

Response to the Report
of the House of Lords
Select Committee on
the Assisted Dying for
the Terminally Ill Bill

August 2005

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The National Council for Palliative Care's response to the Select Committee report on the Assisted Dying for the Terminally Ill Bill

Foreword

The House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill published its report on 4 April 2005. This document contains the response of The National Council for Palliative Care to that report. It has been debated and approved by The National Council's Board of Trustees, with support and advice from its Ethics Committee.

The National Council hopes that this response will inform and influence the forthcoming debate in the House of Lords on the Select Committee's report, as well as the broader and continuing debate within society on this issue.

This response seeks to set the issues raised by the Select Committee in the context of current developments in palliative care. It should be emphasised that palliative care is important and worthwhile in its own right, and should not be portrayed simply as an alternative to assisted suicide or voluntary euthanasia.

As the Chairman of the Select Committee, Lord Mackay of Clashfern, commented when the report was published, "ending or helping to end someone's life, albeit with their consent, is an awesome issue". The National Council fully concurs with that, and considers that further evidence and debate is required to enable a sound decision to be made whether or not to change the law.

The National Council recognises that diverse views are held within palliative care about the principles underlying voluntary

euthanasia and assisted suicide. A call for further investigation and evidence should not be used as an excuse to delay legislation by permanently putting off a decision. However, given the magnitude of what is involved, it is particularly important that any decision to legislate be based on robust evidence.

In considering any future action in relation to the Select Committee report, the Government should recognise that resources need to be committed to enable the necessary research to be undertaken.

The National Council wishes to contribute to the process of obtaining further evidence and to work with any government body that may undertake or commission such work. As indicated in this response, The National Council will seek to establish a collaborative of partner organisations that could undertake some of the proposed areas of work required.



Francis Plowden

Chairman,
The National Council for Palliative Care
August 2005

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Executive Summary

The key points of The National Council for Palliative Care's response to the report of the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill are:

- The National Council welcomes the significance attached by the Select Committee to ensuring access to high-quality palliative care for all who need it. This is an important objective in its own right, regardless of whether or not voluntary euthanasia or assisted suicide come into law.
- Priority should be given to providing equitable access to palliative care for all before pursuing assisted suicide or voluntary euthanasia, particularly given the major legal and ethical challenges and demands on resources that implementation of legislation would involve and the proportionately small number of people likely to benefit.
- Whilst the Select Committee reached a number of conclusions, it also left some very significant questions open. There is a need for more evidence-based information about these issues, rather than the myths and prejudices which currently predominate. The National Council wants to contribute to establishing some of these facts. If the law is to change, it should only be undertaken on the basis of the fullest possible information. In the absence of such information, this is therefore not the right time to change the law.

Summary of actions recommended or in progress

- The National Council's mission is to promote access to palliative care for all who need it. Through its policy unit, it is developing evidence-based policy designed to identify and meet the needs of all patients regardless of diagnosis. The work of ensuring that all who need it have access to palliative care is for society as a whole, and will be brought about through partnership between the

public, voluntary sector and independent sectors.

- The National Council will seek to establish an ethics collaborative of interested organisations, with the aim of researching and exploring further the issues raised by the Select Committee in the report which remain unresolved.
- The National Council believes that the following issues identified by the Select Committee, in particular, require further research:
 - a. Qualitative understanding of the views both of the public and of professionals affected by implementation of proposed legislation
 - b. The extent to which assisted suicide or euthanasia is being practised illegally in Britain
 - c. Ethical issues created by the proposed legislation
 - d. The extent to which palliative care can address the non-physical aspects of suffering, through psychological, spiritual and social care, as well as physical suffering
 - e. The extent to which a slippery slope might exist
 - f. The quality and availability of palliative care in jurisdictions where assisted suicide or voluntary euthanasia are legal
 - g. The concerns raised by vulnerable groups such as older people and people living with disability
 - h. The impact on the relationships between patients and their professional carers in the context of British medical practice.

Further comment on the above issues is set out in this publication.

Introduction

The House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill published its report on 4 April 2005. The National Council for Palliative Care (then called The National Council for Hospice and Specialist Palliative Care Services) was amongst the organisations that submitted written evidence on the Bill,¹ and was subsequently invited to give oral evidence.

This document sets out The National Council's response to the Select Committee's report.

About The National Council for Palliative Care

The National Council is the umbrella organisation for all those who are involved in providing, commissioning and using hospice and palliative care services in England, Wales & Northern Ireland. It promotes the extension and improvement of palliative care services regardless of diagnosis in all health and social care settings and across all sectors to government, national and local policy makers.

Its policy unit undertakes evidence-based policy work to facilitate the development of palliative care services. The unit collects data on a national basis to enable policy makers to understand and make provision for the palliative care needs of any given population, for patients with cancer and other diagnoses. It has established 4 policy groups, consisting of policy leads, service users and professionals, to link sound evidence to the real-world experience of professionals, organisations, patients and their carers. The policy groups are: cancer;

circulatory and respiratory conditions; neurological conditions; and a cross-cutting older people group.

Terminology

In this response, the following terms are used:

“The Bill”: The Assisted Dying for the Terminally Ill Bill

“The Select Committee”: The House of Lords Select Committee that considered the Assisted Dying for the Terminally Ill Bill

“The report”: the report published by the Select Committee on 4 April 2005

“The National Council”: The National Council for Palliative Care (formerly known as the National Council for Hospice & Specialist Palliative Care Services)

This response also uses the following terminology adopted by the Select Committee in the report:²

“Assisted Suicide”: Providing someone with the means to end his or her own life

“Voluntary Euthanasia”: ending another person's life at his or her own request

Structure

The report summarised the evidence that the Select Committee received, and some preliminary conclusions, in chapters 3 to 6. It then set out further conclusions in chapter 7. This response will comment on the evidence and conclusions reached by the Select Committee on each issue, rather than divide the evidence from the conclusions.

1. The underlying ethical principles (report Chapter 3)

A. Patient autonomy

The Select Committee reviewed the evidence that it received in relation to arguments on autonomy and sanctity of life, and:

1. agreed that “patient autonomy cannot be absolute and that there must be some limits set, in the interests of the wider community, to what a patient can require his or her doctor to do;”³
2. could not reach consensus on what those limits should be,⁴ but agreed that:
 - a. the issue of where limits should be set is one for society to decide through its legislators in parliament;⁵
 - b. whilst the issue is societal, because of the crucial role that doctors would play in the implementation of the Bill, were it to become law, the views of medical and nursing professions must be considered very seriously;⁶ and
 - c. the issue of personal autonomy cannot be viewed in isolation, but must be considered in the light of the practical “real world” issues which proposed legislation raises;⁷ and
3. noted that very different claims on either side of the debate are made about the practical impact that legislation would have.⁸

Comment

The National Council agrees with the Select Committee’s approach to weighing the importance of patient autonomy in the balance against both sanctity of life and wider societal factors. Individual autonomy should not be a decisive and over-riding consideration.

In relation to bullet point 3, as set out in its written evidence, The National Council considers that there is a dearth of methodologically robust research into the practical impact that legalisation of assisted suicide or voluntary euthanasia would have in the UK. In the absence of robust evidence, it is impossible for society, or professionals, to hold a properly-informed debate. Further comment on the current state of the evidence about the potential practical impact of legislation is set out below.

B. Ethical distinctions

The Select Committee considered the ethical distinctions between assisted suicide or voluntary euthanasia on the one hand, and refusing, withholding or withdrawing life-prolonging treatment on the other.⁹

(i) Refusing life-prolonging treatment

The Select Committee found that from a physician’s perspective there is a clear ethical distinction between a patient refusing life-prolonging treatment, and requesting assisted suicide or voluntary euthanasia, because the intention in the former case

is not to bring about the patient's own death, whereas the intent in the latter cases indisputably is.¹⁰

Comment

The National Council agrees that this is a clear distinction. The distinction is not just one of intention, but of causation. Where a patient refuses life-prolonging treatment, the cause of death, if it occurs, is the underlying disease or condition. In the case of assisted suicide or voluntary euthanasia, the cause of death is a deliberate active intervention to administer a lethal dose.

The Select Committee also said that "from the patient's view (these) may appear little different." That is only true in so far as the end result is that the patient dies. That is not always the case when life-prolonging treatment is refused. Even if it were, there is clearly an ethical distinction between an end and the different means by which it might be arrived at. To suggest otherwise is to say, for example, that there is no ethical distinction between a man jumping, slipping, or being pushed off a cliff.

(ii) Withdrawing or withholding life-prolonging treatment

The Select Committee rightly found that in cases where this takes place at the patient's request, it should be considered in the same category as a refusal of life-prolonging treatment.

The Select Committee found that the position is less straightforward where

life-prolonging treatment is withdrawn or withheld without the patient's consent. However it saw "the force of the counter-argument that the intention is not to end the patient's life but to discontinue treatment which is futile and burdensome."

Comment

Again, there is a clear ethical distinction. Physicians are well-used to weighing the potential benefits and burdens of a proposed course of treatment. Provided that is done, and the intention is to discontinue treatment that is burdensome to the patient, that is different, as a matter of conventional ethical teaching, to an active intervention to bring about death by administering a lethal dose.

The Mental Capacity Act 2005 states that, when making a decision about life-sustaining treatment in relation to a patient who lacks capacity and so cannot consent, a doctor "must not be motivated by a desire to bring about (the patient's) death" in assessing his best interests.¹¹

(iii) "The Policeman's Dilemma"

This scenario, which was advanced by supporters of the Bill as ethically analogous to circumstances which would justify voluntary euthanasia, postulates a motor accident in the USA in which a lorry driver is trapped in the cab of his burning vehicle with no prospect of release before he will be burned to death. He asks an armed policeman at the scene to shoot him

rather than be burnt alive. The policeman complies. It is said that, if it is conceded that the policeman acted in a moral way, then the principle that it is right to assist death in cases of extreme distress where the condition is terminal has also been conceded.¹²

The Select Committee found that this analogy represents very rare circumstances, on the basis of which no legislature would make law.¹³

Comment

The Select Committee was right to treat “the policeman’s dilemma” as an extreme example which should not be used to support a change in the law. However, it could have gone further. There is no relevant factual or moral parallel between the situation postulated: i.e. somebody who faces the certain and immediate prospect of a horrifying and painful death with no prospect of any alleviation, relief or release, and the circumstances of a patient living with a life-threatening condition in 21st century Britain with the array of health and social care that is available. It is not a helpful analogy - indeed it is positively counter-productive in that it risks entrenching in the public mind the misleading impression that there is nothing that can be done to help people as they reach the terminal stages of their condition.

Overall comment on Chapter 3

This section of the report is supported. Ethical debates on these issues are too-often characterized by confusion and conflation (sometimes deliberate) of the ethical issues at stake. It is particularly important that ethical issues are discussed with clarity and understanding of what is involved. Otherwise confusion and ignorance will prevail.

This proposed legislation raises many other ethical issues as well, for example: How does society view and value older people or people living with disability? What is suffering? Where should society decide the limits of individual autonomy are to fall? How do we regard death and the process of dying?

Proposed future action

All parties to this debate need to ensure that the ethical principles are clearly understood, and that issues are not inaccurately presented or confused. The National Council, through its Ethics Committee will seek to contribute clarity to the debate, and to support the education of professionals and the public about the ethical principles and distinctions that are raised.

The National Council’s experience is that it is difficult to persuade funding organisations to support research into end of life ethical issues. However, there is a real need for public education and debate. The National Council will actively seek partners to join a collaborative ethics project to research and explore these issues.

2. Practical issues (report Chapter 4)

A. Is covert euthanasia being practised in the UK?

The Select Committee accepted that the current law is probably being flouted to some extent by doctors performing assisted suicide or voluntary euthanasia, but concluded that it “would be surprised if covert euthanasia were being practised on anything like the scale which some...surveys suggest.”¹⁴

Comment

The Select Committee was right to find that there is no reliable evidence about the extent to which covert euthanasia might be going on in England and Wales, and that extrapolation from surveys probably tends to overstate the situation.

Obtaining reliable evidence on this point is inevitably very difficult, and may not be possible. Designing a sound methodology would be a challenge.

Having said that, it is important to try to gain as clear an understanding as possible of how many patients would be likely to take advantage of legislation if passed. There is also a public interest in establishing whether assertions that illegal practice of assisted suicide or euthanasia is widespread are correct.

Suggested action

The Department of Health and the General Medical Council should consider whether it is possible to produce a reliable methodology to establish the current

likely scale of illegal voluntary euthanasia or assisted suicide. If it is possible, such research should be funded as a matter of public interest.

B. Palliative care

(i) Definition

The Select Committee posed the question “what exactly is palliative care?” and answered it by applying the World Health Organisation (WHO) definition.¹⁵ It recognised that “palliative care extends more widely than pain relief or the administration of medicine” to cover the physical, psychological, social and spiritual impact that a life-threatening condition has on a patient.

Comment

The definition of palliative care, for the purposes of service provision in England and Wales, is set out in the National Institute for Clinical Excellence’s Guidance on Improving Supportive and Palliative Care for Adults with Cancer, 2004 (“The NICE Guidance”):

“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.”¹⁶

Importantly, there are 4 domains of care: the treatment of physical symptoms, including but not confined to pain relief; psychological care; spiritual care; and social care.

The Select Committee’s recognition that palliative care extends further than pain relief or the administration of medicine is welcome. Lack of understanding of what palliative care is, on the part of professionals as well as the public, has been identified as a consistent barrier to the development of palliative care services.¹⁷ In part, the word “palliative” is a barrier to understanding, although no satisfactory alternative has been identified.

In this context, where aspects of non-physical suffering, such as existential suffering and loss of autonomy, are identified as being the principal reasons why a patient might seek assisted dying, it is particularly important to recognise the equal value of the holistic aspects of palliative care, i.e. psychological, social and spiritual care.

There were important omissions in the Select Committee’s discussion of what palliative care encompasses.

- The Select Committee’s principal focus was on palliative care provided by services that specialise in it. The report did not contain any real discussion on the provision of palliative care by the usual professional carers of the patient delivered outside the specialist

setting. This is sometimes referred to as “general palliative care”. However, that refers to the fact that it is delivered outside a specialist unit, and is not a comment on the quality of care. Such care can and does bring significant benefits to patients.

- Perhaps inevitably, given the nature of the Bill, the Select Committee appeared only to focus on the impact of palliative care for people in the terminal stage of their condition. In fact, as the NICE Guidance emphasised, palliative care “has a crucial role in the care received by patients and carers throughout the course of a disease.”¹⁸ Good palliative care throughout the course of a disease, beginning in the early stages, will have provided benefits to patients before they reach the terminal stages. Early care might affect their attitude towards their condition, although further research on this point is required.

Further comment on the steps that are being taken to educate professionals about the benefits of palliative care is set out below in the section on the effectiveness of palliative care.

(ii) Availability of Palliative Care

The Select Committee found that there was a consensus amongst the witnesses that “palliative care in the United Kingdom is of a very high quality but inadequately resourced and unevenly spread.”¹⁹ In making that finding, it highlighted the following evidence in particular:

1. There are 237 palliative care consultants in England (whole-time equivalent 169) with 100 posts unfilled²⁰
2. There are 3195 palliative care beds in the UK, of which 2522 are in the voluntary sector²¹
3. There is insufficient primary care support for those patients who wish to die at home²²
4. Most access to specialist palliative care services is by people with cancer
5. Geographical provision is uneven and does not always match need.²³

The Select Committee noted that the government had devoted increased resources to palliative care in the 2001-2005 Parliament, and was unanimous in saying that “high priority should be given to the development and availability of palliative care services across the country.”²⁴

Comment

The Select Committee was right to conclude that current provision of specialist palliative care services does not always match local need. The National Council identified this and has been working for some time to address issues of inequity, including inequity by reason of geography, diagnosis, ethnicity and social disadvantage. It should be emphasised that this work forms a key part of our mission to ensure palliative care for all who need it, and is not driven by the possibility of legislation in relation to voluntary euthanasia or assisted suicide.

The National Council particularly welcomes the Select Committee’s unanimous recommendation that high priority should be given to the development and availability of palliative care services across the country, and that all efforts in that direction be intensified. This follows similar recommendations made by the House of Commons Health Committee following its enquiry into palliative care in 2004²⁵, and means that Select Committees in both Houses of Parliament have now recognised the importance of developing palliative care services for all who need them. All 3 main political parties expressed their support for the further development of palliative care in the new parliament. There is now a significant consensus that this is the right course of action, and The National Council will continue to press for that and work with all interested parties to bring it about.

Geographical inequity

In 1999 The National Council published the Palliative Care Survey, which had been commissioned by the Department of Health. This provided systematic evidence of geographical inequity in access to palliative care for the first time, and was instrumental in persuading the government to increase its contribution to specialist palliative care for adults with cancer by £50 million per annum.

The National Council’s subsequent research, tracking the £50 million, demonstrated that the money was not reaching front-line services, which led to the establishment of

the National Partnership Group (NPG) to oversee the allocation of the £50 million to the 34 cancer networks. The NPG, on which The National Council plays a key role, is now considering a range of strategic issues relating to the development of palliative care, including those relating to workforce, and reviewing the mechanisms that govern funding flows from NHS commissioners and providers of specialist palliative care services.

In 2005 The National Council published guidance on Population-based Needs Assessment for Palliative Care – a manual designed to help Cancer Networks in partnership with cancer service providers and commissioners to implement the NICE Guidance. Work is underway to adapt this tool so that the needs of people with other conditions can be identified.

The work to ensure that local service provision matches local assessed need is continuing. Social disadvantage and ethnicity are relevant factors here as well. There is much evidence to suggest that service development in both the NHS and the voluntary sector has been historically random without reference to the comparative needs of different populations. Addressing these issues is part of the remit of The National Council's new policy unit.

Because of the random development of services across the country, some communities enjoy much better access to palliative care services than others – in fact a post-code lottery. This could result in individual patients in communities with good

access to services being less likely to opt for voluntary euthanasia or assisted suicide, with the reverse true in other communities. That would be a serious injustice. The presence of social disadvantage and ethnicity as contributing factors only emphasises that point.

Inequity by diagnosis

Again, the Select Committee was right to identify diagnosis as a barrier to access to specialist palliative care services. Currently 95% of specialist palliative care is accessed by adults with cancer, even though only 25% of adults die from cancer. The National Council's research indicates that approximately 300,000 people die each year from diseases other than cancer all of whom would benefit from improved palliative care from their usual professional carers and some of whom would benefit from access to specialist palliative care services, which are currently denied them.²⁶

The need to extend provision of palliative care beyond cancer is now almost universally acknowledged. In particular, the cross-party House of Commons Health Committee identified this as a key challenge in its 2004 report.²⁷

Action

Work on improving the quality and provision of palliative care and to address inequity of provision is already underway. This work has been driven by the consensus that good palliative care is an important goal

for society, rather than in response to this proposed legislation.

In 2004 The National Council restated its mission to help develop policy to enable all those in need of palliative care to receive it. Minimising inequity of access, and in particular the need to develop palliative care beyond cancer, is central to that mission. The National Council's policy unit is already working with partner organisations and specialists in other conditions in order to understand and find ways of meeting the needs of people suffering from non-malignant as well as malignant conditions.

The extension of palliative care for people with non-malignant conditions will require considerable resources. At present too little is known about the level and extent of need to be able to make a reliable estimate. However, the Palliative Care Manifesto, published by The National Council before the 2005 general election, estimated that of the order of £450 million is currently spent each year on hospice and specialist palliative care services in England. That includes the funding contributions from all sectors including voluntary hospices. Achieving the goal of palliative care for all who need it is likely to require a large increase in funding.

It was against this background that the Palliative Care Manifesto sought pledges from the incoming government of additional spending of £50 million a year to initiate the development of palliative care services beyond cancer, as well as a further £50 million to facilitate the implementation of the NICE Guidance.

It is encouraging that the new government promised to “double the investment” in palliative care for adults with cancer in its pre-election manifesto. Whilst it is not yet clear precisely what is meant by this pledge, if it is implemented it should mean that further funding will be coming to palliative care for cancer at least.

(iii) Effectiveness of Palliative Care

The Select Committee found that “good palliative care, tailored expertly to the individual needs of the patient, can largely relieve the symptoms of physical pain.”²⁸

At the same time it found that there was “a general consensus amongst witnesses as to the limitations of palliative care in relieving patient suffering”, and in so doing, highlighted evidence from the Voluntary Euthanasia Society, a consultant oncologist, and the BMA.²⁹ The limitations referred to centred not on pain, but around patients' perceptions of loss of dignity, autonomy and bodily function.

In relation to MND, the Select Committee found that “the picture...appears to mirror that for the effectiveness of palliative care overall – that in qualitative terms it can mitigate to a large extent the medical suffering associated with terminal illness but that it is, at least at present, spread too thinly within the United Kingdom.”³⁰

Comment

When the then National Council for Hospice and Specialist Palliative Care Services set out its position statement on euthanasia in

1997 (which has since been withdrawn) it said:

“Universal availability of excellent palliative care services will not and can never eliminate all rational and persistent requests for euthanasia”.

Whilst this statement remains true, the key issue is the extent to which the best practice in modern palliative care, having developed over the years, can now address both physical and non-physical suffering and would, were it more generally available, be able to reduce the potential numbers of requests for assisted suicide or voluntary euthanasia.

In explaining in the report how it formed its view about the effectiveness of palliative care the Select Committee did not cite any evidence from palliative care specialists, except for a report commissioned from Dr Richard Hillier in relation to MND.³¹

There is clearly a difference between being able to relieve suffering, and being able to remove it. It is not possible to remove all suffering; suffering is part of the human condition. However, it is possible to address all suffering, and to relieve it at least to some extent. Specialist palliative medicine continues to develop as a specialty and there have also been significant improvements in the quality of palliative care delivered in a non-specialist setting. This will lead to an overall increase in the effectiveness of palliative care in addressing suffering.

It is accepted by most specialists in palliative medicine that, in the case of physical pain,

symptoms can be completely relieved in more than 90% of cases and significantly alleviated in the remainder.

Given the Select Committee’s view that take-up of assisted suicide or voluntary euthanasia in England and Wales would largely be by individuals fearing for a loss of autonomy, or experiencing existential suffering, it is clearly important to gain a better understanding of how and to what extent palliative care can assist such individuals to come to terms with their condition. What can be done now, and what more could be done, to help those individuals?

Solutions include both looking for ways to maintain or enhance autonomy, and also helping people to “let go”. Enabling patients to give up autonomy as death approaches is a significant part of palliative care. The relinquishing of autonomy is a central tenet of many religious traditions. The appropriate support of patients within those traditions in giving up autonomy as death approaches is a significant part of the spiritual element within palliative care. If sensitively done, it can also be helpful to patients with little or no religious belief.

There has been considerable focus on the extent to which physical suffering can be addressed, and that is a vital part of palliative care. However, more needs now to be focussed on the evidence for the benefits to patients that can be achieved through psychological social and spiritual care and support as well. Whilst that understanding exists amongst palliative care specialists, more needs to be done to inform and

educate non-specialists and the wider public.

If the Select Committee was hesitant in reaching a conclusion about the extent to which palliative care is capable of addressing suffering, that is possibly because palliative care itself has also been too hesitant about identifying precisely what it can offer. The National Council does not wish to over-state or under-state the extent to which palliative care can address both physical and non-physical suffering, and recognises that more evidence would contribute to this aspect of the debate.

Action

The work of The National Council's policy unit will contribute to a better understanding of the benefits of palliative care for all patients. In addition, The National Council recognises the need to develop evidence about what the capability of palliative care is to address and relieve both physical and non-physical suffering.

The National Council will continue to work with its partners to facilitate research in this area, and to promote understanding of the benefits of palliative care. This will be achieved chiefly through education and training of all health and social care professionals who provide care to people living with life-threatening conditions, and through education of the wider public.

Current initiatives in this direction include:

- The 2004 NICE Guidance highlights good practice and a series of tools that specialist palliative care professionals

can use to help educate other professionals in better understanding the benefits of palliative care.

- The Government's End of Life Care programme has committed £12 million to "skilling-up" non-palliative care specialist professionals involved in delivering end of life health and social care. This should help to increase understanding of palliative care, and is very welcome, but more needs to be done. The National Council's Palliative Care Manifesto, published before the 2005 general election, called on the incoming government to establish a national training programme in palliative care for all health and social care professionals who care for patients with advanced progressive illness.
- The Select Committee highlighted evidence that "up-skilling of the 600,000 care assistants in residential homes presented even greater challenges."³² The National Council has begun to develop policy and guidance, in partnership with care home providers and other interested parties, that is intended to enable care home providers to better identify and meet the palliative care needs of their residents.³³ This work is at an early stage.

- (iv) The role of palliative care in the Bill and in relation to assisted suicide/voluntary euthanasia

The Bill sought to involve palliative care specialists in the assisted dying process by

requiring that they discuss “the option of palliative care” with the patient making the request. The Select Committee received evidence that this is not a realistic provision in the context of palliative care in England and Wales - assessing a patient’s palliative care needs takes considerably more work than is possible or appropriate in a discussion about the option of such care.³⁴

The Select Committee concluded that:

“Clearly therefore something more than a simple consultation with a palliative care doctor or nurse is needed if patients contemplating assisted suicide or voluntary euthanasia are to be able to make fully informed choices. The difficulty lies in the somewhat patchy availability of good quality palliative care. If however a future bill is to be able to claim with credibility that it is offering assistance with suicide or voluntary euthanasia as complementary rather than as an alternative to palliative care, it may need to find a way of resolving this dilemma.”³⁵

Comment

The National Council agrees that if a future Bill includes palliative care in its provisions as being complementary to what is proposed, it should engage credibly with the reality of palliative care practice. The Select Committee clearly concluded that the Bill it had to consider did not achieve that. Any future Bill should set out ways in which patients can access full information, to include understanding, about what palliative care has to offer them as individuals.

The Select Committee appeared to assume that only palliative care specialists can provide good palliative care. This is not the case. As set out above, palliative care can be provided both in specialist units and by the usual professional carers of a patient in other settings. In all cases it is important to work in partnership with patients and carers to identify with them what their palliative care needs are and agree a plan together to address the patient’s priority needs.

A cause of particular confusion in the Bill, which The National Council raised in its written evidence, was the requirement that patients requesting assisted suicide should see a palliative care specialist to discuss the option of palliative care. As the Select Committee found, much more thought is required about what information is needed, and what is required and of whom, in order that the patient can make real and informed choices. It should be ensured that the limited time of palliative care specialists would not be given disproportionately to patients seeking voluntary euthanasia or assisted suicide, with such patients possibly being treated as over-riding priorities, at the expense of patients who do not wish to follow that route.

Finally, The National Council wishes to emphasise that palliative care is important in its own right. It should not be seen as a competing alternative to or a bulwark to be raised in defence against voluntary euthanasia or assisted suicide, with its effectiveness to be measured in that light; it has intrinsic value and worth irrespective of the debate on this issue. Regardless of

whether or not this proposed legislation is introduced, it will still be necessary for service commissioners and providers to deliver high-quality palliative care to all those who need it.

Action

The National Council is willing to discuss any future proposals that may be brought forward by supporters of legislation about the practical involvement of palliative care.

General comment

The National Council welcomes the reference in the evidence to the World Health Organisation's recommendation that governments should give priority to developing palliative care before introducing assisted dying or euthanasia.³⁶

Palliative care is a developing service. The agenda for service commissioners and providers is already full: extending palliative care for patients with non-malignant conditions; improving it for cancer patients; addressing inequity of access by reason of geography, ethnicity or social disadvantage; training and educating non-specialists about palliative care – all these already present sufficient challenges for the foreseeable future.

C. Slippery slope

The Select Committee rehearsed “slippery slope” arguments, and sub-divided them into 5 categories, without reaching any fixed conclusions. The 5 categories were:

1. Incremental extension to the law
2. Elastic interpretation of the law's provisions
3. Hidden pressures
4. Abuse of the law
5. The paradigm shift

Comment

Incremental extension to the law

It is clear that the Select Committee felt unable to dismiss concerns over the slippery slope. That is not surprising. For example, Lord Joffe's own evidence to the Select Committee made it clear that he did not regard this Bill as the end point but rather the beginning of legislation in this area.³⁷ The Select Committee received evidence from The Netherlands that the slippery slope exists in terms of political lobbying for an extension in the law.³⁸

Elastic interpretation

The Select Committee was also right to identify elastic interpretation of the law as a possible manifestation of the slippery slope. Elsewhere in the report, the Select Committee identified two particular aspects of the Bill in relation to which it was difficult to frame a legal definition that met the realities of practice: the requirements that a patient (1) be terminally ill and (2) be experiencing unbearable suffering.³⁹

These requirements were identified as being important and appropriate safeguards by

the Bill's supporters. In recommending that those aspects of the Bill be re-visited, the Select Committee evidently found that those provisions of the Bill as drafted did not provide sufficient safeguards.

It will be incumbent on those proposing any future legislation to ensure that a Bill is drafted in such a way that it contains workable definitions which provide appropriate, secure and enforceable safeguards.

Hidden pressure

The Select Committee identified this as the concern raised most frequently in the context of the slippery slope.⁴⁰ It recommended that a psychiatrist carry out a mandatory consultation with a patient requesting assisted suicide, one of the purposes of which would be to ensure that the request is “free from external pressure.”⁴¹ Presumably it would not have made such a recommendation unless it considered this to be a risk that needed to be addressed.

This issue was also discussed when the Select Committee considered evidence relating to potentially vulnerable people, in particular elderly and disabled people. Fears have been expressed by older and disabled people, and organisations working on their behalf, which should be taken seriously and addressed by supporters of any legislation in the future.

Abuse of the law

The principal evidence put forward on this point is empirical data from The Netherlands indicating that about 1,000 cases of euthanasia occur each year without an explicit request (see page 25 below). The Select Committee noted the chief executive of the Voluntary Euthanasia Society's acknowledgement that “this is a concern.”⁴² She emphasised that the Dutch recognise this, and that there are attempts to deal with the issue through changing best practice.

It emerged at the end of 2004 that doctors at Groningen Academic Hospital have practised euthanasia on new-born infants. On the face of it, this would appear to breach the 2002 Dutch law. This potential breach of the law is now being used as a tool to argue for an incremental extension of the law.⁴³

Paradigm shift

This is the label given to the concern that, if legislation were passed, voluntary euthanasia and assisted suicide would become accepted therapeutic options, and thus would eventually be seen as morally acceptable outcomes for patients. As a result pressure would grow for them to be applied more widely, for example to adults lacking capacity or to minors.⁴⁴

There is some overlap here with the first slippery slope category identified – incremental extension to the law. As already set out, there is evidence of pressure for further change in The Netherlands to extend the categories of patient for

whom euthanasia might be applicable. The 1,000 deaths by euthanasia without request that take place each year, and the recent instances of neonatal euthanasia in Groningen are evidence which might support the “paradigm shift” theory.

Conclusion on slippery slope

The Select Committee did not make any express finding as to whether or not the slippery slope is a real phenomenon, nor, if it is, the extent to which that is the case. However, there was clearly evidence before the Select Committee which is capable of supporting slippery slope arguments. These issues require further analysis and consideration before legislation is proceeded with.

Action

This is an issue that The National Council wishes to explore further in partnership with other interested organisations as part of an ethics collaborative.

D. Impact on doctor-patient relationships

The Select Committee noted that there had been a significant change in the patient-doctor relationship over the last 30 years in favour of greater openness and patient autonomy.⁴⁵ It also said that the relationship needed to be examined from both standpoints: that of the patients and that of the doctor.⁴⁶

Comment

There was little evidence before the Select Committee from the patient’s perspective, save for some opinion polling. The Select Committee, rightly, adopted a cautious and sceptical approach towards opinion poll evidence.

There was however evidence of anxiety on the part of some doctors that the patient-doctor relationship would be damaged.

Importantly, the Select Committee highlighted evidence of different practice between The Netherlands and the United Kingdom, which might be expected to have an impact on the patient-doctor relationship.⁴⁷ In The Netherlands GPs tend to know their patients over a long period of time, whereas in the UK, with a team approach to primary care, building a long-term relationship between patient and GP is more difficult.

This question should not be confined to the doctor-patient relationship –the relationship between a patient and all his health and social care professionals might be affected, particularly where care is provided in multi-professional teams, as it is in specialist palliative care units. The views of all professional disciplines which might be affected by legislation should be taken into account.

This is an important issue, which requires further research and consideration. It cannot be assumed that the experience in different countries would simply be repeated in Britain; it is essential to take into account

the starting point of our current health and social care culture and practice.

As set out in the comment on page 27, in relation to experience in Switzerland, one possibility is that an assisted suicide or voluntary euthanasia service might be provided by non-medical staff. The practical ramifications of that would require very careful consideration.

E. Conscientious objection

The Select Committee recited evidence relating to conscientious objection in chapter 4⁴⁸ and set out further comment in chapter 7.⁴⁹ It made the following findings and recommendations:

- 1.** A physician with a conscientious objection should not be required to refer a patient to a physician prepared to participate in assisted suicide or voluntary euthanasia
- 2.** Conscientious objection should extend to all professionals, not just physicians, and should also cater for the multi-disciplinary nature of modern care, where some members of the team might wish to participate, whilst others objected on grounds of conscience.

Comment

The National Council agrees with these recommendations.

F. Prognosis

Prognosis is of particular importance, because the Bill as framed included a requirement that a patient be terminally ill in order to qualify for assisted suicide or voluntary euthanasia. “Terminally ill” meant that the patient would die “within a few months at most.” A good deal of evidence before the select committee focussed on the period of six months.

The Select Committee found that the evidence from medical practitioners was that “the prognosis of a terminal illness is far from being an exact science.”⁵⁰

Comment

The Select Committee was right to highlight the inherent difficulty in making a prognosis about the likely date of death. It is already known that the trajectories of different life-threatening conditions vary in numerous respects, including the length of time between diagnosis and death, the rate and sharpness of decline, and the number of acute episodes. Work has already started to understand those differing trajectories, and what their impact might be on palliative care needs. However, it is not clear whether this will shed any insight into whether a patient has reached a “terminal stage” in his illness.

It should also be kept in mind that, as the Select Committee found, forecasting the course of a degenerative condition, such as MND, is a particularly difficult judgement.⁵¹ Yet it is precisely those conditions that are often used by advocates to illustrate

the need for legislation in this area. This reinforces both the difficulty and the importance of drafting good law.

G. Competence

The Select Committee differentiated between a patient having the mental capacity as a matter of law to make a decision to embark on assisted suicide, and being affected by depression which, whilst falling short of mental incapacity, would nevertheless cloud his judgement, and which also might be temporary or capable of treatment.⁵²

The Select Committee also found a general consensus that the attending and consulting physicians, who are envisaged as being the “gatekeepers” in relation to applications for assisted suicide, could not in all cases be expected to spot depression or other factors, such as external pressure, leading to impairment of judgement.

The Select Committee therefore recommended that consideration be given to making a psychiatric referral mandatory to confirm that the patient was making a fully-reasoned decision, that the decision was free from external pressure, and that the patient was not suffering from a disorder causing impaired judgement, but falling short of incapacity.⁵³

Comment

The National Council made a similar recommendation in its written evidence. The National Council would go further than the

Select Committee and say that this should indeed be a mandatory requirement. Any proposed legislation should make clear what the duties of the psychiatrist would be, and in particular, identify the issues that the psychiatrist would be expected to address. This could require the involvement of a multidisciplinary approach in the assessment of the patient’s circumstances. It is possible that more than one session would be required for a psychiatrist to be able to make the determination that a patient had made a decision free from external pressure.

H. Unbearable suffering

The Select Committee appeared to accept the point that “unbearable suffering” carries with it a high degree of subjectivity that is very difficult for doctors to assess objectively.⁵⁴ Many aspects of suffering are non-physical and therefore difficult for a clinician to assess.

The Select Committee therefore suggested that the test of “unbearable suffering” be replaced by “unrelievable” or “intractable” suffering, which would both insert a measure of objectivity, and make it clear that the first priority would be to try to relieve such suffering.

Comment

In the event of further legislation, these seem sensible alternatives to consider. The National Council drew attention to the difficulties inherent in assessing “unbearable suffering” in its written evidence, and would

not wish to see legislation containing that test as a supposed safeguard. The particular challenge is to find an objective means of assessing something that is by its very nature subjective – i.e. the degree to which another person is experiencing suffering. Assessing “existential suffering” related to an individual’s perception of loss of autonomy is particularly difficult.

One important aspect of “unbearable suffering”, that is not met by the terms “unrelievable” or “intractable” suffering, is that “unbearable” carries with it the (subjective) element that suffering must be experienced to a significant extent. It is possible that relatively minor levels of suffering might be unrelievable or intractable.

The Select Committee found that the “suffering” test was the most difficult of the qualifying conditions to define.⁵⁵ It is certainly very difficult, although not necessarily more difficult than achieving a definition of “terminal illness” that matches clinical reality.

Considerable thought will have to be given by supporters of legislation to any future definitions to ensure that they are both workable in reality, and represent an adequate and secure safeguard. The National Council is prepared to engage in discussions about the practicability of any proposals that may be brought forward.

I. The demand for assisted dying or voluntary euthanasia

The Select Committee concluded that: “the demand for assisted suicide or voluntary euthanasia is particularly strong among determined individuals whose suffering derives more from the fact of their terminal illness than its symptoms and who are unlikely to be deflected from their wish to end their lives by more or better palliative care. In any new bill which may be brought forward seeking to legalise assistance with suicide or voluntary euthanasia consideration should be given primarily to focusing on this group of people.”⁵⁶

The Select Committee also distinguished between Oregon, where only assisted suicide is available, and The Netherlands, where both assisted suicide and voluntary euthanasia are available. It noted that the death rates for people choosing assisted suicide were significantly smaller than for those seeking euthanasia. It concluded that was probably because, with assisted suicide, ultimate responsibility for the final act lies with the patient, which suggests that “they think very carefully before taking action.”⁵⁷

On the basis of a pro rata extrapolation from The Netherlands and Oregon, the Select Committee estimated that, were the Oregon model of assisted suicide to be introduced in the UK, the annual take-up rate would be about 650, and if The Netherlands experience was repeated, there would be about 13,000 deaths, of which 12,000 would result from voluntary euthanasia.⁵⁸

Since the Bill would only apply to England and Wales, and not to the UK, those figures would need to be reduced correspondingly. England and Wales make up 88.6% of the UK's population.⁵⁹ On that basis, the Oregon experience, extrapolated to England and Wales, would be repeated in roughly 575 deaths per year, and The Netherlands experience would be repeated in roughly 11,500 deaths, of which 10,600 would result from voluntary euthanasia. Considerable caution must of course be attached to such extrapolated figures.

Comment

The conclusion that demand for assisted suicide would be at its highest amongst the particular type of determined individual described may well be correct, although this must always remain a matter for conjecture in the absence of a change in the law. Loss of autonomy was a particularly strong feature in evidence from Oregon, but not in evidence from The Netherlands (see page 26 below).

Assessing the likely number of people falling into that group is more difficult. It would be a mistake simply to transfer the Oregon or Dutch experience into England and Wales without taking account of the different medical and social cultures, or the availability of palliative care. More comment on this is set out when considering overseas experience.

Whilst it is important to try to estimate the number of people likely to take advantage of legislation, as the Select Committee made

clear, this will be influenced by the way that any law is framed. Also, this will inevitably be a matter for conjecture until a law is implemented.

In addition to trying to estimate the likely scale of demand, there is a need, as the Select Committee endeavoured to do, to understand what lies behind the demand. If the main reason is one of lack of autonomy, what can be done now and what could be done that is not being done to address that?

Action

This links to the discussion and recommended actions in the section on the effectiveness of palliative care on pages 11–13.

J . Vulnerable groups

The Select Committee was particularly concerned by two groups that might be vulnerable in the event of legislation: disabled people, and older people.

The evidence reflected differing points of view as to whether older or disabled people might find themselves at risk under the proposed legislation, and the Select Committee did not reach any conclusions in relation to the evidence.

Comment

Evidently there are organisations and individuals who believe that older and disabled people might be vulnerable to

pressure were legislation to be enacted. These include the Disability Rights Commission, Help the Aged and Age Concern. The experience and concerns of these organisations should not be readily dismissed.

The evidence covered a number of themes:

- How does society view and value the lives of disabled and older people?
- In particular is there a sense that their lives are some how less worthwhile?
- Is there discrimination against disabled or older people in terms of access to services?
- Will disabled and older people perceive any pressure to request assisted dying or voluntary euthanasia?

Research indicates that proportionately fewer older people receive access to palliative care than younger people.⁶⁰ The reasons for this need to be fully understood.

The National Council's policy unit includes a group focussing on the palliative care needs of older people, which will attempt to address some of the above issues.

Even if these fears were groundless (which The National Council believes not to be the case, at least in part), it would be incumbent on those proposing legislative change to ensure that those fears were addressed.

The fact that the Select Committee recommended that consideration should be given to ensuring that a psychiatrist interviews patients seeking assisted suicide or voluntary euthanasia, in part to ensure

that their judgement was unclouded by external pressure, suggests that the select committee believed that this was a live issue.

Recommended Action

This links to the ethical issues raised in the report, in particular how our society views and cares for its more vulnerable people. The National Council will be seeking to establish an ethics collaborative of interested organisations to investigate these issues.

3. Overseas experience (report Chapter 5)

A. Oregon

Oregon law permits only assisted suicide, not voluntary euthanasia. The evidence before the Select Committee suggested that in Oregon many consider that there is a significant ethical gap between the two practices.

The Select Committee found that the Oregon experience is that take-up of assisted suicide appears largely to be by “pragmatic, matter of fact persons who have always been in control of their lives and ordered their lives and want control.”⁶¹ This chimes with the select committee’s findings in relation to likely take-up in Britain.

The Select Committee’s findings in relation to palliative care in Oregon included the following:

1. “Hospice care” in Oregon is “comfort” care only. Entering a hospice care programme involves waiving the right to curative treatment. The reason for this is largely financial: to qualify under Medicare for comfort treatment, a patient must gain access to a hospice service. This requires a prognosis of six months of life or less remaining. Opting into hospice is a one-way ticket, from which patients cannot emerge to obtain curative treatment.⁶²
2. “Hospice” in the United States and especially in Oregon is a service largely based around home care, rather than access as an in-patient to a specialist palliative care unit.⁶³

3. End-of-life care has developed significantly in Oregon in the last 10-15 years.⁶⁴

Comment

Clearly it is important to look to Oregon and see what lessons can be drawn from that state’s experience with assisted suicide. The evidence taken by the Select Committee will be a helpful resource from that point of view.

In further examining the Oregon experience, it will be important to identify and understand differences between the reality of the medical and social cultures in Oregon and Britain. For example, there are clear differences between hospice care provided in Oregon, as described in the Select Committee’s report, and the palliative care that is available in Britain, whether in hospices, other specialist units, or at a primary care level. In particular, “hospice care” in Oregon is not the same as what is meant by a hospice in Britain.

The Select Committee appears not to have explored in any great depth the quality and standards to which palliative care in Oregon is provided, as opposed to the quantity of available programmes. Nor did it seem to explore the extent to which Oregon offers access to specialist palliative care, when compared with what is available in Britain. In Britain, the specialty of palliative medicine requires accreditation after a four-year training programme. This is not the case in Oregon.

The fact that entering hospice care in Oregon excludes access to curative treatment is also a significant difference. In this country, palliative care complements curative care, and is recognised as being of importance throughout the course of a disease.

One quality-related issue requiring further exploration is the extent to which hospice care in Oregon goes beyond pain management. Whilst the Select Committee received evidence that “Hospices (in Oregon) are providing a lot of the medical kinds of social work, psychosocial needs, looking at patients who might have a mental condition, like depression, monitoring those maladies, and making sure they are addressed”,⁶⁵ it did not delve further to examine the level at which such care is provided.

Given that it appears that the primary reason for seeking assisted suicide in Oregon appears to be fear of losing control,⁶⁶ it is important to have some insight into the psychological, social and spiritual care that is available.

The Select Committee also received evidence that suicide is illegal in Oregon, and that failed suicide carries with it legal recrimination. If somebody takes an overdose and survives: “They can be prosecuted. Usually they are not but they can be”... “A lot of fear goes into it”. Physician assisted suicide is the only legal means of ending one’s own life in Oregon.⁶⁷ The extent to which this might affect the cultural background against which decisions are taken was left unexplored.

Take-up of assisted suicide in Oregon is low compared to The Netherlands. The Select Committee received evidence that, in 2003, 67 prescriptions were written for lethal doses of medication. 39 of those patients died after ingesting medicine. 18 died from their illness, and 10 were still alive on December 31 2003.⁶⁸ Caution must be exercised in extrapolating between a population the size of Oregon’s,⁶⁹ and one the size of England’s and Wales’s.

The National Council recognises that there are lessons to be learned from the Oregon experience, but emphasises that it is essential to understand the overall Oregon experience in context, so that true comparisons can be drawn with Britain.

B. The Netherlands

Legislation was introduced in The Netherlands in 2002, to codify existing practices that had built up through case law. The Netherlands permits both assisted suicide and voluntary euthanasia. The medical profession there sees no moral or ethical difference between the two practices.⁷⁰

Voluntary euthanasia and assisted suicide in The Netherlands are not limited to adults, nor does the patient have to be terminally ill. The test is that suffering must be “lasting and unbearable”. The patient must have made a “voluntary and well-considered request to die.”⁷¹

Approximately 16 million people live in The Netherlands, of whom 140,000 die each year. About 9,700 requests for euthanasia are received, and about 3,800 of those actually receive euthanasia. About 300 of those deaths are assisted suicide. In addition there are about 1,000 deaths each year where physicians end patients' lives without an explicit request.⁷² There is evidence that a proportion of deaths go unreported. The official figure is that only 54% of deaths by euthanasia are reported⁷³ but the committee received evidence which appeared to cast some doubt on the reliability of that figure.

The Select Committee considered evidence as to why there are 1,000 cases of euthanasia without explicit request each year, and why doctors do not always report every case. However, it reached no firm conclusion on either point.

The Select Committee considered the state of palliative care in The Netherlands. There was clear evidence that palliative care had been at low level before euthanasia legislation had been considered. Public and parliamentary discussion about legislation had stimulated significant investment in palliative care, starting in 1996. However, there was evidence that investment had now ceased, and that funding had now been ended.⁷⁴

The approach to palliative care in The Netherlands is generalist. Palliative medicine is not recognised as a clinical speciality.⁷⁵

Comment

Again, whilst The National Council recognises the importance of looking overseas, it is important to ensure that the right lessons are drawn. This must involve an understanding of the similarities and differences between The Netherlands and Britain.

The state of palliative care and funding are important issues. Euthanasia was introduced into The Netherlands against the background of very low levels of palliative care. Whilst there is evidence that legislation acted as a catalyst for investment into palliative care, it now appears that palliative care funding has ceased. The Select Committee did not explore why that funding has been allowed to stop, or whether there is any proposal or public pressure for it to be re-instated. It is important to understand properly the relationship between palliative care funding and the availability of voluntary euthanasia or assisted suicide. Would the availability of voluntary euthanasia or assisted suicide act as a brake to further spending on palliative care, given that the quality of palliative care provision in Britain is more advanced than elsewhere?

If hospices were to become involved, it is possible that this would undermine their public support. This again requires research.

The lack of a recognised specialty in palliative medicine is also a significant difference between The Netherlands and Britain. One witness suggested that whilst the number of palliative care units had

increased, because of the lack of a specialty there had been no real improvement in the quality of palliative care.⁷⁶

The Select Committee highlighted two pieces of evidence about the symptoms experienced by patients on whom euthanasia was performed:

- In the case of the 1,000 cases each year where euthanasia was performed without request, there was evidence that in almost all such cases the patients were incompetent (whether due to coma, unconsciousness, lack of capacity or age). One witness said “It is about patients who are mostly very ill, dying and seen to be suffering very much, by vomiting their stools, having very bad bed sores, severe dyspnoea and such like.”⁷⁷
- When asked why patients in The Netherlands ask for euthanasia, one witness said: “84% of them have pain; 70% have extreme fatigue; 50% have gastrointestinal complaints and loss of weight; 70% have coughing, dyspnoea or suffocation; 70% feel extremely weak. Each of these symptoms or combination of symptoms may lead to a situation that, for these patients, is unbearable suffering, and that is basically the reason why they ask their GP to have their life ended.”⁷⁸

Although the Select Committee did not expressly say so, this appears to be in significant contrast to the Oregon experience. There is no suggestion here that loss of autonomy is an issue for these

patients – these are all physical symptoms. Importantly, in Britain, such symptoms are all routinely treated in specialist palliative care units. Patients experiencing such symptoms can be treated – their suffering is not unrelievable.

The Select Committee received evidence from witnesses who suggested that some doctors, when faced with physical symptoms which they do not know how to treat because they do not have experience of palliative care, and a patient requesting euthanasia, do not consider alternative treatments but regard euthanasia as an easy solution.⁷⁹

In short, the evidence in the report raises questions about the funding, availability and quality of palliative care services in The Netherlands, as well as the extent to which the capabilities of palliative care are understood by other medical professionals. These issues need to be understood before legislation is introduced in Britain.

The Select Committee did not reach a conclusion about whether there is evidence of a slippery slope in The Netherlands. In particular, it did not decide whether the 1,000 deaths that occur each year without a request for euthanasia (despite the requirements of the 2002 Act), or the fact that some cases (possibly as many as 46%) of deaths by euthanasia go unreported amount to evidence of a slippery slope. It did not comment on the announcement in 2004 that doctors in Groningen Hospital have performed euthanasia on neo-natal infants.

The Select Committee cited one witness as saying “that there had been no slippery slope.”⁸⁰ However later in his evidence the witness clarified that remark to say that whilst he considered there had been no slippery slope in terms of GPs becoming more lax, the slippery slope had appeared at a different level in terms of political pressure to extend the law to new categories of patient.⁸¹

C. Switzerland and Belgium

Switzerland permits only assisted suicide, not euthanasia. Unlike Oregon, assisting suicide is not restricted to the medical profession; any citizen can assist. Although a prescription for lethal medication is required, that is due to reasons of drug control, and not any sense that assisted suicide is a medical function.⁸² Uniquely, voluntary suicide organisations are involved in providing assisted suicide.⁸³

The Select Committee appears to have confined its evidence sessions to understanding the legal situation in Switzerland and examining the mechanics of how assisted suicide takes place. It did not ask about palliative care in the same way that it did in Oregon and The Netherlands.

In its conclusions the Select Committee raised the possibility that, were legislation to be introduced here, assisted dying or voluntary euthanasia might take place outside the medical setting: “if society wishes to legalise acts that run contrary to

accepted medical ethics, it would be wise to consider whether such acts might not be carried out by other means.”⁸⁴

Belgium’s law, passed in 2002, legalises only euthanasia, and not assisted suicide.⁸⁵ At the same time, a law was passed in general terms prescribing that every Belgian should have access to palliative care.⁸⁶ The report contains no evidence about the state of palliative care in Belgium.

Comment

The Select Committee’s work overseas focussed principally on Oregon and The Netherlands. Further research in Switzerland and Belgium should be undertaken, to see what lessons can be drawn from the experience of those countries.

The Select Committee, and a number of witnesses, raised the possibility that if there is a change in the law, it might fall to a non-medical service outside mainstream health care to provide assisted suicide or euthanasia, as in Switzerland. The practical implementation of such a proposal would require very careful consultation and consideration.

4. Public opinion (report Chapter 6)

The Select Committee commissioned a review of opinion surveys in the last 10-20 years, which was carried out by Market Research Services (MRS). MRS found that virtually all the surveys carried out were quantitative rather than qualitative.⁸⁷ In other words, they were polls directed at counting numbers of people agreeing with simply-expressed propositions, rather than at exploring the understanding and depth of feeling on complex issues.

The MRS report contained the following conclusions:⁸⁸

1. “The research carried out up to this point into public and health sector attitudes to the legalisation of euthanasia is limited in value and cannot be accepted at face value as an authentic account of opinion within the United Kingdom. The subject matter is extremely complex and sensitive and therefore very challenging for anyone attempting to gain a meaningful understanding of opinion.
2. “This is particularly the case with regard to the attitudes of the general public, whose real views on euthanasia are clearly obscured by a lack of information on the subject and by the lack of opportunity to reflect in an informed way upon the implications of any change in the law for themselves and for society. The levels of agreement/disagreement with the concept of euthanasia which the numerous polls record are effectively built on what might be termed a “knee-jerk” reaction to the simple options provided by these polls and do not form a very useful guide to public opinion as support for legislative change.

3. “Nevertheless, the apparent groundswell in public agreement with the concept of euthanasia cannot be dismissed and it is evident that there is much sympathy at a personal level for the concept of legally releasing those wishing to die from their pain and those willing to help them from legal consequences. However, if the decisions of the Committee are to take authentic account of properly informed public opinion, a significant investment in more appropriate forms of research is undoubtedly required.”

In chapter 7, the Select Committee concluded that the issue whether to change the law is a matter for society as a whole to decide through its legislators in Parliament. However, it went on to say:

“Parliament must obviously weigh public opinion very carefully in an issue of this nature. But...it must also assess to what extent opinion research based on answers to questions placed with little surrounding context represents a sound basis for changing the law.”⁸⁹

Comment

The National Council agrees with the conclusions of the MRS report and the Select Committee. Opinion polls are important but they can too often be simplistic and misleading. It will be important that decision making on assisted suicide and voluntary euthanasia should be based on independently commissioned research.

5. Implementation

The Select Committee in its conclusions made the point that the Bill contained no detail about the actions that a doctor would have to take in order either to “assist” a patient to die or administer voluntary euthanasia.

The Select Committee evidently did not consider this to be satisfactory and recommended that any future Bill “spell out what a doctor may and may not do.”⁹⁰

Comment

This point was raised by The National Council in its written evidence. The lack of any detail in the Bill about how voluntary euthanasia or assisted suicide would be performed is a very significant gap. Without understanding how this would work in practice, it is impossible to gauge fully the practical impact that the Bill would have.

It is surprising that the Bill contained no detail about how the performance of assisted dying would be regulated, given that the need for regulation was advanced as one of the reasons for the Bill.⁹¹

There are a number of very practical questions that need to be addressed in relation to implementation. In addition to the type of lethal drugs to be used, the method of administration, the role of pharmacists, the storage of drugs by patients, and so on, these include the question of where voluntary euthanasia or assisted suicide might be administered, as well as who might carry it out. How would the registration and notification of deaths be treated?

As set out above, the select committee suggested that consideration be given to the possibility of it happening outside a medical setting. This is an important issue that the NHS and health care providers and commissioners would need to carefully consider. It should not be assumed that this would be the future responsibility of hospices; there should be no implication that this would be a role that hospices would be prepared to undertake.

Action

The National Council wishes to be involved with any proposals brought forward as to how proposed legislation would be implemented in practice and to consider all the implications for health care commissioning and provision.

6. Assisted suicide or voluntary euthanasia

The Select Committee distinguished between assisted suicide and voluntary euthanasia, and recommended that they be presented as separate options in any future proposed legislation, stating that the considerations involved are very different.⁹²

Comment

Whilst there are of course differences between assisted suicide and voluntary euthanasia, it should not be supposed that one is more straightforward than the other.

Ethical distinctions

On one view there is a very significant ethical difference: with assisted suicide, the patient self-administers the lethal dose and so ultimate responsibility rests with the patient; whereas with voluntary euthanasia, the doctor (or another professional) administers the lethal dose, and so directly intervenes to end life. As set out above, the Select Committee found that this was a commonly-held view in Oregon.

An alternative view is that both practices involve the doctor (or another professional) taking active steps to intervene to bring about the patient's death by administration of a lethal dose. Regardless of whether the patient or professional administers the dose, in both cases the patient's death by such means is seen as a "good." There is no serious ethical difference between the two. The Select Committee found that this was a pre-dominant view in Holland.

The National Council's view

There is clearly an ethical difference between supplying someone with the means to commit suicide, and actually administering a drug to them to bring about their death. However, adopting either practice into British law would involve a very significant shift in current practice and thinking. At present, an active intervention to bring about death is not regarded as a "good". That would change with legislation.

Although it is possible that there would be fewer requests for assisted suicide than there would be for voluntary euthanasia, that would not necessarily reduce the practical challenges that implementation would bring. For example, professionals would still require practical and ethical education and training. Indeed, the regulatory problems of implementing assisted suicide might be more significant than those relating to voluntary euthanasia: the patient would have a lethal dose in his or her keeping for an unspecified period. How is that to be kept? What is to happen if the patient dies before using it – and who should be responsible for it? Would the patient be able to use an agent to collect the prescription from the pharmacist?

Both assisted suicide and voluntary euthanasia would bring significant implementation challenges. As set out above, The National Council is prepared to continue dialogue in relation to any proposals that may be put forward.

7. Conclusions (report Chapter 7)

The Select Committee made the following recommendations about any future Bill:⁹³

1. a clear distinction should be drawn in any future bill between assisted suicide and voluntary euthanasia in order to provide the House with an opportunity to consider carefully these two courses of action, and the different considerations which apply to them, and to reach a view on whether, if such a bill is to proceed, it should be limited to the one or the other or both (Paragraphs 243-246);
2. any future bill should set out clearly the actions which a doctor may and may not take either in providing assistance with suicide or in administering voluntary euthanasia (Paragraphs 247-248);
3. if a future bill should include terminal illness as a qualifying condition, this should be defined in such a way as to reflect the realities of clinical practice as regards accurate prognosis (Paragraphs 250-251);
4. a definition of mental competence in any future bill should take into account the need to identify applicants suffering from psychological or psychiatric disorder as well as a need for mental capacity (Paragraphs 252-254);
5. consideration should be given in any future bill to including “unrelievable” or “intractable” suffering or distress rather than “unbearable” suffering as a criterion (Paragraphs 255-256);
6. if a future bill is to claim with credibility that it is offering assistance with suicide or voluntary euthanasia as complementary rather than alternative to palliative care, it should consider how patients seeking to end their lives might experience such care before taking a final decision (Paragraphs 257-258);
7. in setting a waiting period between an application for assisted suicide or voluntary euthanasia and the carrying out of such actions, any future bill should seek to balance the need to avoid increased suffering for determined applicants against the desirability of providing time for reflection for the less resolute. Such a waiting period is of less importance in the case of assisted suicide but needs to be considered carefully in the case of voluntary euthanasia (Paragraphs 259-260);
8. any new bill should not place on a physician with conscientious objection the duty to refer an applicant for assisted suicide or voluntary euthanasia to another physician without such objection; it should provide adequate protection for all health care professionals who may be involved in any way in such an application; and it should ensure that the position of persons working in multi-disciplinary teams is adequately protected (Paragraphs 261-263);

9. any new bill should not include provisions to govern the administration of pain relief by doctors (Paragraphs 264-266).

Comment and next steps

The National Council agrees with these recommendations, and raised many of them in its written and oral evidence to the Select Committee. It considers that the Select Committee has produced a balanced report which clearly identifies many of the issues that need to be addressed before a decision whether to legalise voluntary euthanasia or assisted suicide in England and Wales can safely be made. The report is not, as has been suggested in some quarters, a “green light” for legislation. It is however a green light for further research to inform significant discussion and further informed debate.

In light of the Select Committee’s report, it would seem inappropriate for supporters of change in the law to be over-hasty in re-introducing legislation without having first addressed in detail the substance of the issues raised by the Select Committee.

The National Council’s written submission of evidence to the Select Committee stated:

“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.”

The submission went on to call for further research, and identified areas in relation to which such research is required. This was echoed by the call in the MRS report, cited approvingly by the Select Committee, for “significant investment in more appropriate forms of research.”

If society and parliament are to have the informed debate that is required, more research and evidence is necessary. Considerable time and financial resources need to be committed and it will be important to identify sources of funding to enable this work to proceed as soon as possible. The National Council is willing to work with interested partners to address some of the identified gaps. An option could be to establish a collaborative where funding and expertise could be pooled, and perhaps supported by additional grants identified through the Big Lottery Fund or Government sources to deliver a programme of targeted actions.

References

- ¹ The National Council's written evidence can be found on-line at www.ncpc.org.uk. Its oral evidence can be found on the Select Committee's website at http://www.parliament.uk/parliamentary_committees/lordsassisted.cfm
- ² Report: para. 18
- ³ Para. 62
- ⁴ Para. 62
- ⁵ Paras. 11 & 64
- ⁶ Para. 64
- ⁷ Para. 63
- ⁸ Para 63
- ⁹ Paras 64-65
- ¹⁰ Para 64
- ¹¹ Mental Capacity Act 2005 s. 4 (5)
- ¹² Para. 47
- ¹³ Para. 68
- ¹⁴ Para 239
- ¹⁵ Para. 81
- ¹⁶ The NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004), para. 112
- ¹⁷ See: 20:20 Vision – shaping the future of palliative care, NCPC, 2005
- ¹⁸ Guidance on Improving Supportive and Palliative Care for Adults with Cancer, NICE, 2004, para 114
- ¹⁹ Para. 84
- ²⁰ Para. 85 – 2004 figure
- ²¹ Para. 85 – 2004 figure
- ²² Para. 85
- ²³ Para 87
- ²⁴ Para 90
- ²⁵ Palliative Care, House of Commons Health Committee, 2004
- ²⁶ Palliative Care for Adults with Non-malignant Diseases, NCPC, 2003
- ²⁷ Palliative Care, House of Commons Health Committee, 2004 (para 79)
- ²⁸ Para 89
- ²⁹ Para 88
- ³⁰ Para 89
- ³¹ See paras 88-89
- ³² Para 87
- ³³ The National Council published Palliative Care for Older People in Care Homes in 2004. This was followed by a consensus-building conference in 2005. The recommendations and next steps were published in July 2005
- ³⁴ Para 257
- ³⁵ Para 258
- ³⁶ Para 86
- ³⁷ Paras. 92 and 93
- ³⁸ See page 27 and Ev QQ 1510-11
- ³⁹ Para 269
- ⁴⁰ Para 99
- ⁴¹ Para 254
- ⁴² Para 101
- ⁴³ Doctors in Groningen announced in December 2004 that they had performed euthanasia on infants, and produced "The Groningen Protocol" – guidelines on infant euthanasia – which they hope to persuade the government to adopt, to avoid prosecution. See for example: <http://www.timesonline.co.uk/article/0,,8122-1586066,00.html>. See also Ev. Q 1510
- ⁴⁴ Paras 102-3
- ⁴⁵ Para 106
- ⁴⁶ Para 104
- ⁴⁷ Para 105
- ⁴⁸ Paras 113-116
- ⁴⁹ Paras 261-263
- ⁵⁰ Para 118

⁵¹ Para 120

⁵² Para 123

⁵³ Para 254

⁵⁴ Para 256

⁵⁵ Para 255

⁵⁶ Report Abstract

⁵⁷ Paras 243-4

⁵⁸ Para. 243

⁵⁹ ONS estimates, mid-2003:

www.statistics.gov.uk

⁶⁰ 83% of all deaths are of people aged 65 and over. However percentages for people over 65 gaining access to specialist palliative care services range between under 60% to 68%. See The National Council's evidence to the House of Commons Health Committee Inquiry into Palliative Care, 2004. Also: End of life care: promoting comfort, choice and well being for older people at the end of their lives, Help the Aged, 2005

⁶¹ Para 163

⁶² Para 157

⁶³ Para. 156

⁶⁴ Para 154

⁶⁵ Ev Q 802

⁶⁶ Ev Q 753

⁶⁷ Ev. QQ780-784

⁶⁸ Letter from Oregon Department of Human Services. Vol II, Ev. Page 255

⁶⁹ Oregon's population in 2000 was 3.4m

⁷⁰ Paras 167-168

⁷¹ Paras 170-172

⁷² Para 171

⁷³ Para 180

⁷⁴ Paras 183-5. See also Ev. Q 1491

⁷⁵ Para 183

⁷⁶ Para 185

⁷⁷ Para 179

⁷⁸ Para 185

⁷⁹ Ev QQ 1533-1535

⁸⁰ Para 191

⁸¹ Ev QQ 1510-11

⁸² Para 192

⁸³ Para 200

⁸⁴ Para 242

⁸⁵ Paras 209-10

⁸⁶ Para 213

⁸⁷ Para 217

⁸⁸ Para 232

⁸⁹ Para 240

⁹⁰ Para 248

⁹¹ Vol II, Evidence p.13

⁹² Para 246

⁹³ Para 269

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