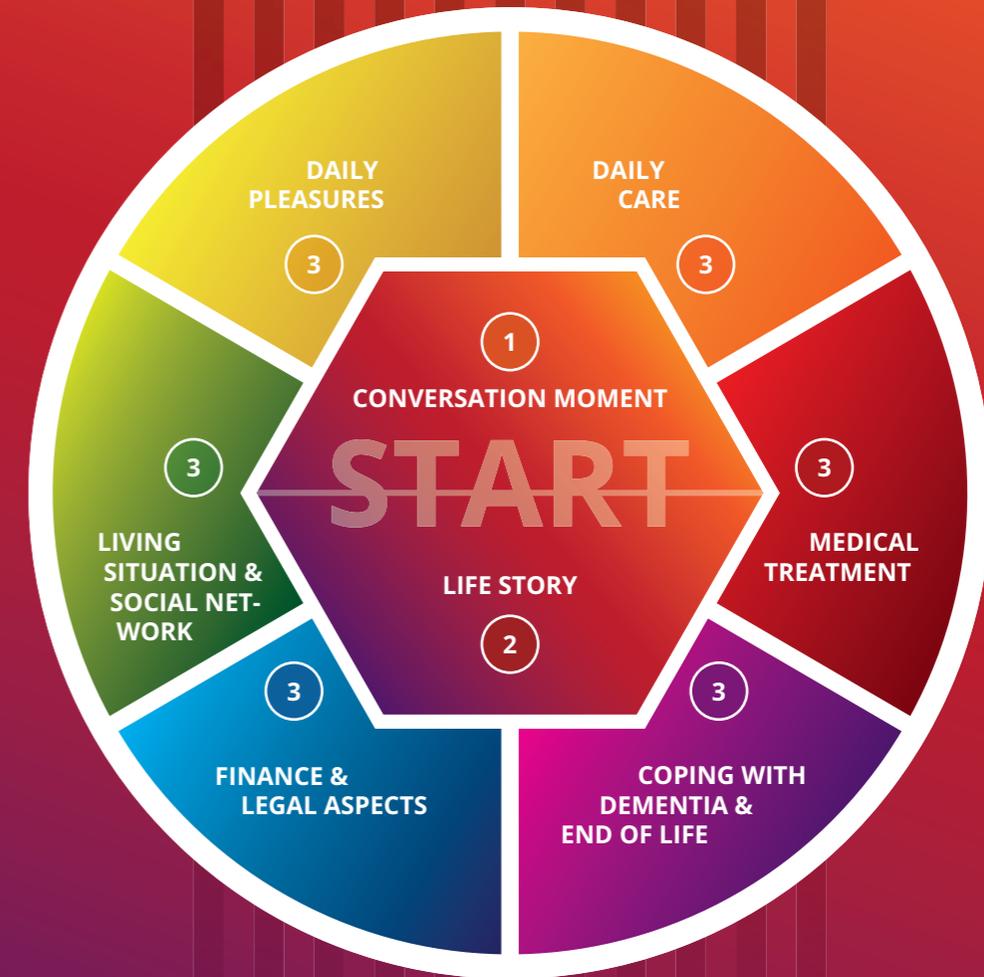


CONVERSATION GUIDE

for advance care planning



COLOFON

The Conversation Guide Dementia was developed by the consortium Ligare and together with the networks for palliative care and dementia in the Dutch regions of Drenthe, IJssel-Vecht and north-east Overijssel.

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THE CONVERSATION GUIDE: WHY?

- To facilitate a timely discussion of the client's wishes and preferences regarding the various themes
- To ensure more structured and pleasant conversations
- To realise person-centered care

USING THE CONVERSATION GUIDE

- Step **(1)**: Determine (together) the optimal conversation moment
- Step **(2)**: Start the conversation with the client's life story and use the example questions
- Step **(3)**: Next, discuss the themes in order of priority and relevance. Each theme has its own colour. You can use the page Life Story (p. 5) besides each of the themes.



You can take this diagram out of the booklet.

STEP 1 START:
CONVERSATION MOMENTS

- Hypothesis/ diagnosis
- Deterioration of symptoms
- Complications
- Observations/ Ongoing conversation with client/ after interprofessional discussion



RIGHT NOW, WHAT IS IMPORTANT TO YOU?

Please prioritise and determine the order in which the themes will be discussed.

Which theme is currently most important and should be discussed first?

STEP 2 BASIS:
LIFE STORY
LIFE QUESTIONS, VALUES
AND QUALITY OF LIFE

- How would you describe yourself?
- What are your talents?
- What is important to you in ... (all themes)
- Who is important to you and would you like to be involved?
- How do you see your future?
- What worries you?

OPEN THE LEFT PAGE

Keep the page "Life story" open when discussing the different themes.

STEP

2

START PAGE:

LIFE STORY

LIFE QUESTIONS, VALUES AND QUALITY OF LIFE

- How would you describe yourself?
- What are your talents?
- What is important to you in ... (all themes)
- Who is important to you and would you like to be involved?
- How do you see your future?
- What worries you?

POINTS OF ATTENTION

Questions the client or relative may ask:

- What are my options?
- What are the benefits and possible risks?
- How likely are these risks and benefits?

Conversation starters for the professional in all themes:

- Did you ever think about this?
- How do you experience this?
- What do you want? This is the moment to organise and take care of things.
- Would you like to discuss this with me or rather speak to someone else? (from the church, or...)

STEP

1

START:

CONVERSATION MOMENTS

- Hypothesis/ diagnosis
- Deterioration of symptoms
- Complications
- Observations/Ongoing conversation with client/ interprofessional

RIGHT NOW, WHAT IS IMPORTANT TO YOU?

Please prioritise and determine the order in which the themes will be discussed.

Which theme is most important now and should be discussed first?

*Keep this page open
when discussing
the different themes*

STEP 3 THEME
**DAILY
PLEASURES**

- What gives you pleasure?
- What is needed to do this (cooking, cycling etc...)?
- Do you still feel safe doing this?

FOLLOW-UP QUESTIONS

**DAILY
PLEASURES**

Please ask further questions/ discuss with relatives:

- Daily activities (alternatives)
- Technological support options
- Meaning of mobility/transport (importance of driving, cycling)

STEP 3 THEME
**DAILY
CARE**

- Can you manage by yourself at home?
- What are your expectations for the future in this respect?
- Can you prepare your own meals and how is that going?
- Do you need help in self-care?
(dressing, bathing, toilet use etc)
- Do you need help with other daily tasks
(cleaning, gardening, groceries)?

FOLLOW-UP QUESTIONS

**DAILY
CARE**

Please ask further questions/ discuss with relatives:

- Getting help with meals/ food
- Demands on informal caregiver(s)
- Safety when preparing meals
- Sleep-rest pattern

STEP

3

THEME

MEDICAL TREATMENT

- Which treatments do you definitely not want to receive?
- What do you want when you for example experience a lot of pain?
- What are your thoughts on dying? E.g.,
 - Would you like to be resuscitated?
 - How about the active ending of living (euthanasia)?
 - Treatment aimed at comfort and quality of life (palliative care)

FOLLOW-UP QUESTIONS

MEDICAL TREATMENT

Professionals: continuous interprofessional consultation.

Please ask further questions/discuss with relatives:

- Topics discussed with various professionals
- Hospitalisation (yes/ no) in case of e.g. pneumonia
- Resuscitation yes or no

STEP

3

THEME

COPING WITH DEMENTIA & END OF LIFE

- How does your illness/ condition make you feel?
- How do you feel about your approaching death (e.g., place, people present)?
- How do you see the future?
- How do you feel about the future?

FOLLOW-UP QUESTIONS

COPING WITH DEMENTIA & END OF LIFE

Please ask further questions/ discuss with relatives:

- Mourning (stages of grief and loss)
- Feelings of safety
- (boundaries of) human dignity
- Desired support
- Current sources of strength

STEP

3

THEME

FINANCE & LEGAL ASPECTS

- What did you arrange for once you are gone?
- What did you arrange in case you cannot make your own decisions anymore?
- Did you think about taking care of business with a solicitor?

FOLLOW-UP QUESTIONS

FINANCE & LEGAL ASPECTS

Please ask further questions/ discuss with relatives:

- Contact with a solicitor: advance directive, power of attorney, living will
- Role and wishes in legal incapacity

STEP

3

THEME

LIVING SITUATION & SOCIAL NETWORK

- Where would you like to live and together with whom?
- What is important for you regarding home?
- Who currently is/are most important in your daily life?
- What does your family mean to you (relate to life story)
- From which family members, friends or neighbours would you like to receive support when you need it (in the future)?

FOLLOW-UP QUESTIONS

LIVING SITUATION & SOCIAL NETWORK

Please ask further questions/ discuss with relatives:

- How future-proof is the current home?
- Moving (including inpatient care facility)
- Safety in and around the house
- Own informal caregiver activities
- Do you sleep together in the same room?