

QUESTIONNAIRE: Finland

To put the assessment and management of behavioural disorders into a broader context of social and health policy and services in Finland, some background information is presented.

The number of inhabitants in Finland is 5.3 million. With an increasing number of older people in Finnish society, the number of people suffering from dementia is bound to increase. The prevalence figures are as follows:

- 4% of persons aged 65-74 years
- 11% of persons aged 75-84 and
- 35% of those aged 85 years or more.

These prevalence figures mean that there're approximately 87,000 persons suffering from at least moderate dementia. In addition, some 30,000 persons suffer from mild dementia. Annually 13,000 people develop some form of dementia.

Table 1. Population forecast in 2007, 2012 and 2020 & the estimated number of persons with at least moderate dementia.

Age groups	2007	2007dem	2012	2012dem	2020	2020dem
0-64	4 422 224		4 376 558		4 270 736	
65-74	462 795	18 512	568 876	22 755	720 478	28 819
75-84	313 920	34 531	328 612	36 147	401 847	44 203
>85	97 958	34 285	122 163	42 757	153 711	53 799
<i>Altogether</i>	<i>5 296 897</i>	<i>87 328</i>	<i>5 396 209</i>	<i>101 659</i>	<i>5 546 772</i>	<i>126 821</i>

The growing number of persons with dementia poses a challenge for Finnish social and health care system. In order to ensure adequate and timely support as well as high-quality services for people with memory diseases, policy and practice guidelines have been launched. The national old age policy is expressed in the National Framework for high-quality and services for older people (http://www.stm.fi/julkaisut/julkaisu/sarja/nayta/_julkaisu/1063089#en) outlines strategies for raising the quality of services for older people in three dimensions: 1) promoting health and welfare and the related service structure, 2) staffing and management, 3) living and care environments. The service system is strongly recommended to be developed with the main emphasis on services that help older people to live permanently at home. The strategies, when implemented, influence in lives of those with dementia and their significant others.

To put the old age policy into the broader context of social and health policy, the National Development Programme for Social Welfare and Health Care 2008–2011 (KASTE) comes into picture by strongly high-lighting the importance of promotive and preventive actions. The KASTE programme is the statutory strategic steering tool of the Ministry of Social Affairs and Health in managing social welfare and healthcare policy. The programme defines the aims and focal development and supervision areas of social welfare and healthcare policy in Finland in 2008–2011, as well as the reforms and legislative projects, guidelines and recommendations in support of the implementation of these. The programme seeks to reduce social exclusion and to enhance the inclusion, wellbeing and health of municipal residents, and also to narrow regional and demographic disparities in health and wellbeing.

When behavioral disorders are discussed two frameworks are worth mentioning:

1. Finnish recommendations for best practices in the treatment of progressive memory disorders (by panel of experts); the main foci of the recommendations are early diagnosis, treatment, and care management of dementia. The assessment, prevention and management of behavioral disorders, are included in recommendations.
2. Diagnosis and pharmacotherapy of Alzheimer's disease – one of the Finnish Current Care guidelines (<http://www.kaypahoito.fi/>); evidence-based guideline including the assessment and management of behavioural disorders.

1. Assessment of behavioural disorders

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

Behavioural and psychological symptoms in dementia (BPSD) are of great importance from the patients', family caregivers and society's point of views. Different kinds of behavioural disorders are common with people with dementia in different stages of the disease. Behavioural symptoms occur especially in moderate or severe stages of the dementing illnesses. Behavioural disorders affect negatively to the quality of life and well-being of both a person with dementia as well as his/her family carer. The disorders cause suffering for the patient himself/herself and severe stress for the family caregivers.

Behavioural disorders increase the usage of social and health care services and they might lead to the need of institutional care. Behavioural disorders and their stressfulness to the family carer are one of the main reasons why home care reaches its end and the need for long-term institutional care occurs.

The Neuropsychiatric Inventory (NPI)¹ is a tool for assessment of psychopathology in patients with dementia and other neuro-psychiatric disorders. This measure names the following 10 neuropsychiatric domains: delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, dis-inhibition, irritability/lability, apathy, aberrant motor activity, night-time behaviour disturbances. These are the most typical ones that need to be assessed. In addition to these, depression needs to be identified and treated appropriately.

¹ Cummings JL, Mega MS, Gray K, Roseberg-Thompson S, Gornbein T: The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology* 1994; 44: 2308-2314.

1.2 Describe the most appropriate approach for this assessment:

It is important to understand the background factors of the behavioural disorders: the physical (neuropathological & neurochemical), psychological and social factors. Thorough assessment is needed in order to identify what symptom(s), how often and in which kind of situations the BPSD do occur. Behavioural disorders should be identified, the causing factors found out and the frequency and severity of the symptoms evaluated. The influence of the BPSD in the family caregiver should also be examined. When aiming at living at home despite the dementia and the BPSD as well as the appropriate management of the BPSD, it's useful to help the family caregiver to find answers to the following questions:

- What happened before the BPSD occurred?
- How did you respond to the BPSD?
- What happened as a result of your action?
- Could you have done something else?

Assessing behavioural disorders is an important part of overall clinical examinations of a patient with dementia; this means taking into account patient's life history, behaviour, mood, cognitive skills, sensory skills and awareness of his/her situation. Beside the clinical examination, the thorough assessment of the BPSD is needed in service needs assessment and in follow-up and evaluation of the effectiveness of the treatments and interventions. The assessment forms the basis for the care and service planning and evaluation of the outcomes.

In evaluating behavioural disorders it is important to use valid and reliable measures of which Neuropsychiatric Inventory (NPI) is an example. The NPI is based on a structured interview with a caregiver who is familiar with the patient. The following 10 neuropsychiatric domains are evaluated: delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy, aberrant motor activity, night-time behaviour disturbances. For each domain a screening question is asked to determine if the behavioural change is present or absent. If the answer is positive the domain is explored at greater depth with the sub-questions. If the sub-questions confirm the screening question, the severity and frequency of the behaviour are determined according to the criteria provided for each domain. Frequency is rated 1 to 4 and severity is scored 1 to 3. The product (severity x frequency) is calculated for each behavioural change present during the previous month or since the last evaluation (eg; in order to evaluate treatment efficacy).

It is necessary to interview both the patient with dementia and his/her family caregiver in order to find out their experiences and emotions in these situations and assess how burdensome family carers find the behavioural disorders. Regular multi-professional follow-up and evaluation are needed in order to find the optimal management method for the BPSD.

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

Beside the NPI – assessment tool, the Cohen-Mansfield Agitation Test (CMAI) is a tool to measure the occurrence of BPSD. In addition to these, the Resident Assessment Instrument (RAI) is used in Finland. The RAI-Home Care is a comprehensive, standardized instrument for evaluating the needs, strengths, and preferences of elderly clients of home care. The RAI-HC has been designed to be compatible with the congressionally mandated Resident Assessment Instrument (RAI) used in nursing homes in the United States and several countries abroad. Such compatibility will promote continuity of care through a “seamless” geriatric assessment system

across multiple health care settings, and will promote a person - centred evaluation in contradiction to a site-specific assessment. One focus in the RAI evaluation protocol is behaviour.

In addition to these, the depression needs to be identified using well-validated tools like Cornell depression scale or Geriatric Depression Scale (GDS).

The municipalities – decision makers and professionals - are guided by the means of information guidance such as recommendations and guide books, to use valid and reliable measures when assessing the needs of persons with dementia and BPSD. Beside using the valid and reliable tools it's of utmost importance to listen to the person with dementia and his/her family caregiver. Observation and interviews offer a good base for planning the support and services needed in each case.

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:

Of the 87,000 persons with at least moderate dementia approximately half live at home and the other half in service housing units and institutions. Half of those living at home, live alone.

Services targeted to people with memory disorders aim to support them in their daily activities, to improve their opportunities for social integration and to ensure appropriate nursing and care. The most important service forms include home-help and home nursing services, support for informal care, service housing, institutional care and health services. The Finnish social and health care system is visualized in figure 1.

Figure 1. The health and social services available for persons with memory disorders.

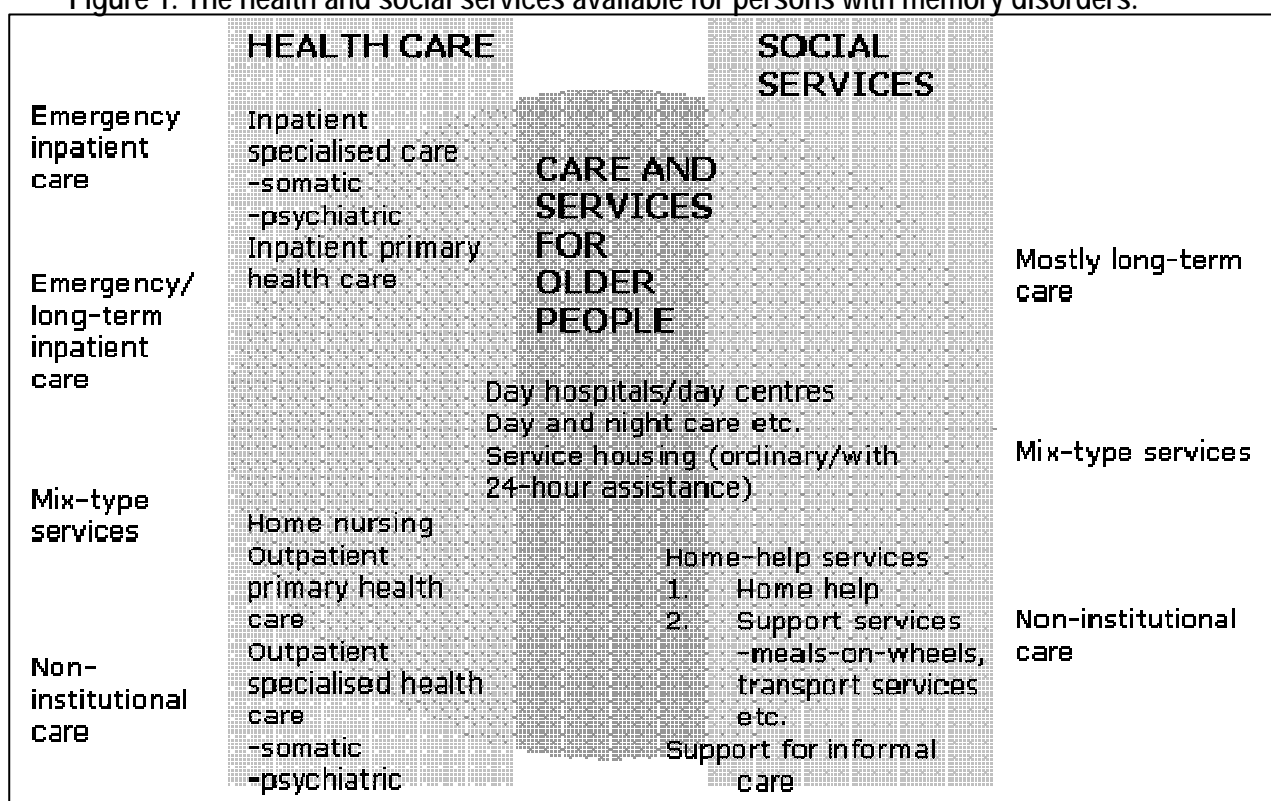


Table 2. demonstrates the number of persons with diagnosis of a dementing disease in different service forms.

Table 2. The clients with dementia (diagnosed) in social and health services in 1999, 2001, 2003 and 2005. (Number & %).

	1999 N	2001 N	2003 N	2005 N	Change 1999- 2005/ Number	Change %
Regular home care	4 683	5 264	6 601	6 809	2 126	45,4
Sheltered housing	2 138	1 325	1 695	1 599	-539	-25,2
Residential homes (such as group homes for clients with dementia)	9 034	11 205	12 737	15 004	5 970	66,1
Health centre hospital ward, short-term	1 654	1 904	2 181	1 869	215	13,0
Health centre hospital ward, long-term	5 871	5 841	5 733	6 487	616	10,5
Specialized health care	621	670	712	722	101	16,3
<i>Altogether</i>	<i>24 001</i>	<i>26 208</i>	<i>29 659</i>	<i>32 490</i>	<i>8 498</i>	<i>35,4</i>

Behavioural disorders cause many challenges and problems in everyday life. They are one of the main reasons why family carers become stressed and burdened and home care ends. So, in order to support home care it is of importance to examine the causes of behavioural disorders. This helps to prevent disorders and find out the appropriate care/manage. In prevention and management, thorough and holistic assessment and individually tailored measures are needed.

The most important issue is to understand the many-sided effects of a dementing disease to the patient and his/her family carer. The loss of skills and other cognitive changes caused by the disease cause frustration and effect on the identity and feelings of a patient. This might lead to depression and apathy. Supporting patient with dementia and family carers and providing appropriate information and individual psychological support as well following the situation of family carers are important factors in home care.

After diagnosis, a person and his/her family carers need appropriate information of the disease, care, services, benefits, rights etc. There is a need for psychological support at the early stage of the disease. This kind of support is needed in order to help to deal with the emotions and thoughts caused by the disease and changed life-situation. Supporting a patient and his/her family is a process: it is important that information with appropriate content is given at the right time. The information is needed in order to help to patient and his/her family to be prepared for the future and to plan their everyday life.

An efficient model to support home care was developed in a project launched by the Central Union for the Welfare of the Aged. The model is based on an intervention study and the effectiveness, incl. cost-effectiveness, of the intervention has been shown. The main pillars of the model are as follows:

- Focus on the family instead of separate individuals
- Focus on the everyday life of the family
- Focus on the strengths and resources instead of the deficits and problems
- Be culturally sensitive
- Collaborate and respect the family autonomy
- Be flexibility in all actions.

Support, services and care are needed on a continuous basis because of the progressive nature of the memory diseases that influence in everyday life of those with dementia and their family members in numerous ways. Early diagnostics, examinations and care at memory clinics, counselling, support and adaptation training, rehabilitative working methods (based on resources) used by home care professionals are important points in care and service continuum. It is also important that all service and care providers have clear responsibilities in care and that there is a good coordination (care management). There should be a named professional for the family (care manager). The care manager manages the overall situation of the family by coordinating the different modes of support and services into an individually tailored home care 'package'.

To summarise: Good home care for persons with BPSD is proactive. It is based on a comprehensive assessment of the client's and his/her family caregivers' functional capacity, coping strategies and other resources, and reacts rapidly to changes in their health and capabilities. Good home care promotes rehabilitation and responds to the client's physical, cognitive, mental and social rehabilitation needs. A 'rehabilitative approach' means encouraging and helping clients to use their remaining personal resources in their everyday life. Rehabilitation helping the persons with BPSD to live at home emphasizes community and outpatient services such as forms of rehabilitation that can be given at home.

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

The main aim is to prevent behavioural disorders. It is possible to prevent disorders by good medical care, by supporting activation and by safe and respecting interaction and by taking into account the environmental factors. It is important to take account other diseases, pain and medication and general health factors like nutrition and sleep. In preventing behavioural disorders, knowledge on dementing diseases and their typical progression and symptoms is needed. To know the disease and its cognitive symptoms helps to understand the patients' behaviour and non-verbal and verbal communication.

It is important to recognise the situations in which disorders occur and identify factors, which cause disorders, evaluate the situations on a holistic basis and find appropriate methods. Understanding the situation from the patient's point of view, identifying the background factors and finding the appropriate methods, follow-up their use and documentation of their effects are all belonging to the process of taking care of behavioural disorders. It is important to understand the background of these symptoms: physical, psychological and environmental factors. To have understanding of the background and causing factors helps to meet the symptoms and behaviour in a reasonable way. Knowledge helps to form right attitude towards these disorders.

Analysing the situations in which behavioural symptoms occur is essential. To understand the events and feelings that might cause these symptoms, to follow the course of symptoms and to analyse what happens after the situation. The environmental factors should always to be taken into account (physical environment as well as psychosocial environment). After analysing the situation it is necessary to find individually tailored ways to take care of the situation.

Psychosocial methods, improvements in interaction and environment as well as guidance and support can be used. Factors in interaction and right attitude are important. Respecting and supporting a patient and to support his/her identity and autonomy are basic principles in good interaction. To support autonomy, identity and agency as well as raising positive experiences and feelings of success helps to maintain feelings of self-respect of a patient. It is essential to show genuine interest in patient's situation, to meet his/her emotions and try to understand his/her experiences and emotions.

Knowing the patient is the basis of good dementia care. It is important to know his/her personality, life course, attitudes and values, the level of functional capacity and resources as well as those things that are important to him. This background information helps to understand the patient and his/her behaviour. This information helps to find individual meaning behind behavioural symptoms and words. The many-sided knowledge of a person helps to find appropriate ways to create safe, respecting and supporting atmosphere in interaction.

An essential part is supporting and giving guidance to family carers. It includes discussing about the symptoms and their meaning to the patient and family. This means teaching family carers to use different methods in order to activate a patient and support his/her physical functional capacity. Family carer's are taught to use problem-solving skills. It is always important to evaluate the resources of a family carer and to take care of his/her possible depression. On method in giving guidance and support is dementia counselling. It contains informational, practical and psychosocial support. Individual discussions, which are based on the needs of family carer, peer-support groups as well as appropriate and immediate help in crisis situations, are efficient ways to support family carer's resources.

Individually meaningful activities are to be used. This means structured and well-planned activities that reflect individual's tastes and background. Activities are based on the information of one's life-course and evaluation of functional capacity. Therefore it is important to identify the skills that is left as well as those, which are already lost or weakened. In situations activities are used it is essential to give space and possibilities. Activities that meet the skills and interests of a person are useful. Activities encourage normalisation, support orientation, provide stimulation, encourage using use remaining activities, enabling the feelings of success and develop feelings of self-esteem and dignity. To avoid the situations in which it is difficult for the patient to manage (causing frustration and further lead to behavioural symptoms).

The psychosocial methods and rehabilitative approach are useful. The aim in using these methods is to maintain psychosocial capacity, to strengthen self-esteem, to use interaction, which supports and strengthens feelings of safety. They enhance the feeling of continuity. In the early stages support in adaptation is important. This is provided by counselling and adaptation-training courses in which it is possible to deal with one's emotions and thoughts and to learn more about the effects of the disease. All this helps to find realistic attitude to one's life situation.

Reminiscence therapy helps a patient with dementia to maintain identity and to find positive things in life. Recreational activities are important and empower patient with dementia. Therapeutically targeted methods like music therapy, aromatherapy, art etc. are useful. Validation therapy, snoezelen, aromatherapy, light, massage etc. have positive effects. They give positive experiences.

Behavioural therapies might be useful. To analyse what has happened before the symptom, what happens in the situation behavioural disorder occurs and what kind of emotions does the patient have and what happens afterwards. To identify the triggering factors and to pay attention in the situation itself are important.

Environmental factors should be taken into account. This means both physical environment and psychosocial safety and atmosphere. The important factors in physical environment are cosiness, safety, orientation, and familiarity. It is important that there are regular and familiar actions in everyday life, which support feelings of safety.

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

In situations when the safety of a patient is threatened (especially if patient is living alone) and when the family carer is suffering from stress or is severely burdened. In crisis situations e.g. if the family carer is severely stressed. The immediate assessment of the situation and rapid action are necessary.

3. Training programmes / information

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

Sharing information with a person with dementia disease and his/her family carer is a challenging task, because coping with the disease is always an individual process and the needs are always individual. It is important that the information is given timely and the content of the given information meets the individual needs and the information is given on an appropriate level. All this means that there is a challenge to understand the needs of a patient and family carer in question. The challenge will be met by holistic evaluation of the situation, resources and functional capacity of the patient and the family carer. Guidance and support should be given on a continuous basis, because the needs and situations change by the progress of the disease. Guidance, counselling and psychosocial support are central forms of rehabilitative approach and they are needed throughout the process.

'First hand' information courses are provided e.g. in many hospital districts (specialized health care) in co-operation with NGO's, or NGO's together with municipalities arrange these courses or NGO's provide them by themselves. In these courses information and support are provided in order to help the patients and families to understand the changes related to the disease, to organise daily life so that it supports the preservation of functional capacity and coping. Typically first-hand information courses are provided in a form of a 'training day', which includes information on the dementing diseases and different kinds of services and support available.

The municipalities - together with NGO's - offer adaptation training. Adaptation training courses are provided in e.g. rehabilitation centres, and these courses are mainly aimed at patients under 65 years of age. Adaptation training for persons with memory disease aged 65 years or more is arranged mainly by NGO's. The courses concentrate on a rehabilitative approach and are aimed at patients and family carers together. Courses offer information, different kinds of therapies (e.g. physiotherapy), as well as psychosocial support and peer support. The aim of adaptation training is to support functional abilities and strengthen coping and resources and help the patient and family carer to understand their situation realistically. These courses support the quality of life and help families to manage risks and cope with the new situations as the disease progresses.

The provision of first-hand information and adaptation training courses is, however, inadequate.

Both individual and group counselling are offered in Finland. Counselling is offered e.g. in hospitals after the diagnostic phase and counselling is provided by memory co-ordinators or counsellors working in municipalities. Both memory co-ordinators and counsellors provide telephone counselling and home visits to evaluate the situation. The aim of counselling is to support the patient and his/her family carer in coping with the disease. Counselling is mainly information on the memory disease and treatment - based on individual needs of the person with memory disease and his/her family member - but also social and emotional support, and services.

There is a lot of information available for the patients and their family members: brochures, guide books, telephone help lines, e-mail info, etc. Many of the Alzheimer's/memory NGO's produce this information with support received from the Slot Machine Association (<http://www.ray.fi/inenglish/index.php>).

Lots of books and brochures on memory disorders and dementia diseases have been published in recent years. Professionals also give information in public lectures.

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

Sharing information is challenging, and information is disseminated using the different media.

In addition to the above-mentioned brochures, guide books, telephone lines, e-mail info, web sites do exist. Peer support ('Sharing the Caring') for the family carers is arranged and it's considered very useful.

NGO's play a key role in this area.

3.3 What training and education programmes do exist for professionals?

Basic training on dementing diseases, assessment and treatment, is offered in vocational training for licensed practical nurses in nursing institutes. The registered nurses graduate from the universities of applied sciences, which offer the basic training on this very theme. However, there's a lot of room for improvement in the field, since there's variation in the education measured in credit points and contents in different institutions and universities of applied sciences. The education system should be developed to take into account the growing number of patients with memory diseases.

NGO'S in Finland are active in providing in-service training for professional working with patients with memory disturbances. E.g. the Society for Memory Disorders Expertise in Finland provides expertise studies for Memory Disorders Coordinator (10 credits points). There's also a programme for Specialist Education (Diploma education 30 credit points) organized by the Society for Memory Disorders Expertise.

Also the public authorities of education provide in-service training for professionals. E.g. the Jyväskylä, Pohjois-Karjala and Satakunta Universities of Applied Sciences provide professionals with a possibility for a course named 'Development of Dementia Care' (30 cp's). Shorter courses and seminars are arranged widely by many actors in the field.

When BPSD is discussed, the above mentioned programmes are worth mentioning and of importance. What comes to the basic education of licensed practical nurses, RN's or physicians, the assessment and management of BPSD is not adequate. In-service training is needed for professionals in the field.