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Panel of experts set up by the Finnish Alzheimer's Disease Research Society:
Jaana Suhonen, Kari Alhainen, Ulla Eloniemi-Sulkava, Pirjo Juhela, Kati Juva, Minna Löppönen, Markku Makkonen, Matti Mäkelä, Tuula Pirttilä, Kaisu Pitkälä, Anne Remes, Raimo Sulkava, Petteri Viramo, Timo Erkinjuntti

Finnish recommendations for best practices in the treatment of progressive memory diseases

- In the next few decades, diseases that occur as the age of the population increases will intensify the need for social and health care services.
- As far as costs are concerned, dementing memory diseases form the most significant disease group. The costs of progressive memory diseases are significant due to the large number of patients and the need for institutional care at later stages of dementia. In addition, patients with memory disease need plenty of tailored social and health care services.
- Even a small change in the therapeutic practice may significantly reduce the costs of treatment and improve the patient's quality of life.
- Centralising tasks to skilled memory units will reduce the need for resources in other social and health care units.
- Successful treatment requires a seamless and personalised chain of care that allows systematic monitoring and appropriately scheduled implementation of measures to help patients and their relatives to cope. A memory coordinator will facilitate a successful chain of care in the outpatient setting.
- The Finnish Alzheimer's Disease Research Society invited a panel of Finnish experts to draw up recommendations for the main aspects of good care in patients with memory disease. These recommendations should be implemented by setting up regional chains of care. The recommendations are meant for all those working with patients with memory disorders and for Finnish decision-makers.
- The recommendations describe the chain of care of memory disorders as a progressive process from diagnosis to severe disease. The recommendations consist of primary statements concerning good care that together form a continuous chain of care.

Based on population studies, it is estimated that there are 85 000 patients with moderately severe or severe dementia and 35 000 patients with mild dementia in Finland (1). According to various studies, the prevalence of dementia among people aged 65 to 69 is 0.8-1.5% and among people over 85 this increases to 35% (2,3,4). Every year, more than 13 000 Finnish people fall ill with some kind of dementing disease (1). At the end of 2005, slightly more than 25 400 patients received basic reimbursement for Alzheimer medicines (5). This would suggest that most patients with Alzheimer's disease have not undergone sufficient examinations to diagnose the memory disease. In the oldest age groups particularly, such diseases are insufficiently diagnosed (6).

In Finland, 6% of the 51.8 thousand million euros spent in total on social and health care in 2004 was used for the treatment of memory diseases. The annual immediate cost per patient with dementia has been estimated at about 24 000 euros, and the total annual cost of the treatment of dementia in Finland exceeds 3 thousand million euros. Most of these costs (85%) are related to institutional care, and only about 1% is for the purposes of diagnostic examinations (2). Therapeutic practice affects the costs significantly. If 5% of the patients with memory disease now treated in institutions could be treated in an outpatient setting, annual savings would amount to 66 million euros (2). By optimising outpatient care, the number of institutional beds could be reduced, but how could we obtain the know-how required to arrange good care for patients with memory disease (7)?

The diagnosis of memory diseases in Finland has become more effective in recent years, and memory clinics have been set up (8). However, service chains break down easily. The support of patients with memory disease and their families is often interrupted when diagnostic tests are performed and medication is started (9,10). Municipal service systems are often inflexible and complicated and professionals are hard to reach, particularly in the event of a crisis (11). Families often find changing professionals and a lack of expertise problematic (12). They also feel that insufficient attention is paid to their needs and wishes (10). Modes of treatment, rehabilitation and support for memory disease patients' home care, which have been shown to be effective, are not yet sufficiently implemented in Finland (12). Institutional resources are scant, and facilities for institutional rehabilitation are limited (13).

Non-pharmaceutical and pharmaceutical means can be used to support the well-being of patients with memory problems and their families and to extend the period that patients can live at home. Good, competent care tailored to the needs of patients and their families is worthwhile and

rewarding for both patients and professionals. To succeed, the treatment of patients with memory disease needs to consist of a structurally well-defined, seamless chain of care facilitating the implementation of measures to help both patients and their relatives to cope. In a functional chain of care, a cooperative party with total responsibility for continued treatment and who is known to the patients and their relatives needs to be appointed.

The Finnish Alzheimer's Disease Research Society invited a panel of Finnish experts to draw up recommendations for the main aspects of good care in patients with memory disease. These recommendations should be implemented by setting up regional chains of care. These recommendations describe the chain of care of memory diseases as a progressive process from diagnosis to severe disease. The recommendations consist of statements that form a continuous chain of care of patients with memory problems.

Definitions of terms used in the recommendations

- 'Memory clinic' refers to a multiprofessional health care group specialised in the diagnosis and treatment of memory diseases.
- 'Memory nurse' refers to a health care professional specialised in the treatment of progressive memory diseases. A memory nurse works together with a doctor to recognise, diagnose and treat memory diseases and to provide guidance and follow-up related to such diseases.
- 'Memory coordinator' refers to a social or health care professional specialised in the treatment of progressive memory diseases, who is responsible for coordinating the treatment of patients with memory disease, and for predicting and solving, together with the family, any problems arising at various stages of their time at home. The coordinator works together with a doctor.

The essence of good treatment – aiming for continuity of care and high quality of life

Prevention is up to to all of us

Statement 1. It is possible to influence the development of memory diseases. Risk factors for memory diseases should be recognised and treated. Everyone should participate in the treatment of such risk factors.

In extensive population studies, several protective and risk factors related to memory diseases have been recognised. There are important possibilities for primary and secondary prevention of the main risk factors. Factors associated with an increased risk of Alzheimer's disease (AD) that we cannot affect include advanced age, presence of the disease in one's immediate family, being an ApoE e4 allele carrier and having rare genetic defects.

The typical risk factors for memory diseases are largely the same as for arterial diseases (14,15). Factors known to increase the risk of AD include symptomatic and asymptomatic signs of cerebrovascular disease, such as TIA, stroke, silent cerebral infarctions, extensive merging of white matter lesions in brain imaging, high blood pressure, high cholesterol levels and being overweight. Disturbances of glucose metabolism, a poor diet and certain cardiac diseases are also known to increase the risk.

Even though the functional ability of aging people would seem to improve cohort by cohort, an increase in diabetes and being overweight in middle age may be risk factors for dementia as the currently middle-aged cohorts reach the age at which the risk of progressive memory disease increases.

Prevention of memory diseases means good treatment of the risk factors of arterial disease in middle age (16). There are data to suggest that good treatment of high systolic blood pressure as late as in early old age (< 80 years) may still reduce the risk of dementia (17).

Population follow-up studies have shown that physical activity protects against cognitive impairment (18), as do a high level of education and mental activity. Cognitive training improves mental performance in the trained areas. Even though the effect of training will not exceed the limits of various cognitive areas, it may persist for as long as five years after training (19,20,21). Socially motivating peer support groups may also improve cognitive performance in the elderly (22).

General mental, physical and social activity, i.e. a way of life providing rehabilitation in many fields, and a healthy diet help to minimise the risk of memory diseases. People should start taking care of their brain health in middle age, at the latest. Occupational and outpatient health services play a central role here, as do public information and the activities of patient organisations. Everyone should work to recognise and treat the risk factors of memory diseases.

Symptoms of memory diseases should be recognised as early as possible

Statement 2. Memory symptoms, dementia and related warning signs should be recognised. When a memory symptom is detected, further examinations should be performed according to the Current Care Guideline.

Symptomatic memory diseases should be recognised at an early stage (Table 1). The patient and his/her relatives should be told how the memory symptom will be examined. When memory symptoms are detected, further examinations should be performed according to the Current Care Guideline for the diagnosis and pharmacotherapy of Alzheimer's disease (23). A memory symptom does not represent a definite diagnosis and should not cause the patient to be stigmatised; there may be other reasons for it apart from a progressive memory disease. The prognosis of a memory disorder cannot be estimated based on a memory symptom alone. Current scientific evidence on the advantages of population-level screening for memory diseases is contradictory (24,25). At this stage, the panel of experts does not recommend general population-level screening for memory symptoms. However, targeted memory screening may be used for patient groups at risk of memory disease, such as home nursing patients. A physician will perform basic examinations of the memory symptom in the outpatient setting, and further examinations will be performed at a memory clinic.

How to make a diagnosis, and what happens then?

Statement 3. The reason for memory symptoms should be investigated according to the Current Care Guideline.

The Current Care Guideline for the diagnosis and pharmacotherapy of Alzheimer's disease states that the reason for any memory symptoms expressed by a patient must be examined (23). Clinical interview and examination form the cornerstones of diagnosis. The symptoms of memory diseases affect many areas and, along with basic examinations, one should use established scales to assess disease-related changes in cognitive performance, mental condition, behaviour and daily coping (Table 2) (23). When examining cognitive performance capacity, the traditional MMSE is not sufficiently sensitive to detect early changes. The cognitive CERAD test battery that can be administered by a trained memory nurse, for example, is more suitable for the first stages of assessment (26). The Finnish normal values for various CERAD tasks were recently published in the Finnish Medical Journal (27). Laboratory tests are performed to investigate both aetiological

and aggravating factors. Brain imaging should be performed for all those suspected of having a progressive memory disease (23).

Basic examinations help to detect the most common treatable memory disorders and secondary causes of memory disorders and to identify patients requiring special examinations (Table 3). Progressive memory symptoms are usually due to a progressive memory disease causing extensive deterioration of memory and information processing (dementia). If the reason for the disturbing memory symptoms remains unclear, the patient should be followed up until the diagnosis can be confirmed.

The diagnosis and organisation of treatment of memory patients should be concentrated in memory clinics

Statement 4. The diagnosis of memory diseases and organisation of care should be arranged as local services concentrated in a specialised multiprofessional memory clinic. In the event of problems, a primary health care memory clinic may consult a specialist in memory diseases at, for example, a specialised secondary care memory clinic. The division of work and responsibilities for basic and further examinations and further care of memory patients should be agreed within regional chains of care.

Continuity is the first prerequisite for good care. Patients and their relatives must know who is responsible for care and whom to contact with any problems. Regional care recommendations should define the division of work and responsibilities for basic and further examinations and further care. This should be recorded in the regional chain of care of memory patients. Fluent communication between various players in the chain can prevent breakdown of the chain at its various points. Figure 1 shows the chain of care of a patient with Alzheimer's disease.

In public health care, examinations of memory patients have mainly been conducted in a specialised care setting at outpatient neurology or geriatrics departments. However, such examinations can be organised in primary health care if the necessary know-how is available in this setting (8). The panel of experts recommends that basic examinations of memory patients should be performed at a health centre and further diagnostic examinations should be provided as local services concentrated in a specialised multiprofessional memory clinic or by an equivalent service provider.

According to a Finnish study, memory clinic services can be provided locally when there is a population of at least 20 000 (8). To be functional, a local memory clinic requires sufficient personnel and research resources and premises. The working group at a memory clinic should include at least the following: a physician with expertise in the examination and treatment of memory disorders, a memory nurse and memory coordinator, and a social worker. The tasks of the memory clinic and the multiprofessional group working there are listed in Table 4. A training programme leading to special competence in memory diseases would ensure the acquisition of professional know-how.

It is estimated that one memory coordinator would be required for a population of 10 000 where 15% are over 65 years old (28). A memory coordinator should optimally be responsible for about 50 to 60 families at a time. In small communities, one person can take care of the tasks of both memory coordinator and memory nurse (Table 4). Members of the working group should have appropriate training and experience in the examination and treatment of patients with memory disease. The physician should be familiar with the clinical pictures of the main memory diseases, be capable of interpreting the results of patient assessment by various methods and should plan any further measures required. The memory clinic should have the necessary facilities for diagnostic examinations according to the Current Care Guideline for the diagnosis and pharmacotherapy of Alzheimer's disease (Table 2) (23).

Regardless of where the disease was diagnosed and the first treatment and rehabilitation plan was made, it must be ensured that when the patient is referred from one health care unit to another, the information required for further treatment is also given. The memory coordinator shall make sure that the patient and his/her family understand the practical aspects of the individual treatment and service plan at a local level. Local social and health care shall arrange further care and regular follow-up of memory patients (at intervals of 6 to 12 months), preferably at a local memory clinic, either as a service provided by themselves or by others. If this is not possible, the memory clinic should at least take care of the further treatment of the difficult cases of dementia.

In the treatment of patients with memory disease, the strengths of the patient's own health centre include familiarity with local issues, a family view and a holistic approach to treatment (29). The local memory clinic works as a consultation centre for the patient's own doctor, health care personnel, family caregivers and dementia care units in the area. In primary health care, physicians in particular working in home nursing, on inpatient wards or in nursing homes have a high level of

knowledge about working with elderly people. This special know-how should be utilised when further developing the treatment of patients with memory disease in cooperation with the local memory clinic.

However, special diagnostic problems related to memory diseases and the treatment of severe behavioural symptoms should be concentrated in a specialised secondary care memory clinic serving a sufficiently large population. The need for consultation depends on clinical diagnostic and therapeutic needs and should not be restricted by age. Table 5 presents situations where it is normally necessary to consult a neurologist, geriatrician, psychiatrist or psychogeriatrist specialised in memory diseases. In addition to diagnosis and consultation, a memory clinic in secondary care or at another special level should provide continuous training and guidance for regional memory clinics in primary health care. Special examinations of patients with memory symptoms in specialised care are presented in Table 3.

The function of the chain of care of patients with memory disease should be assessed regularly. Its function can be assessed by, for example, measures of reliability of operation and service ability, of quality and efficacy of medical or nursing services and, in particular, by real-time measures of service quality as experienced by patients and relatives, such as customer feedback and customer satisfaction surveys.

The diagnosis of memory disease should be explained to patients and relatives

Statement 5. The diagnosis of memory disease should be explained to both patients and their relatives. The person making the diagnosis is responsible for providing early guidance and giving advice and first information.

Physicians find it hard to tell patients about a dementing disease. This also affects the recognition of symptoms and attempts to find out their causes. The reason for this is often a lack of knowledge of the realistic possibilities of the current treatment of memory diseases. The Finnish Act on the Status and Rights of Patients prescribes that all patients have the right to be informed of the state of their health, of the meaning of treatment, treatment alternatives and other aspects related to treatment that are of significance when deciding on treatment (Act on the Status and Rights of Patients, 17.8.1992/785, www.finlex.fi). Only a diagnosis and appropriate information on the disease will

give patients and relatives the chance to structure the present, plan their future with the disease and participate in making decisions on treatment.

Telling the patient about the diagnosis is a personal event, and the ability of different people to handle difficult issues varies. The diagnosis of a memory disease should be communicated in terms understandable for both the patient and his/her relative, and separate discussions should be held with the patient and the relative, as necessary. Particularly at an early stage of memory disease, it is important to make clear that even though the patient has a progressive brain disease, there are plenty of possibilities for treatment and rehabilitation. In the first instance, it is important to impart the name of the disease and the fact that the symptoms originate from the brain, and to explain about the realistic possibilities for treatment and about the prognosis of the disease. Written information in simplified language should be available. The memory nurse should repeat the main points and act as a support person during the crisis related to the diagnosis (9).

Wherever diagnoses are made, primary informative courses should be offered for patients and relatives. Informative support will help patients and carers to understand and face the needs related to the disease, to organise daily life so as to support the preservation of functional ability, prevent behavioural symptoms and help relatives to cope. At the time of diagnosis the aim should be for the patient to move from the chaos experienced due to uncertainty to a feeling of being in control of his/her life and the ability to live with the severe disease.

After diagnosis, a care and rehabilitation plan should be written

Statement 6. A realistic proactive care and rehabilitation plan should be drawn up together with the patient and his/her relative. The main elements of good care are appropriate medical treatment, suitable rehabilitation, the necessary supportive measures, and regular planned follow-up and support.

When the diagnosis has been made, an individual care and rehabilitation plan should be drawn up together with each patient and his/her relative, and the need for benefits should be defined. The plan should be checked regularly at intervals of 6 to 12 months at the centre responsible for the patient's treatment. Whenever a patient moves from one care unit to another, the appropriateness of the care and rehabilitation plan should be checked at the new unit.

The main aims of care are to predict changes and manage risks, to maintain a good quality of life, and to extend the period that patients can stay at home. Predicting changes and managing risks help the patient to cope with new situations as the disease progresses. All this must be based on a realistic prognosis, recognising the possibility of an abnormal course of disease. When planning the future, one should prepare for crises by expressing the patient's own wishes in the form of an ordinary or living will and organising a supportive network. A good quality of life involves preserving the patient's personal way of life and background, maintaining social dignity and network and ensuring autonomy. The period the patient lives at home can be extended through medical treatment, rehabilitation and support for everyday life, as well as financial and psychosocial support. The person responsible for the treatment should make sure that every possibility is utilised, with consideration for the patient's and family's wishes and needs.

Rehabilitation is insufficiently utilised in the treatment of patients with memory disease. The aims and means of rehabilitation will vary at various stages of disease. The effectiveness of actual cognitive rehabilitation has not been clearly defined but cognitive stimulation would seem to be helpful even in moderately severe dementia (30). It improves cognitive performance capacity and mood, reduces behavioural symptoms and improves the quality of life. Any active physical exercise would seem to improve cognitive performance, communicative ability, mood and functional capacity at every stage of dementia, including severe Alzheimer's disease (31,32,33,34). Occupational therapeutic guidance improves daily coping and reduces behavioural symptoms (35). Patients with Alzheimer's disease tend to lose weight as the disease progresses. This leads to muscle wasting, decreased ability to move, and increased susceptibility to inflammation. Therefore, in the rehabilitation plan special attention should be paid at every stage of the disease to nutritious food (36).

When supporting home care, best results are achieved by combining various forms of care, rehabilitation and support (37,38,39,40). Care and follow-up should be planned, proactive and continuous. An important aim of proactivity is to recognise crises and, particularly, risks of placement in institutional care (Table 6). Patients with mild disease need activities to give them social contact. Organisation of such activity is challenging and requires extensive cooperation between organisations for caregivers and patients and the public sector.

The memory coordinator ensures outpatient care of patients with memory disease

Statement 7. When monitoring outpatient care of patients with memory disease, the implementation of individual care and rehabilitation plans requires, in addition to special know-how of the treatment of memory diseases, good knowledge of available services and cooperation with patients and their families. Regular follow-up of care should be reserved for memory coordinators specialised in memory diseases working in cooperation with a health centre physician, home nursing or memory clinic physician also specialised in memory diseases.

After diagnosis, a patient with progressive memory disease is usually transferred from a memory clinic to follow-up by primary health care in consultation with the memory clinic, as necessary. Such transfer should occur with emphasis on the continuity of care. Treatment of memory diseases requires special knowledge and team work. When monitoring the care of a patient with memory disease, implementation of the individual rehabilitation and service plan requires good knowledge of the available services. Regular follow-up of outpatient care and tailoring of services should be reserved for a memory coordinator specialised in memory diseases and working with patients, their families and a physician working for a health centre, memory clinic or home nursing and specialised in memory diseases. The memory coordinator forms a network with memory nurses in the region. In a Finnish nationwide inquiry covering spouse caregivers of patients with Alzheimer's disease only two out of five assessed the follow-up of the spouse's care as well organised (8,9). For the chain of care to further improve the current and future lives of patients and their relatives, cooperation between various parties should be significantly improved (8,9).

There is strong scientific evidence for the efficacy of the work of memory coordinators (9,12,34,38,39,41). In all these randomised controlled studies, help provided by a memory coordinator made it possible to extend the period dementia patients lived at home. In most cases, the coordinator worked in cooperation with a physician specialised in memory diseases, often a geriatrician.

The idea behind the work of a memory coordinator was to support patients with memory disease and their families and to tailor various forms of support for the needs, wishes and changing situations of the families. In some studies, peer group activity was organised for family caregivers. In a Finnish randomised controlled study, multifactorial intervention, which was based on a coordinator-doctor team and peer groups, delayed institutional care, improved targeting of services

and saved social and health care costs (12). The coordinator had 63 families to support. At any given time, 15 to 20 families required plenty of support and help and the others were at a calmer stage of disease. The savings achieved by the group during two years amounted to 500 000 euros. The idea was that each family knew who bore the responsibility with them and who could be contacted. The coordinator had a very independent job and his/her own budget facilitating flexible arrangement of services for the families even in the event of crisis. The main operating principle was to fulfil the needs of the families, meaning, for example, significant investment in home physiotherapy, cleaning services and hiring of temporary caregivers. In spite of this, half of the savings in the study came from the use of outpatient services compared with reference families (12).

In Finland, the functional model with a memory coordinator would be worth implementing even in middle-sized municipalities because even in municipalities with as few as 10 000 inhabitants, of whom about 15% are over 65, there will be a sufficient number of outpatients with memory disease for one full-time memory coordinator. Patients needing support will be at various stages of disease. The memory coordinator should keep regular contact with them to become familiar with them at an early stage of the disease (Table 4). It is most important to support the whole family and normal life, to act as an interpreter between patients with memory disease, their families and the service system, to listen to needs and wishes, and to really believe that people are the experts of their own daily lives (12). Physiotherapy (42,43,44), guidance by an occupational therapist (45), short rehabilitative courses of treatment (periods of 24-hour treatment and day treatment) and the know-how of social workers should be utilised to support the family and to tailor services.

Symptomatic pharmacotherapy of progressive memory diseases needs to be monitored

Statement 8. Symptomatic pharmacotherapy of Alzheimer's disease and Parkinson's disease dementia are important parts of the holistic treatment of patients with memory problems. The implementation of pharmacotherapy and the patient's response to it should be regularly monitored.

Symptomatic medication forms a part of the holistic treatment of AD and Parkinson's disease dementia (PDD). There is scientific evidence of the efficacy of symptomatic medication in other dementing diseases as well (vascular dementias and dementia with Lewy bodies) (46,47), but these are not approved indications of the medication and are not reimbursed by the Social Insurance

Institution of Finland. Before starting the treatment, it is important to discuss with the patient and his/her relative the realistic aims of pharmacotherapy (48).

Acetylcholine esterase inhibitors are recommended as the first-line pharmacotherapy of AD (23). In moderately severe or severe AD, treatment may be started with memantine. Memantine is often used as additional medication at more severe stages of AD. Rivastigmine is recommended for the treatment of PDD (49). When pharmacotherapy is started, the first follow-up visit should be scheduled at 2 to 3 months to check the tolerability and suitable dosage of the medication. At that stage, the therapeutic response cannot yet be assessed. The next follow-up visit should take place after six months of treatment, and at that stage tolerability and efficacy of the medication and, in particular, any stabilisation of the patient's condition should be assessed. Unless particular problems occur, the therapeutic response should be assessed every 6 to 12 months. The primary aim of pharmacotherapy is to maintain the patient's cognitive performance capacity and independence, to stabilise his/her condition and to alleviate behavioural symptoms. Pharmacotherapy should be continued for as long as it is useful (23). In Finland, Alzheimer medicines are often used for a very short time. As the efficacy of these medicines has been shown at every stage of AD, the optimal period of treatment would be close to 10 years. In Canada, for example, these medicines are used for longer periods than in Finland (50).

Special know-how is needed to predict and treat behavioural symptoms

Statement 9. All professionals meeting patients with memory problems should be familiar with the behavioural symptoms associated with memory diseases.

By behavioural symptoms in patients with memory problems we mean symptoms related to the patient's mental state or behaviour that are not directly associated with impaired cognitive abilities. Behavioural symptoms include, for example, depression, anxiety and agitation, sleep-wake cycle disorders, inappropriate behaviour and psychotic symptoms such as paranoidism, delusions and hallucinations. Behavioural symptoms are most common in moderately severe dementia but may occur at any stage of the disease (40). Behavioural symptoms are the main reason for the institutionalisation of patients with dementia (51,52).

Behavioural symptoms can often be prevented and treated by a competent approach and good treatment of the memory disease. Alzheimer medicines clearly reduce the prevalence of behavioural

symptoms and alleviate them (23). Actual psychopharmaceuticals can also be used, as necessary. However, care should be taken when using these because patients with memory problems are sensitive to adverse drug effects (23). Non-pharmaceutical treatments may also alleviate behavioural symptoms (53,54). Competent pharmacotherapy and development of suitable non-pharmaceutical treatments require good knowledge of memory diseases, behavioural symptoms and pharmaceutical treatment.

As behavioural symptoms often occur when the patient with memory disease is somatically ill or in a strange environment such as hospital, it is important for all units and professionals working with these patients to recognise behavioural symptoms and either to be able to treat them appropriately or to arrange appropriate consultations. It is important to try to avoid interventions and medication that may increase behavioural symptoms in these patients.

The treatment of challenging behavioural symptoms should be reserved for memory clinics and psychogeriatric units with knowledge of how to predict behavioural symptoms and the ability and resources to react to crises.

In institutional care, special know-how related to dealing with patients with behavioural symptoms should be available. Both the training and attitudes of the personnel are important here. All units treating patients with dementia must master non-pharmaceutical treatment of behavioural symptoms, and all units must be able to treat patients with behavioural symptoms.

Holistic treatment of somatic diseases in patients with memory disease is worthwhile

Statement 10. Patients with memory problems are often elderly people with multiple diseases. Good, holistic somatic treatment to ensure a good cognitive and general functional capacity is worthwhile.

Most patients with memory problems are elderly people with multiple diseases. According to population studies, Finnish patients over 65 with dementia have an average of 5 to 8 diagnosed comorbidities (29,55,56). In addition, patients with dementia are less likely to undergo diagnostic examinations: 66% of dementia patients and 45% of age-matched individuals without dementia had one or more undiagnosed somatic diseases, and many took unsuitable medication, such as anticholinergic or sedative drugs (57). Patients with dementia and high cholesterol, iron deficiency

anaemia, coronary artery disease, hypertension or stroke were particularly likely to be left untreated. Leaving comorbidities untreated is not acceptable even in the case of patients with memory disease.

A high level of comorbidity and, particularly, states of confusion related to acute disease have been found to accelerate the impairment of cognitive skills in patients with AD (58,59,60). In addition, many individual comorbidities may act as secondary factors, impairing cognition in patients with memory symptoms (23). These should therefore be systematically screened for and treated. Patients with memory disease often suffer from depression that may often be a significant cause of impaired functional ability. The diagnosis and effective treatment of depression have been shown to be worthwhile (61). In the worst-case scenario, a stroke may make the remaining functional capacity in a patient with memory disease break down (62). Secondary stroke prevention has been found to be defective in patients with memory disease (56,63,64,65).

In patients with memory disease, falls and resulting severe injuries, particularly hip fractures, present a significant risk of institutional placement. Patients with AD have a seven-fold risk of hip fracture (66). Multifactorial prevention of falls and fractures by, for example, calcium and vitamin D supplementation, the use of hip protectors and increasing physical exercise is well justified, particularly in patients with memory disease. These patients also benefit from rehabilitation after hip fracture. Intensified geriatric rehabilitation of two or three weeks produces good results, particularly in patients with moderately severe dementia. It promotes quicker recovery, shortens periods of hospital treatment and may significantly delay long-term institutional care (67).

In patients with memory disease, pain is often insufficiently treated (68). Untreated pain may in these patients lead to excessive use of sedatives, with inherent risks (25). Appropriate treatment of pain alleviates suffering in patients with memory disease, improves their functional ability and makes care easier (69).

Multiple drug therapy is often used to treat memory disease patients with multiple diseases. It is a challenging task to be responsible for the entirety of pharmaceutical treatment (48). Sedatives, antipsychotics and strongly anticholinergic drugs are problematic and widely used (29,70,71).

Supervision of interests, a living will and an assessment of the patient's right to drive are part of proactive treatment

Statement 11. All those caring for patients with memory disease should pay attention to the need for supervising the patient's interests and seek to ensure that the patient will, even in future, be treated as he/she would wish (by means of a living will).

In the course of progressive memory diseases, the patient's ability to make decisions and think rationally become impaired. As such abilities decline, society attempts to protect the person from action against his/her true interests. On the other hand, a person's sovereignty and autonomy are emphasised. A person should be allowed to decide on issues concerning him-/herself and his/her property, as far as he/she is capable of understanding their significance and consequences (72).

Early in the course of progressive memory diseases, decisions often need to be made on the patient's ability to drive. Physicians are obliged to report to the police anyone no longer fulfilling the criteria for driving ability. A memory disorder or diagnosis of Alzheimer's disease as such is not a sufficient reason for denying permission to drive, but clear problems with concentration and executive functions will prevent driving (73). A driving test, car handling test or neuropsychological examination may be used to assess driving ability.

Financial and other affairs can usually be managed by power of attorney or as otherwise agreed without appointing an official trustee. However, if the patient's financial interests are at risk and cannot be guaranteed by any other means, a trustee will be needed. This need is usually most apparent in moderately severe dementia and, particularly, in situations where the patient actively tries to manage his/her affairs but no longer masters them as he/she should. Doctors and other people involved in care must make sure that the patient's affairs are managed in his/her best interests and take action to have a trustee appointed, as necessary (74). Financial actions can even be cancelled by means of legal proceedings if one of the parties can be stated to have been incapable of understanding the meaning of legal action or has been pressurised or prompted. An action of annulment of a will can be presented only after the person's death (75).

As symptoms progress, positions need to be adopted on therapeutic procedures, choice of place of care and possible refusal of treatment. If the patient is incapable of understanding the significance of the issue, his/her relatives will be heard to find out how he/she, when still healthy, would have

wanted to be treated. The doctor must act in the patient's best interests and according to his/her assumed wishes (72). Planning and assessment of treatment will be easier if the patient has expressed his/her living will when still healthy. The Alzheimer Society in Finland has published a living will form (in Finnish and in Swedish) providing the possibility of expressing one's wishes relating to general care, participation in studies, and terminal care (www.alzheimer.fi). A physician has to observe the patient's living will. According to recently updated legislation, a person may, when healthy, authorise another person to observe his/her interests (www.finlex.fi/fi/laki/ajantasa/2007/20070648). Such authorisation will come into force when the person who has fallen ill can no longer decide on his/her matters. Patients with dementia are particularly susceptible to exploitation and even physical abuse by their relatives and by care personnel. Recognition of this fact and taking measures against it pose great challenges for social and health care (76).

Memory diseases occur in people of working age

Statement 12. The special needs of people of working age with memory problems should be taken into consideration.

The spectrum of memory diseases in people of working age differs somewhat from that of the elderly. Diseases affecting the frontal lobes, in particular, are more common. In addition, progressive memory diseases beginning before the age of 65 years are more often hereditary. In working age, falling ill usually causes more severe social and mental multiplicative effects for both the patient and his/her family than at a later age. The spouse is often working and is far from oriented to working as a family caregiver. There may be children at home who are under age and need support. Special treatment facilities are needed for relatively young dementia patients, where due consideration is given to their age and related cultural and social factors. The daily rhythm, furniture, clothing and music should make even a younger long-term patient feel at home. For this group of patients, it is particularly important to take sexuality into consideration, even in institutional care (77).

24-hour care of dementia patients requires special know-how

Statement 13. Most old people receiving 24-hour care have dementia. The personnel in institutions providing such care always needs to have expertise in memory diseases. The number of personnel and the size of the premises should be appropriate.

Of people living in institutions providing long-term care, 80-85% have dementia, usually due to a progressive memory disease (78,79). Studies have shown that the most common factors predicting the end of living at home are behavioural symptoms and living alone, strain on the family caregiver and other factors related to the family caregiving relationship, as well as defective functioning of the care and service system (Table 6).

Even long-term care must be based on exact aetiological diagnosis. Geriatric know-how is a cornerstone of therapy, facilitating optimal functional capacity and reducing the risk of behavioural symptoms (7,23,80). However, in daily dealings with a patient with memory disease, the role of the patient should be kept in the background. From the patient's point of view, it is important that their daily life is normal, that people deal with each other like adults do, and that they can participate in activities at every stage of the disease (81,82). A sense of humour, ability to feel and enjoy the moment, and sexuality as well, remain as the memory disease progresses. The possibilities provided by these should be utilised in treatment. Further improvement of interactive skills in particular, forms a challenge for the personnel.

Since the proportion of patients with memory problems among all institutional patients is significant, special know-how of the treatment of memory diseases is required at every level of institutional care, not only in dementia units. Table 7 lists factors contributing to the good institutional care of patients with memory problems. A shift from disease orientation to human orientation emphasises behaviour that is meaningful from the patient's point of view. Good treatment up to the last stages of the disease requires an ability to put one's heart and soul into the patient's experiences and to understand his/her needs (83). Another important challenge is to understand the patient's behaviour against the background of cognitive changes.

In addition to the memory disease and other somatic problems, various practices, attitudes and wrong modes of interaction may prevent patients with memory disease from coping (81). The care team needs to be able to predict and prevent behavioural symptoms. Cooperation with a

multiprofessional team is often needed to take care of a dementia patient with behavioural symptoms.

Psychosocial means should be used primarily to help patients with behavioural symptoms. Any pharmaceutical treatment should be used only in addition to non-pharmaceutical treatment. The need to continue psychopharmaceutical treatment should be reevaluated at least every three months (23). Modes of restraint such as physical or chemical restraint should normally not be used, because they increase the risk of death, for example (82). If restraint is required, permission must be obtained from a physician, and the patient must be constantly monitored by the personnel.

Passifying treatment may quickly impair a demented person's ability to walk and other functional performance capacity. Physical rehabilitation should be offered even for patients with advanced dementia, because it affects their physical performance capacity (45), alleviates behavioural symptoms (42) and may even preserve their cognitive performance capacity (43).

In the treatment of patients with dementia, their relatives are significant cooperative partners. They may help professionals to understand the background of the patient's behaviour and to find means of psychosocial treatment. A person with memory disease is not the property of the place of care. Relatives and, more particularly, spouses should not be considered as visitors only. In this special situation, couples have two homes where their life together continues. In the place of care, they need to have the opportunity to be alone together and require the discretion of others in order to get positive experiences out of the continuity and normality of their relationship as a couple (11).

The special features of institutionalised patients of working age with memory disease should be considered when choosing the place of care. In group homes, for example, the generation gap may often reduce the inhabitants' comfort. Terminal care should be arranged at the same place where the patient underwent long-term care. A home hospital may help with the arrangements, as necessary.

Short-term 24-hour care should be arranged in units for patients with memory disease, where the health care personnel has expertise in memory diseases and resources are sufficient. Periods of treatment must not be merely conservative or impair the patients' condition but they must be rehabilitating and help patients to cope. A specialised dementia unit needs to bear the responsibility for continued home care, cooperation with the patients' relatives, and acknowledgement of the

relatives' need for support, and must be able to deal with risk factors threatening the ability to live at home, such as behavioural symptoms or impaired walking ability (28).

Private and third sectors also provide services required by patients with memory disease

Statement 14. In addition to municipal services, services provided by private and third sectors in cooperation with the public sector can also be utilised in the treatment of patients with memory disease.

Some patients will see a private doctor or attend a private memory clinic for initial diagnostic or further examinations. These patients must also have access to municipal services, such as the services of a memory coordinator. Private doctors are responsible for guiding their patients and informing them about public health care. Public health care bears the responsibility for further follow-up and treatment. A part of the chain of care, such as diagnostic and care services, can be purchased. However, even in this case the public sector will bear the responsibility for supervising the services. Communication between various units should be self-explanatory.

The third sector has a significant role in the chain of care of patients with memory problems. Associations of relatives and patients, in particular, have an important role in supporting patients and their relatives. They also provide various services (memory guidance, day activity, support groups) that are largely publicly financed either by municipalities or by Finland's Slot Machine Association (RAY). Nevertheless, provision of peer support for relatives and patients may be the most significant service provided by associations of relatives and patients. Steering relatives and patients towards associations intended for them and provision of information on their activities are essential parts of rehabilitation and treatment after diagnosis. So far, such associations have mainly been for relatives but in future there will be a need for organisation among patients with memory disease.

Finally

Progressive memory diseases present a significant challenge at a national level. Within the next decade, the costs of memory diseases in Finland are predicted to increase by 24% if the current modes of treatment are used (2). Savings can be achieved by diagnosing memory diseases as early as possible. A patient with a diagnosed memory disease who is being followed up is cheapest and a

patient with undiagnosed dementia is most expensive for society (84). Diagnosis accounts for only a tiny fraction, 1%, of the total costs. Health economic analyses also emphasise early diagnosis and initiation of treatment because an undiagnosed, untreated progressive memory disease also increases the costs of treating concomitant diseases.

Appropriate holistic treatment of patients with memory disease may delay the need for institutional care. For successful treatment, a seamless chain of care is needed both between specialised and primary health care and within primary health care, as are individual care and rehabilitation plans that are updated regularly. A functional chain of care of patients with memory disease can also improve the cost-efficacy of care. In this respect, regional care of memory diseases clearly needs to be made more effective in Finland. Centralising tasks to skilled local memory units will reduce the need for resources in other social and health care units.

More effective support to home-dwelling patients with memory disease would be worthwhile. Targeted pharmaceutical treatment combined with non-pharmaceutical treatment, supportive measures and rehabilitation can reduce costs by extending the period of home care. At the same time, this improves the patient's quality of life. Seamless care is facilitated by the work of a memory coordinator. This will reduce the use of services and costs. Therefore, each health centre should have trained memory nurses and a designated memory coordinator.

In the next few years, prevention and outpatient care will be the main trends in the treatment of memory diseases. Here, risk factors for arterial diseases in middle age, the incorporation of diagnostics into professionally skilled primary health care units and earlier initiation of dementia medication should be considered. In addition, attention should be paid to extending the period of home dwelling and increasing home help and financial support to family caregivers, to utilising computer technology and creating a memory coordinator system in the outpatient setting. Further development of rehabilitation and rehabilitative short-term care is also important. Another essential issue is using home-like care instead of traditional institutional care.

The present recommendations describe treatments and modes of rehabilitation related to the chain of care of patients with memory disease that have been shown to be effective, maintain the patient's functional capacity, help the patient to cope at home, and improve the quality of life of both patients and their relatives. Such good therapeutic practices are recommended to form a part of regional chains of care and services for patients with memory disease. Constant development of practices in

the chain of care of patients with memory disease can be used to address the future challenge posed by progressive memory diseases.

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Jaana Suhonen
Head Physician, Docent in Neurology
Jokilaakso Hospital

Kari Alhainen
Chief Neurologist
Muistikeskus
Ulla Eloniemi-Sulkava
Ph.D., Senior Researcher
Central Union for the Welfare of the Aged

Pirjo Juhela
Deputy Chief Physician
HUCH, Department of Psychogeriatrics
Peijas Hospital

Kati Juva
M.D., Neurologist
HUS, Department of Psychiatry

Minna Löppönen
M.D., Health Centre Physician
Härkätie Health Centre

Markku Makkonen
Specialist in General Practice
Hankasalmi Health Centre

Matti Mäkelä
Chief Physician
Vantaa City Department of Social Welfare and Health Care, Special Services for the Elderly and the Disabled

Tuula Pirttilä
Professor of Neurology
University of Kuopio

Kaisu Pitkälä
Professor of General Practice and Primary Health Care
University of Helsinki, Department of General Practice
HUCH, Unit of General Practice

Anne Remes
Docent in Neurology, Clinical Lecturer
University of Oulu, Outpatient Department of Neurology

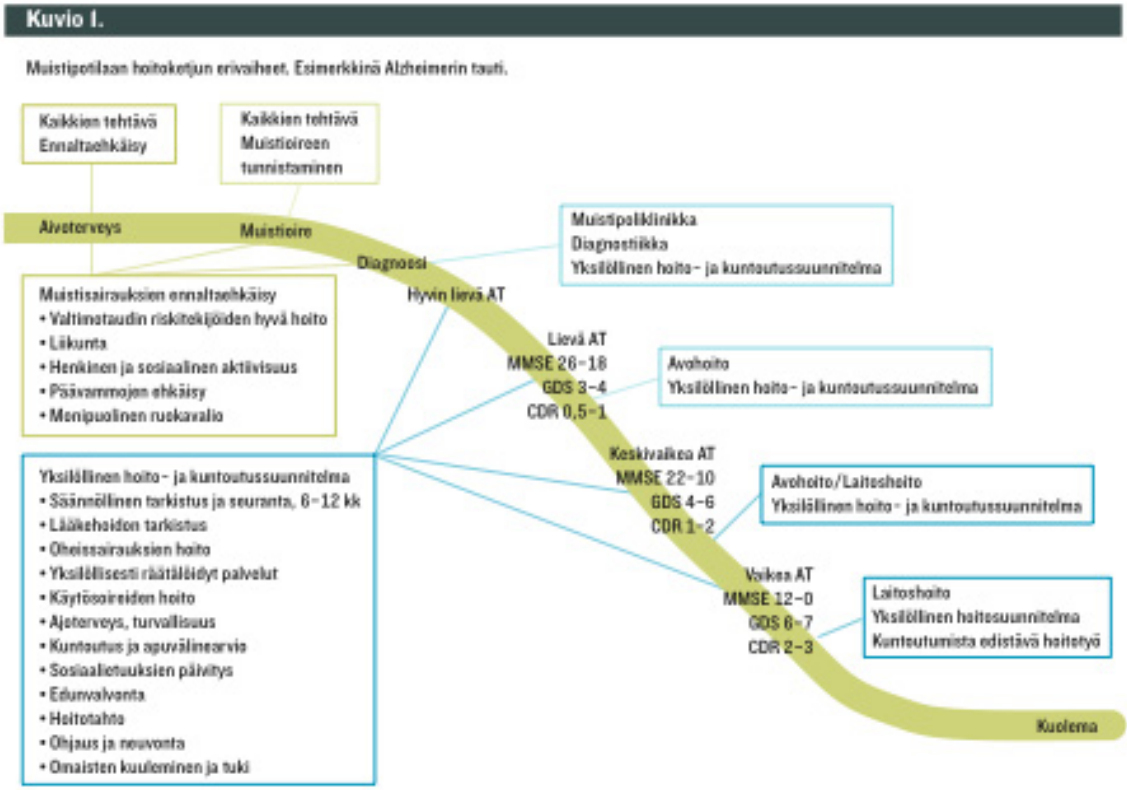
Raimo Sulkava
Professor of Geriatrics
University of Kuopio

Petteri Viramo
Chief Geriatrician
Oulu Deaconess Institute

Timo Erkinjuntti
Professor of Neurology, Chief Physician, Specialist in Neurology and General Practice
University of Helsinki, Department of Neurosciences
HUCH, Department of Neurology

Figure 1.

Stages of the chain of care of a patient with memory disease, with Alzheimer's disease as an example.



Everyone

Prevention

Everyone

Recognition of memory symptoms

Brain health

Memory symptom

Diagnosis

Memory clinic
Diagnostics
Individual care and rehabilitation plan

Prevention of memory diseases

- Good treatment of risk factors of arterial disease
- Physical activity
- Mental and social activity

- Prevention of head injuries
- Varied diet

Very mild AD

Mild AD
MMSE 26-18
GDS 3-4
CDR 0.5-1

Outpatient care
Individual care and rehabilitation plan

Individual care and rehabilitation plan
- Regular check-ups and follow-up, 6-12 months
- Check-up of pharmaceutical treatment
- Treatment of comorbidities
- Individually tailored services
- Treatment of behavioural symptoms
- Driving ability, safety
- Rehabilitation and assessment of aids and appliances
- Updating of social benefits
- Supervision of interests
- Living will
- Guidance and advice
- Listening to and supporting the relatives

Moderately severe AD
MMSE 22-10
GDS 4-6
CDR 1-2

Outpatient/institutional care
Individual care and rehabilitation plan

Severe AD
MMSE 12-0
GDS 6-7
CDR 2-3

Institutional care
Individual care plan
Care promoting rehabilitation

Death

Table 1.

When to suspect a memory disease.

The patient or relatives express their concern about the patient's short-term memory, even though social functional ability would be well preserved

A memory symptom affects work or the performance of daily chores

Forgetting appointments, inappropriate use of health services, difficulty in following instructions for treatment

Difficulty of finding words, or use of inappropriate words

Impaired inference or problem solving capacity

Impaired conceptual thinking, such as difficulty in taking care of financial matters

Losing items, or impaired understanding of how or for what purpose they are used

Mood changes, anxiety and apathy combined with impaired short-term memory

Changed personality, confusion, suspiciousness or fear

Reduced initiative and withdrawal may precede a memory symptom

Table 2.

Means of national memory survey on memory clinic (23).

Memory inquiries

Memory tests: CERAD and MMSE

Daily activities: Tests measuring daily functional capacity: e.g. ADL, IADL, ADCS-ADL

Stage assessment: CDR, GDS-Fast

Behavioural symptoms: NPI

Depression tests: e.g. BASDEC, BECK, GDS, Cornell

Clinical examination

Laboratory tests

Brain imaging

Table 3.

Special examinations of patients with memory disease in specialised health care.

Common special-level examinations	Indications for extensive neuropsychological examination	Cerebrospinal fluid biomarker tests (Ab42, tau)
Extensive neuropsychological examination	Working age	Mild symptoms
Extensive brain MRI	Mild symptoms	Cerebrovascular disease and possible AD
Possible other imaging (angiography, SPECT, PET)	High level of education or training	Depression and possible AD
Cerebrospinal fluid biomarker test	Differential depression diagnostics	Delusion and paranoia and possible AD
Psychiatric examination	Special neuropsychological disturbances	NPH and possible AD
Brain biopsy and neuropathological examination	Assessment of working capacity	Atypical clinical picture
	Atypical features in clinical picture	
	Problematic assessment of legal capacity or ability to drive	

AT = Alzheimer's Disease, NPH = Normal Pressure Hydrocephalus, Ab42 = Amyloid beta 42.

Table 4.

Tasks of local memory clinic and its working group.

Diagnostic examinations of patients with memory symptoms

Writing of individual care, rehabilitation and service plans

Regular follow-up of patients with memory disease

Provision of support to relatives

Prediction, recognition and treatment of behavioural symptoms

Acting as a consultation centre for patients, relatives and professionals in the region

Regional development of the treatment of patients with memory disease in cooperation with other players

Doctor's tasks	Memory nurse's tasks	Memory coordinator's tasks
Diagnostic examinations	Use of various scales based on interview to assess performance capacity, such as intellectual performance capacity, daily activities, mood, stage of memory disease	After diagnosis, regular follow-up of the situation and cooperation with patients and their families
Informing about the diagnosis, and guidance		Total responsibility for supporting home dwelling at various stages of disease
Targeted pharmaceutical treatment of memory disease	Survey of support services	Survey of services and coordination of tailored support measures
Required doctor's certificates		
Writing of references (for rehabilitation, aids and appliances, home nursing, interval care)	Working with the doctor to identify, treat and monitor memory diseases	Prediction and recognition of problems, and coordination of solutions
Preventive measures	Provision of guidance and advice to patients and relatives, and provision of information	Provision of training for the care of dementia patients
Diagnosis and treatment of comorbidities	Responsibility for arranging primary informative courses	Consultation provided to professionals
Total assessment of medication	Provision of training for the care of dementia patients	
Pharmaceutical treatment of behavioural symptoms	Consultation provided to professionals	
Consultation provided to professionals		

Table 5.

Special-level consultation is normally required in the following situations.

Mild symptoms, particularly in a patient with higher education

Atypical features in clinical picture

The reason for memory disease remains unclear at a basic level

Assessment of working ability

As necessary to help in the assessment of ability to drive

As necessary to help in the assessment of legal capacity

Difficult-to-treat behavioural symptoms

Other problematic situations, and the need for consultation observed by primary care physician

Table 6.

Risk factors suggesting need for institutional care in a patient with memory disease.

Factors related to the patient	Factors related to the family caregiver	Psychosocial factors	Factors related to the care and service system
No use of dementia medication	Family caregiver not the spouse	Poor quality of the couple's relationship	Insufficiency of services
Living alone	Experiences of strain	Negative emotional relations within the family	Support not meeting the families' needs
Behavioural symptoms	Care experienced as binding	Poor relations within the family	Unsuccessful short-term care (breakdown of the patient's condition during period of care)
Severity of dementia	Own health problems		Modes of action within the system (bureaucracy and inflexibility)
Difficulties with daily functional capacity			
Difficulty in walking			

Table 7.

Factors involved in good 24-hour care of patients with memory disease.

Sufficient personnel with good knowledge of dementia and good know-how

Doctor as a member of multiprofessional group

Know-how in geriatrics

Operating principles: normality, security, dealing with one another like adults do, and possibility of participating in activities

Good interactive skills of the personnel

Skilful treatment of patients with behavioural symptoms

Taking care of the patient's physical condition, and possibility for physiotherapy

Relatives as cooperative partners

Minimum use of restraint

Meaningful activities and stimulation

Physical environment allowing privacy and participation