

Appendix

This appendix belongs to the article, 'Tools to support advance care planning conversations and documentation in nursing homes', and includes the ACP+ conversation guide, as well as the ACP+ document.

1e: ACP+ conversation guide

2e: ACP+ document



ACP+ conversation guide

This conversation guide supports care professionals in nursing homes in conducting ACP conversations and documenting wishes and preferences of residents and their loved ones.

TO START

This conversation guide includes tips and tricks for preparing and conducting ACP conversations with residents and/or family. Moreover, the conversation guide will offer practical support while filling out ACP-documents and Advance Directives.

Please use this conversation guide as reference book and support tool when planning, preparing and conducting ACP conversations with residents and/or family. Do NOT use this conversation guide during an ACP conversation, as it is too extensive for that. Make sure you are familiar with all recommendations in this conversation guide before you start an ACP conversation or document wishes and preferences.

In the appendix of this conversation guide you can find several supporting materials that you can use during the ACP conversations and when documenting wishes and preferences of residents.

Whom is this conversation guide for?

The need for advance care planning (ACP) can be signaled by all team members (regardless of their specialty) in a nursing home setting and all team members can adhere to it, in line with their competences and function. The aims of this conversation guide are to facilitate (1) ACP conversations with residents and/or their family and (2) documenting wishes and preferences regarding future care and treatment.

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ADVANCE CARE PLANNING (ACP)

With whom?

1 YOU AS CONVERSATION LEADER

As health care professional you can conduct ACP conversations. Throughout this document you will be referred to as the 'conversation leader'. Make sure ACP conversations are not the responsibility of just one person in the nursing home. Signaling the need for an ACP conversation is explicitly the task of ALL nursing home staff. Every resident should have a chance to discuss ACP, especially when they request such a conversation themselves.

2 RESIDENT AND FAMILY

a. Residents with decision-making capacity who were admitted more than six weeks ago

All residents with decision-making capacity can be approached for an ACP conversation. Ideally, they will be informed about ACP on admission to the nursing home. The head nurse assesses the decision-making capacity. Residents and their loved ones can decide if they want an ACP conversation or not.

ACP can never be mandatory, but should be a right for all. In ideal circumstances no one should be left out. However, if you wait until a resident takes the initiative, there is a risk that a first step will never be taken. All opportunities to talk about the subject should be taken, but without being brutal or shocking residents. Therefore, it is necessary to create a climate of trust and open communication in the nursing home.

b. Family

For every resident, with or without decision-making capacity, it is recommended to involve the legal representative. If there is no legal representative, you can ask a loved one/family member of the resident's choice or a trusted person to be present. Appointing a legal representative is an important part of the ACP conversation (see page 15).

3 THE GENERAL PRACTITIONER (GP)

When preparing the ACP conversation, you can check in what way the GP would like to be involved and how you should keep him/her up-to-date when a resident changes his/her wishes or preferences. Some GPs like to be present during the ACP conversation, some are happy to be updated over the phone. Always make sure to send the GP the ACP+ summary (see ACP+ document).

ACP: when and how often?

Box. 1 Signals for the start or follow-up of an ACP conversation	
When the resident's health status or living situation changes:	When the resident or loved one asks for a conversation:
<ul style="list-style-type: none"> - On admission in the nursing home (or 6 to 12 weeks after admission) - After a thorough health status check or yearly control visit of the GP - Monitoring appointment of a (progressive) illness by the GP or hospital - When discussing the diagnosis of a new or progressive illness - On hospital admission (for a serious progressive illness) - In case of severe suffering and a poor prognosis - In case of signs of dementia or a life-threatening illness - In case of signs of an illness which could lead to losing decision-making capacity - Not having much longer to live - The start of palliative care - No family or disagreement between family members 	<ul style="list-style-type: none"> - Resident states wanting to die - If the resident brings up ACP - If the family of the resident brings up ACP - Worries about the care a dying loved one of the resident has received - Moments when speaking about hopes and fears - Questions related to euthanasia or physician-assisted suicide

GENERAL GUIDELINES

Some general guidelines are provided:

- All **new residents** should ideally be offered an ACP conversation between 6 and 12 weeks after admission in the nursing home. We suggest to already mention ACP on admission. This way the resident and his/her family know they can expect the conversation.
- There might be **other moments** when a resident would like to speak about his/her preferences and wishes. Be alert and make use of every occasion to speak about ACP. Let all staff in the nursing home be alert on signs of residents and family wanting to speak about ACP.
- Make sure all documented preferences and wishes are always **up to date**. In case a situation occurs as described in **Box 1**, plan an ACP follow-up conversation with the resident and/or his/her family.

What to do before conducting an ACP conversation?

Every ACP conversation deserves a **proper preparation** and an adjusted setting, both in terms of time and space. Before you start the first conversation with a resident and/or his/her family it is recommended to take the steps described below.

- Step 1: Inform resident and his/her family**
 - Step 2: Assessment of decision-making capacity**
 - Step 3: Identifying a loved one**
 - Step 4: Contact with the GP**
 - Step 5: Collecting background information**

STEP 1: INFORM RESIDENT AND HIS/HER FAMILY

All residents and their family should be informed about ACP. Ideally, this happens on admission to the nursing home, but it can also happen on any other given moment. At first this should be a short information session, unless the resident (or his/her family) wants to know more immediately, aiming to encourage the resident to start thinking about wishes and preferences.

STEP 2: ASSESSMENT OF DECISION-MAKING CAPACITY

Before you start the ACP conversation it is important to assess a resident's decision-making capacity. This way you can determine if it would be possible to have the ACP conversation with the resident and his/her family, or only with the family.

Decision-making capacity reflects the individual ability to make independent decision. Decision-making capacity can be described as: Being able to correctly come to a reasonable appreciation of one's interests concerning a current specific decision or situation and arrive at a well-balanced decision.

This general assessment of decision-making capacity of residents is an essential element of the ACP conversations and should be done before you start the conversation. Of course, you can continuously pay attention to this: during the care you provide to the resident, throughout the conversation, on admission, when exploring the residents' insight in his/her illness, etc.

IMPORTANT:

Always consider the general decision-making capacity of a resident as described below:

- Assume a maximum of decision-making capacity.
- Consider decision-making capacity as fluctuating and pay attention to signals of diminishing capacity. Consider the right moment to initiate ACP. For example, it might be hard for the resident to speak about preferences and wishes after a tiresome session with the physiotherapist. Pick a moment at which the resident is well rested.
- Assess decision-making capacity per task, so for a certain decision at a certain moment. The question is whether the resident would have sufficient decision-making capacity to think about the themes mentioned during the ACP conversation. So, when assessing a resident's decision-making capacity, you should not only consider the resident's cognitive capacity, but also the complexity of the themes you will discuss, the decisions that need to be made, the different options the resident has and the consequences of all options.
- Let the resident participate as much as possible. It is your task as a healthcare professional to adjust your approach and communication style to the resident and to ensure a loved one is present.
- Because of the fluctuating and task-specific nature of decision-making capacity, it could be helpful for you to reach out to other healthcare professionals, for example colleague-nurses who have a lot of experience caring for people with dementia, or the GP.

Assessment: general assessment versus formal clinical assessment

A **general assessment** of decision-making capacity of people living with dementia is a task of the GP, sometimes as part of ACP conversations. Other involved parties (e.g. healthcare professionals or family) can play an important role in this, especially because of the fluctuating and task-specific nature of decision-making capacity. According to the 'Mental Capacity Act', developed in the UK, a person is not capable of making his/her own decision when s/he cannot perform one or more of the following tasks:

- Understanding the information given to him/her,
- Remembering the information long enough to make a decision,
- Weighing different perspectives to make a decision,

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- Communicating the decision made – either by verbal communication, using sign language or making small muscle movements (e.g. blinking the eyes or squeezing with a hand).

A **formal clinical assessment** of the decision-making capacity is not always necessary.

Make a formal clinical assessment of decision-making capacity when one of these situations apply:

- When in doubt or in case of a discussion (between healthcare professionals and/or loved ones)
- When the consequences of decisions can have high impact

A formal clinical assessment of decision-making capacity needs several conversations, observation and assessment by a well-informed healthcare professional. It is recommended to perform a careful clinical and neuropsychological assessment, with the expertise of an inter- or multidisciplinary team, consisting of a neurologist, a geriatrician, and a geronto-psychiatrist with expertise in dementia diagnostics. Decisions on decision-making capacity can never be based on screentest only. For example, only using the MMSE (Mini Mental State Examination) is insufficient to reach a decision.

STEP 3: IDENTIFYING A LOVED ONE

You identify which loved one(s) of the resident is/are able to be involved in the ACP process. If the resident is still capable of deciding upon this, then s/he should be involved.

- In case the resident has already appointed a legal representative,
This person should be invited to be present during the ACP conversation.
- In case the resident did not appoint a legal representative,
You check with the resident who s/he would want to be involved. You can ask the following questions:
 - “Who would you like to be involved in your future care?”
 - “Some people want their loved one(s) to be present during the ACP conversation. Is there someone you would like to be present?”

The resident can also choose to go through the ACP process by him-/herself.

- In case the resident cannot indicate a loved one (due to lack of decision making-capacity), you can contact the contact person(s) noted in the resident’s file to indicate which person would be willing to be involved. It is advised to involve the resident as much as possible. The person is ideally:
 - A person of age
 - A family member in the first degree
 - A person with a good and trusting relationship with the resident
 - A person who can serve the interests of the resident
 - A person who is independent relative to the residents’ medical treatment

STEP 4: CONTACT WITH THE GP

It is important to check with the GP in what way s/he wants to be involved in the ACP process. This can either be done over the phone or face-to-face. Moreover:

- You inform the GP about ACP and the ACP-policy in the nursing home in case s/he is not up-to-date on this yet.
- Ask the GP if s/he wants to be present during the ACP conversation and if s/he wants to take the lead. In case the GP cannot be present, you can send written updates and invite him/her to the monthly multi-disciplinary meetings in the nursing home.
- Ask the GP about ACP conversation in the past and any filled out documents (e.g. ADs).
- Ask the GP about important family dynamics that should be considered.
- Ask the GP about other relevant information, for example the medical file, prognosis, general health status and an assessment of the decision-making capacity.

In case the resident received home care before admission to the nursing home, it is advised to contact this care organization and ask about any ACP conversations that might have happened, or any other relevant information you should know to prepare the ACP conversation.

STEP 5: COLLECTING BACKGROUND INFORMATION

Collect information about the residents' illness, comorbidities and treatment options and make sure you know which information has been given to the resident and his/her family. You can ask other healthcare professionals for this information, as well as information on family dynamics, religious beliefs etc.

Preparation checklist

- ✓ Have I made a proper estimation of the resident's decision-making capacity (keeping the fluctuating and task-specific nature in mind)?
- ✓ Are the resident and/or family aware of the planned ACP conversation? If not, make sure you can explain the purpose and main aims of ACP.
- ✓ Do I have sufficient knowledge about the resident's health status, treatment options and social network?
- ✓ Do I know whom to invite and how to involve the resident as much as possible?
- ✓ Is there a room available where we can have a private conversation? Have a put a sign up stating not to disturb?
- ✓ Do I have enough time?
- ✓ Have I contacted the GP to ask about in which way s/he wants to be involved?
- ✓ Have any ADs been drawn up in the past? If so, are they still relevant for the resident?
- ✓ Did the resident already appoint a legal representative?

How to conduct ACP conversations?

First ACP conversation

Plan the conversation in well in advance so the resident and/or the family are available. You can read about the content of this conversation further along in this conversation guide. If the resident wishes to do so, you can plan a follow-up conversation.

Follow-up ACP conversations

Preferably, you will conduct several conversations with the resident about the future. Some might be short, some long, depending on the time available and the resident's mood. Signals to follow-up on ACP conversations can be found in Box 1. Always bear the wishes of the resident in mind when planning a follow-up conversation.

You can also take the initiative to follow-up on the ACP conversation with the resident and/or family. It is advised to take the ACP+ documents of the last conversation with you and check with the resident if everything is still in line with his/her wishes and preferences.

Examples of questions of a follow-up conversation:

- “A while ago we were discussing... You spoke about... Is this still relevant/applicable to you?”
- “A year ago we spoke about... I would like to check with you if we are still on the same page, would that be alright with you?”

CONTENT OF ACP CONVERSATIONS

ACP conversations can be done according to the following **sections (Section A to I)**. A different order is also possible, depending on the topics the resident and/or wants to discuss first. It is also an option to discuss certain sections during one conversation and other sections during a follow-up conversation.

Section A: Ideas about a good life

Section B: Preferences for current care and treatment

Section C: Preferences for future care and care goals

Section D: Appointing a legal representative

Section E: Documenting end-of-life wishes

Section F: Preferences regarding place of care and place of death

Section G: Other preferences

Section H: Preferences with regard to dying

Section I: Revising preferences and wishes

To help you structure the ACP conversation you will find tips and guidance below. You can find a summary of this on the **ACP+ conversation tool, which you can take with you to the conversation. To document the topics discussed you can make use of the **ACP+ document** and attached **ACP+ summary**.**

Tips and tricks for communication with the resident and/or family

Below, you can find the different sections (**section A to I**) you can discuss during an ACP conversation. Per section you can find examples of questions you can ask the resident and/or family. You can use these questions as inspiration, there is no need to ask them all. They are meant as an example to help you conduct the conversation.

Always pay attention to the verbal and non-verbal reactions of the resident and family.

It is also important to make sure you fully understand the resident. If this is not entirely the case, ask follow-up questions until you do. You can find some general communication tips on **page 19.**

SECTION A: IDEAS ABOUT A GOOD LIFE

Ask broad questions about values. Examples are:

1) What is **important** in life?

- What is important to you in your life?
- Do you think you have had a good life?
- What would you consider a “good life”? Did this change throughout the years and how?
- What are you proud of?
- What makes life worth living?
- Which things give you strength, or support you in life?
- What are things that make you feel happy?
- Is there something you are strongly looking forward to?
- Is there any business that you would like to finish?
- What would you like your family, children and grandchildren to remember about you?
- To which things would you still like to dedicate some time and energy?

2) Are there things that influence a resident's vision on healthcare?

- Cultural, religious or spiritual beliefs?
- Would the resident like a visit from a chaplain or priest?

SECTION B: PREFERENCES FOR CURRENT CARE AND TREATMENT

Ask the resident and/or family questions about:

1) Current quality of life

- How do you consider your current quality of life?
- Do you currently have a good life?
- Do you find it hard to get older?
- What does aging mean to you? What is the hardest part about this for you?
- What is your biggest worry or concern at the moment?
- How can we assist you with that?

Specific for residents living with dementia:

- How do you cope with your dementia and getting older?
- What is the hardest part about living with dementia?

2) Preferences for current care and treatment

- Would you currently like to receive care support for anything?
- What do you hope for when thinking about current treatments you receive?
- Can you share with me the things we should know about you so that we can provide you with the best possible care?
- How can we support you to live as well as possible here in the nursing home?
- How can we care for you in the best possible way?

SECTION C: PREFERENCES FOR FUTURE CARE AND CARE GOALS

1) Ideas and worries about the future and the end of life

You can speak with the resident and/or family about their ideas and expectations, as well as their worries and fears about the future and/or the end of life.

You can ask the resident about the extent to which s/he would like to be informed about illness-related matters and whether s/he has a correct representation of the future (e.g. does the resident have insight in his/her illness). **Some residents or family have unrealistic ideas about the future (either too positive or too negative); during this conversation you can adjust or correct these ideas.**

It is important to let the resident (partly) decide on the pace and the content of the ACP conversation. You adjust the conversation to the reactions of the resident and/or family. Not everyone would like to discuss everything, but everyone should be offered the option to speak about it.

Examples:

- What are you worried about?
- Is there something you are worried about, or something you fear might happen in case your health deteriorates?
- Would you like to think about your health in the future?
- When you think about the future, what do you hope for?
- When you think about the future, what are you worried about?
- In case the resident has an illness or disease:
 - When considering your illness, what would be the best thing that could happen to you?
 - When considering your illness, what would be the worst thing that could happen to you?
- Did you ever witness someone else's death, good or bad?
- Did you ever witness someone getting very ill, becoming dependent, or dying? How did you experience this?

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- Is there something you are afraid of?
 - Are you afraid to die?
 - When would life no longer be worth living for you?
 - What would be too little quality of life for you?
 - **Always ask for clarification if answers are unclear. The way family considers these topics for the resident, often also tells you something about them.**

2) Preferences for future care and care goals

You can speak with the resident and/or family about the aims of ACP and check how important it is for the resident to make his/her own decisions in the future. Wishes of residents can be formalized in Advance Directives (ADs) (see section E and F), a legal representative can be appointed (see section D) and goals of care can be determined. Together with the resident and/or family you can speak about which concrete steps they wish to take. **Besides asking questions, it is important to provide information** (e.g. what is ACP, why is it important to speak about this, what are realistic options, which options are not possible, etc.).

Examples:

- Do you have wishes or preferences for the near future? What can we, as healthcare professionals, do to help you with this?
- Have you ever considered the medical care you would like to receive when you are too ill to decide upon this?

Examples for explaining ACP:

ACP is thinking about and planning care that you might need in the future, in case you become very ill or are no longer capable to make your own decision. Also, in case you can no longer speak, we would like to care for you in a way you would have liked. That is why it is important to already discuss your wishes and preferences with us.

- Did you ever speak with someone about ACP?
- What do you know about ACP?

Examples of questions about the importance of decision making:

- How important is it to you to be able to make your own decisions? About which things would you like to decide for yourself?
- How important is it to you to plan care together?

Examples of questions about determining goals of care together:

Everyone has personal goals and values influencing their plans for future care.

- I would like to know more about your goals concerning your health and future care and the things you value most in life. For some people their main goal is to live as long as possible; for others the main goal is to alleviate suffering, optimize quality of life, dying in a comfortable and peaceful way, etc. I suggest we go through several options together so it is easier for you to voice your goals.
- Your health status could change in the future. Sometimes people can adapt or adjust to the situation, and sometimes they cannot. In the past you told me (e.g. not getting hospitalized) was important to you. Is this still the case?
- As we age the chances of developing medical problems increase. Did you ever speak with a loved one about the types of (medical) treatment you would (no longer) want?
- What is more important to you: suffering as little as possible/focusing on quality of life, or living as long as possible?
- Based on everything you have told me so far, I would suggest ... What do you think about this?

In clinical practice, healthcare professionals often use **ABC care codes** to capture residents' general goals of care. Ideally these are discussed thoroughly with the resident and/or family. We distinguish:

- A: Try all life-prolonging treatments:** Main aim is to improve health status, try to treat complications, hospitalization is desired if this could prolong life.
- B: Maintain function:** Main aim is a maximum of recovery with a minimum of burden. Hospitalizations should be in function of this, with a strong preference to remain in the nursing home.
- C: Comfort care:** Main aim is offering as much comfort as possible. Hospitalization is no longer desired (only in function of optimizing comfort)

The table in the **ACP+ document** can be used to explain the different goals of care to residents and/or family. Moreover, you can ask the following questions:

In case a medical emergency occurs (e.g. heart attack) and you would not be able to speak, what would you prefer?

- Would you like to be transferred to a hospital?
- Would you like to receive life-saving treatments or surgery?
- If you would like to receive life-saving treatments or surgery, what extent should there be a realistic chance for you to recover onto your current level of functioning?
- To what extent would you like to receive life-saving treatments, even if chances of recovery are poor?
- Would you like for these decisions to be discussed with your legal representative?

SECTION D: APPOINTING A LEGAL REPRESENTATIVE

A person of age with decision-making capacity can appoint a **legal representative**. This person can make best-interest decisions on behalf of the resident, possibly informed by the completed ADs.

If the resident did not appoint a **legal representative**, it is determined by law who can make these decisions. Please check your local rules and regulations.

The role of a **trusted person** is, in the first place, to assist the resident (e.g. come to doctor's consultations). This leads to a trusted person often being aware of the health status of the resident. The resident can appoint one or more trusted persons. Usually these are captured in the resident's file as contact person. A trusted person always represents a person with decision-making capacity. In case the resident loses decision-making capacity, the legal representative takes over.

It is important to explain the roles of the trusted person and legal representative very clearly to the resident and family. Legal representatives often have a need for information about what this role entails, including the responsibilities and when it applies.

Examples for starting a conversation about trusted persons and legal representatives:

- Who is your trusted person? Who joins you on a doctor's consultation? Is this person aware of your health status? Who should we contact first in case something happens to you?
- In case you would become so ill you could no longer make decisions about your care for yourself, is there someone you trust enough to make these decisions for you?
- Would you like to appoint a legal representative?
- If you could no longer speak for yourself, who would you appoint as legal representative?
- If you could no longer participate in the decision-making process on your health, with whom should we speak? Would that be the right person for you?

Discuss the role of legal representative:

People differ in the extent they want others to decide for them. Some people put a lot of faith in the hands of their legal representative, others feel it is important that their stated wishes are followed as closely as possible. It is important to discuss this, both from the point of view of the resident and the legal representative:

- How important is it to you that your legal representative follows your stated wishes as closely as possible? Can you elaborate on this?
- Does the legal representative know what is expected of him/her? Does s/he have any questions about this?

SECTION E: DOCUMENTING END-OF-LIFE WISHES

ADVANCE DIRECTIVES AND PREFERENCES REGARDING EUTHANASIA

You can discuss with the resident if s/he would like to compose ADs or maybe already has done so in the past. The **ACP+ document** can be used to document this.

It is important to fully explain all ADs, when they apply and how they are used in practice. Please check your local rules and regulations! For example, euthanasia might not be a legal option in your country.

Examples on speaking about end-of-life wishes and ADs:

- You can document your wishes in several ways. Some people may find it useful to compose an AD. You don't have to do this if you don't want to, and you should certainly not rush into this. Shall we discuss all the options together?
- Have you ever heard of palliative care? What is your experience with this?
- Do you have an AD? Would you like to compose an AD?
- **The topic of euthanasia could come up, if the resident wishes to discuss this.** In case the resident has questions about this, you can ask: What does euthanasia mean to you? What would you like to know about it?

Speaking about preferences with regard to resuscitation:

Explain to the resident and/or family what resuscitation is and what could be the consequences of this:

In case of a heart attack or when your breathing stops, we could proceed to resuscitation (massage of the heart, mouth-to-mouth respiration or defibrillation/electro-shocks). Resuscitation is often less successful than people might think. There is only a small chance that you will survive the resuscitation. Out of 100 people older than 70 years of age, only 8 survive. The other 92 die of cardiac arrest. A recent study has shown that among the survivors 90% suffers from mild damage and 10% suffers from severe damage after resuscitation. The odds of dying of more severe damage increases with age. Elderly people living with dementia rarely survive resuscitation.

- There is a chance that you suddenly experience cardiac arrest, if this happens we can resuscitate you. Are you familiar with this? Do you know anything about this? Would you like to know more about this?
- Have you ever thought about if you would want this? Would you like to be resuscitated?
- Today I would like to speak with you about your wish not to be resuscitated.
- If the doctor or another healthcare professional would still find it worthwhile to start resuscitation, what would you like?

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- Would you like to be resuscitated in case you breathing or your heart stops? 1) No, never; 2) Only if a doctor or other healthcare professional considers it worthwhile; 3) Yes, always, in any occasion.

SECTION F: PREFERENCES REGARDING PLACE OF CARE AND PLACE OF DEATH

Ask the resident where s/he would like to be cared for at the end of life and where s/he would like to die. Examples:

- Have you ever thought about where you would like to stay when you are getting severely ill/older?
Where would you like to be cared for at the end of life?
- Some people have clear thoughts about where they would like to die. Some people prefer the nursing home, other people rather stay at a palliative care unit in the hospital. Do you have specific preferences for this? Could you share them with me?

SECTION G: OTHER PREFERENCES

Ask the resident about other preferences s/he might have. Examples:

- Are there any wishes you would like to share with us in case you are near the end of your life?
- What does religion or spirituality mean to you? Would you like to speak with someone about this?
- How would you like to be cared for in your final days? Do you have specific preferences or wishes?
- Are there other preferences you would like us, as your healthcare professionals, to take into account? Do you have any worries, fears or general remarks?

SECTION H: PREFERENCES WITH REGARD TO DYING

Check if the resident has specific wishes or preferences with regard to dying. Examples:

- Are there any specific (religious) wishes we should consider?
- It is hard for anyone to think about their own death. Are there any thoughts about your own death that bother you?
- Would you like to make funeral arrangements?
- Are there specific details about the funeral or cremation you would like to discuss?

SECTION I: REVISING PREFERENCES AND WISHES

Ask the resident in which circumstances s/he would like to revise his/her wishes and preferences.

A follow-up ACP conversation should be planned in any case, either when a situation occurs as described in **Box 1**, or with a predetermined interval (e.g. every year). In case the resident states specific occasions on which s/he would like to discuss ACP again, it can be recorded here.

EXTRA: HAVING A CONVERSATION WITH FAMILY OF A RESIDENT WITH DEMENTIA

Examples:

- Your loved one is living with dementia. What are you worried about when considering his/her future care?
- Your loved one is living with dementia. What would be important to him/her when considering his/her future care?
- It is very likely that your loved one's decision-making capacity diminishes. Therefore, we will turn to you for decision-making more often. How does this make you feel?
- Are there specific scenarios you know of which your loved one would absolutely want to avoid?
- We know that when the dementia process continues, your loved one will most likely experience difficulties eating and will have a high chance of getting infections. What are your thoughts on this?
- What is your estimation about your loved one's quality of life? How do you think s/he feels right now?

General communication tips

PREPARATION

- Try not to force ACP onto someone
- You should plan the ACP conversation at a time of day that is convenient for the resident (and family) and the GP (in case s/he wants to be involved).
- Make sure there is a quiet space available to conduct the ACP conversation (limit phones) and ensure privacy (e.g. by putting a sign on the door).
- There should be sufficient time to answer questions or repeat information that is unclear. If any of the participants experience time pressure, plan a new ACP conversation in the near future.
- Make sure the resident and/or family know they can always ask questions if anything is unclear to them: "Please interrupt me if anything is unclear to you..."

DURING THE CONVERSATION

- Use an empathic patient-oriented communication style and listen actively.
- Try not to interrupt the resident and family. They might need some time to express themselves. Don't be afraid to be silent in case someone becomes emotional.
- In case the resident and/or family is clearly upset, you can point out what you see: "I can see this is emotional for you, is that right?", "Is it hard for you to speak about this?", "It seems you are in doubt?"
- Always try to react to what the resident or family is saying. It is important to get to the underlying message: "When you say you do not want to suffer, what kind of suffering are you thinking about?", "When you say you do not want to live like a vegetable, what exactly do you mean with that?"
- Ask regularly if you understood the resident and family correctly: "If I understand correctly, you are telling me that..."

SUMMARY AND FOLLOW-UP

- Summarize the conversation and ask if you understood everything correctly.
- Do not forget to check with the resident what s/he thought about the conversation: "How do you feel about everything we have just discussed?", "Is there something you would like to hear again?", "Is everything clear for you?"
- The results of the ACP conversation can be documented on the ACP+ document. Moreover, you should fill out the ACP+ Summary (and ADs and care codes) and add all relevant documents to the resident's file. The ACP+ Summary can be found in the ACP+ Document.
- Plan a follow-up conversation.

HOW TO DOCUMENT?

1. The ACP+ document
2. Advance Directives - **Please check your local rules and regulations!**
3. Care and DNR-codes - **Please check your local rules and regulations!**

1. THE ACP+ DOCUMENT

What do you need to know about the ACP+ document?

The **ACP+ document** is **green** and meant for you to write down everything you spoke about with the resident and/or family AFTER the ACP conversation. The content can always be changed, based on new information from other/new ACP conversations. At the back of the ACP+ Document are also the following documents attached:

- 1) A **red** summary of ACP+ document; the ACP+ summary
- 2) Advance Directives
- 3) Care and DNR code sheets, summarizing the care goals of the resident

Make sure the most up-to-date version of all documents can always be found in the resident's file. They should be accessible to all healthcare professionals in the nursing home and be sent along in case the resident is admitted to the hospital (or elsewhere).

Make sure to send a copy of all relevant documents to the GP.

2. ADVANCE DIRECTIVES

PLEASE CHECK YOUR LOCAL RULES AND REGULATIONS!

3. CARE AND DNR-CODES

What do you need to know about ABC care codes and DNR codes?

Based on the ACP conversations with residents and/or family, nursing homes often use **ABC care codes**. You can document this in the ACP+ document. In a table you can note which care code is applicable to the resident and specify which concrete actions and decisions are linked to the care code. These codes should only be granted after consultation with the resident and/or family in an ACP conversation.

Explanation about the ABC care codes:

CARE CODE	A: try all life-prolonging treatments	B: maintain function	C; comfort care
AIM	Maintain and prolong life	Maintain life and treat any acute illnesses	Comfort care
PERSPECTIVES	Improvement of the health status	Improvement of the acute illness Stabilize health status	Slow decrease of health status. Rapid decrease of health status, dying on fairly short notice. Dying on short notice.
AGREEMENTS	Resuscitation Hospitalization Maximum medical treatment	No resuscitation No ICU No hemodialysis Hospitalization? (Only short visits, aiming to receive a diagnosis or non-invasive short therapy)	Only medication aimed at quality of life and comfort Symptom relief Palliative care

Every nursing home can use its own model. If this is the case, this document can be adjusted accordingly.

ABC care codes can be granted by healthcare professionals in the nursing home, in consultation with the resident and/or family. DNR codes however, can only be granted by a physician (e.g. the GP). DNR-codes are the results of a medical assessment about the usefulness of treatments in combination with the preferences of the resident. Moreover, it is advised that other healthcare professionals are involved in the consultation. Please check your local rules and regulations!

Explanation DNR-codes:

DNR 0	No limitations on therapy (resuscitation can be started, ambulance can be called)
DNR 1	Do not resuscitate (do not massage the heart, no defibrillation, do not call an ambulance), all other therapies are permitted
DNR 2	Do not resuscitate + limitations of therapy (do not start or expand certain life-saving treatments)
DNR 3	Do not resuscitate + only comfort care (withdraw or stop certain life-longing treatments)

IMPORTANT!

Always make sure all different ACP+ documents correspond with each other and are up-to-date!

SPECIFIC INFORMATION FOR RESIDENTS LIVING WITH DEMENTIA

ACP is important for people living with dementia, but can be difficult to initiate. The reasons for this are the typical disease characteristics; cognitive decline, a changed perspective of reality, behavioral symptoms and mood disorders can influence the ACP conversation. **A thorough preparation is key.**

Here we present a summary. For more information you can check (among others):

- Demaerschalk, M., Kindekens, D., Verraest, E., Hoste, V., Van Ooteghem, L., Nys, H., Pype, P., De Vleminck, A. & Gilissen, J., *Draaiboek Vroegtijdige en vroegtijdige zorgplanning in woonzorgcentra. Vlaamse Vereniging voor Steden en Gemeenten, Brussel: Politea, 2016 [IN DUTCH]*

Despite the cognitive decline of residents living with dementia, their changed perspective onto the world and reality and the influence of behavioural symptoms and mood disorders, an ACP conversation is still very often possible and is strongly encouraged. Described below you can find some tips and tricks for conducting an ACP conversation with a resident living with dementia.

1. PREPARE WELL – PROVIDE RELEVANT INFORMATION ON DEMENTIA

Before you initiate an ACP conversation, it is important to speak about dementia as an illness. Check what the resident knows about dementia and correct any misunderstandings. This is a delicate process and you should handle the situation carefully. It is important not to overwhelm the resident, or confront him/her with their mistakes. Be respectful. For example, you can ask the resident if s/he knows why s/he is here, in the presence of family. You can give examples of people you know, or the resident knows, who are forgetful often and who are unhappy about others making all their decisions for them. Based on examples provided by the resident, you can correct misunderstandings and explain which symptoms align with aging and which with the dementia disease trajectory.

By doing this, you help the resident with the process of acceptance and finding new ways of communication. A healthcare professional specialized in dementia care can help you. The process of acceptance will likely influence the way people engage in ACP.

2. STAY HONEST – CUSTOMIZE

Adjust to the reality of the resident, but do not tell lies. Even if the message is not hopeful, the resident is most likely to remember the way in which you explain this to them. You should not minimize the serious nature of the disease. The emotional pain, fear, sadness, anger... that people feel, have a right to be there. Acknowledgment and staying close contribute to a constructive grieving process.

3. DRAW THE ATTENTION

A resident with dementia has often trouble with focusing for a long time. A gentle touch or calling out his/her name can help to stay focused on the conversation. Repeat what you have said regularly. Repeat the name of the resident regularly. Maintain eye contact during the conversation.

4. 'SUPPORTING' COMMUNICATION

Supportive material can best be put in place before you start the conversation. The resident might experience trouble following the conversation due to diminishing concentration, too high a pace of the conversation, unclear word use, etc. What the resident hears, sees or thinks can often not be structured sufficiently anymore by the brain. Communication can then be supported by pictures, written language, signs etc. It is often easier to choose between two pictures than to formulate an answer verbally.

5. INVOLVE ALL IMPORTANT PARTIES AS EARLY AND AS OFTEN AS POSSIBLE

For residents with dementia the ACP process is very intensive. The specific disease characteristics may lead to the resident needing more time to consider all options. The (appointed) legal representative should be involved in the ACP process, as well as other healthcare professionals, especially when the resident no longer has decision-making capacity.

6. OBSERVE

You can obtain a lot of information when observing the interactions between different family members. For example, it can provide you with insight about how they see the resident and dementia (e.g. hesitating when being asked a question, stereotypical answers, emotional answers etc.).

MORE INFORMATION

This conversation guide is made by researchers of the End-of-Life Care Research Group of the Vrije Universiteit Brussels, Belgium. The conversation guide is based on the guidelines about advance care planning and advance care planning with people living with dementia ['Vroegtijdige zorgplanning' and 'Vroegtijdige zorgplanning bij mensen met dementie' (Pallialine, 2016) and 'Vroegtijdige zorgplanning bij mensen met dementie' (KBS, 2014) IN DUTCH], a brochure from the Federation Palliative Care Flanders ['Ook de laatste reis wil je samen bespreken...'] ([Federatie Palliatieve Zorg Vlaanderen](#), 2010) IN DUTCH], an adjusted conversation guide from 'Respecting Choices' (ACTION-ACP project financed by the European Commission, 2016) and the materials of the EUP7 PACE project. The ACP+ conversation guide has been feasibility tested in collaboration with several health care professionals from the nursing home field.

For more information about the activities and projects of the End-of-Life Care Research Group you can visit the website: www.endoflifecare.be.

OTHER SUPPORTIVE MATERIALS FOR HEALTH CARE PROFESSIONALS [IN DUTCH]

1. **LEIF "Guide for health care professionals" [Wegwijs voor de zorgverlener]** – this can be used as extra support. It can be downloaded for free from the website: <http://leif.be/home/>.
2. Health care professionals searching for more information on ACP for people living with dementia can read a publication from Koning Boudewijnstichting: "Advance care planning for people living with dementia; how to do this?" [Vroegtijdige zorgplanning bij mensen met dementie: hoe pakt u dit aan?] (**freely** available from this website: <https://www.kbs-frb.be/nl/>).
3. If you are looking for more background information on ACP and ACP for people living with dementia we recommend the guidelines from Pallialine, available from this website: <http://www.pallialine.be/>.

OTHER SUPPORTIVE MATERIALS FOR RESIDENTS AND THEIR FAMILY [IN DUTCH]

1. **LEIF "Guide for the public" [Wegwijs voor de bevolking]** – this brochure can provide the resident and/or family with extra information. It can be downloaded for free from the website: <http://leif.be/home/>.
2. The publication of Manu Keirse et al. "The last journey" [De laatste reis] explains ACP very clearly. This publication is **freely** available from this website: <http://www.delatstereis.be/template.asp?f=index.htm>.



ACP+ document

When speaking about advance care planning (ACP) with a resident and/or their family or loved one, we recommend to use the **ACP+ conversation tool** to guide the conversation. This **ACP+ document** is meant to be used afterwards to take notes of everything that was discussed with the resident and/or family. The content of this document can always be altered, depending on what was discussed.

At the back/Attached are three important additional documents:

- 1) An extended **ACP+ document** to take notes of the ACP conversation
- 2) An **ACP+ summary** with information on Advance Directives of the resident
- 3) Care code forms (DNR or ABC code), summarizing the care goals for the residents

IMPORTANT

- ✓ **Always make sure that the most up-to-date version of the documents is used.** These documents need to be accessible to all relevant care providers and need to be **send along** in case the resident should transfer (to a hospital or other).
- ✓ **A copy of these documents needs to be delivered to the General Practitioner (GP).**
- ✓ **This ACP+ document was developed under Belgium law, please check your local rules and regulations on Advance Directives and Care codes.**

This is the ACP+ Document of:

First and last name of the resident:

Gender: Male Female Date of birth:(day)/.....(month)/.....(year)

Nursing home (ward): Room number:

Name of GP: Phone number of GP:

This ACP + Document was made on:

.....(day)/.....(month)/.....(year)

ACP conversations were conducted with:

(multiple options possible)

- Resident
- Spouse: (name)
- Child(ren):(name(s))
- Sibling:(name)
- Other:(name and relation)

Date first conversation:(day)/.....(month)/.....(year)

Date last conversation:(day)/.....(month)/.....(year)

Total number of conversations:

Data and observations concerning the **decision-making capacity of the resident**

Decision-making capacity can be described as: Being able to correctly come to a reasonable appreciation of one’s interests concerning a current specific decision or situation and arrive at a well-balanced decision.

Further explanation on how to estimate someone’s decision making capacity can be found on page 6 of the ACP+ Conversation Tool.

.....
.....
.....
.....
.....
.....

SECTION A

Ideas about a **‘good life’** for the resident

For the resident, what is important in life?

.....
.....
.....

Is there anything (religious, spiritual, cultural) that influences the resident’s view on good health care?

.....
.....
.....

SECTION B

Preferences for **current care and treatment**

The current quality of life of the resident:

.....
.....
.....

Preferences for current care and treatment:

.....
.....
.....
.....

SECTION C

Preferences for **future care and care goals**

Important ideas, concerns or expectations about the future:

.....
.....
.....

Important wishes or preferences for future care:

.....
.....
.....

Care goals:

- A: Try all life-prolonging treatments: Main goal is to treat possible complications, hospitalization is desirable if this can prolong life
- B: Maintain function: maximum recovering with minimal burden, hospitalization is desirable in function of this, strong reference to stay in nursing home
- C: Comfort care: The main goal is to offer greatest comfort, hospitalization is no longer desirable (unless this would benefit overall comfort)

Additional remarks about care goals:

.....
.....
.....

SECTION D

Appointing a **legal representative**

Who is the **first contact person** in the residents' file?

.....
.....
.....

Who is/are the **trusted person(s)**?

.....
.....
.....

Does the resident wish to appoint a legal representative? If so, whom (name and relationship with the resident):

.....
.....

Please state this clearly on the **ACP+ summary**

SECTION E

Documenting end-of-life wishes (**Advance Directives**)

Advance Directives (filled out by the resident him-/herself, with assistance of healthcare provider) can be filled out on the attached forms, if the resident wishes to do so.

Document wishes with regard to resuscitation: **Would the resident liked to be resuscitated in case his/her breathing or heart stopped?**

- No, never
- Only if the physician or care provider would think it is worthwhile
- Yes, always, in any occasion

SECTION F

Preferences regarding **place of care** and **place of death**

Tick the box that is applicable:

- The residents' preferences with regard to the place s/he would like to be cared for until the end:
..... (please fill this out)
- The resident has no preferences with regard to the place s/he would like to be cared for until the end.

SECTION G

Other preferences all people caring for the resident should be informed about:

Other specific wishes or preferences:

.....
.....
.....
.....
.....
.....

SECTION H

Preferences with regard to **dying**

Specific wishes with regard to dying (e.g. funeral arrangements, religion):

.....
.....
.....

SECTION I

Revising preferences and wishes

Circumstances/reasons which would cause the resident to revise his/her wishes:

.....
.....
.....

Please fill out the **ACP+ summary and add this to the resident's file, together with the Advance Directives and the **Care codes (ABC and DNR)**.**

A follow-up ACP conversation is planned on:

.....(day)/.....(month)/.....(year)



ACP+ summary

This document provides a summary of the topics discussed during an ACP conversation with the resident and his/her family. This document can be added to the resident’s nursing home file and be added when a resident is transferred (e.g. on hospital admission).

This is the ACP+ summary of:

First and last name of the resident:

Gender: Male Female Date of birth:(day)/.....(month)/.....(year)

Nursing home ward: Room number:

Name of GP: Phone number of GP:

Information on the (first) contact person of the resident:

First and last name of the contact person:

Relation to the resident:

Address:

Postal code and city:

Telephone number of the contact person:

Information about the legal representative:

Did the resident appoint a legal representative?
Yes No
If 'yes', please specify on the next page and have it signed.

Information about decision-making capacity of the resident:

.....
.....

My legal representative

I, the one who signs, appoint this person as my legal representative in case I am unable to practice my rights as a patient:

First and last name of the person who is appointed as legal representative:

.....

Relation to the resident:

Address:

.....

Telephone number:

Social security number:

Place Date/...../.....

Signature (resident):

Information on potential Advance Directives¹ of the resident

Did the resident compose an AD with personal wishes?

Yes No

Did the resident compose a Euthanasia AD? (*only to be used in case of an irreversible coma*)

Yes No

Did the resident compose an AD with regard to the manner of burial?

Yes No

Did the resident compose an AD with regard to organ donation?

Yes No

Please add all the composed ADs to this document.

¹ Based on the Belgian care system, please check your local rules and regulations!



Care & DNR code

CARE CODES²

Below you can indicate which care code (A, B, C) you would appoint to the resident and specify which concrete actions and agreements are linked to that. These codes are appointed after an ACP conversation with the resident and/or family. Please appoint these codes always in consultation with the GP or other specialized care providers.

Date of ACP conversation dd/mm/yyyy	Care code (A, B, C)	Translation of the care code in concrete actions and agreements for all different disciplines + MOTIVATION

² Based on the Belgian (Dutch-speaking) care system.

Explanation Care codes

CARE CODE	A: try all life-prolonging treatments	B: maintain function	C; comfort care
AIM	Maintain and prolong life	Maintain life and treat any acute illnesses	Comfort care
PERSPECTIVES	Improvement of the health status	Improvement of the acute illness Stabilize health status	Slow decrease of health status. Rapid decrease of health status, dying on fairly short notice. Dying on short notice.
AGREEMENTS	Resuscitation Hospitalization Maximum medical treatment	No resuscitation No ICU No hemodialysis Hospitalization? (Only short visits, aiming to receive a diagnosis or non-invasive short therapy)	Only medication aimed at quality of life and comfort Symptom relief Palliative care

Every nursing home can use its own model. If this is the case, this document can be adjusted accordingly.

DNR CODES³

DNR codes are the result of a medical assessment of the usefulness of treatment, combined with the preferences of the resident. DNR codes can only be allocated by a physician but are, in conformation with the legal and jurisdictional frameworks of informed consent, also in consultation with the resident or his/her legal representative.

DNR code <i>(to be allocated by a physician)</i>	Signature of the physician + date dd/mm/yyyy + stamp	Participants of the consultation: Name + role (resident, legal representative, GP,...) + signatures

Explanation DNR codes

DNR 0	No limitations on therapy (resuscitation can be started, ambulance can be called)
DNR 1	Do not resuscitate (do not massage the heart, no defibrillation, do not call an ambulance), all other therapies are permitted
DNR 2	Do not resuscitate + limitations of therapy (do not start or expand certain life-saving treatments)
DNR 3	Do not resuscitate + only comfort care (withdraw or stop certain life-longing treatments)

³ Please check your local rules and regulations!

