

PROACTIVE CARE PLANNING TOGETHER DEDICATED



Tips for proactive care planning for relatives of the person with dementia

Your relative was admitted to our care facility a few weeks ago. As a care organization, we want to engage in timely conversations with you to jointly explore how we can provide the best possible care for your loved one. It is important that we make and record arrangements, so that it is clear to both us and you what has been agreed upon. You will receive an overview of this afterwards.

The following conversation guide will be used by the Head Nurse during the 6-week meeting with you. We have sent this to you in advance so that you can read through it beforehand. This will help you prepare for what we intend to discuss with you. Of course, you are also welcome to add your own topics and ask questions during this conversation.



Your role as loved one

As a loved one, you may experience various roles. These are questions to consider:

- What role do you want to have in proactive care planning?
Examples of roles could be (you can also define these yourself):
 - Representative:* If your loved one is no longer able to do this themselves, you can take over for them and make choices.
 - Information provider:* Because you've known your loved one for so long, you can provide caregivers with information about their past or how to handle certain situations.
 - Care monitor:* You may recognize certain signals sooner because you can better assess your loved one's behavior.
 - Informal caregiver:* This could include all your support services in caregiving.
- Do you need support to fulfill your role?

The role of the Head Nurse (the Head Nurse answers this question themselves):

- What do I consider important in my role as a Head Nurse?

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Support for you as a loved one

Because these conversations concern the future and the end of life, it's important that you receive support, and we are happy to offer you this opportunity. This could include:

- Do you need support? If so, what kind?
- Have you been sufficiently informed about proactive care planning so far? If not, what else would you like to know? Would you like to receive informational documents, such as brochures and leaflets?
- How would you like to be contacted by the Head Nurse?
- How would you like to be informed (email/phone/in person)?
- What would you like to be informed about? Consider information about: the progression of the disease, changes in your health status, and feedback from meetings between various healthcare professionals.

Your involvement as loved one

It's important that healthcare providers know to what extent you want and can be involved in the care process. The following questions may be relevant:

- Which other family members are involved besides you?
- How would you like to discuss care wishes/care goals (multidisciplinary consultation/visit/one-on-one)?
- How often would you like to have this conversation?
- To what extent would you like to be involved in proactive care planning?
You can find this information in the participation levels of Arnstein's participation ladder. This ladder consists of 7 levels, which are shown below. Please note: these are just examples, and you may be at multiple levels simultaneously.
Level 1 Direct decision-making: You have a direct say in the care wishes/care goals for your loved one.
Level 2 Delegated decision-making: You can share your opinion, which will then be incorporated into the caregivers' decision.
Level 3 Co-production: You consult with caregivers and your loved one to reach a decision together.
Level 4 Mediation: You act as a mediator between your loved one with dementia and caregivers.
Level 5 Consultation: You provide caregivers with advice about your loved one.
Level 6 You share information about your loved one with caregivers.
Level 7 You want little to no input in the care process.

The involvement of the Head Nurse (the Head Nurse answers this question themselves):

- What can you contact me about as a Head Nurse, and how?