

## 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.
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- ✓ 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.
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- ✓ 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.
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- ✓ 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?

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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.
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- ✓ 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.
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- ✓ 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](http://www.sprekenoververgeten.nl), [locally relevant example] can also help health care professionals get to know you.
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- ✓ 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.