

Supplementary Appendix

This appendix has been provided by the authors to give readers additional information about their work.

Supplement to: van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, et al. End-of-life practices in the Netherlands under the Euthanasia Act. *N Engl J Med* 2007;356:1957-65.

QUESTIONNAIRE END-OF-LIFE DECISIONS IN MEDICAL PRACTICE

General

1. In respect of this death, where you acting as:	<input type="checkbox"/> specialist/specialist-in-training/assistant-specialist-not-in-training <input type="checkbox"/> general practitioner/general-practitioner-in-training <input type="checkbox"/> nursing-home physician/nursing-home-physician-in-training <input type="checkbox"/> a different function to those named above
2. When was your first contact with the patient?	<input type="checkbox"/> before or at the time of death → go to question 3 <input type="checkbox"/> after death → go to question 25
3. Did death occur suddenly and totally unexpectedly?	<input type="checkbox"/> yes → go to question 24 <input type="checkbox"/> no → go to question 4

Medical practices

4. Did you or another physician carry out one or more of the following acts (or ensure that one of them was carried out), taking into account the probability or certainty that this act would hasten the end of the patient's life: (please answer 4a, 4b and 4c)	
4a withholding a treatment*?	<input type="checkbox"/> yes <input type="checkbox"/> no
If yes, which treatments were withheld?	
4b withdrawing a treatment*?	<input type="checkbox"/> yes <input type="checkbox"/> no
If yes, which treatments were withdrawn?	
4c intensifying the alleviation of pain and/or symptoms by using a drug?	<input type="checkbox"/> yes <input type="checkbox"/> no → go to question 6
If yes, which drugs were used? (please tick as many answers as apply)	<input type="checkbox"/> morphine or morphine-derivative <input type="checkbox"/> benzodiazepine <input type="checkbox"/> other drug
5. Was hastening the end of life partly the intention of the act indicated in question 4c?	<input type="checkbox"/> yes <input type="checkbox"/> no
6. Was death the consequence of one or more of the following acts, which you or another physician decided to carry out with the explicit intention of hastening the end of life*: (please answer both 6a and 6b)	
6a withholding a treatment**?	<input type="checkbox"/> yes <input type="checkbox"/> no
If yes, which treatments were withheld?	
6b withdrawing a treatment**?	<input type="checkbox"/> yes <input type="checkbox"/> no
If yes, which treatments were withdrawn?	
7. Was death the consequence of the use of a drug that was prescribed, supplied or administered by you or another physician with the explicit intention of hastening the end of life (or of enabling the patient to end his or her own life)?	<input type="checkbox"/> yes <input type="checkbox"/> no
If yes, who administered this drug (= introduced it into the body)? (please tick as many answers as apply)	<input type="checkbox"/> the patient <input type="checkbox"/> you or another physician <input type="checkbox"/> nursing staff <input type="checkbox"/> someone else
If yes, which drugs were used? (please tick as many answers as apply)	<input type="checkbox"/> neuromuscular relaxant <input type="checkbox"/> barbiturate <input type="checkbox"/> benzodiazepine <input type="checkbox"/> morphine or a morphine-derivative <input type="checkbox"/> benzodiazepine <input type="checkbox"/> other drug

* In this study, 'treatment' includes artificial feeding and/or hydration.

** Either 'hastening the end of life' or 'not prolonging life'.

Decision making about last-mentioned act

Note: If all parts of questions 4, 5, 6 and 7 were answered with 'no', go to question 20. Questions 8 through 19 relate to the last-mentioned act, that is, the last 'yes' in answer to questions 4 to 7.

8. A question about that last-mentioned act: In your estimation, how much was the patient's life shortened by this act?	<input type="checkbox"/> more than six months <input type="checkbox"/> one to six months <input type="checkbox"/> one to four weeks <input type="checkbox"/> up to one week <input type="checkbox"/> less than 24 hours <input type="checkbox"/> life was probably not shortened at all
9. Did you or another physician discuss with the patient the (possible) hastening of the end of life as a result of the last-mentioned act?	<input type="checkbox"/> yes, at the time of carrying out the act or shortly before <input type="checkbox"/> yes, some time beforehand <input type="checkbox"/> no, no discussion → go to question 13
10. At the time of the discussion, did you consider the patient able to assess his/her situation and to make a decision about it adequately?	<input type="checkbox"/> yes <input type="checkbox"/> no, not fully able <input type="checkbox"/> no, not able at all
11. Was the decision concerning the last-mentioned act made upon an explicit request of the patient?	<input type="checkbox"/> yes, upon an oral request <input type="checkbox"/> yes, upon a written request <input type="checkbox"/> yes, upon both an oral and a written request <input type="checkbox"/> no → go to question 16
12. At the time of this request, did you consider the patient able to assess his/her situation and to make a decision about it adequately?	<input type="checkbox"/> yes → go to question 16 <input type="checkbox"/> no, not fully able → go to question 16 <input type="checkbox"/> no, not able at all → go to question 16
13. Did you consider the patient able to assess his/her situation and to make a decision about it adequately?	<input type="checkbox"/> yes <input type="checkbox"/> no, not fully able <input type="checkbox"/> no, not able at all
14. Why was the (possible) hastening of the end of life as a result of the last-mentioned act not discussed with the patient? (please tick as many answers as apply)	<input type="checkbox"/> patient was too young <input type="checkbox"/> this last-mentioned act was clearly in the best interest of the patient <input type="checkbox"/> discussion would have done more harm than good <input type="checkbox"/> patient was unconscious <input type="checkbox"/> patient had dementia <input type="checkbox"/> patient was mentally handicapped <input type="checkbox"/> patient was suffering from a psychiatric disorder <input type="checkbox"/> other, please elaborate at the end of the questionnaire
15. As far as you know, did the patient ever express a wish for the end of life to be hastened?	<input type="checkbox"/> yes, explicitly <input type="checkbox"/> yes, but not explicitly <input type="checkbox"/> no
16. Did you or another physician discuss the (possible) hastening of the end of life with others previous to making a decision about the last-mentioned act? (please tick as many answers as apply)	<input type="checkbox"/> yes, with one or more other physicians <input type="checkbox"/> yes, with nursing staff <input type="checkbox"/> yes, with partner or relatives <input type="checkbox"/> yes, with someone else <input type="checkbox"/> no
If the (possible) hastening of the end of life was discussed with one or more other physicians: did this discussion concern an official consultation as required by the review procedure? (please tick as many answers as apply)	<input type="checkbox"/> yes, consultation of a SCEN-physician <input type="checkbox"/> yes, consultation of another physician <input type="checkbox"/> no

Other issues concerning the last-mentioned act

17. Which were the most important reasons to make the decision about the last-mentioned act? (please tick as many answers as apply)	<input type="checkbox"/> patient had (severe) pain <input type="checkbox"/> patient had (severe) other symptoms <input type="checkbox"/> request or wish of the patient <input type="checkbox"/> request or wish of relatives <input type="checkbox"/> expected suffering of the patient <input type="checkbox"/> no chance of improvement <input type="checkbox"/> no futile prolongation of life <input type="checkbox"/> other:
---	---

18. What do you think would be the best label for the last-mentioned act?	<input type="checkbox"/> abandoning treatment <input type="checkbox"/> alleviation of symptoms <input type="checkbox"/> palliative or terminal sedation <input type="checkbox"/> ending of life <input type="checkbox"/> euthanasia <input type="checkbox"/> assisted suicide <input type="checkbox"/> other:
19. Did you or another physician report the last-mentioned act to a regional review committee because of the review procedure for the ending of life upon the request of a patient?	<input type="checkbox"/> yes <input type="checkbox"/> no, because <input type="checkbox"/> it was no ending of life <input type="checkbox"/> reporting gives to much hassle <input type="checkbox"/> ending of life is the privacy of the patient and the physician <input type="checkbox"/> the requirements for careful practice were possible not met <input type="checkbox"/> because of possible legal consequences <input type="checkbox"/> other:

Care and treatment

20. To what extent, in your opinion, were the following signs or symptoms present in the patient <u>during the last 24 hours</u> before death (despite possible treatment)?	<table style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 60%;"></th> <th style="width: 5%;">1</th> <th style="width: 5%;">2</th> <th style="width: 5%;">3</th> <th style="width: 5%;">4</th> <th style="width: 5%;">5</th> <th style="width: 20%;"></th> </tr> </thead> <tbody> <tr> <td>no pain</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>severe pain</td> </tr> <tr> <td>no vomiting</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>severe vomiting</td> </tr> <tr> <td>no fatigue</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>severe fatigue</td> </tr> <tr> <td>no dyspnoea</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>severe dyspnoea</td> </tr> <tr> <td>not confused</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>very confused</td> </tr> <tr> <td>not depressed</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>very depressed</td> </tr> <tr> <td>not anxious</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>very anxious</td> </tr> <tr> <td>conscious</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>unconscious</td> </tr> </tbody> </table>		1	2	3	4	5		no pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	severe pain	no vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	severe vomiting	no fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	severe fatigue	no dyspnoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	severe dyspnoea	not confused	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	very confused	not depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	very depressed	not anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	very anxious	conscious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	unconscious
	1	2	3	4	5																																																											
no pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	severe pain																																																										
no vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	severe vomiting																																																										
no fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	severe fatigue																																																										
no dyspnoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	severe dyspnoea																																																										
not confused	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	very confused																																																										
not depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	very depressed																																																										
not anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	very anxious																																																										
conscious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	unconscious																																																										
21. Which caregivers were involved in the care for the patient during the last month before death (beside yourself and as far as you know)? (please tick as many answers as apply)	<input type="checkbox"/> general practitioner <input type="checkbox"/> medical specialist <input type="checkbox"/> specialist in alleviation of pain <input type="checkbox"/> nursing home physician <input type="checkbox"/> palliative consultant or palliative team <input type="checkbox"/> psychiatrist or psychologist <input type="checkbox"/> nursing staff <input type="checkbox"/> spiritual caregiver <input type="checkbox"/> volunteer																																																															
22. Was the patient continuously and deeply sedated or kept in coma before death?	<input type="checkbox"/> yes <input type="checkbox"/> no → go to question 23																																																															
Which medication was given for sedation? (please tick as many answers as apply)	<input type="checkbox"/> midazolam <input type="checkbox"/> other benzodiazepine <input type="checkbox"/> morphine or a morphine derivative <input type="checkbox"/> other type of medication																																																															
At what time before death was continuous sedation of the patient started?	<input type="checkbox"/> hours before death <input type="checkbox"/> days before death <input type="checkbox"/> weeks before death																																																															
Did the patient receive artificial nutrition or hydration during sedation?	<input type="checkbox"/> yes <input type="checkbox"/> no																																																															

