

QUESTIONNAIRE: Germany

1. Assessment of behavioural disorders

1.1 Please specify the different kinds of behavioural disorders which in your opinion need to be assessed:

We prefer not to call this "behavioural disorders" but "challenging behaviour". The last expression focuses on the interaction between the person with dementia and the carer (or whoever is around and feels challenged). We want to avoid a description of normal behaviour.

Challenging behaviour is everything which could challenge: agitation, aggression, vocalisation, wandering but also apathy. Apathy is important since it often seems to be convenient for carers.

1.2 Describe the most appropriate approach for this assessment:

Especially at home it is very difficult for family members to cope with challenging behaviour of people whom they have been known for their whole life. For family members Alzheimer's disease did not appear at one time point suddenly, but usually enters the daily life step by step. However, even family carers have to find a kind of distance to the person with dementia and try to understand, why the persons behaves as she behaves. This is the most important way of finding any interventions which are for the benefit of the person with dementia. On this way the family caregiver needs professional help.

1.3 Describe the most used measurement / assessment tools for these symptoms:

Most used is probably the CMAI (Cohen Mansfield Agitation Inventory). However, this focuses only agitation and it does not search for reasons of the behaviour. Therefore we developed an instrument which can be used as a pathfinder for these reasons based on a theoretical model (need-driven dementia-compromised behaviour model, NDB). It should be used in interdisciplinary case conferences with everybody who is in contact with the person with dementia. This instrument however until now has only been tested in nursing homes.

2. Types of home care provision provided by professional carers

2.1 Please describe different approaches to supporting and caring for people with dementia who live at home related to behavioural disorders:

There are no special approaches for people with challenging behaviour. However there are different offers of support for people with dementia and for their family caregivers, like

- courses (which could be better used)
- day care groups
- informal, volunteer services

- professional nursing services
- primary medical care.

2.2 Describe the appropriate non-drug treatment or measures used:

There is no single or always appropriate measurement. Understanding the behaviour means for family caregivers sometimes, that they can better bear this behaviour, it might be an important way of expression for the person with dementia.

The non-drug treatment depends on the causes for behaviour, the situation, the persons, the competencies etc. First of all validation should be used with the person of dementia and his perspective in the middle. Also the following measures are used: cognitive stimulation, reminiscence, music-based approaches, multi-sensory stimulation, snoezelen, animal-assisted therapies, aromatherapy, movement activities, behavioural interventions and environmental changes. Crisis intervention might also be necessary.

However, studies have yielded conflicting evidence regarding the effects of these interventions. It is not known in which manner and how often these measurements are used in homecare.

2.3 In what circumstances is residential/institutional (including hospital) care required?

When the situation at home is not any more bearable, when the system breaks down, institutionalisation is better for the person with dementia. This does not only depend on the challenging behaviour, it depends on the caregiver, her strength and competencies, on supporting facilities etc. The production of a new care dependent (the family caregiver) should be avoided. Hospital admission should, if ever possible, be avoided since hospitals are not oriented towards people with dementia and can cause deep confusion in these people, it might initiate harmful challenging behaviour.

Of course in acute situations (e.g. falls with fractures) hospital admissions cannot be avoided.

3. Training programmes / information

3.1 Which kind of information, training and education do exist for people with dementia and their carers?

There are brochures, internet information, courses, hotline telephone, nearly everything. Especially the Alzheimer's Association has a very busy information service. The problem lies more in the question who can take the initiative.

There are informative internet pages, but most caregivers are part of an older generation who is not yet familiar with using the internet.

3.2 Which are the most efficient dissemination tools for sharing information (for targeting the patients / the carers) and why?

Approaching the household with a person with dementia is very important. The usual system with general practitioners who might be the first ones to detect dementia and to hear about challenging behaviour is not enough towards these patients. The families need continuous attendance as a support.

The new care support points in Germany might be important for caregivers who can ask professionals. Many caregivers are hesitating to ask because of shame.

3.3 What training and education programmes do exist for professionals?

There is a new guideline for general practitioners on dementia care, and there is a framework of recommendations for nurses dealing with people with challenging behaviour. These tools are sometimes used for trainings; they are also part of research projects. Continuing education with a psycho-geriatric focus is offered for nurses. These trainings are not standardised, a lot of different ones are offered.