choices. For instance they anticipate that the availability of euthanasia would reinforce in elderly patients the belief that they are less deserving of care than the young; that patients may choose euthanasia in order to not to impose emotional or financial burdens on carers; and generally, as euthanasia became more socially acceptable, lingering death would become less so. Respecting the autonomy of those seeking euthanasia may thus ultimately inhibit the exercise of autonomy in others.

Moral rights and duties

15. Questionnaire responses implied three views on the relationship between patients' desire to die and others' duty to assist. About one third regarded the creation of a patient's right to euthanasia as entailing a corollary duty on health care professionals to assist. About one third treated euthanasia as a freedom independent of corollary duty, so although a patient might seek euthanasia it would remain unethical for medical professionals to provide it. About one third of respondents viewed euthanasia as an impermissible moral choice that society should neither permit nor assist.

16. Respondents noted that the Bill does not create a duty in organisations to provide euthanasia, and that some hospices might decline to do so.

Multi-disciplinary care

17. The high standard of hospice care is founded on integrated multi-disciplinary working. Irrespective of moral belief, almost all respondents expressed considerable concern about the impact on multi-disciplinary working of introducing euthanasia. They feared patient care could be compromised, and the hospice movement weakened, through conflict arising from differing ethical beliefs and the exercise by some professionals of their right of conscientious objection.

18. Some respondents argued that the Bill's focus on physician decisions was inappropriate. Staff in multi-disciplinary teams may possess more knowledge and expertise than attending or consulting physicians. (Where palliative care is provided in the home, for example, attending physicians may be General Practitioners with limited knowledge of palliative care, whilst 'attending nurses' would be palliative care specialists.) Moreover, patients and families often develop more intimate relationships with nursing and other staff.

A safe haven?

19. Many respondents suggested the introduction of euthanasia would deny patients the sense of sanctuary hospice care currently offers and compromise the relationship of trust between physicians and patients. However, a minority argued that better communication between professionals and patients would result from implementing the Bill.

20. One fifth of respondents indicated they would find euthanasia more acceptable if the physician assisting death were not the attending physician. One fifth of respondents indicated euthanasia would be more acceptable if assisted deaths took place outside hospices, for example in patients' homes.

21. Anxieties remain that should hospices carry out euthanasia this will have a significant negative effect on fundraising. At present hospices provide 72% of in patient palliative care, levying no charge on patients and receiving less than 50% of their income from public funds.

Can palliative care enable terminally ill patients to die with dignity and free of unnecessary suffering?

22. Respondents selected from five answers to the question: 'In your professional experience can palliative care in all cases provide the care which will enable terminally ill patients to die with dignity and free of unnecessary suffering?' The alternative answers expressed the range of views derived from interviews with hospice staff.

- i. No respondent selected the unqualified 'Yes'.
- ii. Just over one third of respondents selected EITHER 'Yes in principle, but good palliative care is not universally available' OR 'Yes, but only using deep sedation'.
- iii. The remainder, just under two thirds of respondents, selected EITHER 'No, because we cannot fully control pain &/or the terminal stages can be undignified' OR 'No, because some patients wish to control the time and manner of death and this is not a medical issue'.
- iv. Because the 'no' answer rationales are logically inconsistent with a 'yes' response to the question, checking both 'yes' and 'no' alternatives was recorded as a 'no' response.

23. Of the two thirds of respondents who indicated that palliative care could NOT supply relief a majority (about two thirds) ALSO checked a box indicating they believed providing assistance to die was inconsistent with their ethical obligations. For the one third of respondents who believed palliative care COULD provide relief it was not axiomatic that euthanasia was therefore wrong. Of these respondents, about one half identified assisted dying as either morally neutral or morally right, although a clear majority also believed it would be unethical to themselves supply assistance.

24. About three quarters of respondents had experienced a patient request to die. Data do not indicate whether these were persistent requests or statements of distress.

Implementing the Bill

25. Respondents gave detailed consideration to the practical implications of the Bill's implementation.

The hospice context and issues of competence

26. Most hospice in-patients are in terminal stages of cancer. Average length of stay is 13 days, with implications for the Bill's operation in hospices.

27. Many of the decisional stages envisaged in the Bill raise problems regarding competence in terminally ill patients:

- i. Anxiety, depression, and cognitive deterioration can make determining competence in terminally ill patients particularly difficult.
- ii. Competence often fluctuates during terminal stages, so patients may be competent for one stage in the process the Bill provides, but not another.
- iii. Symptom control (e.g. use of psychotropics) often adversely affects competence.
- iv. Patients may be competent but unable to communicate their wishes.

Requesting euthanasia

28. Whilst the Bill anticipates it will be patients who initiate requests to die, some respondents reasoned it would become an ethical obligation to inform patients of their right to euthanasia. The average length of hospice stay, together with the required waiting period, would mean discussion of euthanasia would have to be initiated promptly. Respondents expressed concern that distressed patients and families would be compelled to consider euthanasia early in admission; but feared that if this was not done, some would object they had been denied information.

Respondents pointed out that many patients enter hospice fearful that death may be hastened by medical intervention. If hospices were required to initiate discussion of euthanasia these patients would cease to perceive them as safe havens.

29. Respondents envisaged difficulty in determining what constituted a request to die such that the 14 day waiting period clearly 'started to run'. Patients raise euthanasia for varied reasons, including acknowledging impending death, encountering a setting where they may voice fears, or seeking reassurance. There was concern that such statements would have to be treated by staff as the first stage in a legal process rather than a trigger for psychological support; and that patients might feel inhibited from expressing their feelings in case this was interpreted as a request for euthanasia.

30. Respondents pointed to patients' complex responses to the experience of terminal illness, Patients frequently experience feelings of hopelessness, when desire for death may be expressed; but these feelings are accompanied or superseded by unanticipated enjoyment of remaining periods of life.

Determinations of attending and consulting physicians

31. Difficulties in assessing competence have been set out above. It was argued that further clarification was required in relation to the rights of competent, terminally ill teenagers.

32. Informed decision making presents several problems:

- i. Respondents urged attention to the lived experience of pain. They argued that experience of effective pain control is radically different from the promise of pain control, and cessation of pain almost unimaginable if symptom control has been poor. On this view, patients seeking assistance to die without having experienced good symptom control could not be deemed fully informed.
- ii. Respondents were concerned that the most vulnerable patients – very elderly, very ill or from deprived backgrounds – may have limited capability to process complex information about the course of their illness and treatment options.
- iii. Terminal illnesses have differing trajectories, with some less predictable than others. As the course of a terminal illness decreases in predictability, increasingly complex information about symptoms, their management, and possible side effects, is required. Respondents argued it thus becomes correspondingly problematic to assess a patient as fully informed about treatment options.
- iv. Respondents acknowledged that medical staff intentionally or inadvertently exert influence on decision-making through the way information is presented. It was emphasised that to make informed choices, patients will require clear, neutral communication from carers, and ready access to intelligible information.
- v. The influence of family members and the availability of social support were regarded by many respondents as significant in determining how truly voluntary a request could be.

33. Respondents indicated potential confusion around physicians' roles in determining unbearable suffering. The Bill appears to define it as a subjective assessment by the

patient. However, Ss.2(2)(d) and 2(3)(d) require that two physicians concur in finding that the patient is suffering unbearably. Some respondents concluded the Bill accorded precedence to the patient's view alone. Others concluded that if the physician was required to consider the patient's point of view, s/he may reasonably disagree with it.

34. Some respondents argued that where a physician is to conclude that a patient is suffering unbearably 'as a result of that terminal illness' all palliative care options must first be exhausted. Further to this, a minority proposed that where patients are fully sedated, suffering is not unbearable. On this view, euthanasia as a 'treatment of last resort' is never necessary.

35. To the extent that unbearable suffering is determined by clinical staff, respondents argued that multi-disciplinary teams are better placed to assess this than physicians alone.

36. Many respondents were concerned about the loose definition of terminal illness, contending that physician's prognoses are frequently over-optimistic.¹

37. Respondents expressed concern that the consulting physician may not necessarily have expertise in palliative care. As with an attending physician who is not a palliative care specialist, s/he may not be qualified to conclude the patient was well-informed about palliative care options as the Bill requires (Ss.2(2)(e)(iv), 2(2)(f), 2(3)(e) and 2(3)(f)) or to give the patient information.

38. To the extent that referral to the consulting physician was intended as a safeguard there was anxiety around the scope for collusion, with patients referred to colleagues known either to favour or disfavour euthanasia. Conversely, it was unclear what would happen where the consulting and attending physicians disagreed, and whether this might lead to 'opinion shopping'.

39. Many respondents, irrespective of their own moral views, commented that if a patient were suffering unbearably, and euthanasia were a treatment option, the fourteen-day waiting period was excessive.

Psychiatric referral

40. Respondents argued that only a psychiatrist with specialist knowledge of mental states in terminal illness would be qualified to determine the issue of competence.

Continuing care

41. Respondents expressed concern that once a patient was on the 'assisted dying track', attention would be deflected from seeking and providing the best palliative care. Were it necessary to maintain patient competence throughout the process, symptom control could be compromised through excluding treatments adversely affecting competence.

Legal and lay witnesses

42. Respondents questioned whether - in anything but straightforward cases - a solicitor or lay witness could affirm that patients were of 'sound mind'. Terminally ill patients' fluctuating competence, and the impact of medication, again raised concern.

43. Doubt arose whether legal or lay witnesses could determine that decisions were truly voluntary, particularly where patients saw themselves as burdens on carers and family.

44. Given the restricted classes, finding suitable lay witnesses was thought to present difficulty. It was argued that lay witnesses were expected to discharge an onerous task particularly where there may be differences among family members.

45. On current wording, it is unclear whether hospice volunteers could act as lay witnesses.

46. It is unclear what consequences would flow should witnesses revise their view on whether patients were of sound mind, or their decisions voluntary, subsequent to signing the declaration.

Procuring death

47. Respondents expressed concern that the Bill does not stipulate that patients be competent when advised of the right to revoke. As S.2 and S.3 operate as qualifying conditions for S.4, assistance to die may apparently be provided where a patient becomes incompetent after completion of the declaration; and is therefore incapable of understanding, or exercising, their right to revoke.

48. Respondents suggested that patients may find it difficult to assert a change of mind at this stage, in the face of the emotional and practical investments made by carers and family.

49. Some respondents expressed concern that revocation appears to be 'once and for all'. They wondered how flexible patients could be in choosing the moment of death or whether a request to postpone the time of death would be deemed a revocation. Some speculated that if the declaration operated flexibly it might function as an 'insurance policy' for patients. Patients might be supported to die naturally because they had the 'reassurance' of being able to seek assistance should they need it.

50. Respondents suggested that permitting the attending physician to act alone at the final stage, with no witnesses present to observe dealings with the patient, raised problems of accountability.

51. Difficulties may arise where euthanasia is inconsistent with hospice charitable objects, and memoranda and articles of association.

ⁱ Paul Glare, Kiran Virik, Mark Jones, Malcolm Hudson, Steffen Eychmuller, John Simes, and Nicholas Christakis 'A systematic review of physicians' survival predictions in terminally ill cancer patients' *BMJ*, Jul 2003; 327: 195 - 0.