



UiO : Faculty of Medicine
University of Oslo



Guide

**Advance Care Planning (ACP) –
planning for future health care
and end-of-life care together**

Advance Care Planning (ACP)

Advance Care Planning (ACP) involves the patient and/or next of kin being invited to talk about the patient's near future, health care to come, and the end of life with nursing home staff. They are invited to take part in a conversation some time after the admissions meeting has been held. ACP can bring valuable information to the staff, but the conversation is, first and foremost, a chance for the patient and next of kin to describe what is important to them now, and in the time to come.

The patient's responses and wishes should be recorded and should be used as a basis for decisions regarding treatment and care in the future, and at the end of life. Patients (and next of kin) are different, have different life stories, diagnoses, medical histories and experiences, therefore the conversations will all be different. Participation is voluntary. Patients who are competent to consent must consent to their next of kin's participation in the ACP.

Consent

Most nursing home patients have some degree of cognitive impairment, including dementia. For this reason, it is natural to assess the patient's competence to consent to ACP, to involve the patient in the best possible way. In order to make choices based on an understanding of what that choice entails, the patient needs information that is adequate and adapted to them. If the patient lacks competence to consent, next of kin should be involved to a higher degree. Next of kin should relay the patient's previously expressed wishes and values. If the patient lacks competence to consent, the conversation should strive to include both patient and next of kin.

Assessing competence to consent, and adjusting to the patient's needs does not mean that these patients should be left out of the conversation. Patients who have cognitive impairments can and should be allowed to

participate in ACP, though the content and extent of the conversation may need to be adjusted to the patient's needs. The same is true for patients with hearing impairments or aphasia.

The timing of ACP?

Admission meeting

An admission meeting is usually held within 2 weeks of the patient's arrival. The focus in these meetings is usually medical history and mutual orientation about practical matters. Many nursing homes have routines and use templates to guide the conversation in these meetings. Who is next of kin / proxy? Who should be informed about the patient's condition? Other relevant background information? The admission meeting can also be a preparation for the ACP. This means that health care staff may ask the patient whether he/she wants all the information about their own condition, and the extent to which he/she wants to participate in decisions about medical treatment.

ACP

It is important to carefully consider the timing of the conversation. We recommend that the conversation is carried out within 3 months of arrival, or quicker if the patient's health is very poor. It is an advantage if patient, next of kin and staff have had a chance to get to know each other first.

Follow-up

Once or twice a year – topics brought up in ACP-conversations can be revisited, and potentially revised.



Photo: Kristin Ellefsen/UiO

The purpose of ACP

- to further the patient's participation in care and decision-making.
- to foster mutual security and trust between patient and health care staff.
- to give health care staff decision-making support and a better way to move forward.

Who should participate?

Patient, next of kin (maybe), the caregiver most familiar with the patient (nurse or nurse assistant) and doctor.

Preparing for ACP

Invitation

We recommend a written and verbal invitations to patient and/or next of kin. The invitation should make clear the purpose and the content of the conversation, and who should participate.

Time frame

Set aside 45-60 minutes for the conversation, and make this clear in the invitation.

Choosing a room

The conversation should be carried out in the patient's room or other suitable room. Staff common rooms should be avoided, as well as other rooms where people are going in and out, in order to be left alone. Serving coffee or something similar creates a nice atmosphere and makes it feel less formal.

Leading the conversation

The staff should decide before the meeting who will lead it. It may help the patient and/or next of kin if you choose someone they are familiar with to lead the conversation, perhaps the caregiver most familiar with the patient.

Patient background

Preparation leads to a more comfortable conversation for those leading it. One way to prepare is to read the patient's chart, background information, or recent daily reports.

Invitation ACP

Here is an example of an invitation. Adjust the text to fit your nursing home.

Dear and next of kin

You are hereby invited to a conversation with the doctor and a staff member you are familiar with, about how you like living in the nursing home, and any thoughts you may have about the future and the end of your life. We want to get to know you better, and to know more about what is important to you, so that we, as far as possible, can take your wishes and values into consideration. As a patient in the nursing home, you have the right to information and participation in medical decisions.

Participation is voluntary; you can turn down this invitation if you wish.

Some of the things we would like to talk about are:

- What is important to you now and in the time to come?
- Do you want to participate in decisions about your medical treatment?
- Have you given any thought to the end of your life, and death?

Many people may feel these are unusual topics to talk about. Therefore, it is a good idea to think them through beforehand, and maybe discuss with your loved ones. Think about whether there are other topics you would like to cover, maybe take a few notes.

If for some reason you are unable to participate, the conversation will be carried out with your next of kin as your proxy. This means that your proxy should relate what is important to you.

The conversation is planned:

Date.....from.....to.....,
in.....

Best wishes,

.....

Carrying out ACP

It is important to create a pleasant atmosphere for the ACP-conversation. Small talk, for instance based on background information you have, can contribute patients, next of kin and staff feeling more comfortable. It is a good idea to start by telling everyone what the conversation is going to be about; the patient's experiences from living in the nursing home, whether the patient has wishes regarding level of treatment (active/less active), what is important to the patient now – and what is important at the end of life; whether the patient has any worries, and whether the patient has things to look forward to. Reminding everyone what the purpose of the conversation is is especially important when the patient suffers from a cognitive impairment.

It is a good idea to start with some open and more general questions. As the conversation moves along, it is important to be aware and sensitive to the patient's reactions. Relay information in a simple way so the patient understands what he/she is responding to. By asking "Have I understood you correctly that you want...?" you can see if you have understood the patient correctly. Point out that it is the doctor who makes the final decisions, but that it is good to know the patient's wishes.

The questions must be adapted to the patient, and the documentation we have on the patient. Asking for the patient's preferences for treatment that the staff does not see as appropriate, for instance CPR, should be avoided. Some of the questions can be hard to answer and require time for thought. In the following we have suggested some questions to ask the patient. Many of the questions are meant to be follow-up questions if the patients or next of kin do not bring it up themselves.

Suggested beginning questions

- We, the staff, wish to get to know you better, and to know more about what is important to you.
- How is life in the nursing home?
- Who do you spend time with /talk to here in the nursing home?
- Which of your family members and friends stay in touch with you?
- Have you seen the invitation, and have you given any thought to the questions found there?
- How much information about your illness(es) do you want?
- If your next of kin ask, can we inform them about your illness(es)?
- How much information about your treatment do you want?
 - If your next of kin ask, can we inform them about the treatment you are receiving?
 - Is there anyone you would like us not to give information to?
 - Is there anyone you would like to have with you when you get information?
- Is there anyone you wish to have with you when treatment is being discussed?
- Would you like to participate when decisions are made about your treatment?
 - If no: Do you want someone else to represent you?
 - In that case, who do you want to represent you?
- Have you ever written down your wishes for future treatment?

Suggestions for follow-up questions

- Do you think about the future?
 - Are there things you would like to do/experience?
 - Do you have any special wishes?
 - Are you worried about anything?
- What is a good life to you?

Suggestions for questions about future health care

- Some people have thought about what they want if they become acutely or seriously ill. Do you have any wishes we should know about?
- Do you have any thoughts about what you want if you get so sick that a hospitalization may be necessary?
- When you get to the point of your life when you don't have much time left, what is important to you then?
 - For instance, is it important to you to live as long as possible?
 - For instance, is there someone you want to have by your side?
 - Is there anyone you would like to speak to?
 - Is there anything else on your mind?
- Is there anything else you want to bring up?
- We know that people can change their minds about what they want when they get sick. For this reason, we will talk to you about these things again.

Ask the patient and next of kin how it felt to talk through these topics. Set a time for either continuing or finalizing the conversation. Set at time for a follow-up conversation in 6-12 months. Sum up the conversation to make sure everyone has a common understanding of what was decided.

If the patient does not want ACP

Participation in ACP must be voluntary, and the patient may not want it. If the patient refuses, health care staff can still ask the patient whether he/she (later) wants information about their own illness and treatment, and whether the patient wishes to be present when decisions about treatment are made in the future. Staff can check with the patient whether they can inform next of kin about the patient's health and treatment. If the patient does not want to participate in in ACP-conversation, he/she can be asked whether there are others who can represent him/her regarding information and decisions. The patient can also be asked whether he/she has written down any advance care wishes.

After the conversation

- Document the content of the conversation in the patient's chart. The documentation must be easily accessible so that the information can be useful in acute situations, or when decisions are made. Perhaps there is a special place for this in the computer's documentation system.
- If the patient allows it, the content can be conveyed to others who would benefit from the information, for instance family members, family doctor or others.
- The participating staff members should evaluate the conversation: In which ways was it useful? Was it a comfortable conversation from the staff's point of view? How do we think the patient/next of kin felt about it?
- Topics for reflection/rapport: Who is this patient and in which ways should the things that came up in the ACP-conversation be taken into our approach?
- Invite the patient/next of kin to give feedback to the nursing home, ideally in writing, about wishes/needs that were not brought up in the conversation.

Using this guide

We recommend that staff becomes familiar with the guide before the conversation, but that it is also actively used during the conversation. This will better secure that we touch upon all relevant topics in the conversation. ACP-conversations are not covered in their entirety in this guide. It is a good idea to use questions and topics from this guide in more everyday conversations between staff and patient. Pocket-sized notes have been printed for this use.

Research project

This guide has been tried out in the research project *End-of-life communication in nursing homes. Patient preferences and participation*. This version has been revised following the findings and experiences in the project, in November 2017. The research was carried out at the Centre for Medical Ethics, University of Oslo.

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