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Rights of the sick and dying

Report
Social, Health and Family Affairs Committee
Co-rapporteurs: Ms Marga HUBINEK, Austria, and Mr J.J. VOOGD, Netherlands

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A. Draft Recommendation presented by the Committee on Social and Health Questions [1]

The Assembly,

1. Considering that the rapid and continuing progress of medical Science creates problems, and may even pose certain threats, with respect to the fundamental human rights and integrity of sick people;

2. Noting the tendency for improved medical technology to lead to an increasingly technical – sometimes less humane – treatment of patients;

3. Observing that sick persons may find it difficult to defend their own interests, especially when undergoing treatment in large hospitals;

4. Considering that recently it has become generally agreed that doctors should in the first place respect the will of the sick persons with regard to the treatment the person concerned has to undergo;

5. Being of the opinion that the right to personal dignity and integrity, to information and proper care should be clearly defined and granted to every person;

6. Convinced that the prolongation of life should not in itself constitute the overriding aim of medical practice, which must be concerned equally with the relief of suffering;

7. Emphasising that the prolongation of life by artificial means depends to a large extent on factors such as the availability of efficient equipment, and that doctors working in hospitals where the technical equipment permits a particularly long prolongation of life are often in a delicate position as far as the continuation of the treatment is concerned, especially in cases where all cerebral functions of a person have irreversibly ceased;

8. Insisting that doctors shall act in accordance with science and approved medical experience, and that no doctor or other member of the medical profession may be compelled to act contrary to the dictates of his own conscience in relation to the right of the sick not to suffer unduly, enable them to discuss these problems with persons approaching the end of life, and through psychiatrists, clergymen or specialised social workers attached to hospitals;

9. Recommends that the Committee of Ministers invite member governments:

9.1. a. to take all necessary action, particularly with respect to the training of medical personnel and the organisation of medical services, to ensure that all sick persons, whether in hospital or in their own homes, receive relief of their suffering as effective as the current state of medical knowledge permits;

9.1.1. to impress upon doctors that the sick have a right to full information, if they request it, on their illness and the proposed treatment, and to take action to see that special information is given when entering, hospital as regards the routine, procedures and medical equipment of the institution;

9.1.2. to ensure that all persons have the opportunity to prepare themselves psychologically to face the fact of death, and to provide the necessary assistance to this end both through the treating personnel – doctors, nurses and aids – who should be given the basic training to

9.2. to establish national commissions of enquiry, composed of representatives of all levels of the medical profession, lawyers, moral theologians, psychologists and sociologists, to establish ethical rules for the treatment of persons approaching the end of life, thereby considering inter alia the situation which may confront members of the medical professions, such as possible legal sanctions, whether civil or penal, when they have acted or refrained from acting in such a way as had the consequence of shortening life, and to examine the question of written declarations, made by legally competent persons, authorising doctors to abstain from life-prolonging measures in particular in case of irreversible cessation of brain function;

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1. *a.* Adopted by the committee on 26 January 1976 by 19 votes in favour, 3 votes against and 5 abstentions.

Members of the committee: MM. Grussenmeyer (Alternate: R. Schmltt) (Chairman); *Adriaensens* (Alternate: Tanghe), *Mrs* Berglund, *MM.* Bourgeois, Biichner, Cohen, Coutsocheras, *Desmond* (Alternate: Crowley), *Hauglin* (Alternate: Aaslaiul), *Mrs* Hublnek, *MM.* Hul- p'uiu, Lewis, *Mrs* Miotti Carli, *MM.* Muscat, Page, Peijnenburg, Reinhart, H. Schmidt, *Mrs Sôder* (Alternate: *Mrs* Gradin), *MM.* Spautz, Tonbus, *Mrs Vlachou-Loundra* (Alternate: *Mr* Frangos), *'Mr* Voogd, *Mrs* Wolf, *MM.* Wyler, *Zaffanelk* (Alternate: *Mrs* Cattaneo Petrini), *Zaloglu* (Alternate: Karaosmanoglu).

N. B. The names of those who took part in the vote are printed in italics.

b. See 24tli Sitting, 29 January 1976 (adoption of the draft recommendation as amended), and Recommendation 779.

9.3. to establish national commissions of appeal to consider complaints against medical personnel for errors or negligence in the practice of their profession.

B. Draft Resolution

The Assembly,

1. Believing, for reasons set out in Recommendation 779 (1976) on the rights of the sick and explained in the report of its Committee on Social and Health Questions (Doc. 3699), that the true interests of the sick are not always best served by a zealous application of the most modern techniques for prolonging life;

2. Convinced that what dying patients most want is to die in peace and dignity, if possible with the comfort and support of their family and friends;

3. Concerned that unnecessary anguish may be caused by uncertainty over the most appropriate criteria for the determination of death;

4. Insisting that no other interests may be considered in establishing the moment of death than those of the dying person,

5. Invites the responsible bodies in the medical profession in the member states to examine critically the criteria upon which decisions are currently based with respect to the initiation of reanimation procedures and the placing of patients into long-term care requiring artificial means of sustaining life;

6. Invites the European Office of the World Health Organisation to examine the criteria for the determination of death existing in the various European countries, in the light of current medical knowledge and techniques, and to make proposals for their harmonisation in a way which will be universally applicable not only in hospitals but in general medical practice.

C. Explanatory Memorandum by Mrs HUBINEK and Mr VOOGD

1. Introduction

1.1. Procedure

1. On 24 January 1974, Mr Archer and others presented to the Parliamentary. Assembly a motion for a recommendation on a European Declaration on the Rights of the Sick (Doc. 3401) with a view to patients being accorded all rights and liberties so far as compatible with their condition, in particular the right to information as to their treatment and the right freely to decide on the kind of treatment to be applied to them. The motion recommends that the Committee of Ministers adopt a European Declaration on the Rights of the Sick. On 25 January 1974 it was referred by the Assembly to the Committee on Social and Health Questions (Reference No. 1004).

1.2. Background

2. In recent years, public opinion seems to have been increasingly concerned with such questions as:

a. the rights and duties of patients regarding the form of care and treatment given to them;

b. human experimentation, including the testing of new cures;

c. organ transplants;

d. progress in the field of genetics;

e. problems concerning euthanasia.

What are the reasons for the particular importance now being attached by society to these matters?

3. The background to some of these matters is a complex one, covering, for example: the extraordinary progress made by medicine as a result of its own development as well as of important discoveries in biology, biochemistry and other sciences; the possibility of prolonging life in previously inconceivable circumstances; the performance of surgical operations on vital organs which it was formerly considered to be fatal to stop functioning; the grafting of tissues and organs; and the prevention or halting of the conception of human life without any great disadvantage. Each of these scientific achievements poses complex moral, social, legal and even economic problems, whose implications frequently extend to the human rights sector. Nor should it be forgotten that these important matters are tied up with the question of the funds set aside for hospitals, medical care, drugs, treatment or experimentation on patients to improve human welfare.

4. It is questionable whether national legislation can provide solutions to these problems. It is a fact that the continuous progress of technology and medical science in recent years has given rise to a multitude of new problems for which no legislative solutions have yet been found. Should the aim of medicine be to diagnose and cure diseases or to help people to diagnose, resolve and master their own individual and collective health problems? Of what use is a diagnosis if it is not followed up by effective action arid acceptable results? Whenever a new method is discovered, should society necessarily make it available to all who are looking for it P Or to all who can afford it? Or to all who require it? Should one continue to develop a complex medical technology for the treatment of acute or. fatal diseases, or would it be better to devote more effort to diagnosing and curing complaints which have a major impact on the quality of our lives? What proportion of health budgets should be spent on therapeutics as opposed to medical care? Should funds spent on medicines or forms of treatment whose effectiveness has never been objectively assessed be transferred to services and personnel capable of improving the living conditions of the chronic sick? To what extent can a physician act as a teacher to the sick and to the healthy? Is it sufficient simply to tell a patient that he is suffering from a chronic illness and prescribe treatment for him, or should both he and those around him be taught how to cope with the problem so that he can lead a satisfactory life, in so far as he is able, without being totally dependent on his family or his community?

5. It even seems probable that for certain specific problems neither medicine nor legislation will ever find an adequate solution at either national or international level because of various highly complex moral, or religious factors. But in spite of these difficulties, attempts have been made at both international and national level to arrive at solutions. For several years now doctors and medical lawyers have been holding frequent meetings for this purpose.

2. Development of the concept of rights of the sick

2.1. The international level

6. At international level, numerous codes of ethics have been drawn up since 1945, including the following:

– the Code of Nuremberg (1947),[2]

– the International Code of Medical Ethics (London, 1949),

– the Declaration of Geneva (1948),

– the Declaration of Helsinki (1966),[3]

– the Declaration of Sydney (1968),

– the Declaration of Oslo (1970), and the recommendation adopted by the Round Table on Human Rights, organised by WHO (World Health Organisation) and which took place in Geneva on 14 and 16 November 1973.

7. In October 1967, in co-operation with UNESCO and WHO, the Council for International Organisations of Medical Sciences convened a round table in Paris at which the ethical and even legal problems raised by human experimentation were discussed. The difficulty in obtaining consent in cases of organ transplants, particularly kidney transplants, was emphasised. The members of the round table likewise expressed the wish that in countries where there were centres capable of carrying out such operations but where such operations were forbidden by law, regulations be laid down to prescribe the circumstances in which the voluntary donation of a transplant organ could be accepted.

8. Reference should be made here to the 1968 appeal by the General Assembly of the United Nations, expressing world-wide concern and requesting the Secretary General to prepare a report on the urgency of a number of questions, including the protection of the individual and his physical and intellectual integrity in the light of progress in biology, medicine and biochemistry.[4] Attention should also be drawn to another document, entitled Declaration on the Rights of Mentally Retarded Persons, proclaimed by the United Nations General Assembly on 20 December 1971. In 1971, the United Nations Commission on Human Rights adopted Resolution 10 (XXVII) envisaging a study being made of the implications of progress in medicine, biology and biochemistry for human rights, particularly for the protection of an individual's physical and intellectual integrity, as well as for the right to health.

9. A further important provision, indeed the one which has the closest bearing on our subject, is Article 7 of the International Covenant on Civil and Political Rights, adopted by the United Nations General Assembly on 16 December 1966, which states in particular “that no one shall be subjected without his free consent to medical or scientific experimentation”. However, this article is 'fair 'from providing a solution to tie problems currently arising in this context.

10. These various international texts, particularly the Declarations of Geneva 'and Helsinki, have considerably influenced the terms of numerous codes of ethics relating to the medical profession in several countries, notably France, the Federal Republic of Germany, the Netherlands, Switzerland and the Scandinavian countries.

The Council of Europe

11. A group of experts on human clinical pharmacology, restricted to eleven member states, is making a study of the various problems relating to the scientific investigation of the effects of drugs on man. The group considers it advisable to harmonise national legislation on drug registration so as to achieve reciprocal recognition of the results of pre-clinical and clinical testing of drugs. It recommends in this context the drawing up of recommendations aimed at improving facilities for initial clinical testing and the supervised use of experimental forms of treatment. It also intends to carry out co-ordinated research on the safe and effective use of registered (marketed) drugs and to study the ethical, legal and insurance problems raised by clinical testing (Doc. PA/SP (73) 26, appendix). The legal problems raised by the removal, grafting and transplanting

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2. See Appendix I far text.
3. See Appendix II for text,
4. The United Nations Secretariat prepared a detailed report on this subject (see Doc. E/CN. 4/1028 of 28 February 1970 with six appendices, of which Appendices 2 and 5 are particularly relevant).

of human organs were the subject of a general debate on member states' legislative policy at the 9th Conference of European Ministers of Justice, which took place in Vienna on 30 and 31 May 1974 (Doc. CMJ/ Concl. (74) 1). The Ministers stressed the complexity of the problems involved, pointing out that they had both legal and non- legal aspects. The responsibilities of physicians and the rights of patients were the subject of a Council of Europe symposium held in Lyons in March 1975. The points discussed included:

11.1. the economic aspects of the right to health (public health expenditure trends in the different states; legal and economic aspects of public health planning);

11.2. Patients' Charter (comparative study of Patients' Charters in states where they already exist; problems of harmonising patients' rights in relation to research and teaching; patients' rights depending on whether the medical profession is organised on a private or a public basis);

11.3. public health, preventive medicine and the rights of the individual (compulsory reporting of diseases; individual health record and automatic processing of medical data; compulsory vaccinations; protection of the incapacitated);

11.4. civil liability of physicians;

11.5. ethical and legal limits to medical experimentation.

2.2. B. National level

12. As regards the national level, since 1972 the United States has had a Patients' Bill of Rights (see Appendix III), which has aroused great interest throughout the world, particularly in France.

13. On 14 January 1974, Decree No. 74-27, generally known as the “Charter of the Rights and Duties of the Sick”, was published by the French Ministry of Health and Social Security. It deals, among other things, with conditions for admission to and stays in hospitals. Article 38 lays down that the reception of patients and those accompanying them must be carried out at all levels by staff specially trained for the purpose. Four rights are embodied in the decree:

– the right to be admitted and discharged;

– the right to dignity;

– the right of communication;

– the right of information.

A patient's right to information on the hospital, its staff and his own case is guaranteed by the decree, which also makes provision for the distribution of an explanatory booklet upon arrival, giving the patient practical information on the hospital and its routine. The preparation of a separate charter for the protection of the mentally sick was recently announced.

14. By formulating such rights, these two charters demonstrate a concern to make hospitals more humane and ensure greater respect for the dignity of patients. Generally speaking, the following basic rights may be deduced from them:

– the right to freedom;

– the right to personal dignity and

– integrity;

– the right to information; the right to proper care; the right not to suffer.

2.3. C. Rights defined

15. Right to freedom. This fundamental right includes the right to be admitted to hospital without difficulty and to leave freely at any. time. The French Charter of the Rights and Duties of the Sick, of 14 January 1974, specifies that a patient must be allowed to leave hospital freely if he sees fit not to accept the treatment offered him, regardless of his state of health, provided he has settled any debts and signed a certificate discharging the physician from liability in the event of the latter not giving his agreement (Article 54 et seq.). The right also includes the right to refuse surgery and new forms of therapeutic treatment.

16. Right to personal dignity and integrity. This right implies that medical premises should be so arranged that examinations can be carried out and treatment given without a patient suffering any loss of dignity vis-à-vis other patients, physicians, hospital staff or the outside world. A patient may demand that no information be revealed regarding his presence at the hospital or his state of health, and he may refuse visits from persons he does not wish to see. s It should not be forgotten that a patient's human dignity generally implies a right to the truth, which is therefore closely linked to a patient's right to information. An individual is entitled to respect for the integrity of his being as a whole (body and mind). Naturally, physicians may not violate this integrity, even at the request of the person concerned, unless this is required by the latter's treatment. The law has in fact had to be adjusted to give doctors a say, as it is sometimes difficult to judge whether medical intervention is necessary. This too is a matter for a physician's own conscience.

17. Right to information. A patient's right to information on the hospital, its staff and his own case is also a fundamental right. In several countries (for example, Canada, the United States and France) a booklet is issued to patients upon admission to hospital, giving them all relevant practical information on the establishment and its routine. The recent French decree referred to above makes the distribution of this booklet compulsory. A patient has a right to know who is treating him and how he is being treated. He is, moreover, entitled to accept or refuse any forms of treatment or care offered him. In ail too many cases he is unaware of this. Implicit in this right to refuse treatment is of course the patient's right to receive adequate information on his state of health from the physicians and other, qualified staff, as well as to have the necessary information given to his family and to have his medical record passed on as promptly as possible by the hospital medical staff to the physicians responsible for his treatment both during and after his stay in hospital. All forms of medical care require the participation of the patient, Moreover, his free and informed consent is necessary. It is therefore essential that a physician inform his patient of the chances of his illness being cured. Free and informed consent of this kind is sometimes difficult to guarantee. In most cases the patient will not be qualified to make any choice, and in some instances, although his consent may. be freely given, it will not be particularly informed, as a patient is often unable to take a valid decision about himself. There is no precise definition of the term “consent”. Legal theory and practice are, however, in agreement in requiring that consent be not just free but above all informed, and be preceded by detailed and accurate information on the conditions and effects of the action proposed.

18. Right to proper care. This light overlaps with the right to information and the right to physical integrity, particularly in the case of human experimentation, including the trying out of new forms of therapy. A patient must have the right to benefit from experimentation and new forms of treatment, but also the right not to suffer as a result. The sole purpose of treatment in the case of experimentation with new drugs must be curative, i.e. experimentation should be permitted only where the advantages outweigh the disadvantages. One of the questions to have aroused most reaction in certain countries in recent years is, without doubt, that of human experimentation. The problem was seldom discussed before the second world war. Afterwards there was an increase in the use of volunteers (students, prisoners, migrant workers) as patients. The World Medical Association considered it necessary to publish a declaration known as the Declaration of Helsinki, the text of which is attached (see Appendix II). This declaration, which embodies the gist of the Code of Nuremberg rules, is frequently quoted by medical researchers throughout the world in connection with human experimentation. It makes a distinction between the use of experimental forms of treatment and non-therapeutic experimentation. In the case of the former, it lays down that a physician must be free to apply an experimental method of treatment if he considers it offers a genuine chance of saving the patient's life, restoring his health or alleviating his suffering; where possible, the physician must obtain the patient's free and informed consent. With regard to non-therapeutic experimentation, the declaration specifies that the free consent of the person concerned must be obtained in all circumstances and that he must be informed by the physician of the nature, aims and dangers of the experiment envisaged. As a result of this declaration, codes of ethics have been drawn up for the same purpose in several countries, including the United States, Austria (official publication of the Ministry of Social Affairs, 19 December 1976) and France (Decree No. 72-1062 of 21 November 1962 on specialised drugs and experimentation with drugs).[5]

19. Right not to suffer. This right includes not only a patient's right to benefit from all the newest methods capable of facilitating a diagnosis effecting a cure or alleviating pain but also, in this case, the right to stop suffering altogether. It is an established fact that medical progress has led to greater longevity without always preventing the deterioration of organic functions. Moreover, continuation of a life without hope can cause great suffering, not only for the patient himself but also for those around him. Where the diagnosis has been medically confirmed, should a life devoid of all hope be kept going or should the patient be given the right, if he can express himself, to stop suffering altogether, to be given immediate and painless relief?

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5. Journal Officiel No. 279 of 30 November 1962.

20. There are various other questions relevant to the subject under discussion. Although they cannot be examined in detail, they should nevertheless be mentioned, in particular the question of the protection of medical secrecy and that of the responsibilities and rights of a physician. With regard to professional secrecy, the use of automatic data-processing in medicine, particularly for medical files, prompts the view that medical secrecy and a patient's right to privacy may no longer be protected in the same way as hitherto. This may well turn out to be a real danger, and responsibilities of the medical profession in this field are considerable.

2.4. D. Definition of death and organ, transplants

21. The right to physical and mental integrity is particularly closely connected with the definition of death, as well as the transplanting or removal of organs. This is because it is important to know at what moment it is permissible to stop a heart, artificial lung etc. functioning, and in particular at what moment it is permissible to use a body for organ transplants.

22. At international level, the most frequently quoted definitions of death are those of the Council for International Organisations of Medical Sciences (CIOMS), dating from 1968, the one in the Declaration of Sydney, formulated the same year, and that of the International Transplant Society, dating from 1970. In addition, in 1968 an ad hoc committee of the Harvard Medical School established a new and clear definition of cerebral death which has subsequently been adopted verbatim or with few modifications by many national medical associations. The new definition was deliberately concerned with organ transplant surgery. It made the “killing” of the donor of an organ (chiefly in the case of kidney transplant operations) for the sake of the recipient of the organ medically and ethically permissible. “Killing” for the sake of the recipient normally occurs by switching off the breathing apparatus. As a purely secondary matter the definition permitted switching off the apparatus in the case of other patients whose brains had died but who were not donors of organs. It should be mentioned that there is no specific reference to criteria for establishing death in either the recommendation of the International Transplant Society or the Declaration of Sydney. At national level, there are various definitions of death in both statute law and case law. These include a definition by the American State of Kansas and a Swiss definition (Judgement of 28 June 1972 by the Federal Court, which accepts “cerebral death as a criterion which is now almost unanimously recognised” (Chambre de droit public, Recueil Officiel, pp. 491 et seq.)). The protection of the right to live, and hence a reliable definition of death, is of such importance as to warrant being embodied in a statutory provision.

23. With regard to the transplantation of organs, there is no legislation in France on the removal of organs from living persons, but French legal theory and case law do refer to cases of necessity. The removal of organs from living persons must comply with the following conditions:

– organs may only be donated (i.e. not sold);

– the donor must give his “informed” consent. The consent of the donor is not sufficient if the operation is not carried out for a legitimate purpose. Removal must not be contrary to morality or the rules of social conduct.

3. The question of euthanasia

3.1. Introduction

24. Examination of the list of rights in II. C above, together with the 'formulation in the original motion for a recommendation (Doc. 3401), which mentions in particular the right to dignity, the right to information and the right freely to decide on the kind of treatment, gives rise to reflection on the extent of the rights involved; at least three of the rights mentioned – the right to freedom, the right to decide on treatment and the right not to suffer, might well be thought to point toward a right to euthanasia. From the start the committee showed strong interest in this aspect, and the present section is an attempt to clarify a few of the issues involved.

25. It should be noted that the European Convention for the Protection of Human Rights and Fundamental Freedoms defines, as the first right to be protected, the right to life. At some point a consideration of euthanasia must examine the trade-off between the right to life and the right not to suffer. In so far as attention is confined to the individual whose life or suffering is involved, the conflict may exist only at a superficial level, since rights are not mandatory – one may choose not to exercise a right. On the other hand, at the level of medical ethics an uneasy tension may be generated between the instinct – or even die duty (if there is a right not to suffer) – to prevent suffering and the duty to prolong life. Moreover, at the level of general socio-medical policy, decisions have from time to time to be made between the preservation of life at all costs – where relatively few persons may be involved and the cost may be astronomically high – and the more general

prevention of suffering at a less dramatic stage for a much larger section of the population. The emotional force of the euthanasia issue derives, in one perspective, less from concern that certain individuals might choose not to exercise their right to life, but that society might arbitrarily and in a more or less obligatory way refuse to recognise the right to life of certain individuals, or even categories of individual. An attempt is made below to delimit the sense of euthanasia for the present discussion in a way which would exclude such situations; but in any discussion of euthanasia, the right to life provides- a salutary starting point.

26. The right not to suffer, on the other hand, immediately creates very serious problems. It is an intrinsically ill-formed concept, since the corresponding duty may very well be incapable of fulfilment; in that case, by a fundamental rule of jurisprudence, it is void. More seriously, the alternative implications of a right not to suffer may be mutually contradictory: it may imply a right to be cured, to be anaesthetised or to be put permanently beyond suffering; and the decision between these may be not simply a technical matter but a question of priorities, of balancing short-term suffering by long-term benefit, and so forth. It would be wrong, however, to suppose that the right not to suffer constitutes the only justification for euthanasia, even if it is that most generally cited. In particular, one may refer here to cases of persons kept alive but unconscious over long periods. There is presumably no suffering involved, yet the question of the indefinite prolongation of life in such cases is frequently posed.

3.2. The basis of discussion

27. For the present purpose the term “euthanasia” may be used to refer to any death which is not wholly natural[6] and not accidental – therefore implying that a conscious decision is made – which is not suicide – and therefore involves an agency other than the subject – and is not murder – and is therefore not contrary to the will of the subject. If the term is understood in this way, it clearly throws up several of the larger issues which are usually canvassed in discussions of this subject, namely the taking of the decision, the establishment that the act is voluntary and the role of the outside agent. The first two in turn raise very important issues of information and knowledge where the role of the outside agent (the doctor) as expert is fundamental. In this connection it may be worth considering briefly why the doctor comes naturally to mind as the agent in euthanasia. The answer is twofold: first, the question most obviously concerns those who are already in need of and undergoing medical care; secondly, doctors command the most acceptable means of euthanasia. It is also arguable that in the situations in question the doctors' judgment may be the most balanced. Clearly, in cases of passive euthanasia these two factors coincide.

28. Discussion is regularly based upon a distinction between “active” and “passive” euthanasia; whereas active euthanasia would involve an act which would shorten or terminate life, passive euthanasia signifies failure to take action which may prolong life. In practice, it may be extraordinarily difficult to draw the distinction between the two. The term “indirect euthanasia” is also used to refer to cases where death is caused as an undesired side-effect of action undertaken for some other purpose.

29. It should be noted at this point that attempts are sometimes made to exclude the concept of passive euthanasia on the grounds either that the term euthanasia is misleading in such an area or on the grounds that the kinds of activity referred to by die term are so different – so obviously humane and acceptable – that it should not be discussed in the same context as any form of active killing. This attitude is misleading.

30. For reasons which will become apparent, it is unacceptable to say simply that decisions on further treatment of a dying patient, including the question whether or not to give any further treatment, are simply matters of clinical judgement. Moreover, as Professor Haemmerli has pointed out, “if the overall term euthanasia is restricted to patients who are bound to die of their basic disease, then the distinctions between passive and active euthanasia may be no more than a play on words”. Professor Haemmerli has further shown that the act of switching off breathing apparatus in the case of the patient whose brain has died is active in the sense that it is an act of commission but passive at the level of intention where passive euthanasia constitutes tire omission or interruption of an attempt to save the patient. It is also to be emphasised that, in practice, when certain artificial means of maintaining life are switched off or disconnected, the doctor is obliged to act positively to put an end to the agonising asphyxiation which would otherwise result. Certain members of the committee have expressed the view that, while active and passive euthanasia

6. This is a current term, and useful for purposes of analysis; but it proves very resistant to definition. Inevitably, discussion 6f euthanasia centres upon cases where the distinctions 'between what is “natural” and What is not have been largely broken down. It may be argued that euthanasia is an answer to the danger of keeping people alive “artificially”; but many people, young as well as old, are kept alive “artificially” and lead useful and happy lives.

achieve the same material result, there is a fundamental difference in the moral quality of the act in the two cases. The Rapporteurs cannot share this view; it is essential that a discussion of euthanasia include a discussion of passive euthanasia understood as in the sense formulated above.

31. The concept of death requires a certain clarification in view of the advances in medical thinking in recent years. Traditionally, death was established by the cessation of circulation and respiration. Recently, the question of change in this position has been discussed in the context of the transplantation of organs, and the ethical problems of reanimation and the maintenance of life by artificial means. There is pressure for a new concept of cerebral death on the basis of a total, irreversible loss of central brain function. Where this occurs – or even where the brain functions to the extent of regulating the elementary bodily functions, in particular spontaneous respiration – the life of the body has to be maintained by artificial means. It is natural that there should be a temptation to see death as having already occurred with the onset of such a condition. It would solve serious problems in the supply of organs for transplantation; it would also remove doubt over the justifiability of discontinuing life-saving treatment for patients in the condition described. There remain, however, grave problems of uncertainty. Not only does the concept require expertise and equipment which are beyond the reach not only of laymen but of most doctors; it also creates an uncertainty over the time of death. It will therefore be assumed in what follows that death is for the present to be determined by the traditional means.

32. It is also important to avoid introducing a category of the “dying” intermediate between the living and the dead. Doctors and scientists find it unrealistic to think in terms of a sharp distinction between the two states; some philosophers have held similar views. It is clearly the case that death is a gradual process and that different levels of death may be distinguished. On the other hand, the process in strictly scientific terms is immeasurably longer than is indicated by most of those who wish to use the category of the “dying”; the concept must introduce a degree of uncertainty unacceptable to the law; and in political terms any policy based upon it would arouse a disastrous reaction in public opinion. For all these reasons, therefore, the category is best eliminated. We shall assume that persons are living up to the moment of death as traditionally defined and dead thereafter.

3.3. The medical viewpoint

33. On the basis of statements made to the committee as well as information appearing in the press and elsewhere, it may be said that the medical viewpoint on the topic of euthanasia amounts to a demand for freedom to act in accordance with the doctor's professional judgement and ethical principles, together with a refusal to be involved in killing upon request. There are a few exceptions to the latter while the former proposition is subject only to the qualification that doctors would welcome a legal framework which guaranteed their professional freedom rather than one which may, as at present, burst in haphazardly upon their sphere of activity. Professor Haemmerli, in his statement before the committee, claimed by implication that sick and dying persons do not think rationally in the same way as when they are in good health, and that only “experienced reality” of death, with which doctors and nurses are in daily contact, provides an adequate basis for judgement in this area. Such a position depends heavily upon a conviction, not only of the good faith but also of the good sense of the medical profession as a whole. It is, to some extent, belied by the gap which all medical men are prepared to acknowledge between ideal medical treatment within the limits of current knowledge and the situation as it often exists in practice. This gap may be due to lack of resources, insensitive medical policies or tire over-zealous medication which all deplore. In the last case, regulation is needed to counteract the effects of mistaken zeal by doctors themselves. In the other two cases, the decision is, in any event, one to be taken outside the medical profession.

34. There are, however, more serious objections to the medical viewpoint with its demand to be left free of interference. It is in the interests of doctors themselves, and, therefore, ultimately of their patients, to be protected against the consequences of too much freedom. Any discretion invites disputes as to whether or not it has been properly exercised in a given case. Professor Wilkes, in speaking to the committee, drew attention to the problems faced in the legal sphere by doctors in the USA, where the question of professional liability insurance is in consequence becoming a whole area of study on its own. It is in the interests of doctors that there should be as precise guidelines as are consistent with the progress of medical science. To take an example relative to what has already been said: would doctors in general really welcome the freedom to establish cerebral death, on the basis of an electro-electroencephalogram reading over a period of time, with the enormously costly implications this could have in the field of inheritance law, insurance claims and so forth?

35. Nevertheless, it might be argued, despite the consequences for doctors, that only medical science is competent to define the moment of death. In ideal terms, this may be true so long as medical science is unambiguously concerned with the care of each patient seen absolutely as an individual; but these conditions are very stringent and it is scarcely possible for them to be realised in the present day. Unavoidable complications create ambiguities in obvious ways, such as possible tensions between (lie interests of an organ donor and of the recipient, but also much more generally over the proper allocation of scarce resources between various competing priorities. The therapeutic purpose of a medical act is a key concept in legal thinking and once it is put in doubt, doubt falls equally upon any absolute claim of medical science to non-interference.

36. A particular aspect of the medical viewpoint requires consideration, namely the claim that doctors can judge when a particular course of 'action, or its continuation, would be “pointless”. In any but a purely medical forum this term is dangerously ambiguous. No doubt a conscientious doctor in using this term refers to a matter of technical judgement whether a particular course of action will, in fact, achieve the desired end. To the laymen, on the other hand, the term may naturally convey a value judgement as to the quality of the result which may be expected, and whether it is worth the effort. It may be that such judgements have to be made, but the medical profession is not trained for them, as has often been remarked, and it is arguable that value judgements of this kind do not properly form any part of a doctor's work.

37. It is impossible, in this context, to embark upon full-scale discussion of medical ethics or the doctor's duty. Disagreements are, in general, over questions of emphasis and priority, but all would agree that one may distinguish three principal elements in medical care: cure, care and the preservation of life. The first has traditionally held the pre-eminent position, in part, as was recently pointed out in Le Monde (6 May 1975), because medical ethics developed in a period when the principal duty was to combat fatal diseases among the young. The same attitudes are not immediately transferable to the present-day situation, where two thirds of all deaths occur among the old who are subject to progressive physical decline. By a natural progression of -drought, tire traditional medical view has tended to the belief that failure of attempts to cure or, more recently, to prolong life, marks the effective termination of medical activity. The special skills required for the care of incurable patients have thus received less attention than they deserve.

38. This distinction between curing from caring reveals a further danger in judgements of “pointlessness”. Judgements of this kind are concerned with some goal, either its feasibility or its value, which must give the process its justification. The concept of caring, on the other hand, is not one which implies a goal to be achieved; rather, medical care in this sense is justified at each moment. The relief of suffering is self-justifying.

3.4. The legal aspect

39. There is no specific legal treatment of euthanasia as such in the legal systems of Council of Europe member states, although there are a number of legal provisions which bear on the subject, concerning homicide, suicide and the professional duties of doctors. It would be convenient here to rely upon the distinction between active and passive euthanasia.

Active euthanasia

40. Since suicide is no longer a crime in any Council of Europe member state, it might be supposed that assisted suicide – which is what active euthanasia in the sense defined often amounts to – would equally be permissible. The situation is not so simple, however, and the individual case may often depend upon the degree of participation of those involved. German legislation, according to which complicity in suicide is not a crime, nevertheless includes a specific prohibition of killing on demand, and the subject is variously treated in other systems. In England, a complicated situation was produced by the combined effects of the Homicide Act of 1957 and the Suicide Act of 1961 which made suicide no longer a crime. While killing upon request is still murder, a new offence of complicity in suicide was created; one must therefore take the view that there is a liberty and not a right to commit suicide. This probably corresponds to the position resulting from other legislations also. (This may raise problems as to whether or not one has the right to restrain someone from committing suicide or whether such an attempt would constitute an assault.) It is clear that the permissibility of suicide has not also established the permissibility of assistance in committing suicide. In general, this is an ill-defined area and the position varies from one country to another. While in Germany, complicity in suicide is not a crime, there exists, as in France, an offence of non-assistance to a person in danger. Depending upon the legislation, a doctor who kills a suffering patient at his request may be accused of premeditated homicide, though in certain cases with a less severe penalty.

41. The situation is clearly different where there is no clear consent of the person concerned, for example, by reason of unconsciousness. In such cases, there has been a tendency towards nominal penalties in view of the doctor's motivation, or even of acquittal on the grounds of doubt whether the doctor's act was in fact responsible for the death of the patient. A recent report of the Church of England expressed the view that flexibility of this kind in the application of the legal system was preferable to any change, but it must be doubted whether the position is entirely satisfactory. Explicit reliance upon flexibility in the law brings it into disrepute.

Passive euthanasia

42. The legal position in respect of passive euthanasia depends upon three points: the possibility recognised by some, but not all, legislations of homicide by omission; the professional duty of the doctor; and the right of the patient to refuse treatment. The first is a difficult area into which it would be unprofitable to enter; it is, in any case, unlikely that a charge of homicide by omission would be brought in the present climate of opinion against a doctor who, for appropriate motivation, omitted or interrupted a course of treatment which was senseless. On the obligation of a doctor to provide the best possible care, the vital question from a legal point of view is the objective establishment on purely medical grounds of the soundness of any decision. This will involve such questions as confirmatory or conflicting opinions by other members of the profession, and the establishment of motivation.

43. The right of the patient to refuse treatment is the foundation of the law on medical treatment. Any medical act is, in principle, an assault upon the person unless it can be shown that the patient consented, and the common-law countries take a particularly robust position on this. The patient, therefore, has an established right to refuse treatment, a right which courts will, in general, interfere with only for the most imperative reasons, for example, in the interests of a related child. The same is not true, for example, in France, where doctors have been accused of omitting necessary treatment when they have obeyed a patient's wishes in this respect. It might seem that for the common-law countries there was a clear right to passive euthanasia. However, in practical terms, this has less significance than might appear. In the nature of tire case passive euthanasia is, in general, of significance in cases of patients artificially kept alive, and such patients will very often be in no condition to express their view. Those who are fully conscious and suffering and wishing to die would, in general, need some more active measure. The right to refuse treatment, therefore, provides no clear solution to the problem of passive euthanasia.

Consent

44. The fundamental concept, from a legal point of view, in the whole question of euthanasia, whether active or passive, is that of consent. At the present time, under most legal systems, the general rule with regard to medical treatment might be summed up by saying that therapeutic purpose plus consent amounts to legality. Thus, if the doctor acts with a view to the proper care or cure of his patient, and the patient consents, then legal problems do not arise. However, there are limits to the validity of consent even where there is a therapeutic purpose; consent to an operation which in some way maims the patient is not valid. The act, in other words, must not be intrinsically unlawful. Even outside the medical sphere, the rule applies: it is no defence to a charge of homicide that the victim consented. It has already been noted above, moreover, that the validity of consent is limited in French law and under other systems, in the opposite sense also that the absence of consent to a necessary course of treatment may be overruled. At the conceptual level, therefore, there does not at present exist any absolute right of self-determination with respect to physical treatment in general and death in particular.

45. It is to be noted that consent, in order to have any significance, carries certain implications, above all with respect to the competence of the subject to decide for himself, his freedom from outside pressure, and the adequacy of the information upon which his decision is based. These issues have been very much discussed in recent years in the context of organ transplantation. They clearly require even more serious consideration in tie context of euthanasia. The question of competence, for example, is particularly relevant to precisely the categories of persons who may be envisaged in discussions of certain types of euthanasia, for example the very old, whose physical decline is matched by a decline in their mental powers. Again, the question of adequate information, as a basis for the decision, requires close attention in view of the prohibition by the French code of medical ethics on revealing to a patient a seriously unfavourable prognosis.

46. It is arguable also that consent, even with the safeguards already mentioned, is not a sufficiently strong concept, since it implies that the initiative comes from elsewhere. Such a situation, in practice, would be unacceptable. It is unimaginable that doctors should invite their patients to allow themselves to be killed.

4. Some conclusions

47. With this background, it may be useful to consider what are the situations most likely to arise in practice. They fall, in general, into two categories: first, persons Who are sick but not in a terminal position, conscious, in full possession of their faculties and suffering to an extent which makes them desire a final relief; secondly, those who are in a clearly terminal position, maintained in life by artificial means, unconscious. In general, those in the first category desire a positive relief from their suffering by any means and require assistance to this end. The second category may be presumed not to suffer or to desire anything; yet the question presents itself to those who have care for them whether their condition should be maintained indefinitely. There are also many persons who are in neither condition, who are, in fact, in perfect health and sanity but who, through fear or distaste for the conditions described, wish by means of an advance declaration in favour of euthanasia, to avoid reaching them.

48. With respect to the first category, it is claimed by all doctors that there should be no need for any patient to suffer severe pain, that is, that the technical means are available, if properly applied, to control pain. Two obvious questions arise: are these means always applied and properly applied? Secondly, and especially if the answer to the first question is “no”, should the desire of such patients to end their suffering permanently be respected? The answer to the first question is clearly negative; while the relief of pain in specialised clinics or hospitals and by staff specialised in these questions is, undoubtedly very effective, it is obviously the case that many other persons do suffer unnecessarily. In particular, it is to be noted that an improvement in pain relief is often reported upon transfer from hospitals where the standard of medicine is generally very high, for example, university teaching hospitals, to institutions specialising in the care of patients in this condition.

49. Action, then, is required. Is it possible to anticipate such an improvement in the relief of pain for all patients that no further action will be necessary?. If not, is “mercy killing” an appropriate answer? Should it be the patient's right in any case? There is, in effect, a distinction to be drawn between relieving pain by action to shorten life and shortening life by action to relieve pain. Most doctors are prepared to consider the latter if necessary, that is to say, the provision of such measures for the relief of pain as risk a shortening of life. It is difficult to say that this would conflict with medical ethics. Positive action to shorten life, however, is in principle rejected by almost all doctors. This would be an important barrier to be overcome if the patient's right to request such action were admitted. It is to be noted, in addition, that all doctors report an infinitesimally small number of requests for such action from patients in this condition.

50. On the other hand, it is not unknown for requests in this sense to be received from the friends or relatives of the patient. Such requests are to be absolutely resisted where a patient is in full possession of his faculties and does not express any wish or consent to be killed. Such an act would, at present, certainly constitute premeditated homicide and there can be no justification for a change in that legal position.

51. On 27 January 1975 a motion was submitted to the Conseil national in Switzerland which envisaged an amendment of the existing penal code to the effect that actions against the life or person of a patient would not be an offence if carried out with the intention of shortening the suffering of a patient, who was bound to die painfully and within a short time. The doctor would be obliged as far as possible to procure the consent of the patient and, where appropriate, of his legal representative, and to take into account the opinion of his relatives. In the light of what has been said above, it is clear that this proposal includes two very dubious features: first the qualification on the requirement of the patient's consent that this should be procured “as far as possible”; secondly, the admission of action to relieve pain by shortening life. On the other hand, it should toe noted that tire opinion of relatives is to be sought only where the patient is not in a position to express himself. This point, will be considered below.

52. With respect to those suffering from illness from which there is no hope for a cure, who are not in full possession of their faculties and who are maintained in life by artificial means, the problems are extremely complex. From the legal point of view, difficulties must arise by reason of the fact that the patient is incapable of expressing his own wishes. The question arises in such circumstances of whether, and within what limits, others may take decisions which vitally affect him. Some decisions are of a technical or clinical nature, most notably the establishment that the condition is irreversible and the discovery of the means most suited to prolong life. There is, however, a fundamental decision which is of a non-technical nature, namely, how long should life be prolonged by artificial means.

53. There are serious ambiguities in this area depending upon the point of view adopted and, as has been shown above, the distinction between active and passive euthanasia or between commission and omission may break down. On the one hand, it may seem abhorrent consciously to act in such a way that the life of the patient will be shortened. On the other hand, the maintenance of life by artificial means of those who can never hope to regain their personality over an indefinite period is patently contrary to sense and humanity. But

at what moment may the decision be taken and, above all, on what grounds? If it is no longer a matter of clinical judgement, there seems no good reason why the doctor alone should be entrusted with this decision. There remains only the possibility of empowering relatives of the patient to act in such an area. The dangers here are obvious, not only of bad faith on the part of the relatives, conscious of their own rather than the patient's interests, but more generally, the problem of a judgement clouded by familiarity with the patient and his condition. It may be that, in such a situation, the proper solution would be to leave the initiative to close relatives of the patient, with the decision to be confirmed by more than one doctor; there would have to be special provision for cases where there are no close relatives. In very advanced cases, however, where the patient has reached the stage of “brain death”, it is arguable that the doctor should be explicitly empowered to take the initiative of bringing life to an end.

54. It must be stressed, as all doctors who write upon this subject do stress, that in any case where life-prolonging measures are omitted or interrupted and the therapeutic work of the doctor is, in effect, terminated, there is a vital need for the highest standards of care in the closing stage of the patient's life. Professor Haemmerli went so far as to state before the committee that in any case where such action had been taken in his clinic, and there was, thereafter, any suspicion of a failure in nursing care, the decision was immediately reversed.

55. Problems of the kind described could, to some extent, be avoided by action at a more general level. It is universally acknowledged that the major problems with respect to the indefinite prolongation of life by artificial means have become acute only in the last twenty years, since the development of reanimation techniques in the early 1950s and the general advance in artificial support systems since that date. At a political level, decisions are made daily over the allocation of scarce resources to the medical services – for example not to provide artificial kidneys vital to the survival of a certain number of patients – decisions which may amount to the application of passive euthanasia to whole categories of the population at a time. At a more individual level, general practitioners make comparable decisions each time they decline to refer a patient to hospital. It is clear that what harrows the public conscience is not the failure to keep people alive by al possible means but the decision to switch off or not to switch on a particular machine available to a particular patient. In so far as this problem arises, we have suggested that it may be approached in the manner outlined above, but such an approach should be linked to a more searching examination into wider questions of medical policy.

56. It remains to discuss the desire expressed by many persons of sound body and mind to see instituted a (legally -valid form of declaration by which the individual might request, in advance, that in case of serious suffering or irreversible unconsciousness his life should be ended. Such a proposal, which has been made in a number of countries, most recently in Switzerland, may raise certain difficulties, some of which were brought out in the course of a thoughtful debate in the British House of Lords on tire Voluntary Euthanasia Bill in 1969. The principal points made on that occasion concerned, firstly, the question of the duration of validity of such a declaration – there must be some way of ensuring that the patient is not by oversight, bound by a declaration made thirty years earlier; secondly, the question of avoidance of abuse – if a declaration is forged or made under pressure or otherwise improperly carried out, tire death of the patient makes redress, or even proof of the abuse, singularly difficult. The difficulties were also highlighted in the recent report of the Church of England On Dying Well: “Since the patient who is a candidate for euthanasia is ex hypothesi not in a condition to make a rational choice at the time when it would need to be administered, consent can be secured only by a previous declaration. The declaration has to be formally registered if abuse is to be prevented. Something like the arrangements proposed in the 1969 Bill would seem to be essential. But these arrangements presuppose a reasonable man who decides upon due deliberation that he wishes euthanasia to be administered to him in certain circumstances and remains thereafter capable of deciding with equal rationality whether he shall adhere to his resolution or cancel it. He must be in his right- mind when he signs the declaration (need he be when he wants to cancel it?). In any case it will fall to someone to decide whether he is in his right mind or not, and problems are likely to arise at that point.” Specimen forms of declaration are annexed to this report (Appendix IV). If such a system is to be instituted, careful attention will have to be paid to the practical details, not only of the drawing up and validation of the declaration, but also of its continued validity, its application in practice, and the possibility of withdrawal.

57. In discussing the medical viewpoint, we stated that the doctors' desire for non-interference could put them in a dangerous situation. Any policy on the subject of euthanasia must consider not only what society expects of its doctors, but also how to guarantee their legal position in carrying out these measures. On the other hand, we take it to be of fundamental importance that no doctor may be required to act in any way which conflicts with traditional medical ethics. Whatever decisions society may take and by whatever legal means doctors are to be protected in carrying them out, they must be permissive and. not mandatory.

Appendix 1 – Code of Nuremberg [7]

The Code of Nuremberg lays down the following rules regarding clinical experiments:

1. It is imperative to obtain the patient's voluntary consent.
2. The experiment being conducted must be capable of producing results of benefit to society which could not be obtained by any other method.
3. The experiment must be conducted in the light of experimentation on animals and the most up-to-date information on the disease concerned.
4. The experiment must be so designed as to avoid any physical or moral coercion.
5. No experiment should be conducted if it involves a risk of death or disablement, unless perhaps the physicians themselves take part in the experiment.
6. The risk involved must never be greater than the importance to mankind of the problem concerned.
7. Every effort must be made to avoid any long-term side effects after the experiment.
8. The experiment must be conducted by competent persons. The highest standard of care and competence is necessary at all stages of the experiment.
9. Throughout the experiment, the volunteer patient must be free to decide to halt the experiment if it is causing him mental or physical discomfort or if, for any other reason, he feels unable to continue to undergo the experiment.
10. The experimenter must be ready to halt the experiment at any time if he has reason to believe, on the most qualified advice, that its continuation could result in the patient's death or disablement.

7. Unofficial version.

Appendix 2 – Declaration of Helsinki, 1964 [8]proclaimed by the World Health Association

Preamble

The role of a physician is to be the custodian of health. His knowledge and moral sense must be entirely devoted to the fulfilment of this function. Under the Geneva Declaration of the World Health Association, the physician has a duty to observe the basic principle that his sole concern is the health of his patients.

Believing it is essential for the results of laboratory experiments to be applied to human beings in order to further scientific knowledge and help the sick, the World Health Association has prepared the following recommendations to guide physicians in the conduct of clinical research throughout the world. Naturally, the principles outlined below are merely a code and cannot be regarded as exempting physicians from their criminal, civil and moral responsibilities under the laws of their countries.

A fundamental distinction should be made in the field of clinical research between research whose aim is basically remedial and that whose aim is purely scientific and from which the subject derives no therapeutic benefit.

Basic principles

1. Clinical research must comply with the moral and scientific principles underlying medical research and must be carried out only after thorough experimentation on animals, in the light of scientifically established facts.
2. Clinical research must be conducted by competent ' scientists under the supervision of a qualified physician.
3. Clinical research must not be undertaken unless its purpose is objectively proportionate to the risk it involves for the patient.
4. All clinical research projects must be preceded by a detailed enumeration of the risks involved and the advantages expected.
5. Particular care should be taken to ensure that the experiment does not impair the personality of the patient.

Application to the use of experimental forms of treatment

1. When treating a patient, a doctor must be free to make use of an experimental form of treatment if, in his opinion, it is capable of saving the patient's life, curing him or leading to an improvement in his state of health. Wherever possible, depending on the patient’s psychological state, the physician should obtain the patient's free consent to the experimental form of treatment envisaged (after providing him with full explanations). If the patient is legally incapable of giving such consent, it must be obtained from the person responsible. If the patient is physically incapable of giving his permission, the permission of the person legally responsible should be obtained instead.
2. The physician has the right to combine clinical research and patient treatment with a view to acquiring new medical knowledge; such clinical research must, however, be justified by the patient's treatment.

Application to experimentation proper

1. In the case of pure experimentation, it remains the primary duty of the physician to protect the life and health of the person on whom 'he is experimenting.
2. The nature, aim and dangers of the experiment must be explained to the subject.
3. a. No experiment may be undertaken without the free and informed consent of the subject. If the subject is not accountable for his actions, authorisation must be obtained from his guardian. - b. The physical and mental state of the subject must be such that he can properly exercise his freedom of choice. - c. Consent must be obtained in writing. The experimenter is solely responsible for the experiment and cannot transfer his responsibility to the subject, even with the subject's agreement.

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8. Unofficial version.

4. a. The experimenter must have due regard to the right of each individual to respect for his physical integrity, particularly as the subject is dependent on him. - b. The subject, or his guardian, has the right to halt the experiment at any time. The person or team carrying out an experiment must suspend it if its continuation may be considered harmful to the subject.

Appendix 3 – Statement of the American Hospital Association on a Patient's Bill of Rights affirmed by the Board of Trustees 17 November 1972

The American Hospital Association presents a Patient' s Bill of Rights with the expectation that observance of these rights will contribute to more effective patient care and greater satisfaction for the patient, his physician, and the hospital organisation. Further, the Association presents these rights in the expectation that they will be supported by the hospital on behalf of its patients, as an integral part of the healing process. It is recognised that a personal relationship between the physician and the patient is essential for the provision of proper medical care. The traditional physician-patient relationship takes on a new dimension when care is rendered within an organisational structure. Legal precedent has established that the institution itself also has a responsibility to the patient. It is in recognition of these factors that these rights are affirmed.

1. The patient has the right to considerate and respectful care.

2. The patient has the right to obtain from his physician complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand. When it is not medically advisable to give such information to the patient, the information should be made available to an appropriate person on his behalf. He has the right to know by name, the physician responsible for co-coordinating his care.

3. The patient has the right to receive from his physician information necessary to give informed consent prior to the start of any procedure and/or treatment. Except in emergencies, such information for informed consent should include, but not necessarily be limited to, the specific procedure and/ or treatment, the medically significant risks involved, and the probable duration of incapacitation. Where medically significant alternatives for care or treatment exist, or when the patient requests information concerning medical alternatives, the patient has the right to such information. The patient also has the right to know the name of the person responsible for the procedures and/or treatment.

4. The patient has the right to refuse treatment to the extent permitted by law, and to be informed of the medical consequences of his action.

5. The patient has the right to every consideration of his privacy concerning his own medical care programme. Case discussion, consultation, examination, and treatment are confidential and should be conducted discreetly. Those not directly involved in his care must have the permission of the patient to be present.

6. The patient has the right to expect that all communications and records pertaining to his care should be treated as confidential.

7. The patient has the right to expect that within its capacity a hospital must make reasonable response to the request of a patient for services. The hospital must provide evaluation, service, and/or referral as indicated by the urgency of the case. When medically permissible a patient may be transferred to another facility only after he has received complete information and explanation concerning the needs for and alternatives to such a transfer. The institution to which the patient is to be transferred must first have accepted the patient for transfer.

8. The patient has the right to obtain information as to any relationship of his hospital to other health care and educational institutions in so far as his care is concerned. The patient has the right to obtain information as to the existence of any professional relationships among individuals, by name, who are treating him.

9. The patient has the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his care or treatment. The patient has the right to refuse to 'participate in such research projects.

10. The patient has the right to expect reasonable continuity of care. He has the right to know in advance what appointment times and physicians are available and where. The patient has the right to expect that the hospital will provide a mechanism whereby he is informed by his physician or a delegate of the physician of the patient's continuing health care requirements following discharge.

11. The patient has the right to examine and receive an explanation of his bill regardless of source of payment.

12. The patient has the right to know what hospital rules and regulations apply to his conduct as a patient. No catalogue of rights can guarantee for the patient the kind of treatment he has a right to expect. A hospital has many functions to perform, including the prevention and treatment of disease, the education of both

health professionals and patients, and tire conduct of clinical research. All these activities must be conducted with an overriding concern for the patient, and, above all, the recognition of his dignity as a human being. Success in achieving this recognition assures success in the defence of the rights of the patient.

Appendix 4 – Schedule form of declaration under the Voluntary Euthanasia Act 1969

I. Schedule form

Declaration made . . . . . 19 . . . . (and re-executed 19. . . .)
by . . . . . of. . . . . .

I declare that I subscribe to the code set out under the following articles :

a. If I should at any time suffer from a serious physical illness or impairment reasonably thought in my case to be incurable and expected to cause me severe distress or render me incapable of rational existence, I request the administration of euthanasia at a time or in circumstances to be indicated or specified by me or, if it is apparent that I have become incapable of giving directions, at the discretion of the physician in charge of my case.

b. In the event of my suffering from any of the conditions specified above, I request that no active steps 'should be taken, and in particular that no resuscitatory techniques should be used, to prolong my life or restore me to consciousness.

c. This declaration is to remain in force unless I revoke it, which I may do at any time, and any request I may make concerning action to be taken or withheld in connection with this declaration will be made without further formalities.

I wish it to be understood that I have confidence in the good faith of my relatives and physicians, and fear degeneration and indignity far more than I fear premature death. I ask and authorise the physician in charge of my case to bear these statements in mind when considering what my wishes would be in any uncertain situation.

Signed

(Signed on re-execution)

We testify that the above-named declarant (signed)[9] (was unable to write but assented to)1 this declaration in our presence, and appeared to appreciate its significance. We do not know of any pressure being brought on him to make a declaration, and we believe it is made by his own wish. So far as we are aware, we are entitled to attest this declaration and do not stand to benefit by the death of the declarant.

Signed by of . . . . . .

(Signed by of on re-execution)

Signed by of . . . . . .

(Signed by of on re-execution)

II. To whom it may concern

Should I be unable to communicate, please note that I have signed, in the presence of two witnesses, the following declaration:

If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as the testament to my wishes.

If there is no reasonable prospect of my recovery from physical or mental illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I request that I be allowed to die and not be kept alive by artificial means and that I receive whatever quantity of drugs may be required to keep me free from pain or distress even if the moment of death is hastened.

Name . . . . . .

Address. . . . . .

Phone No. . . . . .

Date . . . . . .

9. Strike out whichever words do not apply.

Signed. . . . . .

Appendix 5 – Dissenting opinions [10]

1. Observations of Mrs Berglund

(Mrs Berglund and Mrs Sôder presented a draft amendment to the report, part of which was adopted by the committee at its meeting on 5 December 1975. As a follow-up to the discussion in the committee, Mrs Berglund has proposed that the following should be included in the report as an appendix.)

A. Proposed amendment to the draft recommendation :

Replace paragraph 9. II as follows:

To establish national commissions of enquiry, composed of lawyers, representatives of all levels of the medical professions and politicians, to work out ethical rules for the treatment of persons approaching the end of life according to the following principles:

a. Every sick person shall, when death approaches, be given the opportunity to prepare himself for the inevitable end of life;

b. At that stage of the death process when returning to a meaningful existence is precluded, the treatment must be concentrated, in a natural way, on the fundamental personal care. The primary task of the doctor shall at this stage be to reduce the suffering of the sick person, while respecting his integrity;

c. The responsible doctor has to decide upon what medical treatment is required with respect to the condition of the patient, taking into consideration the wishes of the patient who shall have the right to full information about his condition and the treatment proposed. The patient's wishes shall be considered even in cases when the patient, through weakness, has lost his capacity to dispose of his own situation but still retains consciousness of his personality;

d. The technically advanced resources of modern medicine shall be used to the extent that they may be considered to be useful to the patient. The usefulness has to be judged according to the need of medical care and not to conceptions about obligations to “prolong the life of the patient” or to “shorten his suffering”;

e. In a situation where all cerebral functions have irreversibly ceased, a treatment in accordance with science and approved experience does not require increased therapeutic-al measures or even the continuation of the treatment which is going on.

B. Commenting remarks

The question of interrupting a medical treatment of a patient who is dying cannot be answered in a general way. Each case has to be judged on its own merits according to the principle that every patient has the right to get a treatment which is related to his condition and which is in accordance with science and approved medical experience.

In the debate that is going on, it has been argued that many people are afraid that advanced technical resources will be used at the end of life, thus provoking prolonged suffering or unnecessary postponement of death. On the other hand, however, it has been argued that some people might have lost part of their confidence in medical care, as a result of the current discussion on euthanasia. Finally, suspicions have arisen that gravely sick persons do not get adequate treatment, for economic reasons.

It must therefore be strongly stressed that the treatment has to be centred upon what is best for the patient. This applies to personal care of a fundamental nature such as feeding, liquid supply, pain relief etc., as well as to directly life-maintaining achievements such as respiratory treatment. The responsible doctor shall decide upon what the treatment should consist of according to the circumstances in the actual case, and he has also to ask the patient for his approval as long as the patient has the strength to articulate his will.

The doctor will have no obligation to start a treatment that would have no meaning, and advanced technical resources should not be used upon unrealistic indications.

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10. These opinions are reproduced in conformity with' Rule 46, paragraph 4 of the Rules of Procedure of the Assembly which stipulates: “The explanatory memorandum shall be presented by the Rapporteur. The committee -shall take note of it. Any dissenting opinions expressed in the committee shall be included therein at the request of their authors...”

The doctor has to act according to what he judges is the medical need for treatment. Different conceptions of the duty “to prolong life” or to “shorten the suffering” may lead to personally biased decisions by physicians and open up the road to influences from relatives or others who might have special interests in the patient's life or death which are not related to his medical needs.

2. Observations of Mr Tabone

1. The excellent and comprehensive report by our Rapporteurs, for which I congratulate them, raises important and fundamental issues, which have left me perplexed and worried on the possible interpretation of the report itself.

2. Issues revolving round “the rights of the sick"and the dying include:

a. the right to life,

b. the right to relief of pain,

c. the questionable right to die,

d. the consent to die,

e. whether we are free to decide on the termination of our own life, and whether we are “owners” of our lives,

f. the time of death,

g. the essence of death,

h. the functions of doctors.

3. The leitmotiv of the report and of the draft recommendation and the draft resolution is the right of the sick person to determine when he has had enough of suffering and when and how to die painlessly.

4. While it is certainly right and proper to reduce pain and suffering, I do not believe that it is right and proper to place the relief of suffering on a footing of equality with the prolongation of life, as seems to be implied by paragraph 6 of the draft recommendation.

5. The first consideration should be whether life is ours to play with, whether we own our lives or whether life is something in trust which we must protect and preserve. We were not born by an act of our will, and the strength of the instinct of survival is such that it conditions all our actions as humans. If we accept the concept that we are the masters of our lives, then we must accept the right to die, the right to suicide, the right to ask someone to kill us, and also the right to kill our unwanted babies before they are born because we would be acting as their guardians. I reject such concepts and, while I strongly uphold the right to life, I do not believe that we have the right to die. At most one could accept the right of not actively prolonging one's life under certain circumstances.

6. If we were to accept the right to terminate our lives, and if we 'believe that such a right is subject only to consent freely given, how can we be sure that consent at the time of health, as is envisaged in the form attached to the report, will remain operative at the point of death, when it will be put into effect, and when the mental faculties of the patient may not be so clear as enable him to withdraw the consent? How can we be sure that unconscious patients about to die would not withdraw their consent to die if they were given the opportunity to do so? Would it not be wicked to tie persons with consent given under remote and quite different conditions? My experience as a doctor teaches me that those who genuinely attempt suicide and who are not allowed to carry out such intentions through fortuitous circumstances, later forget their wish to die and lead normal lives. This means that a desire to die may not he constant. Difficult conditions of life including hopeless prognosis of doctors do not always persist in time.

7. Another point that has been discussed today has been that of living a humane life, and some have mentioned a useful life. Mental patients have been excluded in this report, but one may ask, do they live a humane or a useful life? Why should mental patients be protected, and rightly so, while those who are of sane mind be subjected to different ethical standards?

8. Time of death. The traditional criteria of cessation of circulation and cessation of respiration have served humanity well. The new concept of cerebral death would be acceptable if it were reliable and easily available to all. I am not quite sure that we can tell in an absolute and incontrovertible manner that cerebral

death has occurred. The time of death is not an absolute point of time; not all the cells die at the same time and we should accept as the time of cessation of life – and 'this is the best definition of death – that when the vital functions cease.

9. I am glad to note that there is general consensus to drop the term euthanasia; I had suggested this at our meeting in Strasbourg. There is very little difference in fact between active and passive euthanasia. The failure to do something which would prolong life is in effect the same as doing something which stops life.

10. There is a very important issue on the functions and on the power of doctors since they are being suggested as the arbiters of life and death in certain circumstances. In my view their traditional functions for which they are trained are:

a. the prevention of disease,

b. the cure of disease,

c. the relief of pain and suffering,

d. the prolongation of life;

We are not immortal, and we usually go to the doctor to live as long as possible without pain and other untoward conditions. We must of necessity depend on their skill, but we must not depend on their judgement as to when and how we are to die. It would be a sad day for humanity if this were to come about. We are told in the report that doctors should not be forced to do something against their conscience; the life of 'a patient would not depend on objective issues but on the training, opinions and background of individual doctors.

11. We are all agreed that suffering must be fought against, but we cannot place it as the ultimate aim of our actions as we know that we can never succeed in abolishing it altogether and we also know that pain may be unavoidable in the process of getting well.

12. I cannot approve of the draft recommendation 'and I am in favour of the amendments of Mrs Berglund and Mrs Söder with the addition of the preamble suggested by Mr Page. The draft recommendation may be understood as meaning that the Council of Europe is taking a favourable stand towards euthanasia; the Rapporteurs state that this is not their intention. In that case let us change the form of the recommendation to make it clear that what is being proposed is simply the bringing to the attention of governments certain specific problems for their consideration. It would seem odd, however, if the Council of Europe were simply to state issues without pronouncing itself on them.