

Supplementary Material

Costs of Persons with Dementia Living in Nursing Homes in the Netherlands

Phases of Dementia

Stage 1. Very mild memory symptoms (also called Mild Cognitive Impairment or MCI)

Someone has problems with memory or other brain functions. For example, it takes more effort to find the right word or objects are put back incorrectly.

It is important that the complaints are still relatively mild – someone in this phase forgets details of an event but does not forget the entire event itself.

An important difference with phase 2 is that people are self-reliant.

Stage 2. Mild disease

Complaints are more pronounced, and this becomes noticeable in daily functioning.

Usually, memory symptoms are the most noticeable (for example, someone forgets a recent event), but other brain functions can also be affected. People lose the ability to get an overview of a situation sooner, they find it more difficult to make decisions and they start repeating themselves. They understand things less quickly, talking becomes more difficult and they lose interest more quickly.

Stage 3. Moderate disease

In this phase, the symptoms become more severe. People keep forgetting things, but they also have more trouble recognizing others.

New complaints also become visible. People become angry or suspicious more quickly and sometimes there are hallucinations. People get lost, confused about time and the sleep/wake rhythm is disrupted.

In this phase people need more and more help with, for example, eating and dressing. The complaints are also so serious that people can endanger themselves and others, for example by forgetting to turn off the gas on the stove.

Stage 4. Severe disease

In this phase, existing complaints become increasingly serious. People can no longer recognize even familiar things (other persons, places, or objects). They become more restless and may be angry or sad.

These complaints are so serious that a person becomes completely dependent on others. This dependence is increased because people in this phase have difficulty chewing and swallowing, lose a lot of weight, become incontinent or lose their speech.

Questions for carers and nurses

1. What is your current function?

- Care Aid (level 1)
- Assistant (level 2)
- Caregiver (level 3)
- Nurse (level 4)
- Nurse (level 5)
- Other, namely _____

2. For how long have you been working in this function?

_____ year

3. Do you care for patients with Alzheimer's disease?

- Yes, on a daily basis
- Yes, on a weekly basis
- Yes, on a monthly basis
- No

4. What proportion of patients you take care of are primarily institutionalized for Alzheimer's disease?

_____ %

[Description of phases of dementia]

6. Can you distribute the clients you take of over the phases of dementia?

- Phase 1: _____ % of patients with Alzheimer's disease
- Phase 2: _____ % of patients with Alzheimer's disease
- Phase 3: _____ % of patients with Alzheimer's disease
- Phase 4: _____ % of patients with Alzheimer's disease

We want to know what type of care a patient with Alzheimer's disease receives on an average day.

7. Can you complete the table below? We want to know the time (in minutes) you and your colleagues with the same function on average spend on the care for an average patient.

8. Are there differences between weekdays and weekends regarding tasks and time?

- Yes, namely _____
- No

9. Which user materials are used on average per week for caring for an average patient (e.g., incontinence products, wound care, infusions)?

Materials	Phase 1	Phase 2	Phase 3	Phase 4
Incontinence products				
Wound care				
Infusions				
Other materials				
Other materials				
Other materials				
Other materials				
Other materials				

10. What proportion of patients uses medical equipment?

Medical equipment	Phase 1	Phase 2	Phase 3	Phase 4

11 a. Are there tasks you would ideally perform, but cannot do because of, for instance, time pressure?

- Yes, namely _____
- No

11 b. How much extra time would these tasks costs you?

Extra tasks	Phase 1	Phase 2	Phase 3	Phase 4

11 c. Why are you unable to perform these tasks?

12a. Did the corona-pandemic or the associated measures impact the number of hours you spend on care for patients?

- No, the number of hours has not been impacted by the pandemic or the associated measures
- Yes, I've spend **more** hours of care on patients due to the pandemic or the associated measures
- Yes, I've spend **less** hours of care on patients due to the pandemic or the associated measures

If yes:

12b. How is care been affected by the pandemic or the associated measures?
