

## SUBMISSION ON THE ASSISTED DYING FOR THE TERMINALLY ILL BILL 2004

### Introduction

1. The National Council for Hospice & Specialist Palliative Care Services ("National Council") is the umbrella organisation for palliative care in England Wales and Northern Ireland.
2. It is a multi-professional and collaborative body, being born out of a partnership between national charities in the field, Macmillan Cancer Relief, Marie Curie Cancer Care, Sue Ryder Care, and Help the Hospices; professional associations in palliative care; voluntary hospices; the NHS (including Primary Care Trusts, NHS Trusts, palliative care teams, Strategic Health Authorities, and cancer networks); and the Department of Health. The Board of Trustees consists of members representing those organisations. It has about 500 subscribers, and consults regularly with its Area and Country networks.
3. This submission has been produced by National Council's ethics working group, which advises the Board of Trustees. It has been circulated to the Board of Trustees, National Council's clinical advisory groups, and its Area and Country Representatives. However, the time made available for evidence to be submitted following the publication of the terms of reference has not allowed for full discussion, feedback and approval.
4. In 1997 National Council published a position statement which set out its opposition to any change in the law to permit euthanasia. This statement is now out of date. The Trustees have therefore withdrawn it, with a view to carrying out further research and work in this area. This should not be taken to signal support for euthanasia, nor for the Assisted Dying for the Terminally Ill Bill ("the Bill").
5. **National Council recognises that diverse views on euthanasia are held by palliative care professionals (health and social care) in the United Kingdom. We consider that there is a dearth of methodologically robust research into the impact that legalisation of Physician Assisted Dying ("PAD") would have in the UK; and that because of the**

**absence of sound evidence, there has not been a properly-informed debate (whether between professionals or amongst the wider public) of all the issues that must be resolved before a decision whether to proceed with PAD can safely be made**

6. Accordingly, National Council will not comment now on the principle of whether PAD should be legalised in the UK in the future. Instead, this document will comment on:
  - a. Areas which must be researched and clarified before any decision to legalise PAD can be made; and
  - b. Practical issues raised by the current Bill

## **THE BILL**

### **“Assisted dying”**

7. Conventionally, a distinction has been drawn between a physician providing the patient with the means to end his own life - physician assisted dying or suicide - and a physician acting directly to end the patient’s life - euthanasia.
8. Notwithstanding its title, this Bill provides for euthanasia as well as PAD, albeit in the limited circumstances that the patient is physically unable to end his own life.

### **“Terminal illness”**

9. The Bill’s definition of a “terminal illness” is wholly dependent upon the opinion of the consulting physician.
10. Hence, it is impossible for the attending physician to form an independent determination that the patient has a terminal illness, as he is required to do under clause 2 (2) (c). This would necessarily preclude the attending physician from informing the patient of his prognosis, clause 2 (2) (e) (ii); and from making the referral to a consulting physician, clause 2 (2) (g).

### **“Unbearable suffering”**

11. The Bill’s definition of “unbearable suffering” is dependent both on the ability of the patient to express the level of his suffering to the attending and consulting physicians, and also on the subjective interpretation of that expression by the physicians.
12. Inevitably, assessment of suffering must always depend upon the patient. It is impossible for any health professional to assess

objectively whether or not a patient is suffering to an unbearable degree. It would be impossible to agree any objective professional standards or benchmarks against which the extent of suffering could be assessed.

13. Whilst it may be possible for the attending physician, based on a longer relationship with the patient, to assess changes in his level of suffering, such an assessment cannot be made during the course of the single visit to a consulting physician that the Bill envisages, during which all the activities detailed in clause 2 (3) must be undertaken. The time available for such a consultation may vary between only 15 minutes and one hour.
14. This necessary subjectivity in assessing the degree of a patient's suffering means that this requirement cannot be a wholly effective safeguard.

### **“Waiting period”**

15. We strongly support the principle that there should be a waiting period as a safeguard. Careful consideration is needed as to the length of that safeguard, and the point from which it starts.
16. In the Patient (Assisted Dying) Bill 2003 the waiting period was only triggered once a declaration had been made.
17. In contrast, the 14-day waiting period in the present Bill runs from the moment that a request for PAD is first made. It is probable that patients making a request to be assisted to die will come to expect that this 14-day period is the maximum they will have to wait. The implication is then that all the procedures required in clauses 2, 3, 4 and 5 must have been completed within 2 weeks. It is clearly possible that the 14-day period will have expired by the time the patient is able to make his written declaration, and so qualify for immediate PAD.
18. It is possible that the period leading up to the signing of the declaration will become focussed heavily on process as the patient and his professional carers seek to ensure that the Bill's requirements have been complied with. Consideration should be given to whether there should be a waiting period after the declaration has been signed, which would enable the patient to focus not on the process of qualifying for and making a declaration, but on the decision whether then to proceed with PAD.

### **“Competent and Incompetent”**

19. The definitions of "competence" and "capacity" must be consistent with those contained within other legislation currently in statute or under consideration e.g. The Mental Capacity Bill.
20. The Assisted Dying for the Terminally Ill Bill leaves the assessment of a patient's competence to the consulting physician and of incompetence to the attending physician, neither of whom is required to have any special expertise in such assessments.
21. Importantly, the Bill contains no safeguard for patients who are competent, but suffering from depression. Depression is a recognised part of the disease journey which may take considerably longer than 14 days to resolve.
22. The Bill requires a psychiatric referral only for those patients whose competence is in doubt. Any patient who requests PAD, and whom is thought to be suffering from significant depression, should receive a psychiatric referral.

### **Discussion of Ethical Issues:**

#### **Pain relief: (cl 15)**

23. This is an unnecessary clause. The administration of pain relief is well-established in clinical practice, and need have no bearing on or connection to PAD. It is unprecedented that a therapeutic course of action requires an act of legislation. All patients have the right already to appropriate management of any symptom including pain.
24. There is absolutely no need for a conscientious objection clause in relation to the administration of pain relief (cl. 7 (2)). This clause risks confusing the administration of pain relief with PAD in the public mind and in statute. That would harm the physician-patient relationship, and encourage popular misconceptions about the role of pain relief in end of life care.

#### **Death as a deliberate intervention**

25. If PAD is legalised, it becomes a legitimate form of treatment given with society's approval. It will be a recognised way of bringing an end to suffering. Physicians will be under a professional duty to raise it as an option with their patients if they complain of suffering unbearably, as it will be considered to fall in the category of 'best interests'. It will be a patient's right to be informed of all available options.

26. The means by which a patient receives information about assisted dying will be of immense importance. It will have a significant impact both on the patient and his relationship with his healthcare professionals. The Bill does not deal with this.
27. There is a risk that, if healthcare professionals are to be required to raise the issue of PAD for discussion with their patients, the conscientious objection clause (cl. 7) might be undermined.
28. Whilst the Bill's emphasis is on the role of doctors in providing PAD, responsibility will inevitably be placed on all health care professionals, particularly nurses, whose specific responsibility it is to care for and support patients and families at the end of life.
29. The title to clause 7 refers to the duties and conscientious objection of "physicians", rather than more broadly to healthcare professionals.

### **What amounts to a request?**

30. Clarity is required about the degree of formality that is required for a patient to have informed the attending physician of his wish to be assisted to die for the purposes of the Bill. This is important because the date that such a request is first made triggers the 14-day waiting period. It is therefore essential that the date of first request can be identified with certainty.
31. Professionals will need to clarify whether a patient is making a formal request for assistance to die, as opposed to expressing unhappiness in a general way.
32. The following statements might be expected in the setting of distress when faced with the many practical, physical and psychological complications of a life-threatening illness...  
  
*"I wish it were all over"*  
*"Can't you end it all?"*
33. Whilst such comments must always be taken seriously, and investigated, they would not necessarily amount to a direct request for PAD.
34. The Bill requires physicians to make enquiry, every time such sentiments (or similar) are expressed, to establish whether a patient is making a formal request for PAD that would trigger the

process set out in clause 2. The Bill does not say whether such a request needs to be serious or persistent.

### **Palliative care and PAD**

35. The Bill places considerable emphasis on palliative care, and identifies being “informed of” palliative care as a safeguard. However, palliative care is of benefit throughout the course of a disease and not just at the end of life. Appendix A contains a definition of palliative care.
36. By presenting palliative care as being an alternative to PAD, the Bill risks reinforcing the misconception held by patients, carers and some health and social care professionals that palliative care is solely concerned with the process of dying, whereas in fact palliative care benefits patients before they reach the terminal stage of their illness.
37. That this misconception has significant implications for acceptability and access, and so may inhibit the development of palliative care, has already been identified by the National Institute for Clinical Excellence.<sup>1</sup>

#### Information about palliative care and care in a hospice (clauses 2 (2) and (3)).

38. The Bill requires both the attending and then the consulting physician to “inform” the patient “of alternatives”, including palliative care and care in a hospice.
39. This requirement begs a number of questions:
  - a. What is meant by “inform...of”? A single sentence to the effect that “there are alternatives to PAD, which include palliative care and care in a hospice” could amount to adequate information. That is scarcely a safeguard at all.
  - b. If it is intended that more information than that be given, the Bill should specify what information is required.
  - c. If the attending physician has not already considered the option of palliative care for the patient, it is unlikely that he will be able to give an adequate description of the potential benefits of this care.

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<sup>1</sup> NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer, March 2004, para. 114. See also Appendix A.

- d. The reality is that access to a palliative care specialist might not be instantly available, or indeed available at all. Similarly, care in a hospice is not currently available to all who request it<sup>2</sup>. The Bill does not recognise the reality of current palliative care provision. 95% of specialist palliative care at present goes to patients with some types of cancer. Many patients are excluded from palliative care by their diagnosis.
- e. Could a request for PAD be used to prioritise a particular patient over others needing palliative or hospice care? Would it trigger an entitlement to palliative care? This raises clear issues of justice and equity. Why should a request for PAD enable one patient to supersede another?

"Discussing the option of palliative care" (clause 3)

40. The patient must also have been attended by a palliative care specialist "to discuss the option of palliative care"
- a. Again "discussing the option" is too vague to be an effective safeguard. Nothing is said about the length, depth, or substance of discussion required.
  - b. Clarification is needed as to when this consultation must take place, to ensure that it is in the context of a request for PAD. The Bill is silent as to whether this must take place before or after a request for PAD has been made.
  - c. This requirement does not reflect the reality of specialist palliative care practice. Palliative care depends on continuity and relationship. It would not be possible to undertake a full and proper assessment of a patient's full palliative care needs in the time allowed for a short consultation.
  - d. As above, palliative care might not be (instantly) available.
41. The intention behind the Bill may well be to ensure that patients are given full information about palliative care, and

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<sup>2</sup> See also paras. 43-46 below on current palliative care resources.

receive a proper assessment of their palliative care needs. However, this Bill does not achieve that.

### **Minimum compliance**

42. In order to assess whether adequate safeguards exist, the Select Committee must consider what the minimum requirement would be for each condition of the Bill to be met. Safeguards must be devised which require substantial information discussion and reflection over an adequate period. Safeguards which can be satisfied by the barest of lip service are not sufficient.

### **Discussion of Practical Issues**

#### **Allocation of resources**

43. Although palliative care provision is more advanced in the UK than in any other country, it is still under-funded and unable to meet the needs of all those who would benefit from palliative care. Implementing this Bill would carry with it considerable costs in terms of training, facilities, staff time and compliance. Those advancing the Bill have not sought to quantify these.
44. There are 237 palliative care consultants in England, with a whole-time equivalent to 169.<sup>3</sup> At least 100 posts for consultants in palliative medicine remain unfilled.<sup>4</sup> There is no set definition of a specialist cancer nurse and it has not been possible to collect national figures on numbers of specialist palliative care nurses.
45. There are 3195 palliative care beds in the UK, of which 2522 are in the voluntary sector. The average stay in a hospice is 13 days.<sup>5</sup>
46. The availability of Day Care and Home Care Services is also relevant here, as they will have considerable impact upon a patient's quality of life.<sup>6</sup>
47. This Bill will make demands on those limited resources. The Committee should consider whether resources would be better expended on improving access to palliative care, which would have a broad benefit for a large number of patients, or on

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<sup>3</sup> 2002. Source: Association for Palliative Medicine

<sup>4</sup> Evidence by Dr. Keri Thomas to House of Commons Health Select Committee.

<sup>5</sup> Hospice Directory 2004

<sup>6</sup> For further information about these services, see National Council's Evidence to the House of Commons Health Select Committee, which is enclosed with this submission.

establishing PAD, which even the Bill's supporters argue would benefit only a few.

### **Process of being assisted to die**

48. The Bill says nothing about the means or place of death.

### **Means**

49. We assume that the lethal dose will be a barbiturate to be self-administered by drinking, unless the patient is physically unable to take the dose himself. In cases where a physician euthanases a patient, death might be administered by injection. In either case, the means by which death is to be provided needs to be tightly regulated.

50. The same applies to the prescription and dispensing of the medication. A terminally ill patient might not be able to collect the prescription himself, but wish to use an agent. The lethal dose would be in the hands of a member of the public for whom it was not intended.

51. Despite the language of the Bill, the attending physician is not required to be present at the moment the patient ends his life. For obvious reasons, the patient is under no obligation to use the medication that he has been provided with.

52. This raises the possibility that the patient will be provided with a lethal dose, which will then be kept in a non-secure place for an open-ended period.<sup>7</sup>

53. Safeguards are required to ensure that lethal doses are not misappropriated, deliberately or accidentally.

54. The Bill does not address these issues at all. Nor does it provide any power for regulations to be made.

### **Place of death**

55. Very careful consideration needs to be given as to where the lethal dose is administered. It may often be in the patient's own home, but the potential impact, on other patients and staff, of offering PAD in buildings where healthcare is undertaken must be researched.

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<sup>7</sup> The Oregon Reports show that 67 patients received lethal dose prescriptions in 2003. 28 (41.8%) of those did not ingest the prescribed medication. 18 died of their illness. 10 were still alive on 31 December 2003.

## **Research**

56. Legalisation of PAD would have a significant impact on clinical practice in the UK. The impact would be widespread, affecting the provision of medical services, professional ethics, and the patient-professional relationship. This is a societal issue, not simply a health or palliative care issue. Public debate has been largely based on opinion poll findings and much influenced by strongly held, and expressed, opposing views. Much of the research that is available is based on weak methodology.
57. There is a need for robust research into attitudes towards PAD in the UK, amongst patients, carers, professionals and the wider public. Likewise, very careful consideration is required of the practicalities involved, should PAD be introduced into UK practice.
58. We do not have the evidence to assess fully the probable extent and nature of the impact of PAD on UK practice. Until we do and there has been a full and informed debate of what PAD would involve in practice, we will not as a society be in a position to decide whether or not to legalise PAD, nor will we be ready to adjust to the impact that legalisation will have.
59. Anecdotally, we are aware of colleagues in Belgium who have expressed shock at the speed with which legalisation took place, and have encountered significant problems because they were not adequately prepared for legalisation and had not had the opportunity to think through all the issues that legalisation raises.
60. In particular, but not only, research is needed in the following areas:
- a. **Patient views:**
    - i. How do views change along the disease journey?
    - ii. Do physical symptoms and psychological symptoms differ in their influence on a patient's wish for death?
    - iii. How do different social, cultural and religious backgrounds affect a person approaching the end of his life?
    - iv. How do views change once patients have received palliative care, as opposed to being told about it?
  - b. **Carer views:**
    - i. How do carers' views influence patients?
    - ii. How do those views change during the course of an illness?

- iii. How does the availability of supporting services influence the views of carers?

**c. Professional views:**

- i. A more accurate understanding of the actions and intentions of doctors who state that they have ended a patient's life.
- ii. An understanding of the consequences of requiring doctors to offer and then bring about the ending of a patient's life
- iii. An understanding of the impact on other healthcare professionals who would be involved in PAD. The Bill places a very heavy onus on doctors, as opposed to other professionals. Is it right that doctors should shoulder so much of the responsibility in relation to this issue?

**d. The general public:**

- i. How will permitting assisted dying affect society's view of the sick, frail and elderly?

**e. Experience in other countries**

- i. To what extent can experience and research in other countries, both where PAD is legal and where it is not, inform our understanding of the impact that PAD would have in the UK?

**f. Practical implementation**

- i. How would PAD be introduced into UK practice?
- ii. How would PAD safeguards be consistent or compatible with current practice?
- iii. What lessons can be drawn from other jurisdictions?

61. Legislating for PAD would represent a radical departure from medical practice in this country. Such a step should not be taken until there has been thorough research into the issues raised above, based upon robust methodology. National Council would be willing to participate in any steering group meeting to agree methodology and oversee research.

62. Properly robust and detailed research would take considerable time and money. However, the controversial nature of these issues means that many funders are reluctant to support research in this area.

63. Much further consideration is required of the whole area of how, as a society, we care for those who are approaching the end

of their lives. When considering whether to legislate in favour of PAD, Parliament should proceed with great caution and on the basis of robust and complete evidence. In particular there must be careful consideration as to whether PAD can be introduced without an adverse impact on medical services and those patients who do not wish it.

**August 2004**

## APPENDIX A

### Definition of Palliative Care

112. Palliative care is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

113. Palliative care is based on a number of principles and aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death and to help the family cope during the patient's illness and in their own bereavement
- Be applied early in the course of the illness in conjunction with other therapies intended to prolong life (such as chemotherapy or radiation therapy), including investigations to better understand and manage distressing clinical complications.

114. It is now widely recognised that palliative care has a crucial role in the care received by patients and carers throughout the course of the disease and should be delivered in conjunction with anti-cancer and other treatments. In the minds of patients, carers and some health and social care professionals, however, it tends to be associated with care for dying people. This has significant implications for acceptability and access.

*The above definition is taken from the NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer, March 2004, paras. 112-4*