LATEST DEVELOPMENTS ON ASSISTED DYING IN EUROPE
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Bills, Investigations or Debates in National Parliaments

France

There have been three draft bills presented in France in 2004. The first was on 24 February when a number of senators presented a draft; the second on 11 May presented by Green Deputies. The third and probably most important is the most recent; it is attached to the report by M. Leonetti, who chaired the Parliamentary Committee set up in October 2003 following the case of Vincent Humbert.

The main provisions of the draft law are:

1. Treatment not to be continued unreasonably when there is no hope of improvement in patient’s condition.
2. Patients to have the right to a second medical opinion. Request for assisted dying to be repeated within reasonable time. Such request to be written into person’s medical records.
3. When patient no longer able to take decisions, doctors may cease or limit treatment but subject to collegiate procedure as in existing law and consultation of next of kin.
4. When patient in advanced or terminal state of incurable illness decides to limit or cease all treatment, doctor must respect that decision after informing them of the consequences. Decision to be written into medical records.
5. When person no longer able to take decisions and has nominated representative, that person’s view shall, subject only to emergency etc, take precedence over any other non-medical view as regards the treatments carried out.
6. All persons over age of majority to have the right to make a Living Will, which will set out their wishes as respects the end of their life in relation to limiting or ceasing treatment. This can be revoked at any time. Provided it is prepared at least 3 years before incapacity, doctors must take account of it in all relevant decisions.
7. The medical authorities shall identify all elements of palliative care in an establishment and specify the number of beds provided for such cases.
8. The existing definition of palliative care should be expanded to identify the services at the particular establishment where treatment is carried out.
9. Increased costs of these measures to be recovered by increasing the medical insurance charges laid down in tax legislation.

There has been no debate on the bill as yet but on 27 August the Minister of Health, M. Douste-Blazy told the press that the government accepted the conclusions of the committee and that a draft law incorporating them would be introduced soon and its examination would begin before the end of the year. He also reported that the President of the National Assembly had assured him that sufficient Parliamentary time would be made available for the new law to be rapidly adopted. The Minister said he did not wish to follow the Belgian or Dutch models and intended no change to the penal code. The new law would create the right to die with dignity, which would enable the terminally ill to choose their way to die. The medical profession could help with these decisions but would not be directly responsible. The law would establish a distinction between those cases where there was no hope of recovery and those where some chance still existed. Living wills would apply only in the case of those who had become unconscious and would not be binding on doctors. If there were no living will, at least two doctors would have to be involved in any decision to cease treatment.

**Luxembourg**

The general election in June overturned the previous coalition of Democrats and Christian Democrats (CSV) and replaced it with a coalition of the CSV and the socialists. This still leaves a heavy majority of the Catholic party, opposed to legislation on assisted dying, but a number of the socialist ministers and MPs have been supporters in the past. The ousted Democratic party’s new President has declared the decriminalisation of assisted dying one of his party’s new aims.

**The Netherlands**

Under-Minister for Health Clemence Ross and Justice Minister Donner only recently sent their formal comments on the 2003 Van der Wal/Van der Maas report to Parliament. So far there has been no real Parliamentary debate, although some MPs (especially from Christian parties) have put down questions. These mainly concerned the grey zone between assisted dying and terminal sedation (TS); this last was based on a report by Professor Crul of Nijmegen, specialist in pain treatment, which claimed that pain treatment could replace euthanasia. Importantly, Ross and Donner’s comments specifically deny that (legally speaking) TS/palliative care is to be considered as a real alternative to euthanasia.

**Switzerland**

The National Council is due to discuss a motion on "Voluntary Euthanasia and Palliative medicine" which has been submitted by the Parliament and examine the extent to which legislation on indirect and passive, and active voluntary euthanasia is necessary. It will also debate promoting palliative medicine and the problem of so-called "death tourism".

NB. For the moment the Minister of Justice has postponed the discussion; no new date has been set.

Dr Sobel, President of EXIT A.D.M.D. Geneve Suisse Romande, joined with representatives of other organisations to write to MPs and Councillors urging them to reject "the Vallender initiative" which, prompted by the perception of "death tourism", seeks to change the law in order to make assisted suicide more
difficult. They pointed out that the existence of the proposal had already had an adverse effect on the work of EXIT ADMD Suisse Romande and EXIT Deutsche Schweiz.

Parliament has accepted an initiative brought before the Council by Jost Gross, member of the National Council. This means that an addition is to be made to the Civil Code directives which will make living wills legally binding, provided only that they comply with the law and represent the patient’s actual or presumed wishes at the time of death.

**UK**

Lord Joffe’s *Assisted Dying for the Terminally Ill Bill* was, as reported in "Developments Across Europe", given an unopposed Second Reading (ie approval in principle) in the House of Lords in June 2003. In July 2004 the Lords established a special Select Committee to examine the Bill and consider evidence submitted to them; all written evidence had to be submitted by 3 September. The Committee is now preparing to take oral evidence and has meetings scheduled through to end December.

Main provisions of the Bill are: it would allow a doctor actively to assist a terminally ill patient to die; such a patient would have to been resident in the UK for at least 12 months and to be over the age of majority; terminally ill is defined as likely to die within a few months and suffering unbearable pain.

A Scottish MSP proposes to introduce a similar Bill into the Scottish Parliament.

The *Mental Capacity Bill* introduced in the 2003/4 session of Parliament would give formal legal backing to advance directives/Living Wills and health care proxies. There is provision for a court to decide whether an advance directive exists and whether it applies in the circumstances.

In July 2004 the Health Select Committee of the House of Commons published a report on palliative care. One of its key conclusions was that the right to a "good death" was fundamental.

The Select Committee on Human Rights examined the Assisted Dying Bill and concluded that it was not incompatible with ECHR Article 2, in the light of the safeguards built into the text.

**Case Law Developments or Cases in National Courts**

**Belgium**

The Commission established to monitor the operation of the assisted dying law has issued its first, unanimous, report. Its main findings are that the number of cases of assisted dying has stabilised after the first few months and nearly half of them take place at the patient’s home. The vast majority of cases involved cancer and to a lesser extent neuro-muscular diseases, including some cases where death was not imminent.

To date only one case concerned assisted dying for an unconscious person on the basis of an advance directive. Most cases affected persons of middle age – there were few cases under 40 years (only one of someone under 20) or over 80. An
unexpected finding was that the great majority of statutory reports were in Flemish rather than in French.

The Commission found that there were some initial misinterpretations of the procedural requirements but that the quality of the doctors’ statutory reports on each case has steadily improved. They recommend a revision of the registration document to avoid future misunderstanding. They note that patients can refuse palliative care if it has side effects or the means of administering it is deemed unbearable in itself: they propose more discussion between patients and doctors in such cases. Doses of morphine are not seen as a means of assisted dying and cases do not need formal reporting even where high doses may have hastened death.

The Commission conclude that there is no case to make further legal changes but consider that greater publicity is needed both for the medical profession and the public. Finally they suggest that there should be regular inquiries into the totality of medical decisions concerning the end of life, as is already the case in the Netherlands.

**The Netherlands**

1. Two doctors who "together" helped a patient to die, where it was not completely clear that she had asked for this, were discharged from prosecution by the Court of Appeal because of the long time (18 months!) it had taken the prosecution to do its job. Unfortunately they offered no verdict on the principle.
2. A case is being reported of the prosecution of a doctor who administered sleeping drugs and morphine to a terminally ill patient and did not report it. Defence: it is TS and thus a "normal" medical decision; has nothing to do with euthanasia.
   *November 10 breaking news*: the doctor was acquitted, the court followed the defence in its arguments.

**UK**

Two cases in 2004 have strengthened the role of the Living Will.

1. In May a woman in her 50s won the right to prevent local authority carers from intervening to save her life. This established that Living Wills have to be respected by non-medical personnel as well as medical carers.
2. In August the courts ruled that a person had the right to use a Living Will to ensure the continuation of treatment when he was no longer capable of requesting it directly. Thus pro-choice Living Wills become legally enforceable for the first time.

**Books Published**

**The Netherlands**

The NVVE is preparing the publication of a book in which experiences with euthanasia from the point of view of the patient/relatives will be described as a form of assessment/evaluation of the law. Expected publication date: January 2005.
Switzerland
ADMD Suisse Romande produces two reports each year. In addition Dr Jerome Sobel, their President, regularly publishes articles in both French and English, most recently "The Good Death" in Medicine et Hygiene.

Research published or currently undertaken

The Netherlands

Professor Crul (anaesthetist and pain treatment specialist) of Nijmegen University pre-published (by way of a TV documentary) the results of his ongoing research into the effect of pain treatment on decisions around the end of life. He concludes that pain can generally be treated in such a way, that pain can no longer be seen as causing unbearable and hopeless suffering and thus as justification for euthanasia. This was of course widely discussed. The NVVE put the argument that pain is seldom the reason for requests for euthanasia (cf the research results of Van der Wal and Van der Maas).

The same documentary and discussion showed the results of an opinion poll of Dutch people’s attitude towards assisted dying: 90% still consider it a good thing that euthanasia (and/or TS) can be chosen at the end of life; 84% did not agree with the statement that now TS is possible, euthanasia should be forbidden.

Switzerland

The Swiss Academy of Medical Sciences has produced a report on the Care of patients in the terminal phase of life which is designed to provide medical-ethical guidelines for the profession, including the health authorities. This version of the guidelines would replace that of 1995 and deals solely with the situation of dying patients; other guidelines cover ethical questions in relation to intensive medicine and treatment and care of the elderly. Following is a summary of the report’s main points

This latest version stresses the rights of all patients, who are competent, to determine whether or not various treatments may be administered. This is the case even if third parties think the patient’s wishes against their best interests and apply irrespective of whether the patient is a child, an adolescent or is legally incapacitated. Advance directives completed when a patient was able to express their own views must be followed if they apply and if there is no reason to think they no longer reflect the patient’s wishes.

All patients in the terminal phase of life would have a right to palliative care, which should be made available in good time and wherever the patient may be ie in hospital, in another institution or at home. Doctors would be obliged to relieve pain and suffering even if in some cases this might affect the duration of life (so-called "indirect active euthanasia"). Where palliative sedation is employed, care would need to be taken to sedate the patient only as much as is necessary to relieve symptoms.

The draft guidelines state that in certain cases the rejection of life-preserving measures or their discontinuation (also called "passive voluntary euthanasia") can be justified. Criteria would include the prognosis, the expected outcome of
the treatment in terms of quality of life and the intensity and severity of the treatment itself.

Helping someone to commit suicide is not a punishable offence when it is done for unselfish reasons. This applies to everyone. Where a doctor is involved, s/he should check that the following minimum requirements have been met:
- the patient’s disease justifies the assumption that s/he is approaching the end of life;
- alternative possibilities for providing assistance have been discussed and, if appropriate, implemented;
- the patient is capable of making the decision and has persisted in this wish with no external pressure.
- These points must be verified by a third party, not necessarily a doctor.

Even if made seriously and insistently by a patient a request to give death to a patient (also called "active voluntary euthanasia") must be refused by a doctor. This remains a criminal offence.

NB. In the view of EXIT ADMD Suisse Romande this report is encouraging in making a small step towards admitting the possibility of a doctor helping a suicide but generally remains too restrictive in its approach.

**Opinion Polls**

**Germany**
In October/November 2003 DGHS carried out surveys on living wills and attitudes to doctors who carry out assisted dying. It seems that 53% of German citizens know about living wills, over 70% in the case of those over 60. 84% said they would not lose confidence in their doctor if s/he helped an incurably ill person to end their life; only 20% thought they would lose confidence in a doctor who provided active and direct assistance in the case of an incurably ill patient. Contrary to the established views of the medical profession, a majority of the population want more scope for assisted dying and to see norms set out in law for active and direct assisted dying.

**Luxembourg**
Prior to the national elections held in June 100 prominent citizens of Luxembourg issued a petition to the government earlier this year on the following lines: "We the undersigned believe that palliative medicine and direct voluntary euthanasia do not exclude but complement each other. In this spirit the undersigned appeal to the to-be-elected Members of Parliament and government to undertake steps towards a legislation which would decriminalise assisted dying in precise defined conditions". This was given prominent coverage in 3 national newspapers.

ADMD Luxembourg has been pleased to see over 2,000 spontaneous further signatures added to this petition by members of the public, including doctors, lawyers, politicians and other public figures. More continue to be registered and ADMD has agreed to hold the petition open for signature till the end of the year. They hope to recruit new members from among the petition signatories.
Switzerland
Before the last election to the National Council EXIT/ADMD, in collaboration with a group from the Vaud region, persuaded Councillor Mme Menetrey Savary to submit a motion calling for suicide assistance to be included in medical training, either as part of end-of-life courses or in psychology seminars. The organisations then wrote to all the councillors to ask their views on the motion. They have listed on the ADMD web site the names of those who were re-elected (Oct 2003) and who had supported the motion.

France
ADMD organised a petition in 2004 to campaign for an immediate public debate on assisted dying. This has attracted 90,743 signatures. A call by doctors for the decriminalisation of euthanasia has so far received 2,635 signatures.

Campaigns

France
The ADMD in France continues to organise public debates on right to die issues in various venues throughout the country. In June and July alone there were five such events.

Germany
In November 2003 DGHS organised a second awareness week dedicated to patients’ right of self-determination at the end of life. Lectures were given by German and other specialists and meetings held in a number of cities such as Berlin, Augsburg, Hamburg and Cologne.

At a Round Table held at DGHS initiative at the end of last year to discuss end of life issues, a resolution was agreed calling for self-determination at the end of life. This had 6 authors, including a priest, and 16 signatories. Most important was the call for a change in the law to decriminalise active help to die in extreme cases.

In March 2004 the University of Giessen held an international symposium on physician assisted dying. This was timed to precede the expected revised guidelines on physician assisted dying due to be issued this year by the German Medical Association. This was a major event with speakers from many countries, including some where medically assisted dying is permitted.

UK
The VES has been conducting an active campaign in support of Lord Joffe’s Bill on assisted dying (see Bills etc above). They have been requesting members and the public to write to the Select Committee and succeeded in obtaining close to 100,000 signatures to the supporting petition. They have also been actively involved in briefing Lord Joffe on the issues raised by the Bill and keeping him and members of the Committee informed of the position in other countries. A Committee of the House of Lords continues to study the draft and some of its members will be going to Oregon USA and to the Netherlands to see how the law operates there.
Switzerland
ADMD has established an annual medical forum with 55 participants teaching doctors to practise assisted suicide. In addition, in May to July 2004 a number of seminars were organised for members of ADMD and others in three cities to promote discussion of end of life questions.

Cases that have attracted public/media attention

Germany
In autumn 2003 the press reported the case of a cancer doctor who had been arrested on the charge of actively helping patients to die – the case only came to light when someone checked the hospital accounts. The case was picked up in our report "Developments Across Europe" last year but in February DGHS issued a press comment to the effect that the doctor may have overstepped the mark, in that there should at the very least be adequate records of patients having expressed their wish to die, which seemed not to be the case here.

The case to attract most media attention was that of Inge Meysel, the actress and probably best known member of DGHS for many years, who died in July this year aged 94. She had long defended everyone's right to self-determination and a copy of her living will had been deposited with the DGHS. There was a great deal of press speculation as to whether she had exercised this right herself and even whether DGHS had supplied her with the means, which they strongly denied. Her most recent public statement on this subject seems to have been her welcome for the change in the law in Belgium permitting assisted dying.

Other issues

Switzerland
The Swiss have identified a problem relating to those who move into residential/nursing homes. It appears that several of these are opposing their residents’ wishes for assisted suicide, ignoring living wills and even returning correspondence from ADMD unopened. ADMD has drawn attention to this in their newsletter and offers advice to members on how to circumvent these actions.

Europe
In addition to the above there has been considerable activity in the Council of Europe on the issue of assisted dying. In September 2003 Mr Dick Marty presented a report to the Committee on Social, Health and Family Affairs. However in January 2004 the Assembly agreed to a proposal from the Committee to postpone any discussion and in April they referred the report back to the Committee for a further year. In June the Committee renewed Mr Marty’s mandate but changed the title of the report.

A preliminary revised draft report, entitled "Assistance to Ill persons at the end of life", was presented by Mr Marty in October 2004 and is to be discussed at Hearings this month and will be voted on in December. The recommendations now are:

- that all governments should develop a positive policy on caring for patients at the end of their lives, involving the following measures:
1. Promoting the creation of centres for palliative care, conscious that alleviating the patient’s suffering may also shorten his/her life in some cases;
2. Set in place proper health care arrangements for the terminally ill, with specially trained staff;
3. Wherever possible encourage care in the patient’s own home and include family/close friends in the care required;
4. Develop medical codes of ethics to avoid terminally ill patients being subjected to overly obstinate attempts to keep them alive at all costs.

- that patients’ rights should be strengthened and the tasks and responsibilities of the medical profession more clearly defined, in particular that the patient should be able to refuse treatment and an independent body created to consider complaints from patients.

- that governments should be invited to discuss the wisdom of providing for the possibility of respecting a patient’s wish to die and establishing whether and in what circumstances a doctor or other person (who was willing to do so) can help such a patient to end his/her life without exposing themselves to criminal sanctions, though the possibility of decriminalising assistance by doctors or others to help a person to end their life should be restricted to special, defined cases, such as those involving constant pain with no hope of improvement and patients who repeatedly ask to die. This does not mean that medical help can be given to those who might yet live a long time.

- that, although a single formula is difficult to devise for the range of countries and beliefs represented in the Council of Europe, all countries should debate the issue, should examine objectively the application of the assisted dying laws in Belgium and the Netherlands and should examine the findings of the several studies showing that assisted dying is more often practised in fact than was believed, with a view to recognising the need for more transparency on this issue.

The Luxembourg election brought the Green party into official opposition, and their new delegate to the Council of Europe is committed to supporting the Marty Report.

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