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COMMENTS BY THE GOVERNMENT OF THE NETHERLANDS ON THE CONCLUDING OBSERVATIONS OF THE HUMAN RIGHTS COMMITTEE (CCPR/CO/72/NET)

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POSITION OF THE DUTCH GOVERNMENT IN RESPONSE TO THE EVALUATION OF THE CURRENT STATE OF AFFAIRS CONCERNING EUTHANASIA AND OTHER MEDICAL DECISIONS AT THE END OF LIFE

Introduction

1. On 27 May 2003, we sent both Houses of the States-General a research report evaluating medical decision-making at the end of life, associated medical practice and euthanasia review procedures ("*Medische besluitvorming aan het einde van het leven; de praktijk en de toetsingsprocedure euthanasia*"), together with the accompanying report and recommendations of the supervisory committee and a report by Statistics Netherlands on medical practice at the end of life ("*Het levenseinde in de medische praktijk*"). The publication of these research findings fulfils the commitments made on various occasions by the two previous Governments to re-evaluate the current state of affairs on medical decisions at the end of life a few years after the last evaluation (presented to the two Houses of the States-General on 27 November 1996).

2. Following the publication of the previous evaluation report, various measures were taken in response to the recommendations made in it. On 1 November 1998, the five regional euthanasia review committees were appointed. Initially, their task was to produce an opinion on whether the attending physician in each reported case had acted in accordance with the statutory due care criteria. The Public Prosecution Service then referred to this opinion when deciding whether to institute criminal proceedings. The committees continued to follow this procedure until 1 April 2002, when the Termination of Life on Request and Assisted Suicide (Review Procedures) Act came into force. Under this new legislation, the findings of the review committees are final in any case where the committee finds that the attending physician has acted in accordance with the due care criteria.

3. After the Act came into force, the Institute for Research in Extramural Medicine and the Department of Social Medicine at the Free University Medical Centre in Amsterdam, the Department of Public Health at the Erasmus University Medical Centre in Rotterdam and Statistics Netherlands were commissioned to investigate whether the euthanasia review procedures were fulfilling their purpose and, if not, whether improvements could be made. In addition, the Ministry of Justice and Ministry of Health, Welfare and Sport raised a number of supplementary questions, for example concerning patients who are "tired of life" and palliative care. In order to examine these issues as effectively as possible, the researchers decided to conduct a four-part investigation. The first part was a study of a random sample of all deaths in the Netherlands over a specific period. Secondly, a random sample of attending physicians was taken from a predefined population and each of them was asked to take part in an oral interview. Thirdly, a random sample was taken of notifications to the regional euthanasia review committees over a specific period. Both the attending physicians and the next of kin were interviewed about these cases. Finally, the fourth part was a survey of public opinion using a random sample of members of the general population.

4. Since the year under review in this evaluation was 2001, the study was confined to the working procedures of the regional review committees in the period before the new legislation entered into force. Wherever possible, however, its results take account of experience since then.

Representativeness of the evaluation

5. Like the previous evaluation, this study was conducted by Professor P.J. van der Maas, holder of the chair in Social Health Care at the Erasmus University Rotterdam, and Professor G. van der Wal, holder of the chair in Social Medicine at the Free University of Amsterdam.[1] Since the design of the research is broadly similar to that of the 1990/1991 and 1995/1996 evaluations, reliable comparisons can be made between the results. Once again, the aim was to understand the factors influencing the way in which decisions are taken on euthanasia, assisted suicide and other end-of-life medical issues. Unlike the previous evaluations, however, this study focused in particular on terminal sedation, experience with the review procedure, notification behaviour, and the relationship between euthanasia and palliative care. New elements in the research were a survey of public opinion and interviews with next of kin.

6. The research was supervised by a committee chaired by Professor A.J. Knottnerus, holder of the chair in General Practice at the University of Maastricht and chairman of the Netherlands Health Council.

7. We share the opinion of the supervisory committee that the research was conducted with proper academic rigour, answers the questions and offers useful insights into various aspects of Dutch practice concerning medical decisions at the end of life.

8. Like previous evaluations, the study elicited a high response rate among the health professionals approached and this, combined with the way the resulting data was analysed, guarantees that its results are representative and useful.

9. This position paper discusses the main issues addressed by the recent evaluation and expresses our views on the recommendations made by the supervisory committee and the researchers themselves with regard to independent assessment, the due care criteria, review procedures, notification of euthanasia and assisted suicide, requests from patients without any serious physical or psychiatric disorder, patients suffering from senile dementia who have previously drawn up advance directives, minors, action to end life where no express request has been made, other medical decisions relating to the end of life and euthanasia, sedation of dying patients, other medical decisions relating to the end of life and palliative care and euthanasia.

Independent assessment

10. One of the due care criteria is that the attending physician should seek an independent assessment by another physician with no connection to the case. Clearly, the quality of the independent assessment will depend in part on the familiarity of that physician with end-of-life issues. For this reason, the Royal Dutch Medical Association (KNMG) has been running the

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[1] G. van der Wal, A. van der Heide, B.D. Onwuteaka-Philipsen and P.J. van der Maas, "*Medische besluitvorming aan het einde van het leven. De praktijk en de toetsingsprocedure*". De Tijdstroom, Utrecht, 2003.

Euthanasia in the Netherlands Support and Assessment training project (SCEN) over the last few years. As a result, some 500 general practitioners have now been trained to provide independent assessments. The Association sees this as a way to improve the quality of such assessments and to offer reassurance to physicians faced with requests for euthanasia.

11. For some years now, the annual reports of the regional euthanasia review committees have shown that the committees feel that independent assessments by physicians trained by SCEN tend to be of better quality than those of other physicians. The SCEN project has been separately evaluated in a study commissioned by the KNMG and conducted by the Free University of Amsterdam's Institute for Research in Extramural Medicine. That study confirmed the value of SCEN training in enhancing performance. The evaluation to which this position paper relates reveals a relationship between the introduction of SCEN training and the rate of notification. In areas where SCEN training has been introduced, the notification rate has risen, even though this is not in fact an aim of the project. The evaluation also shows a substantial increase in the number of cases where the attending physician has sought an independent assessment. In many of these cases, the attending physician has already agreed to honour the patient's request before the independent physician sees the patient. This is undesirable but the evaluation of SCEN shows that it is less likely to occur in cases involving a SCEN physician.

12. So far, SCEN training has been offered only to general practitioners. The review committees report a difference in quality between independent assessments conducted by hospital specialists and those conducted by general practitioners with SCEN training. Moreover, the evaluation shows that the notification rate among general practitioners is higher than among hospital doctors. With these factors in mind, an obvious next step was to extend SCEN training to hospital specialists and doctors working in nursing homes. This is to be done over the next few years, starting in 2004. In addition, structural funding for independent assessments has been introduced, starting on 1 October 2003. The organizational costs of the SCEN project are met out of the general health budget, as are the costs of extending SCEN training to hospital specialists and nursing home doctors.

Due care criteria

13. The review committees assess whether the due care criteria have been met in each case reported to them. The evaluation shows that the findings of the review committees are fairly uniform and that the subjects on which the committees tend to ask additional questions are the independent assessment, the unbearable nature of the patient's suffering and the absence of any prospect of improvement. The uniformity of their findings is enhanced by the common practice of discussing difficult cases not just internally, but also with the chairs of other committees.

14. According to members of the committees, the unbearable nature of the patient's suffering is the most difficult aspect to assess. Unlike the lack of any prospect of improvement, it is a highly subjective factor for which it is difficult to find any objective measure. The retrospective conclusion that the patient's suffering was unbearable is tantamount to a test of reasonableness; in other words, what the committee has to decide is whether the attending physician could reasonably have concluded that this was the case. The opinion of the second, independent physician is therefore of particular importance in this respect. Accordingly, SCEN training places a heavy emphasis on the assessment of the patient's suffering.

15. It is extremely important that the interpretation of the due care criteria should be as clear as possible. In their conclusions, the researchers suggest that physicians need still greater insight into the way in which the review committees interpret them. To meet this need, we have already begun preparations for setting up a database in 2005.

Review system

16. When the regional euthanasia review committees were established in 1998, one of the main aims was to encourage the medical profession to report cases. Since the Termination of Life on Request and Assisted Suicide (Review Procedures) Act entered into force on 1 April 2002, review committees have had the final word in those cases where they feel that the physician has acted with due care. During the interviews, half of the physicians' indicated that they had experienced the review procedure as "neutral". Physicians who had been asked to provide further information were more likely to say that they felt the procedure was negative. However, to do their job properly, the review committees have to be able to ask extra questions. In general, the physicians who were surveyed took a positive attitude to the membership of the review committees and their aims, such as openness and enhancing the quality of decision-making. Most of them felt that measures such as the establishment of the review committees and the Termination of Life on Request and Assisted Suicide (Review Procedures) Act were an improvement.

17. Based on these findings, we feel that the review arrangements, including the establishment of the review committees, are a good thing. We welcome the researchers' finding that the review committees reach broadly uniform findings on the cases reported to them. This produces a clear situation for physicians. We believe that the review committees' annual reports give a good impression of the work they do.

18. The Public Prosecution Service has indicated that, although it is not always possible to conclude that due care has been fully exercised (for example, where there has been a failure to meet one of the formal criteria), criminal proceedings are not always appropriate in such cases and the offence could better be dealt with as a disciplinary matter. In this context, it should be remembered that the review committees, the Public Prosecution Service and the Health Care Inspectorate each have their own criteria. The review committees judge cases from a multidisciplinary point of view, the Public Prosecution Service from that of the criminal law and the Inspectorate from that of the medical disciplinary code.

19. The documents supporting the Termination of Life on Request and Assisted Suicide (Review Procedures) Bill (see Parliamentary Papers, House of Representatives, 1999/2000, 26 691, No. 6, p. 53 and No. 9, p. 26) indicate that varying degrees of importance can be attached to the non-observance of different due care criteria. The criteria relating to unbearable suffering with no prospect of improvement and to the presence of a voluntary and well-considered request are of a different order from those relating to the independent assessment and the performance of euthanasia in accordance with good medical practice. The first two come close to what might be termed substantive criteria legitimizing euthanasia and assisted suicide, while the last two are more formal and procedural in character. We can see why non-compliance with the first two requirements might be taken more seriously than the failure to

observe the last two. At the same time, a failure to observe due procedure may make it impossible to establish whether the first two requirements have been met. In other words, procedural requirements should also be taken entirely seriously. For this reason, we would consider it undesirable to draw a sharp distinction in the regime whereby non-compliance with certain types of due care criteria is permissible.

20. Although the evaluation reveals a feeling on the part of the review committees that it is not permissible for them to qualify their findings, we shall discuss with them the possibility of indicating that the physician has "complied with the due care criteria, with the reservation that … etc." or, alternatively, that the physician has "not complied with the due care criteria, although … etc." This would not be incompatible with the legislation. The finding would still be based on the due care criteria but it would be accompanied by observations enabling it to be correctly interpreted. This would do more justice to the committee's task of reviewing the actions of the physician and we feel that this is important with an eye to encouraging physicians to report cases.

21. If the physician is found not to have complied with the due care criteria, the committee's findings are forwarded to the Board of Procurators-General and the regional Health Care Inspector. A decision must then be taken on how best to respond to the omissions identified by the committee in the physician's actions. Action may be taken either by a medical disciplinary board or in the criminal courts. Obviously, one factor in the decision will be the degree of importance to be attached to the non-compliance with the due care criteria. The reasons given by the review committee have a major role to play in this respect. In some cases where the physician has been found not to have complied with the due care criteria, the Public Prosecution Service feels that criminal proceedings are a disproportionate response. A disciplinary approach might be more appropriate. The Ministry of Health, Welfare and Sport will contact the Health Care Inspectorate to discuss how best to deal with findings forwarded by the review committees.

Notification of euthanasia and assisted suicide

22. The Act imposes on physicians a duty to notify cases of euthanasia and assisted suicide. A high notification rate makes the practice of euthanasia transparent and that is an extremely important aim of government policy on the subject, second only to monitoring the situation and promoting the observance of due care.

23. The number of recorded cases of euthanasia and assisted suicide considered in the latest evaluation is not significantly different from that in the previous one. The supervisory committee and the researchers themselves feel that numbers have stabilized. The number of notifications as a percentage of total cases has increased since the previous evaluation. Between 1995 and 2001, the notification rate increased from 41 per cent to 54 per cent. The increased readiness to notify cases has been particularly marked among general practitioners. It seems, therefore, that the establishment of the review committees in 1998 has led physicians to take a more positive attitude to notification.

24. Physicians who consistently notify cases say that they feel a moral and legal duty to do so. They believe that openness helps to increase both public acceptance of medical action to terminate life on request and the quality of medical decision-making in this respect. The

evidence suggests that growing numbers of doctors feel that notification has benefits for themselves personally and for society as a whole. Nevertheless, the study shows that some doctors notify some cases but not others, depending on the doctor-patient relationship and the circumstances of the individual case.

25. More recently, the number of notifications to the review committees has again declined, as shown by their annual reports. However, the total number of cases of euthanasia is not known for each and every year. This means that the trend in the notification rate cannot be calculated for the last few years. To find out whether the reduction in notifications has been accompanied by a reduction in euthanasia cases, I have begun preparations for a follow-up study to be conducted in 2005. This study should also show why physicians decide not to notify cases, although the background to these decisions and the reasons for non-notification are not easy to discover.

26. The study will also examine the role of palliative care and hospices and investigate a number of aspects of euthanasia practice on which little light has so far been cast. For example, less is known about the practices of medical specialists and physicians working in nursing homes than about those of general practitioners, while doctors in those situations are less likely than general practitioners to report cases.

27. We realize that the completion of the report form places an administrative burden on physicians and therefore wish to simplify matters in this respect. One possibility is to cluster the responses to questions. However, the administrative burden must not be reduced at the expense of due care. For this reason, a working party is currently examining the way physicians can show how they have complied with the criteria.

28. In this context, we are particularly keen to report the finding that introducing SCEN training among general practitioners substantially increased the notification rate from 52 per cent in 1995 to 66 per cent in 2001. For this reason, the extension of SCEN training to hospital specialists (see section 3) is a very welcome development. It should at any rate ensure that institutions have access to greater knowledge regarding medical decision-making at the end of life. A specialist will be able to seek an informal second opinion from a colleague in the same hospital without necessarily immediately proceeding to a formal independent assessment.

29. The presence of expertise within hospitals is important. It would be good if more institutions were to develop specific policies on the procedures for medical decision-making at the end of life. This would help to produce greater clarity for both staff and patients. We want the study on readiness to notify to examine in addition the relationship between institutional policies and readiness to notify. Institutions should make it clear that they regard public accountability as important.

Requests from patients without any serious physical or psychiatric disorder

30. Over the last few years, there has been much debate about whether patients without serious physical or psychiatric disorders can request euthanasia. We realize that a section of the Dutch public is in favour of people having the right to request euthanasia if they attach no value

to their remaining quality of life. However, the evaluation shows that a majority of physicians are not prepared to assist patients in this respect. Moreover, recent case law from the Supreme Court of the Netherlands shows that, in the opinion of the Court, the present legislation must be understood to mean that the physician can expect to escape prosecution in such cases only if the patient's suffering is based on a medically classifiable physical or mental disorder (HR (Supreme Court) 24 December 2002, NJ (Dutch Law Reports) 2003, 167). Accordingly, although further public debate on this subject cannot be ruled out, the Government will not itself encourage it.

Patients suffering from dementia who have drawn up advance directives

31. The validity of written directives is governed by the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. Such directives are meant for use in situations where patients are no longer capable of expressing their wishes. Patients who are still capable of making a reasonable appraisal of their interests but can foresee a future situation in which they may not be capable of doing so can draw up such a written directive specifying the future situations in which they wish to request termination of life. Such an advance request can, of course, only be honoured if all the statutory due care criteria are fulfilled.

32. We realize that this is one of the most difficult areas associated with medical decision-making at the end of life, especially if the patient is suffering only from dementia without any attendant disorders. Dementia is not in itself sufficient reason to terminate life. However, attendant disorders may produce a situation in which the patient is suffering unbearably with no prospect of improvement. Moreover, in cases of advanced dementia, it is often difficult to determine the extent to which suffering is unbearable, because the patient is incapable of putting his situation into words.

33. The evaluation has shown that physicians are extremely cautious in relation to the advance directives of patients with dementia. This is especially true of doctors working in nursing homes. As a result, there is a discrepancy between the expressed wishes of patients and the action taken on them.

34. A physician is under no obligation to comply with a request for euthanasia recorded in an advance directive. Moreover, the current wishes of the patient are more important than any advance directive drawn up in the past. For that reason, the first step is for the physician to assess the patient's ability to express his or her wishes. He will only take account of the advance directive if he finds that the patient is incapable of this. At a certain stage of dementia, a patient may be generally incapable but have moments of lucidity. In that case, the physician should take advantage of such a moment to verify the request for euthanasia.

35. The caution shown by physicians is not only related to the fact that dementia is not in itself a sufficient ground for termination of life on request. Physicians often find it difficult to be certain exactly what situation the patient had in mind when drafting the advance directive. To ensure that a physician is in a position to decide whether the situation envisaged by the patient has actually transpired, the patient must describe the future situation as clearly as possible and give reasons for requesting termination of life at that point.

Minors

36. Euthanasia can also be performed in the case of minors. The statutory provisions regarding the legal position of minors and their parents are based on those enshrined in the Civil Code concerning medical treatment contracts. These stipulate that minors over the age of 12 can make their own treatment decisions. Up to the age of 16, the child's parents or legal representative must be involved in decision-making and the consent of a parent or guardian is required. In the case of minors aged 16 or 17, this explicit consent is no longer required.

37. The evaluation shows that euthanasia in the case of children is rare. It was involved in only 0.7 per cent of all child deaths and is usually practised only in the case of children with cancer.

38. In 2 per cent of cases involving minors, life-terminating procedures had not been expressly requested by the patient. In every case, this was because the patient was too young to be consulted (usually a neonate). As a rule, however, the age of the child is never a reason to abstain from consultation.

39. In the rare cases where euthanasia is performed on a minor, the utmost care is taken. The research suggests that parents are invariably involved in decisions concerning life-terminating procedures. In view of the results of the research, we are confident that end-of-life decisions relating to minors will continue to be taken with great caution and the utmost care.

Life-terminating procedures not expressly requested by the patient

40. The Termination of Life on Request and Assisted Suicide (Review Procedures) Act relates only to life-terminating procedures undertaken in response to a request from the patient. Termination of life in any other circumstances is a criminal offence and must be reported to the Public Prosecution Service. Even then, a physician can invoke necessity as a defence provided that he has acted with due care. In such cases, it is up to the Public Prosecution Service to decide whether to prosecute. Unrequested termination of life is very rarely reported. For this reason, we are currently consulting with the profession. This autumn you will receive a separate letter addressing the issue of how to meet the medical profession's need for greater clarity about procedures for dealing with termination of life where there is no request from the patient. The Public Prosecution Service will be involved in finding a solution.

Other medical decisions relating to the end of life and euthanasia

Terminal sedation

41. This evaluation was the first to address the issue of sedation generally and terminal sedation in particular. Sedation or terminal sedation can be an appropriate form of care for seriously ill or dying patients. Their suffering can be such that their physicians believe that it is best for them to be rendered unconscious in order to relieve it. There are various definitions of terminal sedation. In this evaluation, the term is used to refer to cases where sedatives are administered while food and fluids are simultaneously withheld.

42. A physician will not be committing a criminal offence if his actions can be deemed to be a normal medical procedure. This includes, for example, abandoning a procedure or refraining from initiating it because it is deemed to be medically futile.

43. The evaluation shows that sedation is sometimes used explicitly to hasten a patient's death. Sometimes this is even done at the repeated request of the patient, which amounts in fact to a request for euthanasia. Where the physician then performed a procedure which can reasonably be assumed to have hastened the patient's death, that procedure must be regarded as termination of life on request. It is doubtful whether physicians are sufficiently aware of this. From the point of view of patient care, it may be questioned whether terminal sedation was the most appropriate means to achieve the end the physician had in mind. For this reason, we feel that it would be desirable for the profession itself to produce guidelines on procedures for the sedation of patients, paying due regard to the statutory provisions and including guidance on appropriate means and ends. Some form of peer review system with regard to the practice of sedation might considerably simplify matters for people on the ground. The Royal Dutch Medical Association (KNMG) has indicated its willingness to draw up guidelines in cooperation with other organizations representing the medical profession and in consultation with the Public Prosecution Service.

44. In calculating annual statistics for euthanasia, the researchers have included cases in which sedation was practised at the request of the patient with the explicit purpose of hastening the patient's death. Assuming that the method used by the physician actually had the effect of shortening the patient's life, this is the right approach. After all, in such cases sedation does constitute a procedure for the termination of life on request and cases ought therefore to be notified and reviewed. In view of the fact that notifications of this kind are in practice virtually unknown, it is clear that the medical world interprets the situation differently. The supervisory committee has pointed to this fact in its report.

45. Since the publication of the research report to which this position paper relates, terminal sedation has been the subject of oral and written questions from members of the Dutch Parliament on several occasions. On 2 June 2004, a member of the House of Representatives asked whether terminal or palliative sedation could be regarded as an alternative within the meaning of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. The question refers to the provision in the Act that, in order to comply with the due care criteria, the attending physician must have concluded that there is no alternative form of treatment available. To constitute a reasonable alternative, treatment must - in the light of current medical knowledge and if properly delivered - offer the prospect of reasonable improvement within the foreseeable future. Sedation does not. There may be coincident medical reasons for sedating a patient who is suffering unbearably with no prospect of improvement and who requests termination of life but sedation will not necessarily constitute, in the terms of the Act, a reasonable alternative in the light of the patient's situation.

46. According to the researchers, however, some physicians say that they would have dealt differently with a euthanasia request from a patient in the past if they had had greater knowledge of palliative care at the time. For this reason, we think that it is extremely important to continue to encourage developments in palliative care and to improve the opportunities for relevant sections of the medical profession to increase their expertise in the terminal care field. The medical schools have a major role to play in this respect.

Other medical decisions relating to the end of life

47. End-of-life medical decisions are not confined to those concerning termination of life on request. The terminal stages of life also raise issues concerning the extent of pain relief to be administered and the withholding or cessation of treatment that is medically futile. All these decisions are part of normal medical practice. Even if chosen procedures can have the effect of shortening the patient's life, they do not constitute euthanasia. It is also important to realize that medical decisions of this sort do not constitute euthanasia without a request from the patient. That would have to involve something other than normal medical procedures.

48. The research shows that there has been no great increase in these other end-of-life decisions. We think it important to keep a close eye on them in order to maintain expertise regarding the distinctions to be drawn in this area.

49. On 2 June 2004, the House of Representatives asked us to include in this position paper some consideration of the procedure commonly known in the Netherlands as "*versterven*" (the practice of withholding artificial nutrition and hydration). Even though this issue was not examined in the evaluation to which this position paper relates, we would like to devote a few words to it. A physician may decide on this course of action if it is clear that a patient is refusing food and/or fluids or if artificial nutrition and hydration appears for some other reason to be medically futile. By declining food and drink, a patient is indicating that he does not wish to be treated. This decision should be respected. The issue of whether artificial nutrition is medically futile will be decided by the physician in accordance with the existing medical standard, since it is in principle a normal part of medical treatment. On 8 October 2003, the House of Representatives received a letter on this matter (29 200 XVI, No. 12) containing an in-depth discussion of the context in which the procedure can be performed.

Palliative care and euthanasia

50. During the passage of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, palliative care and its influence on the frequency of requests for euthanasia was one of the topics that attracted most discussion. The last few years have seen many new measures in the field of palliative care, prompted in part by the recommendations following the previous evaluation.

51. One of these new measures is the promotion of networking by means of structural increases in grants and expansion of the grant scheme for coordination of voluntary work in the domiciliary and family care sector. In addition, regional centres have been set up in order to provide support throughout the country by establishing palliative care departments at the nine Integrated Cancer Centres. Regional consultation teams are also being established and maintained, likewise by the Integrated Cancer Centres. Finally, the money available for the care of terminal patients in nursing or residential care homes has been increased and a national knowledge, information and support centre (known as AGORA) established. These are just some of the measures decided and introduced between 1999 and 2004. They are currently being implemented at regional level and have been reported to the House of Representatives in two letters (20 December 2001 (House of Representatives 28 000 XVI,

No. 97) and 11 March 2002 (House of Representatives 28 000 XVI, No. 109)). The measures were initially funded through the programme of special government support for palliative care implemented between 1997 and 2004. Since 1 January 2004, however, they have been integrated into general health-care spending.

52. The details above show how much palliative care policy has been stepped up over recent years. Given the huge range of problems experienced by patients in the terminal stages of life and the many different forms of care, it is difficult to investigate the relationship between the quality of care and the frequency of requests for euthanasia and their fulfilment. Not surprisingly, therefore, the evaluation offers no clear answer to the question of how far the response of physicians to requests for euthanasia is actually influenced by their knowledge of palliative care and its availability. However, the interviews with physicians reveal that 61 per cent of them believe that euthanasia will still have a place however good the availability of care and support for the terminally ill and of adequate pain relief, while 31 per cent thought this was not the case. The in-depth interviews with a non-representative group of physicians revealed that those who do not regard euthanasia as an option either refuse to perform it on principle or use other techniques, such as administering more medication. The same interviews showed that physicians' attitudes to euthanasia requests evolve in the course of their careers. As time goes on, they tend to adopt a more concerned and thoughtful approach to the subject. Apart from that, all the physicians interviewed welcomed the increased support and greater clarity now available to them in dealing with requests for euthanasia.

53. A number of physicians who took part in the research indicated that they would have dealt differently with a euthanasia request from a patient in the past if they had had greater knowledge of palliative care at the time. For this reason, we think that it is extremely important to continue to encourage developments in palliative care. The medical schools have a major role to play in this respect.

Conclusions

54. The evaluation offers a faithful reflection of the practice of euthanasia review and a number of related topics in the year to which it relates (2001).

55. The main aim of the policy is to increase compliance with the due care criteria in medical end-of-life decision-making and to ensure public accountability in this area. This must be achieved by opening up the subject of difficult medical decisions at the end of life to public debate and by establishing clearly formulated due care criteria. Physicians will be readier to notify cases for review if they are clear about the basis on which their actions will be judged.

56. The evaluation shows that the policy being pursued is helping to achieve this. For example, the various parties involved take a positive view of the review procedure and the reported readiness of physicians to notify cases was greater in 2001 than in 1995. However, the various policy objectives have not been fully met and further measures are still needed.

57. The work of well-trained independent physicians makes a major contribution not only to the quality of the medical decision-making process and subsequent action, but also to the review process. Their reports are an important source of information on cases. SCEN training is therefore important and we shall continue to support it.

58. To increase transparency and ensure a clearer understanding of the due care criteria, a public database will be set up containing the anonymized findings of the review committees. The performance of the review committees will be thoroughly evaluated. A working party is currently considering the report form and will advise on the potential for reducing the administrative burden on physicians without making concessions as regards due care. I will discuss with the Health Care Inspectorate how they deal with notifications from the review committees.

59. I think it is important to investigate as soon as possible whether the reduction in the number of cases notified reflects a decline in readiness to notify. For this reason, I have begun preparations for research on the total number of cases and various related topics, such as the reasons for non-notification and practice within institutions.

60. Institutions can clarify the situation for their staff and patients by pursuing well-defined policies on medical end-of-life decision-making and appointing an independent physician to assess euthanasia requests.

61. On the question of euthanasia without a request from the patient, I am still pursuing consultations with the profession and will write to you at a later date. The issue of “terminal sedation” is also being addressed again within the medical profession. It is important that the position on this should be clarified.

62. In recent years, major investments have been made in palliative care and further action will be required on this over the next few years. It will continue to be important to encourage developments in this area.
