Government response to the report of the Select Committee on Medical Ethics / presented to Parliament by Command of Her Majesty, May 1994.

GOVERNMENT RESPONSE TO THE REPORT OF THE SELECT COMMITTEE ON MEDICAL ETHICS

Presented to Parliament by Command of Her Majesty

May 1994

Cm 2553

LONDON: HMSO

£2.00 net

GOVERNMENT RESPONSE TO THE REPORT OF
THE SELECT COMMITTEE ON MEDICAL ETHICS

Introduction

1. This Command Paper sets out the Government's response to the report of the Select Committee on Medical Ethics.

2. The Government welcomes this report, and acknowledges the Committee's diligent and thorough examination of what is a very sensitive area. The Government hopes it will promote constructive discussion of a very difficult subject.

3. The Committee's remit was to examine the issues surrounding the withholding of life-prolonging treatment, including euthanasia. The Government's overriding concern in this area is to:

protect the interests of patients, particularly those who are in no position to make a competent decision for themselves, and to ensure that health care is provided in a way which is humane as well as ethical and legal;

safeguard the patient's right to consent to treatment or withhold consent to treatment (save in the limited circumstances where the law provides for treatment without consent—for example, the Mental Health Act 1983);

ensure adequate protection is given to people in a vulnerable position—especially those who, by virtue of their medical condition, are unable to exercise their right either to consent to treatment or to withhold consent;

ensure that actions which have as their intention another person's death continue to be unlawful.

4. The Government broadly endorses the position adopted by the Committee. The Law Commissions for England/Wales and Scotland are currently examining various issues related to mental incapacity and decision-making, including medical treatment. The Government will wish to examine some of the Select Committee's recommendations alongside those of the Law Commissions for England/Wales and Scotland when they report later this year.

5. Responses to the Select Committee's individual recommendations are given below. (The paragraph references are to those in the Select Committee's report.)

Response to recommendations and conclusions

Paragraph 278: We recommend that there should be no change in the law to permit euthanasia (para 237).

The Government strongly supports the Committee's rejection of the case for the legalisation of euthanasia and endorses the reasoning by which it has arrived at this conclusion. Euthanasia is, of course, a controversial subject on which the Government acknowledges strong views are held. However, the Government's firm view is that the deliberate taking of life should remain illegal.

Paragraph 279: We strongly endorse the right of the competent patient to refuse consent to any medical treatment (para 234).

The Government agrees with this recommendation, which accords with existing policy in this area as set out in the booklet "A Guide to Consent for Examination or Treatment" issued by the Department of Health and Welsh Office. The Patient's Charter also emphasises the individual's right *"to be given a clear explanation of any treatment proposed, including any risks and alternatives, before you decide whether you will agree to the treatment".*

An exception to this would be in the strictly limited circumstances prescribed in law where treatment may be given without the need for patient consent. For example, patients detained under the Mental Health Act 1983 (or Mental Health (Scotland) Act 1984) may be given treatment for their mental disorder without their consent but only in certain circumstances and under the direction of the responsible medical officer.

Paragraph 280: If an individual refusal of treatment by a competent patient is overruled by the Court, full reasons should be given (para 235).

If circumstances should arise where a competent patient's refusal of treatment is overridden by a Court, the Government agrees that full reasons should be given by the Court to demonstrate why the patient's wishes are being overridden and to enable an appeal to be lodged where appropriate.

Paragraph 281: We strongly commend the development and growth of palliative care services in hospices, in hospitals and in the community (para 241).

Paragraph 288: Palliative care should be made more widely available (para 276).

The Government shares the Committee's view of the importance of palliative care services. In the past decade, palliative care (and pain relief) have emerged as specialities in their own right. While most palliative care is currently provided by the voluntary hospice sector, there has been a growth in the provision of these services in NHS palliative care units, in hospitals, in nusing homes and, increasingly, through day care, respite care and care at home.

For example, the Cancer Relief Macmillan Fund and Marie Curie Cancer Care work in partnership with the NHS to provide specialist nurses, doctors and other health care professionals to provide and co-ordinate care for terminally ill people. Other local voluntary groups provide "hospice at home" schemes.

The number of in-patient hospice beds has doubled over the last ten years. In January 1994, there were about 3,000 hospice beds in the UK, over 350 home care teams and over 200 day units. Many nursing homes also provide care for terminally ill people.

The Standing Medical Advisory Committee/Standing Nursing and Midwifery Advisory Committee Report "The Principles and Provision of Palliative Care" (1992) recommended that all patients needing palliative care services should have access to them, and that the principles and good practice of palliative care which have been stimulated by the voluntary sector should be incorporated at all levels in the NHS.

The SMAC/SNMAC report also recommended that there should be an expansion of education programmes in palliative care to ensure continued support for higher medical training programmes and advanced nursing studies. There is evidence that this is happening with the development of post-graduate training for doctors, nurses and other professionals intending to practise in palliative care. Courses are widely available, run by university faculties, hospices and cancer charities.

The Department of Health and Welsh Office have asked NHS management to take the report's recommendations into account in developing strategies for palliative care. In Scotland, a similar strategy was initiated following the 1991 report of the Scottish Health Service Advisory Council on the care of the dying and the bereaved.

Government funding allocated to health authorities in England for hospices and similar palliative care organisations increased from £8 million in 1990/91 to £32.3 million in 1993/94. This will be increased to £35.7 million in 1994/95, a real terms increase of more than 6 per cent. The other UK Health Departments also provide special funding for palliative care.

In addition, £6.3 million will be made available to fund a scheme to enable hospices in England to obtain drugs for their patients free of charge. A similar scheme applies in Scotland.

The Government will continue to encourage the development of palliative care in all settings to ensure that patients receive sensitive care and relief from pain and other distressing symptoms.

Paragraph 282: Double effect is not in our view a reason for withholding treatment that would give relief, as long as the doctor acts in accordance with responsible medical practice with the objective of relieving pain or distress, and without the intention to kill (para 242).

The Government agrees.

Paragraph 283: Treatment-limiting decisions should be made jointly by all involved in the care of an incompetent patient, on the basis that treatment may be judged inappropriate if it will add nothing to the patient's well-being as a person (para 255).

The Government will consider this recommendation along with any recommendations which the Law Commissions make in this area.

Paragraph 284: We recommend that a definition of pvs and a code of practice relating to its management should be developed (para 258).

The Government agrees that a code of practice would be valuable, and notes that it is primarily a matter for the health professions. The Government is beginning discussions with them on the best way to take forward the recommendation. Such a code will need to take account of any decisions taken by the Government as a result of the Law Commissions' recommendations in this area.

Paragraph 285: Development and acceptance of the idea that, in certain circumstances, some treatments may be inappropriate and need not be given, should make it unnecessary in future to consider the withdrawal of nutrition and hydration, except where its administration is in itself evidently burdensome to the patient (para 257).

It is already incumbent on doctors and other staff caring for the patient to consider very carefully whether any new treatment they are about to provide for the patient is in his/her long term best interest. This is an important general principle, not confined to patients in persistent vegetative state or who may develop PVS.

Where the withdrawal of nutrition and hydration is at issue, as in the case of Tony Bland, cases in England and Wales should continue to be referred to the Courts. The Law Commission is considering the circumstances in which a judicial body should authorise the cessation of artificial hydration and nutrition.

Paragraph 286: Treatment-limiting decisions should not be determined by considerations of resource availability (para 275).

As the Committee recognises, resources for health care are not infinite. Health Authorities are responsible for making the best use of these funds by assessing the needs of their local populations, deciding overall priorities and purchasing services from hospitals and other health care providers. Within provider units decisions have also to be made about the type and level of resources devoted day to day to particular clinical specialities.

However, choices at the individual patient level between treatment, non-treatment and treatment-limitation remain a matter for clinical judgement. Continuation or otherwise of treatment should always be determined by reference to the overall benefit the treatment is providing for the patient.

Paragraph 287: Rejection of euthanasia as an option for the individual entails a compelling social responsibility to care adequately for those who are elderly, dying or disabled (para 276).

The Government agrees. The Patient's Charter affirms the right of every citizen of whatever age to receive health care on the basis of clinical need. Similarly local authorities are required to arrange appropriate community care services for everyone who needs them. We expect these services to be tailored as far as possible to the needs of the individual person receiving them.

Paragraph 289: Research into pain relief and symptom control should be adequately supported (para 276).

The Government agrees and is currently considering commissioning work to assess current technology in this area.

Paragraph 290: Training of health-care professionals should prepare them for ethical responsibilities (para 276).

In recent years considerable progress has been made in teaching health care ethics to doctors and nurses at both pre- and post-qualifying level. Examination of the ethical responsibilities of health care professionals and the dilemmas faced in practice are significant elements in most undergraduate and post-graduate curricula.

The General Medical Council (GMC), which is responsible for the standards and quality of undergraduate medical education, has recently issued new recommendations. These include, as one of the suggested curriculum themes, "Man in Society" which covers issues relating to palliation and care of the dying. It suggests that this theme should be present throughout the full five years of the course.

The GMC's recommendations also set objectives which include attaining knowledge and understanding of the importance of communication and the ethical issues relevant to medical practice. Another objective is the awareness, at an early stage in the course, of the moral and ethical responsibilities involved in patient care.

The Government accepts that training in communication skills, counselling and ethical issues should continue as a part of post-graduate training and indeed throughout a doctor's career. It will bring the Committee's recommendation to the attention of the Royal Colleges, regional post-graduate deans and others involved in the post-graduate and continuing training and education of doctors.

The UKCC, the statutory body responsible for regulating the nursing, midwifery and health visiting professions, specifies that in pre-registration (Project 2000) nursing courses, students must achieve "an understanding of the ethics of health care and of the nursing professions, and the responsibilities which these impose on the nurse's professional practice".

Paragraph 291: Long-term care of dependent people should have special regard to maintenance of individual dignity (para 276).

The Government agrees. Respect for privacy and dignity is one of the National Charter Standards in the Patient's Charter, which was published in October 1991.

Paragraph 292: We support proposals for a new judicial forum with power to make decisions about medical treatment for incompetent patients (paras 245, 246).

Paragraph 298: We do not favour the more widespread development of a system of proxy decision-making (para 271).

These recommendations raise different issues for Scotland and the rest of the UK because of differences in law.

In England and Wales, the Law Commission is currently engaged in a review of the law and procedures for decision-making on behalf of mentally incapacitated adults including medical decision-making. The Commission are considering, amongst other things, the merits of proxy decision-making, and whether there should be a new jurisdiction or other forum with power to make decisions about medical treatment for mentally incapacitated patients. A Consultation Paper entitled "Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research" was published in April 1993 and the Commission hopes to report to the Lord Chancellor in the course of 1994.

The Scottish Law Commission has been involved for some years in a large-scale exercise examining many legal issues in relation to the mentally disabled, and intends to publish a report later in the year which will deal, amongst other things, with the legal arrangements for managing their welfare. The report will make specific reference to the needs of PVS patients. (Scots law, unlike the law in the rest of the UK, already provides for proxy decision-makers to be appointed by the Court.)

The Government will consider the Select Committee's recommendations on these areas in the light of the reports of the Law Commissions for England/Wales and Scotland, when received.

Paragraph 293: We do not recommend the creation of a new offence of "mercy killing" (para 260).

The Government agrees with this recommendation. We do not believe that active intervention to end life should be excused on the basis of either motive or the victim's consent. To do so would undermine the law's uncompromising attitude towards deliberate killing and might bring with it many of the dangers associated with the legalisation of euthanasia.

Scottish law on homicide differs from the law in England and Wales in certain respects, but neither jurisdiction accepts a defence of consent or an unselfish motive on the part of the accused as an answer to a charge of murder.

Paragraph 294: We strongly endorse the recommendation of a previous Select Committee that the mandatory life sentence for murder should be abolished (para 261).

The Government is not at present persuaded that it would be right to abolish the mandatory life sentence for murder. The mandatory life sentence marks the unique nature of the offence of murder, and it represents the only certain way of ensuring that anyone who deliberately takes the life of another person forfeits his liberty to the state for the rest of his life.

The arrangements for release on licence do, however, provide considerable scope for flexibility with regard to the amount of time served in prison. The Home Secretary or the Secretary of State for Scotland can take into account considerations such as motive and the circumstances of the individual case in considering the period of imprisonment which must be served to meet requirements of retribution and deterrence. In exceptional cases prisoners can be released after a comparatively short period in prison.

Paragraph 295: We recommend no change in the law on assisted suicide (para 262).

We agree with this recommendation. As the Government stated in its evidence to the Committee, the decriminalisation of attempted suicide in 1961 was accompanied by an unequivocal restatement of the prohibition of acts calculated to end the life of another person. The Government can see no basis for permitting assisted suicide. Such a change would be open to abuse and put the lives of the weak and vulnerable at risk.

Paragraph 296: We commend the development of advance directives, but conclude that legislation for advance directives generally is unnecessary (paras 263, 264).

Advance directives enable individuals to make their prior wishes known, against the possibility that at a future date they may be unable to express their views to those caring for them. The Government agrees generally with the Select Committee's conclusions about their value.

Both the English/Welsh and Scottish Law Commissions have been looking at advance directives. The Government will consider their conclusions when they report.

Paragraph 297: We recommend that a code of practice on advance directives should be developed (paras 265–267).

This recommendation is directed at the colleges and faculties of the health care professions, but the Government agrees that a statement of good practice would be valuable and will discuss with the health professions how it might best be taken forward. Such a code will need to take account of any decisions taken by the Government as a result of the Law Commissions' recommendations in this area.

ISBN 0-10-125532-2

Printed in the United Kingdom for HMSO
Dd 5062357 5/94 C10 65536 Ord 286823 17/29940