



# BMJ Open Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: a mixed-methods evaluation study

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## ABSTRACT

**Objectives** In oncology and palliative care, patient question prompt lists (QPLs) with sample questions for patient and family increased patients' involvement in decision-making and improved outcomes if physicians actively endorsed asking questions. Therefore, we aim to evaluate practitioners' perceptions of acceptability and possible use of a QPL about palliative and end-of-life care in dementia.

**Design** Mixed-methods evaluation study of a QPL developed with family caregivers and experts comprising a survey and interviews with practitioners.

**Setting** Two academic medical training centres for primary and long-term care in the Netherlands.

**Participants** Practitioners (n=66; 73% woman; mean of 21 (SD 11) years of experience) who were mostly general practitioners and elderly care physicians.

**Outcomes** The main survey outcome was acceptability measured with a 15–75 acceptability scale with ≥45 meaning 'acceptable'.

**Results** The survey response rate was 21% (66 of 320 participated). The QPL was regarded as acceptable (mean 51, SD 10) but 64% felt it was too long. Thirty-five per cent would want training to be able to answer the questions. Those who felt unable to answer (31%) found the QPL less acceptable (mean 46 vs 54 for others; p=0.015). We identified three themes from nine interviews: (1) enhancing conversations through discussing difficult topics, (2) proactively engaging in end-of-life conversations and (3) possible implementation.

**Conclusion** Acceptability of the QPL was adequate, but physicians feeling confident to be able to address questions about end-of-life care is crucial when implementing it in practice, and may require training. To facilitate discussions of advance care planning and palliative care, families and persons with dementia should also be empowered to access the QPL themselves.

## Strengths and limitations of this study

- We employed a mixed-methods design which allowed for integration of relevant secondary analyses of the quantitative data based on a question that emerged from the qualitative interviews.
- We did not assess perceptions of persons with dementia and family; we assessed perceptions of physicians only.
- The responding physicians may represent a sample with an above average interest in the topic of advance care planning or in dementia care.

## INTRODUCTION

In long-term care, an ongoing dialogue between patient, family (caregivers) and the healthcare team in the form of advance care planning (ACP) can improve the quality of end-of-life care.<sup>1–3</sup> With dementia, timely ACP is crucial to enable persons to participate because of the cognitive decline and rather unpredictable disease trajectory.<sup>3–5</sup>

However, in practice there are numerous barriers to early ACP initiation. Some people do not want to talk about the future, but rather live one day at a time.<sup>5,6</sup> Moreover, healthcare professionals (practitioners) may struggle with moral dilemmas around, for example, best interest judgements.<sup>7</sup> Practitioners may also hold very different beliefs regarding when to best initiate the ACP discussion,<sup>6,8,9</sup> which may relate to different conceptualisations of what ACP entails.<sup>10</sup> Interventions to increase ACP often address either the practitioner or the family.<sup>11–13</sup>

Several decision aids have been developed to enhance ACP and improve the quality of

decision-making including a family booklet for dementia at the end of life that was found acceptable and useful by physicians, nurses and family in multiple countries.<sup>14–16</sup> However, the booklet only contains information, while explicit example questions provided by a question prompt list (QPL) can empower people to ask questions that are specific to their individual information needs. QPLs may also prompt patient and family to ask about sensitive topics that they might not otherwise think of or feel comfortable with. Research in oncology and palliative care indicates that QPLs increased question asking during medical consultations especially if physicians also encourage patients to use the QPL, enhance participation in decision-making and sometimes improve psychological outcomes such as anxiety in a longer-term.<sup>17 18</sup>

Similarly, a QPL specifically for persons with dementia and their family might alter the dynamics of discussions on end-of-life care. Therefore, we developed a QPL for persons with dementia and their family and addressed the research question of what are perceptions on acceptability and possible use of the QPL among practitioners involved with advance care planning in dementia care.

## METHODS

We performed a mixed-methods evaluation study of a QPL among practitioners because their perceptions are crucial for implementation strategies in practice and preparing for trials.<sup>19</sup> We used validated instruments followed by interviews to understand perceptions around how the QPL would or would not fit practice.

### Patient and public involvement (in QPL development)

In 2018, a multidisciplinary team drafted an initial QPL in the form of a booklet with information and sample questions. The QPL's goals were to: help elicit perceptions and beliefs about the end of life, help think about what to ask professionals, encourage conversations and facilitate decision-making. The contents was based on the earlier booklet,<sup>14–16</sup> an Australian QPL for persons with dementia and their family<sup>20</sup> and a Canadian QPL for family of nursing home residents with dementia.<sup>21</sup> Content about euthanasia was specific for the Netherlands as in the earlier booklet.<sup>22</sup> In the Netherlands, the general public finds euthanasia in dementia more often acceptable than physicians do and there are many questions around usefulness and acceptability of a euthanasia living will.<sup>23 24</sup>

The first draft of the QPL was presented to two panels of older people affiliated with the academic centres, many of whom had experience with dementia in various roles and experts in grief and bereavement, spiritual caregiving and ethics, cultural issues, layout and lay language use (a professional language centre reducing the level to B1).<sup>25</sup> We provided the three goals we wanted to achieve with the QPL and solicited for any feedback. We collated and discussed their feedback which was used to improve the QPL, in particular the information provided,

### Box 1 Overview of topics covered in the question prompt list

Talking about the later stages of life in dementia: Information and example questions for people with dementia and their relatives

#### Part 1: About illness and care

- ▶ Dementia and changes in health.
- ▶ Care goals, palliative care and end-of-life decisions.

#### Part 2: About treatment and choices

- ▶ Decisions about treatments and agreements (advance care planning).
- ▶ Treatment and care for common problems.
  - Eating and drinking and swallowing problems.
  - Pneumonia and other infections.
  - Shortness of breath.
  - Pain and feeling uncomfortable.
  - Restlessness and challenging behaviour/behavioural problems.
  - Incontinence (in later version only).
  - Depression, anxiety and lack of initiative.
  - Feelings of loss and existential questions.
  - Other illnesses and what these may require.
- ▶ End-of-life decisions regarding prolonging or shortening life.
- ▶ Choice of location of care and change of living environment.

#### Part 3: About and for the relative

- ▶ Care for you as a relative.
- ▶ The dying phase and after death.

\*Topics of the 2018 evaluation version. For adaptations in response to the evaluation, see online supplemental file 1.

simplifying it and addressing the reader more personally and empathically (box 1). The 2018 version comprised 76 questions in total, 2 to 11 sample questions per topic (online supplemental file 1).

### Evaluation procedures

The academic medical training centres for primary and long-term care of universities in Leiden and Nijmegen, the Netherlands, granted access to residents and supervisors in elderly care medicine and general practice. These professions are responsible for primary care for persons with dementia, with elderly care physicians usually being on the staff of a nursing home or also practicing in the community in collaboration with general practitioners (GPs).<sup>26</sup> Further, we thus sampled for large variation in experience and a population of practitioners who may be early adopters.

The QPL and survey were distributed on paper during meetings at educational centres or sent via postal mail in June 2018. We provided two copies of each, for the physician themselves and for a colleague. Completing and returning the survey on the QPL served as informed consent for the study's survey part. We sent one general reminder via email. We offered an optional accredited (1-hour) educational exercise that involved developing a strategy for future implementation of the QPL in practice with feedback from the researchers.

## Survey

The questionnaire examined physician's perception of the acceptability of the QPL (primary outcome), the usefulness and quality of contents (secondary outcomes) and possible barriers to implementation in practice. We assessed acceptability with a slightly adapted validated 15-item scale of statements<sup>15 16</sup> (online supplemental file 2) based on acceptability decision aid evaluation methodology.<sup>27</sup> Usefulness and quality of content was assessed by asking physicians to rate the contents<sup>15 16</sup> and statements of anticipated benefits based on the QPL's goals. Barriers to optimal use of the QPL were assessed based on earlier questionnaires on barriers to symptom relief in dementia and perceptions of ACP among GPs and elderly care physicians.<sup>19 27–30</sup>

All items were rated on 1–5 point scales with only the extremes labelled ('strongly disagree' and 'strongly agree') except for quality of content for which extremes were labelled 'poor' and 'excellent'.<sup>16</sup> The 15 acceptability items were summed to calculate an acceptability score ranging 15–75 points. We regarded (mean) total scores of 45 (mean item score 3) and higher as acceptable, and scores of 60 and higher as highly acceptable.<sup>16</sup> The survey data were managed in Castor EDC (2018) (Castor, Amsterdam) and for analysis exported to SPSS V.23 (2018). We used descriptive statistics to present the results and we compared professions with appropriate tests (in footnote to tables).

## Interviews

In line with an explanatory sequential mixed-methods design,<sup>31</sup> at the end of the survey, physicians could indicate whether they were willing to be approached for an additional qualitative interview by providing their contact details. We selected physicians for an interview based on a particularly high or low acceptability scores (purposive sampling). We aimed to perform about 10 to 12 individual interviews for probable saturation for our specific aim.<sup>32 33</sup> Before the interview, participants signed an informed consent form modelled after the template of the Dutch Central Committee on Research Involving Human Subjects. Interviewees were offered a gift card of €30. Semi-structured face-to-face interviews (seven) were held by SH—male master's student working in nursing homes, JTvdS—female PhD epidemiologist (double interview) and AK—female MD researcher who had not been involved in QPL development (one, and one with SH).

The interviews were guided by an interview guide (online supplemental file 3) that contained key questions addressing the participant's views on the QPL, their personal approach to end-of-life conversations and considerations regarding possible implementation of the QPL. If relevant, specific questions were asked based on reviewing participant's survey responses in an open manner. Not all questions were asked and in later interviews, we asked more about personal strategies employed to introduce ACP triggered by discussing both the QPL as a concrete tool and end-of-life conversations more

generally. All interviews were audio-recorded, and SH transcribed verbatim while guaranteeing confidentiality through procedures consistent with the general data protection regulation (GDPR). Interview data were managed and coded in Atlas.ti (V.7.5.18, 2012). We used inductive thematic analyses to analyse the interviews along with open-ended items of the survey (whether they agreed with the QPL's contents and format, any missing information or questions, any other comments). The three researchers who conducted the interviews, coded the first interviews and discussed and agreed on the coding (188 codes and 11 inter-related subthemes available at request). We selected citations to represent and illustrate the themes consistent with good research practice.<sup>34</sup>

## RESULTS

### Survey participants

We approached all residents and supervisors (160) to participate, providing a copy of the questionnaire also for a colleague (ie, 320 in total). Between June and December 2018, 66 (21%) were returned completed by 18 GPs including 2 general practice-based assistant practitioners and 46 elderly care physicians, 1 geriatrician and 1 geriatric nurse. The response rates of the Leiden (21%; 40/190) and Nijmegen centre (20%; 26/130) were similar.

The majority (73%) of the participants were woman, with a mean of 21 years' experience and over half (56%) cared for persons with dementia on a daily basis (table 1). Elderly care physicians were more likely to see persons daily (70% vs 22%) and in more advanced stages of dementia (70% vs 11%).

### Survey acceptability and possible use

Table 2 shows that the physicians judged the QPL as acceptable (mean acceptability score 51), however, with a high SD (10), but there was no difference in acceptability score between GPs and elderly care physicians. Mean usefulness was 7.2 points on the 1–10 scale. The contents were mostly appreciated (mean quality 64 points, SD also 10; online supplemental file 2: most, care for relatives; least, the introduction about illness and care). Although few participants thought there were too many example questions (9%), 64% of the physicians found the QPL too long and 59% felt there was too much information.

The survey items on barriers and benefits did not show clear patterns, but 49% believed that persons in early stages of dementia could not use the QPL themselves (table 3). When available, most (59%) would give the QPL to the individual and their family and 26% to family only (14% would not give it to anyone). Most (56%) physicians anticipated the QPL will increase provision of palliative care, and 21% anticipated more requests to hasten death, which was concerning to about half of them (10% overall).

Table 4 shows that almost one-third (31%) of the physicians found they were unable to answer all example questions in the QPL adequately, despite the instruction with this item recognising that for some questions, there is no, or no certain answer. Overall one-third (35%) of the



**Table 1** Physicians' characteristics and dementia care practice patterns (n=66)\*

Female sex, %	73
Age, mean (SD)	48 (11)
Experience as a physician, mean (SD)	21 (11)
Resident trainee, %	17
Supervisor, %	53
Care for patients with dementia; frequency, %	
At least daily	56
At least weekly	34
At least monthly	6
At least every 2 months	3
At least every 6 months	0
<Every 6 months	0
Care for patients with dementia; stage of disease, %	
Mostly early stage (mild dementia)	8
Both early and late (moderate or advanced) stage, about equally distributed	39
Mostly late (moderate or advanced) stage	53
Estimation of patients with dementia dying in the past year, %	
0	2
1–4	27
5–9	25
10–19	34
20 or more	13

Significant differences ( $p < 0.05$ ) between GPs and elderly care practitioners were not observed for sex, trainee or supervisor status ( $\chi^2$ ), age and experience (t-test). With the hierarchical gamma test there were differences between the last three items; elderly care physicians cared for patients with dementia more frequently (eg, daily 70% vs 22%), cared for patients in later stages (eg, advanced stage 70% vs 11%) and more patients with dementia died in their practice in the past year (eg, 20 or more 17% vs 0).

\*Two of 66 respondents missed characteristics other than sex and age. GP (n=18) included two general practice-based assistant practitioners (often nurses or social workers, referred in the Netherlands as 'praktijkondersteuner huisarts', POH). Elderly care practitioners (n=48) included 46 elderly care physicians, a geriatrician and a geriatric nurse. Experience refers to experience as a physician and was missing for the general practice-based assistant practitioners (POH) and the nurse. GP, general practitioner.

participants felt a need for training to answer the QPL's example questions; more often GPs than elderly care physicians (72% vs 20%).

### Interviewees

We invited five physicians with a high acceptability score (55–64), four others (score 24, 35 or no score but negative comments) and one with combined GP/elderly care background and all were interviewed at their workplace from July to November 2018. Of the physicians (seven

**Table 2** Evaluation of acceptability and the contents of the question prompt list (n=66)

Acceptability score, mean (SD)*	51 (10)
Usefulness for persons with dementia and family, mean (SD)†	7.2 (1.7)
Quality of the content of the question prompt list, mean (SD)‡	64 (10)
Length, %	
Too long	64
Too short	2
Just right	34
Amount of information, %	
Too much	59
Too little	0
Just right	41
Balance in proportions of information vs example questions, %	
Too much information	20
Too many example questions	9
Just right	70

No differences ( $p < 0.05$ , t-test or  $\chi^2$  as appropriate) were observed between general practitioners (GPs) and elderly care practitioners for any of the items, including after adjustment for sex, experience and stage of dementia cared for most (first three outcome items, linear regression). Missing values: 2, except for usefulness, 1.

\*Theoretical range score: 15–75. Cronbach's alpha in this sample was 0.94. The acceptability score covers: informing families, supporting decision-making, communication with families, satisfaction with care, use in practice and use in training (see online supplemental file 2, table S1 and table S2 for individual items and item scores).

†Theoretical range score: 0–10.

‡Theoretical range score: 16–80 (see online supplemental file 2, table S3 for item scores).

female and three male), three were trainees, four were supervisors; seven were elderly care physicians, one GP, one both and one geriatrician. Eight were individual interviews, and we interviewed one dyad of supervisor and trainee. The interviews lasted on average 46 (SD 15) min.

### Interview themes

We identified three major themes with the last three interviews (with highly critical elderly care physicians and the only geriatrician) pointing to saturation: (1) enhancing conversations through discussing difficult topics; (2) proactively engaging in end-of-life discussions in practice; and (3) considering possible implementation of the QPL.

### Enhancing conversations through discussing difficult topics

The physicians who rated the QPL as highly acceptable anticipated added value in end-of-life discussions, mainly to enhance the conversations. They expected that it would encourage the person and family to consider questions about dementia and care options:

**Table 3** Barriers, benefits and views about use, % (n=66)

Range of perceived barrier scores (means and SDs five items)*	2.4–2.9 (0.89–1.1)
Goals and anticipated benefits of use (means and SDs seven items)*	3.1–3.9 (0.79–0.94)
Do you think patients with dementia can use the QPL themselves?	
Yes, but only in early stages of the disease (MMSE >20)	49
Yes, in early but also in moderate stages of the disease (MMSE >10)	2
No, (almost) no one with dementia can	49
When the QPL is available, I will give it to...	
Patients and relatives	59
Relatives	26
I will not give the QPL to anyone	14
QPL will lead to earlier or more frequent providing of palliative care	
Yes	56
No	44
This QPL will lead to more requests to hasten death	
Yes, and I do not have any objection	11
Yes, and I object to that	10
No	79

\*Items are shown in online supplemental file 2, table S4 and S5. Agreement is scaled on the same scale as the acceptability scale, from 1 to 5 point scale with only the extremes labelled ('strongly disagree' and 'strongly agree'). No differences ( $p < 0.05$ ,  $\chi^2$  or t-test as appropriate) were observed between general practitioners (GPs) and elderly care practitioners for any of the items, except for the barrier item 'The hectic pace of practice will prevent me from using the question prompt list' (higher barrier score for GPs). Missing values: use themselves 1, give it to 2, palliative care 2, hasten death 3. QPL, question prompt list; MMSE, Mini-Mental State Examination.

"I think if the patient has it [the question prompt list], he or she will have some questions of his/her own before we have this conversation. So I think the doctor will be triggered and get more questions from the client side, yes." (elderly care physician in training 2, positive; citation a)

Moreover, they felt that having an overview of topics that could be discussed would be helpful for themselves:

"I was pleasantly surprised because I think something like this is very useful. It actually provided a very good guide for the things you actually want to know from a patient." (elderly care physician-in training 1, positive; citation b)

On the other hand, both physicians with a high and a low acceptability score were concerned about possible information overload, leading to confusion, or even fear:

**Table 4** Confidence in using the question prompt list (n=66)

I am able to answer all the questions asked in the question prompt list, %*	
Yes	69
No	31
Need for training, % confirmed	35
Training on subject/content	19
Training in conversation techniques	5
Training on subject/content and conversation techniques	11

Differences ( $\chi^2$ ) were observed between general practitioners (GPs) and elderly care practitioners (first item,  $p=0.015$ , unable to answer, elderly care physicians 22% vs GPs 56%; second item,  $p=0.001$ , any training elderly care physicians 20% vs GPs 72%). \*The item included this explanation: 'this does not mean that you have a ready-made answer to all questions, but that you think you can respond adequately to all questions'

"I'm afraid that because of its extensiveness, it won't be used that much and that would be a pity because the subjects that are raised are all very relevant." (elderly care physician and GP 6, positive; citation c)

"Yes, I think that because of the amount of information, people will start thinking and can also get, well, confused." (elderly care physician in training 1, positive; citation d)

"Because, for example, a feeding tube is also touched on here, but it is mentioned very briefly and then: well, that often doesn't help. I think it can also sometimes cause people to get confused if there is information that is perhaps a little too concise and consequently raises expectations of: gosh, it might be worthwhile; that it can also generate unrest in such a conversation." (elderly care physician-in training 8, negative; citation e)

"But sometimes you... Maybe it's a good thing not to know things and not to ask about them." (elderly care physician supervisor 7, negative; citation f)

Another issue was whether terms such as 'care goals' and 'advance care planning', although explained in the QPL, should be used at all.

"...you keep hammering on care goals, what's your care goal. That is our problem, we want to label everything a goal or a problem, why should you call it a care goal, you could say: we would like to know, what is important for you to have a good life." (elderly care physician 4, supervisor, negative; citation g)

Some physicians' had concerns regarding specific questions in the QPL such as those about life expectancy, progression of the disease over time and religious matters. While participants felt these questions would be meaningful for the person, some physicians felt they had no clear answers, and they reasoned that this might result

in persons with dementia and family becoming more anxious.

“A slightly more critical look is needed at some of the questions being asked, questions that make me wonder, what doctor can answer that.” (elderly care physician 4, supervisor, negative; citation h)

### Proactively engaging in end-of-life discussions in practice

The physicians would normally employ various approaches in initiating conversations about the end of life. Most mentioned they start with asking general non-threatening questions, and through the answers, consider whether the person with dementia or family is ready to further discuss more sensitive or confrontational topics at that time, or to postpone the discussion:

“You explore: what is a person’s attitude to life and what can the person handle and in that way you try, you basically ask questions. And that’s how you try to find a starting point (...) you are very careful, you don’t go in like ‘wham’.” (elderly care physician-in training 1, positive; citation i)

However, some physicians take a more proactive yet confrontational approach with specific examples that people can imagine and understand easily:

“You’re actually describing the situations, is that what you’d want in that case? For example, resuscitation, because that is also a difficult concept to explain: we will bring you back from the dead, actually you are already dead, but then we bring you back from the dead, but that can cause a lot of brain damage. Then they say “brain damage, why?”; we often use the term [living like a] ‘vegetable’ [in Dutch: ‘kasplant’], that’s an association.” (elderly care physician 3, positive; citation j)

“‘Vegetable’ [...] is very easily accepted as a word. It is clear to 99% of people.” (elderly care physician 5, supervisor, positive; citation k)

The most important factor in how to approach the person and family was their educational level, according to the interviewees, which was corroborated by comments to open-ended survey items. The more highly educated would be equipped for the conversation through a better understanding of the subject, where others would need more guidance and explanation. The physicians believed those with a lower educational level may hold misconceptions regarding treatment and care and have more trouble processing the QPL.

“That depends. Around here we have quite a few highly educated people, so shared decision-making is very doable. People are well-informed, they read up [on the topic].” (elderly care physician 3, positive; citation l)

“Yes, and I think it can be very confusing for some people. But maybe that’s with the poorly educated

population I occasionally work with in mind, that this is a lot and difficult to grasp. [...] then you ask do you want to be resuscitated and people say yes, but they have no idea... They think if they say no, they’ll get an injection tomorrow and that’s it, those are people’s perceptions sometimes.” (elderly care physician-in training 1, positive; citation m, continued citation d).

Apart from educational level, some participants mentioned the relevance of the setting in which the QPL conversation takes place. Nursing home residents with dementia and family may have had more opportunity to think about the end of life than persons (still) living in a community setting, regarding specific treatment and values and preferences relating to care. Therefore, the more sensitive topics regarding end of life may be easier to discuss:

“People in nursing homes have already faced much more dependency, so most of them have thought about it. In primary healthcare this is much more difficult, because people who are never ill think they will live forever, and then suddenly they are confronted with it.” (elderly care physician 4, supervisor, negative; citation n)

A good connection based on trust was regarded as an important factor to improve the quality of end-of-life discussions:

“...you get to know your client over a long period of time, you get to know the family over a long period of time, the care staff get to know someone over a long period of time, because that’s also important... yes, these are people you know well, that’s the advantage of being a GP, that you have a connection with a person.” (GP 1, negative; citation o)

### Considering possible implementation of the QPL

The interviewees selected for being positive about the QPL would like to consider the QPL used by physicians and nurse practitioners. Some physicians would want the QPL to be used as early as possible in general practice, with the general practice-based assistant practitioner being the right person to not only give the QPL to patients and families, but also start the conversation about possible future care options, supervised by the GP:

“Maybe this is not a job for the GP? Maybe for the general practice-based assistant practitioner. They often have more time and they know the people better, are more accessible and they can probably explain things in everyday language.” (elderly care physician 3, positive; citation p)

The physicians who found the QPL less acceptable envisioned barriers to implementation and were not considering possible solutions. They mentioned lack of time if

there would be many questions or stated that the format is not viable:

“I think that you can have a really good conversation with two or three questions, and that you have to be careful it doesn’t turn into an hour of conversation, because we simply don’t have that kind of time.” (GP 1, negative; citation q)

“I think it [the length of the list] is such a major drawback that I think, I don’t know... that I also find it hard to figure out how to make it work.” (elderly care physician 4, supervisor, negative; citation r)

### Integration of survey and interview results

Some interviewees expressed concerns about not being able to provide good, or specific answers to certain questions in the QPL. For example, they mentioned not being able to answer a question on life expectancy and the progression of the disease. This emerged as an important issue that could affect adoption of the QPL. Therefore, based on the interview findings, we hypothesised that lack of self-efficacy or fear of not having the answer might be a decisive factor in using or appreciating the QPL. We then did a post-hoc secondary analysis of the survey data and found that the average acceptability score of those who felt they could not give answers to all example questions was lower, compared with those who felt they could (46 vs 54;  $p=0.015$ ), with a higher SD (13 vs 8).

## DISCUSSION

### Main findings and interpretation

This is the first study to assess practitioners’ acceptability and views on a QPL about end-of-life issues specifically designed for persons living with dementia and their families. Physicians (and a few other practitioners) who provide long-term and end-of-life care for persons with dementia rated the QPL to be acceptable and the quality of the contents as good. However, many found the amount of information problematic, and were concerned it could be overwhelming. Importantly, the physicians were divided about whether the QPL would be too difficult for use by persons with dementia themselves due to the cognitive impairment associated with dementia, and they also differed in the extent to which they would confront persons with dementia and family with sensitive or difficult issues about end of life. Some physicians felt it would be better to ask initial screening questions to probe the persons’ readiness to discuss these issues before providing a QPL.

When comparing the physician acceptability score of the QPL to earlier research in which we evaluated a family booklet with information only about dementia at the end of life, the mean acceptability score for the QPL was lower (56 vs 51, respectively).<sup>16</sup> The QPL also targets persons with dementia themselves in a community setting, rather than family only. In the secondary analysis prompted by the interview findings, we found lower acceptability of

the QPL by physicians who were concerned about their ability to answer questions in the QPL adequately. The physicians, although associated with an academic centre and probably with an interest in the topic, may not feel comfortable to discuss some topics included in the QPL, perhaps also including around hastening death.<sup>24</sup>

### Strengths and limitations of this study

The mixed-methods design allowed for a richer understanding of the quantitative survey data, in particular regarding barriers and concerns, and also provided an efficient iterative approach of analysing the quantitative data based on a question that emerged prominently from the qualitative interviews, additional to interviewing about completed surveys. The response to the survey was low but within the range of responses commonly observed for physician surveys, while trends point to declining response rates.<sup>35–37</sup> The concerns we identified from respondents, who were probably interested physicians connected with an academic centre, may not be generalisable and may underestimate concerns in physicians caring for persons with dementia.

We did not assess the acceptability of the QPL by persons living with dementia and their families, and further research in this area is warranted. In other research, on a lengthy QPL in palliative care more generally, despite its length, patients and professionals would not drop any topic or question for choice.<sup>38</sup> Indeed, the physicians in the evaluation study suggested adding questions rather than deleting any, the revised version including seven more questions and new, practical tips (online supplemental file 1). Further research should determine various modes of delivery, for example, deciding together in advance to limit the conversation to one or two topics.

### What this study adds: implications and conclusions

Training is required to increase confidence of physicians to be able to address questions from family and persons with dementia about end-of-life care when implementing a QPL in practice. Training should focus on increasing self-efficacy in addressing difficult questions, and for this, training of actual conversations with actors or e-simulated patients may be effective.<sup>39 40</sup> This may generalise to other countries as other work has shown that many Dutch elderly care physicians but also many GPs in Northern Ireland are reluctant to initiate ACP with people in the early stages of dementia.<sup>9</sup> Shared decision-making is worthwhile in situations where there is choice based on individual preferences.<sup>41</sup> Persons with dementia may hold a neutral or negative stance regarding ACP<sup>3 13</sup> and a first extra step, before starting a decision-making process with a person with dementia is to agree on the necessity to make a decision.<sup>42</sup> Therefore, a prudent approach, probing readiness to engage in ACP, as adopted by some physicians, makes sense. On the other hand, persons with dementia and family may need proactive encouragement and support from physicians or other practitioners to discuss ACP so that they do not miss out on the opportunity to participate in decisions about their future care. This can help empower persons



with dementia and avoid regret and crisis later on for family when making difficult decisions on behalf of the person with dementia.<sup>43</sup> Further research should include evaluations of use in practice, including formal evaluations from persons with dementia and family.

A QPL may help persons with dementia and family to select exactly the topics they find relevant at that time, and this could also inform the practitioner about readiness to discuss end of life. They should be offered choice from a collection of structured sample questions, but if overwhelming, they may decide in advance with their professional caregivers which topic to discuss (first). QPLs have the potential to alter the dynamics of conversations and empower persons with dementia in encounters with professional caregivers. These are worthwhile endeavours for persons with dementia who essentially would like to be part of society, appreciated and their identity recognised.<sup>44 45</sup> Further, shared decision-making about goals for future care as the persons' dementia progresses is important because not all goals of care can be achieved, and there may also be trade-offs between goals for the family and the person with dementia.<sup>41 45-47</sup> To empower persons with dementia and their family, implementation strategies should also circumvent possible gatekeeping to include free access so they can ask practitioners and thus take initiative to start conversations.

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## Supplement 1. Question prompt list “Talking about the later stages of life in dementia” sample questions, tips and “things to think about”

- Translated from Dutch to English by a professional bi-lingual translator. The Dutch question prompt list additionally presents brief information on each of the topics.
- The pilot version used in the evaluation study with practitioners in 2018 was improved in 2019 based on the evaluation, and again with input from family caregivers and professional caregivers in 2020. Where versions differ, the 2018 text is presented in the lightest grey shade, 2019 in dark grey and 2020 text and unchanged text is presented in black [explanation added after the first questions].
- Changes are indicated with grey mark. The 2018 version included 76 questions. The 2020 and 2019 versions comprise 83 similar questions. After the evaluated 2018 version, various tips and nine questions were added (highlighted blue), one question was deleted, and two were combined in a single question (both highlighted green).
- The 2020 version also offers the sample questions as a separate list to facilitate preparing for a conversation with a health care provider.
- The 2020 question prompt list and separate list are available in Dutch from: <https://www.lumc.nl/org/unc-zh/onderzoek/Palliatievezorgbijdementie/Ontwikkelengesprekshulpdementie/>
- **Reference:** van der Steen JT, Juffermans CCM, Gilissen F, van der Linden YM, Koopmans RTCM. Gesprekshulp de latere levensfase bij dementie. Tijdige informatie en voorbeeldvragen voor mensen met dementie en hun naasten. [Talking about the later stages of life in dementia: Timely information and example questions for people with dementia and their relatives]. 2<sup>nd</sup> Edition. Leiden, The Netherlands: LUMC, 2020.

## Talking about the later stages of life in dementia:

information and example questions

for people with dementia and their relatives

timely information and example questions

for people with dementia and their relatives

timely information and example questions for people with  
dementia and their relatives

**Part 1 About illness and care****Part 1 About illness and care in general****Part 1 About illness and care in general****1. Dementia and changes in health****2. Care goals, palliative care and end-of-life decisions****Part 2 About treatments and choices****Part 2 About treatments and choices regarding health issues****Part 2 About treatments and choices regarding health issues****3. Decisions about treatments and agreements [advance care planning]****4. Treatment and care for common problems****5. Choice of location of care and change of living environment****5. Choice of location of care and change of living environment****6. Choice of location of care and change of living environment****6. End-of-life decisions regarding prolonging or shortening life****6. Resuscitation and euthanasia****5. Resuscitation and euthanasia****Part 3 About and for the relative****Part 3 The relative****Part 3 The relative****7. Care for you as a relative****8. The dying phase and after death****8. The dying phase and the period after death****8. The dying phase and the period after death****Tips**

- ✓ There are many questions you could put to your health care professional.  
If you have difficulty choosing a question at this point, you could start off with this one:  
*In your opinion, what is important for us to know about care now and in the future?*
- ✓ There are many questions you could put to your health care professional.  
If you have difficulty choosing a question at this point, you could start off with this one:  
*In your opinion, what is important for us to know about care now and in the future?*
- ✓ People who have experience with dementia often say that it is important to start thinking in advance about decisions and support that will be needed in the future. This is in part so you can call in assistance from health care providers on time.
- ✓ Never hesitate to put any questions you may have to your care provider. Asking questions will prevent you worrying unnecessarily.
- ✓ Never hesitate to put any questions you may have to your care provider. Asking questions will prevent you worrying unnecessarily.
- ✓ Please don't hesitate to ask your care provider questions. Asking questions or expressing concerns may provide reassurance or clarification [of uncertainties].



## 1. Dementia and changes in health

- *Can you tell me more about the type of dementia I have? [unchanged, same in 3 versions]*
- *What changes can I expect, and in particular: what changes in behaviour? [2018 version]*
- *What changes **can be expected**, and in particular: what changes in behaviour? [change in 2019]*
- *What changes can be expected, and in particular: what changes in behaviour? [2020 = 2019]*
- *How long does it take before the symptoms clearly become worse?*
- *How long does it **usually** take before the symptoms clearly become worse?*
- *How long does it usually take before the symptoms clearly become worse?*
- *Can you explain how I can recognize the final stage of life?*
- *How can I make sure I can do the things I enjoy for as long as possible?*
- *How can I make sure I can do the things I enjoy for as long as possible?*
- *How long do I have?*
- *Can you tell me how much time I have left?*
- *Can you tell me how much time I have left?*

## 2. Care goals, palliative care and end-of-life decisions

### Things to think about

What is important to me in terms of the care?  
 What is important to me in terms of the care?  
 What is important to me when I am in need of care?  
 What should the care focus on (i.e. which 'care goal' am I looking for?)

- *Can you tell me what palliative care in dementia is?*
- *Can you tell me **more about palliative care in dementia?***
- *Can you tell me more about **palliative care** in dementia?*
- *Which **palliative care** is available in my situation?*
- ***Who can help me formulate care goals? [newly introduced in 2019 version]***
- *Who can help me formulate **care goals**? [same in 2020 version, etc.]*
- *Who can I contact about care and **care goals** in which type of situation, and how?*
- *What care, matching my **care goal**, is available for me?*

**Tips**

- ✓ Palliative care clearly entails much more than just care in the stage of dying: the focus of care is on a good quality of life now and later on. And to prepare you for it. So do not let the term palliative care put you off when you are thinking about future care.
- ✓ Palliative care clearly entails much more than just care in the stage of dying: the focus of care is on a good quality of life now and later on. And to prepare you for it.
- ✓ Palliative care clearly entails much more than just care in the stage of dying: the focus of care is on a good quality of life now and later on. You can start preparing for 'later' now.
- ✓ It may be difficult to think about the future and to talk about the future, but it is still good to do so. Knowing preferences and wishes can bring peace later on.
- ✓ It may be difficult to think about the future and to talk about the future, but it is still good to do so. Knowing preferences and wishes can bring peace later on.
- ✓ It may be difficult to think about the future and to talk about the future, but it is still good to do so. If you and others know what the preferences and wishes are, this can bring peace now and later.
- ✓ Start talking about what is important for the present. This is often easy to start with.
- ✓ Start talking about what is important for the present. This is often easy to start with.
- ✓ Start talking about what is important for the present. This is often easier to start with.
- ✓ When the end of life is in sight, the importance of supporting and being there for each other, of feeling connected increases.

**3. Decisions about treatments and agreements [advance care planning]****Things to think about**

The most important question is: 'Which type of care best suits me or my loved one in this stage of life?'

- *I would like to talk about my wishes and hopes for the future. When can I discuss this and with whom?*
- *I would like to talk about how I experience dementia and about my wishes and hopes for the future. When can I discuss this and with whom?*
- *I would like to talk about how I experience dementia and about my wishes and hopes for the future. When can I discuss this and with whom?*
- *What do you want to know about me, so you can provide quality care that suits me, now and later on?*
- *Is it possible to record my wishes regarding end-of-life care now, and if so: how?*
- *Which documents or plans are significant for me and what do I need to know about them?*

- *How confidential is the information about me? For example: who is allowed to know about my medical problems or behaviour problems?*
- *What is my role in the decision-making? And what is the role of my relatives?*
- *Who makes the decisions for me when I am no longer able to?*
- *Who decides that I am no longer able to make my own decisions? And how does the person in question decide that?*
- *How can I appoint a representative?*
- *Who decides that I am no longer able to make my own decisions? And how does the person in question decide that? How can I appoint a representative?*
- *Who decides that I am no longer able to make my own decisions? And how does the person in question decide that? How can I appoint a representative?*
- *What should I or my relative do in case we disagree with each other about a decision, or when we disagree with the doctor?*
- *Will I be able to change previously arranged agreements? And can my relatives do this when I am no longer able to?*

### Tips

- ✓ It is important to make arrangements regarding finances, care and wellbeing at an early stage
- ✓ You and your relatives may have different principles and needs. It helps to identify these differences and talk about them.
- ✓ You and your relatives may have different principles and needs. It helps to identify these differences and talk about them.
- ✓ You and your relatives may have different principles and needs. It helps to identify these differences and discuss them together.
- ✓ What should always be central is the wish of the person with dementia even if it is an earlier wish. Others must be able to later determine the intentions of the person with dementia, i.e. determine what is the best course of action at that particular point in time, taking into consideration the previously expressed wishes.
- ✓ What should always be central is the wish of the person with dementia. Including any earlier wishes. Others must be able to later determine the intentions of the person with dementia, i.e. determine what is the best course of action at that particular point in time, taking into consideration the previously expressed wishes.
- ✓ What should always be central is the wish of the person with dementia. Including any earlier wishes. Others must be able to later determine the intentions of the person with dementia. In other words: ultimately determine the most suitable course of action at that particular point in time, taking into consideration the previously expressed wishes.
- ✓ It is good to discuss at an early stage who can represent you when you are no longer able to make your wishes known.
- ✓ It is good to discuss at an early stage who can represent you when you are no longer able to make your wishes known.



## 4. Treatment and care for common problems

### Things to think about

Which are treatments I definitely do NOT want to undergo?

What (action) do I want (taken) when I am in serious pain?

What do I want when I am in serious pain?

What do I want when I am in serious pain?

When there is no solution for burdensome symptoms, do I want the doctor to lower my level of consciousness ('*palliative sedation*'), so I am less aware of them?

When there is no solution for very unpleasant symptoms, do I want the doctor to lower my level of consciousness (put me to sleep by means of '*palliative sedation*'), so I am less aware of them?

When there is no solution for very unpleasant symptoms, do I want the doctor to lower my level of consciousness (put me to sleep by means of '*palliative sedation*'), so I am less aware of them?

Do I also want to record these things, for example with the general practitioner?

What can help me accept that I am no longer able to do things, or know things (with experiencing losses)?

What can help me accept that I am no longer able to do things, or know things (cope with loss)?

What can help me accept that I am no longer able to do things, or know things (cope with loss)?

### Questions about restlessness and challenging behaviour / behaviour problems

- Where does the behaviour come from, for example refusing care?
- How can the problem behaviour be reduced?
- What might help in case of unsafe behaviour?
- What might help in case of unsafe behaviour?
- Are medications necessary or can we try something else first?
- Which potentially helpful medications are available?
- What side effects can these medications have?
- Can the use of medications be stopped when the problem behaviour is gone?

### Questions about incontinence

#### Questions about incontinence

- What can help in case of incontinence?
- What can help in case of incontinence?
- How do we ensure incontinence does not affect dignity?
- How do we ensure incontinence does not affect dignity?

**Questions about feelings of depression, anxiety and lack of initiative**

- *How can you diminish my depression or alleviate my anxiety?*
- *How can you diminish depression or alleviate anxiety?*
- *How can you diminish depression or alleviate anxiety?*
- *Which psychosocial interventions are available?*
- *How can my need for contact be met when I am no longer able to make contact?*

**Questions about feelings of loss and existential questions**

- *How can I and my relatives adequately cope with experiences of loss?*
- *How do we cope adequately with experiences of loss?*
- *How do we cope adequately with experiences of loss?*
- *Which type of spiritual care (based on world view, spiritual beliefs, religion), is available that is suitable for me?*
- *How do we ensure that every day brings positive and meaningful experiences?*

**Questions about eating and drinking problems** [order of paragraphs revised after 2019 version, which until then started with this paragraph; the paragraph title includes swallowing problems]

- *What can you do for me to help my eating, drinking, or swallowing problems?*
- *What can you do for me to help my eating, drinking, or swallowing problems?*
- *What can you do about my eating, drinking, or swallowing problems?*
- *How can I reduce the risk of choking on food and drink?* [bullet 1 and 2 reversed order after 2018 version]
- *Would soft or pureed food, or thickened liquids help?*
- *Would a drip be helpful in my case?*
- *Would a feeding tube or a drip be helpful in my case?*
- *Would a feeding tube or a drip be helpful in my case?*

**Questions about infections** [the paragraph title is Pneumonia and other infections]

- *Can I prevent pneumonia? What would help reduce the risk of developing pneumonia?*
- *What can you do in case of pneumonia or bladder infection?*
- *Are antibiotics a good option in my case?*
- *Are antibiotics suitable in my case?*
- *Are antibiotics suitable in my case?*
- *What about going to the hospital?*
- *What about going to the hospital?*
- *What are the options to alleviate symptoms, to make me more comfortable?*
- *Can you alleviate symptoms and provide some comfort?*
- *Can you alleviate symptoms and provide some comfort?*

**Questions about shortness of breath**

- *What can you do for me when I am short of breath?*
- *What can you do in case of shortness of breath?*
- *What can you do in case of shortness of breath?*

- *Could I suffocate?*

- *Could I suffocate?*
- *Can morphine make me die sooner?*
- *Will morphine make me die sooner?*
- *Will morphine make me die sooner?*

**Questions about pain and feeling uncomfortable**

- *How will you determine whether I am in pain? And is a relative able to see it too?*
- *How will you determine (later) whether I am in pain? And is a relative able to see it too?*
- *How will you determine (later) whether I am in pain? And is a relative able to see it too?*
- *What is the cause of the pain or discomfort?*
- *What is the cause of the pain or feeling uncomfortable?*
- *What is the cause of the pain or feeling uncomfortable?*
- *How can you alleviate the pain?*
- *Can I get addicted to morphine?*

**Questions about other illnesses and what these may require**

- *Which medications or medical checks will remain necessary for me?*
- *Do the different medications that I need work well together?*
- *How do the other illnesses affect the care in later stages or at the end of life?*

**Tips**

- ✓ Stay focused on the *care goal*, for example comfort or prolonging life
- ✓ Stay focused on the *care goal*, for example providing comfort, or prolonging or not prolonging a person's life.
- ✓ Stay focused on the jointly determined *care goal*, for example providing comfort, or prolonging or not prolonging a person's life.
- ✓ You can raise existential with your health care professional to find support, even if you are not religious.
- ✓ You can raise existential questions like 'Why is this happening to me?' and 'How can I cope with being ill?' with your health care professional to find support, even if you are not religious.
- ✓ You can raise existential questions like 'Why is this happening to me?' and 'How can I cope with being ill?' with your health care professional to find support, even if you are not religious.



## 5. Choice of location of care and change of living environment

### Things to think about

How important is remaining at home for me when I compare it, for example, to my safety and the care that my relatives will then have to provide?

How important is remaining at home for me when I compare it to my safety and the care that my relatives will then have to provide?

How important is remaining at home for me when I compare it to my safety and the care that my relatives will then have to provide?

Are there any situations in which I would not want to be taken to hospital?

Are there any situations in which I would not want to be taken to hospital?

How do we look at the end of life, for example: where and who will be present?

### Questions about choosing the care location and living environment

- Do you think I will be able to stay at home, and what does this depend on?
- Which help is available so I can stay at home for as long as possible?
- Which help is available so I can stay at home for as long as possible?
- When is hospitalisation necessary?
- When could hospitalisation be necessary and when is it not a good idea?
- When could hospitalisation be necessary and when is it not a good idea?
- Can I be admitted to a hospice, or a nursing home or residential home?
- Can I be admitted to a hospice, or a nursing home?
- Can I be admitted to a hospice, or a nursing home?
- Which (other) options are there when staying at home is no longer possible?

### Questions for you when you change living environment and health care provider

- How can I make sure that a change goes as smoothly as possible?
- What will be done to secure my safety in the new environment?
- Who works in the new environment and which health care professional does what?
- How often will I see the doctor here?
- How do I make sure that the health care professional gets to know me, my background and my preferences?

## Tips

- ✓ Accept help such as home help when necessary. Do not hesitate and please don't wait too long.
- ✓ Accept help such as home help when necessary. Do not hesitate and please don't wait too long.
- ✓ Health care providers can give you care tips, for example about special beds or incontinence materials. And also about care at a later stage, like moving and legislation [such as the Social Support Act (Wmo), Long-term Care Act (Wlz) [locally relevant legislation], and health insurance.
- ✓ Health care providers can give you care tips, for example about special beds or incontinence materials. And also about care at a later stage, like moving and legislation [such as the Social Support Act (Wmo), Long-term Care Act (Wlz) [locally relevant legislation], and health insurance.
- ✓ Ask your GP or acquaintances about good nursing homes. For example, not all small-scale nursing homes are equipped to provide good quality care.
- ✓ Ask your GP or acquaintances about good nursing homes. For example, not all small-scale nursing homes are equipped to provide good quality care.
- ✓ Day care or day treatment in a nursing home is a good way to become familiar with the home while you still live at home.
- ✓ Day care or day treatment in a nursing home is a good way to become familiar with the home while you still live at home.
- ✓ To check whether a care facility like a nursing home or residential home is suitable for you, you could visit several to take in the atmosphere.
- ✓ To check whether a care facility like a nursing home is suitable for you, you could visit several to take in the atmosphere.
- ✓ To check whether a care facility like a nursing home is suitable for you, you could visit several to take in the atmosphere.
- ✓ Investing in good contact with the new health care professionals, who need to get to know you and your relatives, is helpful.
- ✓ Invest in good contacts with new health care professionals who want to get to know you and your relatives. Volunteer information about what is going on and what your wishes are.
- ✓ Invest in good contacts with new health care professionals who want to get to know you and your relatives. Volunteer information about what is going on and what your wishes are.
- ✓ If you want to share it, a life book, for example [www.sprekenoververgeten.nl, [locally relevant example] can also help health care professionals get to know you.
- ✓ If you want to share it, a life book, for example [www.sprekenoververgeten.nl, [locally relevant example] can also help health care professionals get to know you.
- ✓ A hospital is generally not a 'dementia-friendly environment'. If hospitalisation is necessary, then it is good idea to have someone there who has the time and patience to reassure you. For example a health care professional, volunteer, or a relative.
- ✓ A hospital is generally not a 'dementia-friendly environment'. If hospitalisation is necessary, then it is good [used other Dutch term, closer to nice] idea to have someone there who has the time and patience to reassure you. For example a health care professional, volunteer, or a relative.
- ✓ A hospital is generally not a 'dementia-friendly environment'. If hospitalisation is necessary, then it is good [used other Dutch term, closer to nice] idea to have someone there who has the time and patience to reassure you. For example a health care professional, volunteer, or a relative.

## 6. Resuscitation and euthanasia [order of topics in 2020 version; in the 2018 and 2019 versions, this topic was placed before topic 5]

### Things to think about

How do I feel about prolonging or shortening life?  
How do I feel about prolonging or shortening my life?  
How do I feel about prolonging or shortening my life?

### Questions about resuscitation

- *What are advantages and disadvantages of resuscitation in my case?*
- *How can I document that I do not want to be resuscitated, or do not want resuscitation under certain circumstances?*

### Questions about euthanasia

- *Is euthanasia an option in my situation?*
- *Is euthanasia an option at a later stage when I am no longer able to say that that is what I want?*
- *Can my relative or the doctor decide about euthanasia?*
- *Can my relative or the doctor decide about euthanasia?*
- *What possibilities are there to not prolong life in a more natural way?*
- *What possibilities are there to not prolong life in a more natural way?*

## 7. Care for you as a relative

### Things to think about

How do I as the relative prepare for the deterioration of my loved one with dementia?

What takes most of my energy, and what can I do to improve that?

- *How can I best support my loved one who has dementia?*
- *What emotions am I likely to experience?*
- *Which support am I entitled to, and where can I get it?*
- *What can I do to prevent becoming overburdened?*
- *How do I recognise that I am overburdened?*



**Tips**

- ✓ Make sure that you as the relative always get enough rest. This benefits everyone.
- ✓ In addition to your GP, also inform your employer that you are a family caregiver, because this is something that needs to be taken into account.
- ✓ Check what support the municipality provides for family caregivers.
- ✓ Check what support the municipality provides for family caregivers.
- ✓ The Alzheimer's telephone helpline lends a sympathetic ear and offers advice on coping with dementia. The Alzheimer's telephone helpline can be reached via the free phone number 0800 5088, 7 days a week from 9:00 am to 11:00 pm.

**8. The dying phase and the period after death****Things to think about**

What do we want the final moments to be like?

- *Can you warn me, as the relative, when death is near?*
- *Who can help me sit up with my dying loved one?*
- *Who can help me sit up with my dying loved one? Are there volunteers we can call in?*
- *Who can help me sit up with my dying loved one? Are there volunteers we can call in?*
- *What if my loved one dies when I am not there?*
- *What spiritual or religious care is available?*
- *What spiritual or religious care is available to us?*
- *What spiritual or religious care is available to us?*
- *How does a person feel when he does not eat or drink anything?*
- *What can you do about the loud breathing due to mucous build-up?*
- *What should or can I, the relative, do at the moment of death and afterwards?*
- *Do I, as the relative, get an opportunity to speak to the doctor again?*
- *What aftercare is available to me?*

**Tips**

- ✓ If a stressful treatment or operation is suggested while your loved one is already in a poor condition: ask the doctor how necessary it is, despite the emotions that may be present.
- ✓ If a stressful treatment or operation is suggested while your loved one is already in a poor condition: ask the doctor whether the treatment is really necessary, despite the emotions you may be experiencing. Remember that doctors are generally in 'treatment-mode'.
- ✓ If a stressful treatment or operation is suggested while your loved one is already in a poor condition: ask the doctor whether the treatment is really necessary and what will happen if it is decided to discontinue treatment. Despite the emotions you may be experiencing. Remember that doctors are generally in 'treatment-mode'.
- ✓ Many nursing homes provide relatives the opportunity to spend the night there during the final days. If this is what you want, ask about it on time.

## Supplement 2. Acceptability and all scale item scores: Tables with individual items and item scores

### S1. Acceptability scale **adaptations (track changes)** compared to acceptability scale for evaluation of a family booklet<sup>12-14</sup>

Use of the question prompt list in practice

This section is about your expectations when using the question prompt list in your practice. Could you please indicate the extent to which you agree or disagree with each statement? (*circle the number that applies*)

	strongly DISagree		→		strongly agree
a. This <del>question prompt list</del> <del>booklet</del> will help families <del>and a (capable) person with dementia</del> better understand the natural course and possible complications of dementia	1	2	3	4	5
b. This <del>question prompt list</del> <del>booklet</del> will result in <del>them</del> <del>my patients' families</del> making more informed decisions	1	2	3	4	5
c. This <del>question prompt list</del> <del>booklet</del> is suitable for helping <del>patients' families</del> <del>etos</del> make value laden choices	1	2	3	4	5
d. <del>The</del> <del>is</del> <del>question prompt list</del> <del>booklet</del> will positively affect my relationships with <del>the person with dementia and the</del> families	1	2	3	4	5
e. <del>This</del> <del>is</del> <del>question prompt list</del> <del>booklet</del> will improve the quality of discussions with <del>families</del> <del>them</del>	1	2	3	4	5
f. <del>This</del> <del>is</del> <del>question prompt list</del> <del>e-booklet</del> will increase <del>family</del> satisfaction <del>of the person with dementia and the family</del> with my care	1	2	3	4	5
g. This <del>question prompt list</del> <del>booklet</del> will increase shared understanding of <del>patient's</del> preferences <del>of the person with dementia</del>	1	2	3	4	5
h. This <del>question prompt list</del> <del>booklet</del> will increase <del>family</del> consensus on decision making <del>between the person with dementia and family, and within families</del>	1	2	3	4	5
i. This <del>question prompt list</del> <del>booklet</del> complements my usual approach	1	2	3	4	5
j. This <del>question prompt list</del> <del>booklet</del> will be easy for me to use	1	2	3	4	5
k. I would decide to adopt <del>this question prompt list</del> <del>it</del> even before experimenting with it	1	2	3	4	5
l. Using this <del>question prompt list</del> <del>booklet</del> will save me time.	1	2	3	4	5

m. This <a href="#">question prompt listbooklet</a> is likely to be used by most of my colleagues	1	2	3	4	5
n. This <a href="#">question prompt listbooklet</a> should be used as a teaching aid <a href="#">in training or continued medical education</a> for physicians*	1	2	3	4	5
o. This <a href="#">question prompt listbooklet</a> should be used as a teaching aid <a href="#">in training or continued medical education</a> for nurses*	1	2	3	4	5

\* Includes training before and after certification

## S2. Acceptability of the question prompt list item scores (n=66 respondents)\*

	mean	SD
a. This question prompt list will help families and a (capable) person with dementia better understand the natural course and possible complications of dementia	3.7	0.93
b. This question prompt list will result in them making more informed decisions	4.0	0.72
c. This question prompt list is suitable for helping to make value laden choices	3.6	0.89
d. This question prompt list will positively affect my relationships with the person with dementia and the families	3.4	0.92
e. This question prompt list will improve the quality of discussions with them	3.7	0.86
f. This question prompt list will increase satisfaction of the person with dementia and the family with my care	3.3	0.89
g. This question prompt list will increase shared understanding of preferences of the person with dementia	3.7	0.89
h. This question prompt list will increase consensus on decision making between the person with dementia and family, and within families	3.5	0.87
i. This question prompt list complements my usual approach	3.5	1.2
j. This question prompt list will be easy for me to use	3.0	1.0
k. I would decide to adopt this question prompt list even before experimenting with it	2.5	1.1
l. Using this question prompt list will save me time.	2.7	0.99
m. This question prompt list is likely to be used by most of my colleagues	2.9	0.94
n. This question prompt list should be used as a teaching aid in training or continued medical education for physicians	3.8	0.96
o. This question prompt list should be used as a teaching aid in training or continued medical education for nurses	3.8	0.89

Interpretation: summed scores range 15-75 with  $\geq 45$  meaning "acceptable." This equates to item scores  $\geq 3$ .

Summed scores of  $\geq 60$  mean "highly acceptable" and this equates to item scores  $\geq 4$ . Cronbach's alpha 0.94.

Bold indicates either **not** acceptable (red) or **highly** acceptable (green), and **large variation** (red,  $> 1$  SD).

No differences ( $p < 0.05$ , t-test) were observed between elderly care physicians and GPs, except for the items f (mean 3.2 SD 0.88 for elderly care physicians vs. 3.7 SD 0.84 for GPs) and j (mean 3.2 SD 0.93 for elderly care physicians vs. 2.6 SD 1.1 for GPs).

\*Number of missing values of 66, per item: 2 (because 2 respondents did not complete the scale), except for item c (a total of 3 missing values) and item m (a total of 4 missing values).



**S3. Quality of the content of the question prompt list**

	<b>mean</b>	<b>SD</b>	<b>N*</b>
<i>Part 1: About illness and care</i>			
Dementia and changes in health information questions	3.7 3.5	0.84 <b>1.0</b>	65 65
Care goals, palliative care and end-of-life decisions information questions	3.8 3.7	0.99 0.80	65 63
<i>Part 2: About treatment and choices with health problems</i>			
Decisions about treatments and agreements (advance care planning) information questions	4.0 4.0	0.85 0.84	64 65
Treatment and care for common problems information questions	4.0 3.9	0.82 0.81	64 64
Resuscitation and euthanasia information questions	<b>4.0</b> <b>4.0</b>	0.91 0.87	63 62
Choice of location of care and change of living environment information questions	<b>4.1</b> <b>4.0</b>	0.72 0.73	64 64
<i>Part 3: Relatives</i>			
Care for you as a relative information questions	<b>4.3</b> <b>4.2</b>	0.67 0.61	64 64
The dying phase and the period after death information questions	<b>4.2</b> <b>4.1</b>	0.77 0.74	63 62

Bold indicates either **close to poor** (red, mean rating 1 to 2; did not occur) or **close to excellent** (green, mean rating 4-5), and **large variation** (red, > 1 SD).

No differences ( $p < 0.05$ , t-test) were observed between elderly care physicians and GPs.

\*One missing value ( $n=65$ ) was due to a respondent who did not rate any quality item—but did complete the acceptability scale as the primary outcome.

#### S4. Perceived barriers to implementation of the question prompt list (agreement scaled as in Table S1, acceptability)

	mean	SD	n
The hectic pace of practice will prevent me from using the question prompt list	2.8	1.1	64
This question prompt list will cause the person living dementia or the family to be anxious	2.9	1.1	64
I don't expect people living with dementia and family will want to use the question prompt list	2.5	0.93	64
Going through the question prompt list gives me enough inspiration for conversations: it is not necessary to hand it out to people living with dementia and family	2.4	1.1	64
The advantages of working with the conversation aid will not outweigh the time and effort invested	2.6	0.89	64

Bold indicates either **close to strongly disagree** (red, mean 1 to 2; did not occur) or **close to strongly agree** (green, mean rating 4-5; did not occur), and **large variation** (red, > 1 SD).

No differences ( $p < 0.05$ , t-test) were observed between elderly care physicians and GPs, except for the item "The hectic pace of practice will prevent me from using the question prompt list" (mean 2.5 SD 1.0 for elderly care physicians vs. 3.6 SD 0.98 for GPs).

#### S5. Goals achieved and anticipated benefits of the question prompt list (agreement scaled as in Table S1, acceptability)

	mean	SD	n
<b>Question prompt list goals achieved</b>			
This question prompt list will help the (capable) person living with dementia and the family organise their thoughts about the later stage of life	3.8	0.84	64
This question prompt list will help them formulate important questions about dementia and end-of-life care, making it easier to ask the health care professional questions	3.9	0.81	64
This question prompt list will help them to have conversations with healthcare professionals and also conversations with each other	3.8	0.79	64
This question prompt list will make choices about care and treatment easier for them	3.2	0.91	64
<b>Other possible benefits of the question prompt list</b>			
This question prompt list will help them to get information that is important to them in a timely manner	3.7	0.82	63
This question prompt list will make a person living with dementia or family feel supported and understood as to what they go through, and they will be better prepared for the future	3.6	0.94	63
Thanks to this question prompt list they can get the best possible personalized care.	3.1	0.88	62

Bold indicates either **close to strongly disagree** (red, mean 1 to 2; did not occur) or **close to strongly agree** (green, mean rating 4-5; did not occur), and **large variation** (red, > 1 SD; did not occur).

No differences ( $p < 0.05$ , t-test) were observed between elderly care physicians and GPs.

### Supplement 3. Interview guide

**Interview guide for evaluation of the question prompt list "Talking about the later stages in life in dementia"** Translated from Dutch by a professional translator.

#### INTRODUCTION

First of all, thank you for your willingness to participate in this interview, after you have already assessed the question prompt list in a questionnaire. The purpose of this interview is to elaborate on what you think of the question prompt list and how it might be applied. It would be helpful to refer to the question prompt list you received from us during the interview. Of course we can provide a copy if you don't have it with you. We will also ask you about your views on openly discussing end-of-life care and palliative care in dementia in general.

The interviews will be recorded. Your information will be treated confidentially and analyzed in the secure environment of LUMC. The data used for any publication will not be traceable to your personal data. If you agree, please sign the informed consent form.

Do you have any questions before we begin?

#### THE QUESTION PROMPT LIST

1. What do you think of the question prompt list in its current form?  
*Possible follow-up question: Which themes are missing?*
2. What do you like about the question prompt list?
3. What don't you like about the question prompt list?  
*Possible follow-up questions: Do you have tips on how to improve these points? If so, what are they?*
4. Are there parts or factors in this question prompt list that could impede the conversation between you and the patient and (loved one) (family)?
  - a. **If yes:** Which?
  - b. **If no:** Do you feel that the question prompt list as a whole facilitates conversations?  
*Possible follow-up question: How can these impeding factors be reduced or resolved?*

For interviewer, to the participant:

Explain that the subject of the questions will now shift from the question prompt list to discussing sensitive subjects with persons living with dementia and family/loved ones. Also indicate that there will be more questions about the question prompt list later.

## DISCUSSING SENSITIVE SUBJECTS

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1. How difficult (or easy) do you find talking about the course of dementia and end of life (care) with patients and family/loved ones?
  - a. **(if little experience):** Which subjects seem most difficult to discuss? What do you think is the easiest way to make them discussible? Do you think this will become easier over the years (experience)?
  - b. **(if very experienced):** Is it easier for you now than at the beginning of your career? What factors played a role? **If yes:** How do you deal with difficult subjects now and how is that different from the beginning of your career?
2. Do you think the subjects highlighted in the question prompt list are easy to discuss in general?
3. Are there any subjects you find difficult to discuss with patient and family?
  - a. **If yes:** Which subjects?
  - b. **If no:** Are all subjects easy to discuss for you?  
*Possible follow-up questions: Does this have to do with your experience regarding these conversations? (if not yet discussed under 1., and then elaborate in same manner) Does the question prompt list (also) contain certain example questions that you find difficult to answer?*  
*Possible follow-up question: What would you need to be able to answer these questions?*  
*Possible follow-up question: How to act when resistance is sensed from patient/family?*
4. Have you (personally) found ways to make certain subjects easier to discuss in these types of conversations?
  - a. **If yes:** How do you go about it?
  - b. **If no:** What do you need to change/improve your approach?
5. Will the question prompt list contribute to initiating/starting the conversation with the patient and family/loved ones? And will it influence the moment of initiation?

## IMPLEMENTATION IN PRACTICE

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1. When a final version is available, would you want to apply this question prompt list? Why/Why not? **If yes:** How would you want to apply the question prompt list?
2. Are there any particular preconditions that must be met in order to be able to use this question prompt list?
3. Could this question prompt list also be applied by other healthcare professionals? **If yes:** By whom, and would you recommend it?
4. Do you think that question prompt lists should be used more frequently in the future in other fields or for other diseases, when available? **If yes:** What fields/diseases?

## QUESTIONS BASED ON QUESTIONNAIRE RESPONSES

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### Explanation of goal:

In the final part of the interview, we would like to hear the physician's opinion, based on certain answers he/she provided in the questionnaire. As the answers to the questionnaires will vary from person to person, our goal is to record a few specific questions based on the answers to make sure all of the physician's perspectives and opinions are heard. This allows us to highlight as many different perspectives as possible.

Questions will partly have the same structure (but may deviate):

- In the questionnaire your answer to question [?] was [?]. We would really like to know what reasoning led to this answer. Can you please elaborate on your answer?
- **When physician is positive:** How do you think [?] can influence the conversations between physicians and persons with dementia and family/loved ones?
- **When physician is negative:** What should be changed in your opinion? What do you feel is necessary to do this?