MEMORY DISEASE & WORK-LIFE – POSSIBLE TO COMBINE?

A guide to people with early-onset memory disease, their families, work communities and employers
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Early-onset memory disease inevitably weakens the ability to work and unexpectedly interrupts careers. Work experience, skills and the ability to work do not disappear overnight, but can be maintained for a long time in spite of the illness.

"He never particularly worried about getting ill. He grieved leaving his work, but not the illness."
– woman, 59, spouse has memory disease

"The question is, is the person seen as himself or through prejudices. Far too often it is the latter, where old stereotypes about a foolish, silly and even dangerous person mark our views. Due to this, important decisions, such as to do with a person’s working life, are often made based on prejudices and not on facts. Thus we should make such decisions which result in people coping better and longer in their working life; both those who are well and those who have an illness or injury."
– Sirpa Pietikäinen, MEP
ABILITY TO WORK

The ability to function is good when the person feels able to cope well in life and is capable of doing things that bring meaning and joy to life. The ability to work is more closely defined by the requirements of the given tasks and the specific organization. Even if personal resources feel sufficient, the ability to work might be too impaired from the employer’s point of view, if the working efficiency significantly decreases.

The ability to work is not static from day to day and year to year; many factors affect it during a lifelong career. It is not possible to define the ability to work simply as either being able or unable to work. The ability to work need not be 100 percent in order to be able to work either independently or with support.

A person's current ability to work must always be assessed in relation to current tasks, because a person can cope differently with different tasks.

The ability to work of people with memory disease
Memory disease itself does not cause disability to work but the symptoms caused by it may be a reason for retirement. The symptoms are so varied and unique that the diagnosis itself cannot yet determine the chances of continuing to work. Thus, the ability to work must always be evaluated before the decision regarding continued work can be made.

The effects of memory disease on the ability to function and to work are undoubtedly serious, but many of the challenges can actively be reduced and lowered.
There are up to 10,000 people under 65 with memory disease, most typically Alzheimer’s disease, in Finland. There are several diagnoses, and each of them has slightly unique symptoms and progression. What they all have in common is that over time they increasingly affect everyday life.

Memory disease most commonly begins to show symptoms at retirement age. The risk of developing the disease increases with age, so the majority of the people with early-onset memory disease, who are still working, are approaching retirement age. However, in rare cases, the disease may start even under the age of 40.

Memory disease progresses individually and sometimes does not require major changes in life until even ten years after the diagnosis.
Memory disease and worklife – possible to combine?

Symptoms of memory disease

Symptoms of memory disease that complicate working may include:

Cognitive symptoms

- Short-term memory impairment
  - Repeated forgetfulness, which hinders working or everyday chores
  - The disappearance of objects and the continuous search for them
- Disruption of attention and concentration
- Difficulties in learning new things
- Impaired communication, such as difficulty finding words
- Difficulties in decision making or problem solving
- Weakened sense of time and place
- Difficulties in using money or telling the time
- Difficulties in understanding the meaning of objects or their operating instructions

Deterioration of fine motor skills

Variations in alertness depending on the time of day and changing from one day to another

Unawareness of illness

Changes in behaviour, psychiatric symptoms

- Anxiety, changes in mood
- Confusion, suspiciousness, fearfulness
- Loss of initiative, withdrawal
- Delusions

Memory disease can also occur as deterioration of the quality of work, slower working pace, increasing length of work days, or as increased sick leave and non-attendances.

The symptoms may lead to the person growing tired very easily, which further worsens the symptoms. In addition, the stress caused by commuting to work, as well as other aspects of life, can make it difficult to work even if the person could still manage the work itself.

Some symptoms may directly inhibit the ability to continue working. With other symptoms it is possible to cope for a longer time if suitable aid and work arrangements are organised well.
Openly ill

Memory disease is a personal journey, which, however, affects all of the loved ones. Thus, it is recommended that the disease is openly known within the workplace.

If the disease is kept secret, it would be a constant struggle to keep it hidden, which may prove to be more stressful than telling others. Keeping a secret may be difficult, but being open about the disease may even help to occasionally forget about it.

At some point the symptoms inevitably start to show, and the uncertainty can be awkward for everyone. Co-workers may interpret unexplained blunders and changed behaviour in ways that lead to discrimination.

The employer has the right to know if an employee has a disease that affects the ability to work. The boss cannot give the needed support and facilitate the work load if the disease is not openly known. Openness makes it possible to build working conditions that take into account the wishes of both the employer and the employee.

It is recommended that the work community be informed of the disease, but only with the consent of the person with the disease. Occupational health care can lead a common discussion on the subject. If the colleagues understand the symptoms of the disease and their effects on the ability to work and on social communication, they can support the employee when needed. At best, the work community treats the person the same way as before the disease, but at the same time understanding the changing needs.

Sadly there are prejudices which the person with the disease often has to fight against. However, the more people openly to talk about their illness, the more disease-related prejudices and fears can be overthrown. Occupational health care and trade unions give support in difficult situations.

Many times forgetfulness at work can be dismissed by saying that I seem to be getting demented. That’s what others jokingly say as well. Their situation is just not as bad as mine...
– man, 62, Alzheimer's disease, working

This is no secret. First I talked to my employer and after that I told about the illness around the workplace coffee table. The fact that I treat my illness openly probably helped others to relate to me. It was obvious that I would tell of the situation – if only because I keep forgetting things. I should be reminded. The girls in the office sometimes phone me to ask if I remember some important issue.
– man, 60, Alzheimer's disease
People with early-onset memory disease have to face retirement earlier than planned. However, the disease does not necessarily mean that the ability to work has been lost, and an immediate disability retirement should not be the only option. Both the employer and the society benefit from a skilled employee, and a competent professional with tacit knowledge should not retire too early.

Especially in the early stages and in cases where the disease is not progressing aggressively, it is possible to continue working with the right kind of support. The continuation of work is planned together with the employee, the employer and occupational health care so that everybody gains and no one is unduly burdened.

I’m at work so far, and I will try to be for as long as they let me. I certainly would not want to quit because of this illness.
– man, 62, Alzheimer’s disease, working

Current practices

At the time of the diagnosis the symptoms have very likely already affected the ability to work for a long time. Often medical examinations are done once the person is already on sick leave.

Only few people with memory disease continue working. Most people have sick leave and then retire right after the diagnosis or even before it. For many this is the only option and many also want to stop working when the disease becomes a burden. However, this does not have to be the case.

Evaluations of rehabilitation needs are not common. However, it is also possible to request a rehabilitation evaluation be made by a professional, such as a physicist or a psychologist, to support the deteriorating ability to work and meet the requirements of your work.

Often there are no alternative modes of action, which is partly the reason for a quick and sometimes unwise termination of work. There is hardly any knowledge or understanding about supporting an employee with memory diseases. For many doctors giving a medical certificate for a decision of retirement is the primary option if not the only choice.

Attitudes matter. It takes courage and will to make changes when it is clear that eventually the person with the disease will be incapable to work anyway. However, everyone is entitled to be treated equally at work, and nobody should be discriminated due to a health condition. Retirement plans should not be made before diagnostic and rehabilitation evaluations have been made.

As early diagnostics and treatment evolve, people with memory disease will have, even in the near future, the possibility to keep working longer and retire in stages according to the individual changes in their ability to work.

I hope that I could cope at work for a couple of years longer. I have to because my pension is still so small that I could never survive on it.
– man, 62, Alzheimer’s disease, working
Possibilities

Work places have a responsibility to undertake reasonable changes in order to help keep the person working despite the disease. “Reasonable” is determined from case to case but there are many possibilities to flexibly adapt the work in ways that are both free of charge and do not require much effort.

Of course not all means are suitable for everyone, won’t work for long and new challenges will come along the way, but it is always worth a try. Sometimes the disease progresses very slowly and the symptoms are very mild for a long time.

Regular contact with occupational health care helps to determine when it is no longer productive or possible to continue working. It is important to take actively part in the planning process together with the boss, a representative of the occupational health care and, if possible, a relative. Ultimately the decision has to be made by the attending neurologist, but at best it is done based on everybody’s view.

Occupational health care assesses the ability to work, plans and proposes measures to improve the ability to work as well as monitors the implementation of the measures selected. It can therefore be a great support when the tasks and environments are being adapted to meet the changing needs of the employee. The boss is responsible for the changes and the entire process, but a representative of the occupational health care (for example an occupational health nurse or an occupational physiotherapist) can visit the workplace and consider the possibilities of adjusting work conditions.

Discussions with occupational health care – as social and health-care professionals in general – are absolutely confidential and subject to professional secrecy, and the occupational health care representative will not tell about anything discussed for example to their customer’s employer.
Continued working is supported by:

**Own desire to continue working**

**The support of the work community and the boss**

**Individual and/or group work counselling, occupational psychologist’s services**

**Good treatment and rehabilitation**
- Medication and its monitoring
- Treatment of other symptoms and illnesses
- Psychosocial support, advice and guidance
  - Identification of service needs (e.g. transport aid, personal assistance)
  - Adaptation training
- Medical and/or occupational rehabilitation
- Physiotherapy, occupational therapy and other therapies

**Help from others**
- A part-time employee to share the tasks, which helps to pass the tacit knowledge on while the person with the disease gradually gives up responsibilities
- A designated support person at work or a personal assistant
  - Help in everyday problems
  - Planning the day together and prioritising the most important tasks every morning
  - Reminding about important things

**Reducing cognitive load**
- Reorganisation of work time and flexibility
  - Part-time work
  - Flexitime
  - The possibility to work from home
  - Reasonable and frequent rest and coffee breaks
  - Partial disability pension
- Reorganisation of responsibilities and working environment
  - Changing and/or reducing responsibilities
  - A peaceful workstation
  - Clarity and functionality of the working environment
  - Notes, reminders and calendars
  - Reducing passwords and unnecessary technology
  - Using familiar tools
  - No unnecessary upgrades or changes to the equipment

**Reducing mental load**
- Support and guidance
- Possibilities to influence own work and its organization
- Reducing work related responsibilities
- Limiting the work to agreed working hours and tasks
  - Recovering from work takes more time, and there should be energy left for relaxing hobbies and family

**Healthy lifestyle**
- Sufficient sleep
- Sports and other hobbies
- A varied diet
- Avoiding alcohol
We discussed lightening my workload but together with my employer we decided to continue things as they are and see how things go. I can do my job but it happens more often that I forget something. Sticky notes are a great help in everyday life. There are plenty of helpful tools, and people without a memory disorder use them too. You shouldn’t be too hard on yourself. Nobody remembers everything. Besides, only few of the things I forget actually cause problems.

– man, 60, Alzheimer’s disease

An individual action plan to maintain the ability to work is drawn up at tripartite discussions between the employee, the employer and the occupational health care:

• **Defining the problems with the ability to work:**
  What are the challenges and how do they affect the person?

• **Defining the desired ability to work:**
  What does the employee want to be capable of? What should an employee be capable of from the employer’s point of view?

• **The choice of measures to be taken:**
  Necessary changes and reorganisation of work, providing support persons and defining the goal — such as the completion of a project or continuing to work until a successor has been selected.

• **Monitoring and evaluation:**
  How often will the situation and agreement be re-evaluated? Who are the ones in charge?

The plan serves as a common agreement and everyone commits to its procedures.
MEMORY DISEASE IN THE WORKPLACE

Challenges

Memory disease leads to disability to work faster in some occupations than in others. An electrician, an air traffic controller, a surgeon, a cabdriver or a pharmaceutical chemist cannot make mistakes in their work, while an artist, a gardener, a cleaner, or even a director with the help of a good assistant can. The greater the freedom the work offers, the easier it is to succeed in it after falling ill. The disease does not necessarily reduce experience and vision, although details may be forgotten or confused.

Humane aspects are important, but it cannot be indefinitely required that the employer retains an employee with non-profitable quality of work. In particular in team work problems in keeping joint agreements, time management and carrying out tasks in a responsible manner can cause additional pressure if the input of one team member affects the common outcome. The current ability to work so that the illness does not cause undue burden to anyone should be considered. If the disease has essentially weakened the ability to work, both the person and the work community may need to work at the upper limits of their power, while others take care of things and supervise the work of the person with the disease. An illness is a crisis of the whole community, and support is needed.

The requirements of a job may be a very big burden to oneself even in an early stage of the disease. Although work can be an important supporting factor for identity and well-being, it can also consume unreasonable amounts of energy when the ability to function is decisively decreased. Many people notice they are making mistakes or they feel that working tires them so much that they do not want to return to the workplace after the diagnosis. The symptoms and changes in ability to function may seem embarrassing, which is why retirement can be a relieving solution already in the early stages.

Sometimes the person does not understand or accept how and to what extent the illness has changed the ability to function. Thus, in order to be able to continue working, awareness of the illness is essential, i.e. how the person perceives the situation and own ability to function. The most dangerous situation is one in which the disease poses risks for occupational safety – for the person with the disease, co-workers or clients – and the person does not see or understand this. Since in this situation it is impossible for the person to assess their ability to work and capabilities, the role of the boss and the doctor is emphasized.
Working is made more difficult by

- Lack of own motivation
- Unawareness of illness and difficulties in accepting impairment of the ability to function
- The progressive nature of the illness and individual changes
- Sensitivity to fatigue and cognitive symptoms
- A long sick leave in the assessment phase
- Negative attitudes from the work community as well as prejudices and lack of information
- Compromising the person’s own and others’ occupational safety
- Work where even the smallest error can have serious consequences
- Failing to keep the required quality and pace of work
- Not having the possibility to customize the job description and hours of work
- Not having anyone at home to help with e.g. morning routines and to cope in general
The objective of rehabilitation is to maintain the ability to function, invest in strengths and to support the continuation of work, a good quality of life and adaptation to the illness. The starting point should be the person’s own needs and desires.

Rehabilitation services support everyone whose ability to work is impaired by illness or injury. An ill employee is entitled to an assessment of his ability to work and rehabilitation needs.

The person with early-onset memory disease is involved through the whole rehabilitation process: from planning to implementation and evaluation. Measures that support rehabilitation are targeted for both the person and the family. Unobstructed environment and positive attitudes towards rehabilitation are at least as important as individual measures themselves.

Rehabilitation package

The rehabilitation has to be based on a rehabilitation plan, which is made at the time of the diagnosis or shortly after and which will be updated regularly or whenever needed. The rehabilitation plan defines the objectives and measures of the rehabilitation, as well as the persons participating in the rehabilitation.

A person with early-onset memory disease is entitled to the following rehabilitation services, according to individual needs:

- **Medical rehabilitation** supports physical and mental ability to function.
- **Vocational rehabilitation** supports the continuation of work or finding a suitable job. Vocational rehabilitation may also mean re-training for a new profession but it is often wise for a person with a progressive disease to stick with the old and familiar and seek to reorganise this to fit the current situation.
- **Social rehabilitation** supports, for example, inclusion and independent living. Continuing to work may in itself be excellent rehabilitation, because it offers brain exercise and social relations that ties the person to an active life.

In addition, self-motivated rehabilitation provides excellent support for rehabilitation, adaptation to the illness and good life quality. Self-motivated rehabilitation means that you build your life in such a way that everyday routines and activity, as well as a healthy lifestyle, support your ability to function and your quality of life.
Employers do not always have sufficient knowledge about early-onset memory disease and its effects on the ability to work, as very few employers encounter them during their career. However, the same rules can be applied when it comes to memory disease as with illnesses in general.

The special features of memory disease include the progressive nature of the illness and the person’s potential inability to judge their ability to function and to work. In this case, the employer’s consistency and firmness benefit both the person and the entire work community. If the ability to work does not meet the requirements even with support and restructuring, the boss should address the situation without delay.

**The boss has an obligation to take the necessary measures:**

- to bring up concerns about the employee’s condition
- to guide the employee to the appropriate assessments
- to seek to restructure the work so that it would correspond the person’s ability to function.
- to maintain a peaceful working environment for all and protect everybody’s well-being
- to identify and eliminate hazards at work
CONTINUING TO WORK AS A SOCIAL QUESTION

Unfortunately memory diseases are not cheap. The disease is costly for the person with the disease, their relatives and society. Some of the so-called indirect costs consist of the loss of the ability to work, and as a result of that, of the permanent, premature disability preventing work. When a productive employee suddenly becomes a pensioner due to an illness, the society loses a valuable worker and taxpayer. In some cases, the spouse of the person with the disease has to, or wishes to, leave the labour market as well in order to support and help at home, which further increases the costs.

Although memory diseases form only a part — albeit a significant one — of all the neurological diseases of working-age people, its importance has to be considered. In the future each employee’s contribution is even more important because of increased pressure to extend work careers as the proportion of the elderly in the population grows and life expectancy increases.

In the long run single experiences of success form a functional model, that makes it easier in the future for people with early-onset memory disease to continue working if they so wish and the disease allows. The demands of the job must in the future change so that they correspond to the resources of the employee, instead of the employee to be flexible towards the ever growing demands of work. This way careers could be extended even more efficiently — and more humanely — than by rising the age of retirement.

The representatives of the European Parliament gave in 2013 a written declaration of the challenges of neurodegenerative diseases, such as memory disorders, at the workplace. Unfortunately it did not get the necessary support. However, discussion about the matter should be continued.

READ MORE
Retirement is possible as soon as the person with memory disease feels like it, the incapability to work notable or the illness burdens the work community too much. Not everyone wants to continue working, and this wish should be respected.

It is only fair to be able to enjoy retirement, spend time with loved ones and have hobbies when the illness has yet not progressed too far. Work days should not be a constant struggle to survive, but everyone should be able to enjoy their work and have time and energy left for leisure time.

However, it is not always easy to give up working. Retirement might have sounded nice when it was a far thought in the future. Instead it might be scary when a person suddenly is forced to retire because of the deteriorating ability to function. Giving up work symbolises giving up many other important aspects of life, which the illness causes more and more.

Giving up work due to an illness is a challenging situation for many, even if they do retire voluntarily. Not many plan retiring “too early”. Staying at home may cause feelings of uselessness as well as depression, anxiety and withdrawing from other social contacts as well.

Work identity is often a big part of self-image, and people have a basic need to fulfil their work role. Many need to figure out who they are when they are no longer teachers, sales persons or CEOs. Work gives the chance to feel successful and develop oneself as well as makes the person an important and productive part of the society. Often work takes up a large portion of time and provides social contacts as well as financial security. The social vacuum and the need to do something have to be filled with something else. Strong psychosocial support in adjusting to the new situation is needed so that the person is not left alone.
A new kind of life

Even though the changes can seem to be hard and unwanted, there can still be positive sides to the new everyday life. Retirement gives the "permission" to let go of the busy everyday life and enjoy the big and small joys of life.

It would be good to find something nice to replace work, such as daily walks, taking care of the home or grandchildren, doing sports and meeting friends for coffee. It is a good idea to keep in touch with former co-workers, depending on their own strength. All kinds of activities are good, but also getting enough rest is more important than earlier.

Life can be actively moulded so that it seems and feels familiar and all the necessary help is close at hand. It is wise to cherish the social safety network, so that the person with memory disease is not left alone in the new situation. New practises can be created in everyday life to help with deteriorating memory.
Memory disease and worklife – possible to combine?

HUMANE TRANSITION – SUCCESS STORIES

Retiring with dignity

My husband was 58 years old when he retired due to memory disease. He was in a high position in an international organization, and liked his work very much.

They noticed at the workplace that there was something wrong but didn’t immediately know how to handle the situation. A concrete turning point was when the company had foreign visitors that had been introduced to my husband. When he met the same guests for the second time on the same day, he introduced himself again. This was a very clear memory lapse and as a result a co-worker had a talk with the boss. The CEO then had a talk with my husband and asked him to go see the occupational health care. He also called me, his wife, and I replied that well that’s good, I will accompany him to the doctor.

I too had noticed a variety of things. The man who had always been really enthusiastic about his work asked me one morning, when leaving for work, that is this how it’s going to be from now on. He was no longer passionate, probably because he saw that he couldn’t cope as well as before. But I thought it was stress or depression.

The neurologist diagnosed memory disease and asked if he’d want to stay home on sick leave right away. I said no.

The possibility of a soft landing

I contacted the CEO of my husband’s company. We agreed on a soft landing so that my husband would continue working for two months and the whole work community would be told about the illness openly. The whole issue was discussed in a very positive manner. The CEO talked about my husband’s long career and accomplishments and said that due to the illness that was diagnosed, my husband would stay home to take care of himself. Colleagues came by to talk to him and to say how sorry they were. Nobody had to guess anymore.

The two months that my husband still worked went as usual. There were no support persons or special arrangements. Although of course co-workers supported him. Also the working hours were flexible and the company wasn’t so strict on other things either. My husband was able to be there and participate, keep his old title and basically his old duties as well. However, everyone at work knew that my husband was not able to work very actively anymore and that he was going to retire.

The CEO handled the situation in a very exemplary manner. He took hold of the situation and made the necessary decisions. Long after his retirement my husband was invited to all company parties and to have a cup of coffee. His co-workers picked him up and brought him back. He was still welcome. I never got a feeling that they wanted to get rid of him. His illness and retirement were managed without prejudice and as humanely as possible.

The need to be needed

After the retirement my husband wrote a book about his field of specialty, encouraged by his CEO. Of course it took long, and he kept calling me at work to ask what button to press on the computer. But he did it and it was immensely important to him. The company even published the book.

It was very difficult for my husband to understand why he could no longer work because he was unaware of his illness. He thought there was nothing really wrong with him. All of the convincing and explaining was my responsibility, as was organizing everything else. No rehabilitation assessment was made. And no rehabilitation was received. Nobody offered us anything, from anywhere. I was very disappointed with that.

My husband was quite lonely during the days. There was nothing to do and he would have welcomed some company. Some kind of a workshop where you could do something useful or even just a place where to meet people and talk would have been great. When I got home from work, my husband was almost angry for not having anything to tell me about his day. Nothing bad happened, nothing nice. That was the worst part about leaving your job, not having any safety net.
Individual choices

My subordinate Aino* was 52 years old when she was diagnosed with Alzheimer’s disease. We had already worked together for three years and continued to work together for one and a half years after her diagnosis. There were altogether more than ten members in our team.

She had had problems with her memory for several years. Aino might ask the same thing many times, which puzzled her colleagues. There were no “big blunders”, just mild absentmindedness. She had been to see a doctor earlier as well, but since she was so young and so youthful, Alzheimer’s disease was not suspected at first.

The neurologist wrote Aino a certificate for disability pension when he made the diagnosis, without finding out what the employer thought about her ability to work. Our work community as well as our occupational health care loudly said “No!” after which the disability pension was withdrawn. Of course the diagnosis was a great shock to both Aino and the whole work community, but it was a common decision that she should continue working. Our team felt that Aino’s input was still needed. Besides, we knew that she could continue working.

Being open helps

Aino told me right away about her diagnosis and I encouraged her to tell our co-workers. I thought that this way Aino would not be alone with her diagnosis. Being open about the situation stopped any possible talk behind her back and guaranteed the support of the work community if needed. Aino told me that one of her colleagues apologised for getting angry with her because she forgot things. Because we talked about the illness openly, Aino did not need to feel anxious about how she can cope nor carry the burden brought by the diagnosis by herself. Knowledge increased understanding. It was very brave of her to tell everyone.

I thought it would have been way too big a change for her to retire immediately after the diagnosis. It felt cruel to think that she should stay home. I wanted to treat my employee the same way I’d want to be treated in the same situation. I also felt that working, feeling useful, social contacts and staying in the work community would keep up her daily rhythm and activeness. For Aino, staying home would have been a hasty and premature solution.

The significance of work community and its support

I am especially proud of our whole work community. Everybody took the situation very well. Aino got a designated support person, who was her close colleague. They both wished for this arrangement and entered it voluntarily.

After the diagnosis we organised a tripartite negotiation, where Aino, her designated support person, me and representatives from our occupation health care and human resources unit took part. We made many arrangements in order to help Aino continue working. Her work day and week were shortened, her workstation remained the same and she was given tasks where the same routines were repeated and strengthened.

Retirement was eventually a natural decision, because it was clear – also for Aino herself – from the beginning that she could not keep on working for years. By the end there were clearer problems with coping and Aino clearly had to try harder. Her problem solution ability deteriorated clearly which could be seen in situations where everything was not routine. Unfortunately she had used all of her energy on work and had none left for leisure time. The tiredness also led to sick leaves. The final decision was made by Aino herself, her support person, me, a representative from our human resources and occupational health care. This was a decision none of us could have made alone. Also the work community had their say in the matter.

From the employer’s point of view it must be remembered that early retirement is extremely expensive. This, however, was not our only motivation. We wanted to deal with the situation the best way possible for all participants.

* Aino’s name changed
MORE INFORMATION ABOUT MEMORY AND MEMORY DISEASES:

www.muistiliitto.fi/en

WORK ON YOUR MEMORY