

Appendix

General questions

1. What is your age?

..... years

2. What is your gender?

Male

Female

3. How many years of experience do you have as a general practitioner (GP)?

..... years

4. Do you work as a locum GP or as a regular GP?

Locum general practitioner

Regular general practitioner

5. Where do you work most of the time (4 numbers of Postal Code)?

6. How many advance euthanasia directives (AED) do you think you receive monthly?

<1 per month

1 per month

>1 per month

7. How much time do you spend on average discussing AEDs monthly?

<20 minutes per month

20 minutes per month

>20 minutes per month

8. How often is, estimated, a euthanasia request for dementia included in the AED?

Less than 50%

About 50%

More than 50%

9. Have you ever contacted any of these healthcare professionals to discuss a case of a person with dementia? (*Several answers possible*)

Colleague GP

Elderly care physician

SCEN physician

Consultant palliative care

Health care chaplain

Humanistic caregiver

Spiritual care provider

Practice nurse specialized in psychiatrics

Psychologist

None

- Other
10. Have you ever had a euthanasia **request** from a patient WITHOUT dementia?
 Yes
 No → Skip to question 13
11. Have you ever **performed** euthanasia on a patient WITHOUT dementia?
 Yes
 No
12. What kind of burden have you experienced regarding the euthanasia **request** and possible euthanasia **procedure**? (*Several answers possible*)
- Pressure from the patient
 - Pressure from relatives
 - Emotional burden
 - Uncertainty concerning the technical execution
 - Uncertainty concerning the mental competence
 - Uncertainty concerning the advance euthanasia directive
 - Time pressure
 - No burden
 - Other

Questions regarding to patients with dementia

13. Have you ever had a euthanasia **request** from a patient WITH dementia?
(*Several answers possible*)
- Yes, the patient was competent at that time
 - Yes, the patient was incompetent at that time
 - No → Skip to question 17
14. Have you ever **performed** euthanasia on a patient WITH dementia? (*Several answers possible*)
- Yes, the patient was competent at that time
 - Yes, the patient was incompetent at that time
 - No
15. What form of burden have you experienced regarding the euthanasia **request** and possible euthanasia **procedure**? (*Several answers possible*)
- Pressure from the patient
 - Pressure from relatives
 - Emotional burden
 - Uncertainty concerning the technical execution
 - Uncertainty concerning the mental competence
 - Uncertainty concerning the advance euthanasia directive
 - Time pressure
 - No burden
 - Other

16. Please give a short outline of the situation in which there was ambiguity regarding the competency of the patient, if applicable.

17. Is it possible that you will perform euthanasia in a patient with dementia in the future?

- Yes, I think that can be possible
- No, but I will always refer these patients to a colleague
- No, and I will never refer these patients to a colleague

18. Did the recent debates about euthanasia in patients with dementia influence your way of acting?

(Several answers possible)

- Yes, I am more reserved in performing euthanasia
- Yes, I am more fearful for the legal processes
- Yes, I am more prone to forward these patients to a colleague/end-of-life clinic
- Yes, I consult other healthcare professionals more often
- No, no influence
- Other

19. Which treatment options regarding end of life listed below, do you discuss with your patients with dementia? *(Several answers possible)*

- No antibiotics for infections
- No life-extending treatments
- No CPR
- No hospital admissions
- Palliative sedation
- Physician-assisted suicide
- Not applicable

Support of healthcare professionals regarding euthanasia requests in patients with dementia

If you have never had a euthanasia request of a patient with dementia, you can skip to question 21.

20. What kinds of support have you used when dealing with previous euthanasia requests or procedures? *(Several answers possible)*

- Consulting palliative care
- Geriatric consult team
- Humanistic caregiver
- End-of-life clinic (physician/nurse)
- Moral deliberation
- PaTz-group¹
- SCEN physician
- Spiritual care provider
- Other

21. What kinds of support would you like to use when dealing with euthanasia requests in the future? *(Several answers possible)*

- Consulting palliative care
- Geriatric consult team
- Humanistic caregiver
- End-of-life clinic (physician/nurse)
- Moral deliberation
- PaTz-group¹
- SCEN physician
- Spiritual care provider
- Other

22. How important do you rate the support of healthcare professionals in the different phases of the euthanasia procedure below on a scale of 0 to 10? (0 = not important; 10 = very important)

Euthanasia request before starting the euthanasia procedure

0 1 2 3 4 5 6 7 8 9 10

During the euthanasia procedure towards the euthanasia performance

0 1 2 3 4 5 6 7 8 9 10

The performance of the euthanasia

0 1 2 3 4 5 6 7 8 9 10

The procedure after the performance of the euthanasia

0 1 2 3 4 5 6 7 8 9 10

¹ Group of general practitioners and district nurses that debate six times a year under the supervision of a palliative care consultant to identify palliative care early, to act proactively.

Training regarding euthanasia in patients with dementia

23. In which area would you like to increase your knowledge during training?

(Several answers possible)

- Communication techniques to discuss end of life
- Signaling symptoms (pain for example) in patients with a cognitive impairment
- Dealing with the pressure by relatives
- Legislation and interpretation of euthanasia regarding PWD
- Advance care planning
- Disease trajectory of dementia
- How to compose and handle an advance euthanasia directive
- No wishes to increase knowledge of skills
- Other

Due care criteria

24. Meeting and judgment of the due care criteria are often considered to be complicated in euthanasia in patients with dementia. An example of this is the judgment of the patient's unbearable suffering with no prospect of improvement. In what extent do you agree with the statements below?

a. I experience difficulties by judging the due care criteria of the patients' unbearable suffering with no prospective improvement adequately in an incompetent patient.

- Totally disagree Disagree Neutral Agree Totally agree

b. I am convinced that the due care criteria are met, when a competent patient considers his perspective of future suffering as unbearable, with no prospect of improvement.

- Totally disagree Disagree Neutral Agree Totally agree

Case vignette

The following questions are about a fictional situation that could occur during the last phase of life. Please, choose the answers that resemble your opinion the best.

Mr. Smit is 70 years old and is indisputable diagnosed with dementia by the geriatric physician. He does not recognize his wife and children anymore, refuses to eat, isolates himself increasingly and discussing his treatment is not possible anymore. Ten months ago, when he was still found competent, he composed an advance euthanasia directive, in which he declared that he would opt for euthanasia when suffering from dementia.

His family is now asking for performing this, given the patients' AED and his unbearable and hopeless suffering with no prospect of improvement. The general practitioner considers the patient cognitively incapable, recognizes the patient's suffering and is convinced that the patient's advance euthanasia directive can replace an oral request. The consulted SCEN physician and elderly care physician confirmed this. A sedative is orally administered to prevent possible unpredictable behavior, agitation and startle reactions at which the patient might walk away, after which the general practitioner performs the euthanasia. The regional review committee invites the general practitioner to give an explanation of his actions.

25a. Do you judge the way of acting of this general practitioner to be correct?

- Yes
- No

My personal view regarding to euthanasia in patients with dementia is:

b. An advance euthanasia directive can replace an oral request if communication with the concerned patient is impossible.

- Yes
- No
- Maybe, if

c. The family can initiate the start of a euthanasia procedure representing the interests of the concerned patient.

- Yes
- No
- Maybe, if

d. A sedative medicine prior performing euthanasia to the concerned patient is allowed.

- Yes
- No
- Maybe, if

Your own input

If you feel like something you want to share is missing in the questionnaire, please write it down in the box below.

*This is the end of this questionnaire. We want to thank you very much for participating. If you are interested in the results of this study, write down your email address in the box below.
Your email address will only be used for sharing the results.*

You can return the completed questionnaire in the attached self-addressed envelope.