## English excerpt

## DEMENTIA

## EVERYTHING YOU SHOULD KNOW ABOUT DEMENTIA AND HOW IT CAN BE PREVENTED (Demens - Alt du bør vite om demenssykdommer og hvordan de kan forhindres)

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**Translation supported by NORLA**

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**FOREWORD**

The brain is our most important organ. It controls what happens in the rest of our body. Even though it makes up only 2 percent of the body’s weight, the brain uses 20 percent of the body’s energy. Blood transports energy to the brain, but apart from that, everything that goes in or out of the brain is carefully regulated. Sometimes, the system fails. The brain can receive too little energy, or it can be exposed to substances that are harmful to it, or waste products can remain there. When this happens, our memory can fail, we can become disoriented, and we absorb less of what is happening around us. This is called cognitive impairment.

We will all experience some kind of cognitive impairment when we are older, but when a cognitive impairment is greater than the age of a person would otherwise indicate, thus impacting how they function in everyday life, it can be a sign of dementia.

 Dementia can be caused by a number of different illnesses. What they all have in common is that the careful regulation of the brain’s energy use and the disposal of waste materials becomes disturbed. An old brain is particularly vulnerable to these types of disturbances. This is why dementia is a condition that first and foremost affects the elderly.

 The fact that we are living longer is one of the great triumphs of society, but with old age comes a higher chance of contracting dementia. Currently, around 100,000 people in Norway have dementia, and this number will rise to nearly 240,000 in the next thirty years. A corresponding rise can also be found in the rest of the world. This is probably the greatest health challenge we are faced with.

Nowadays, dementia is on everyone’s lips, and it is mentioned daily in the media. This wasn’t the case 20 years ago. Back then, dementia wasn’t a societal talking point. These days, however, politicians and other decision-makers are showing interest. They outdo each other in their attempts to underline how important it is, but concrete ideas and new ways of thinking remain non-existent. This is a shame, because now is the time for us to start planning how to cope with almost 140,000 additional people with dementia in 2050, or to work towards lowering that number. The search for a treatment that can at the very least delay the illness must continue. We have to find new methods of giving people with dementia the help and care they need. Last but not least, we need to work out how the public health measures of today can decrease the risk of us contracting dementia in the future. This book is a contribution to that last point – how we can prevent dementia.

Dementia is the most important part of my working life. I am a doctor and specialist in psychiatry, and I have always been interested in a broader approach to people than the purely scientific. Working with dementia offers the opportunity to combine different professional disciplines and to bring in perspectives from both the humanities and social sciences. Dementia is a group of illnesses that belongs to a number of professional disciplines. Dementia is undoubtedly an organic disorder, but it can also be placed clinically within geriatrics and neurology as well as within psychiatry. Even though dementia is caused by medical illnesses that impact the brain, the symptoms are often psychological or linguistic, and societal perspectives are always central.

 I have worked in the field of dementia for over 20 years. The work switches between research, teaching students, and meeting people with dementia and their relatives in the clinic. Through my work in the Norwegian National Centre for Ageing and Health, I get the chance to influence processes, both nationally and regionally, that lead to real-life results and ideas. I feel privileged to do this work, and I enjoy it very much. The variation is a blessing. Each part puts me in a better position to understand the whole. And I find my work with dementia to be deeply meaningful. Now, through writing this book, I have had the opportunity to expand my line of work.

 It was a great challenge to write about a specialised area in a way that everyone would be able to take something from it. Simplifying technical language without being inaccurate is a demanding task. I frequently write scientific articles, but I quickly discovered that more knowledge was required in order to present the material in the way I have presented it in this book. In several chapters, I had to take a step back and read up on the topic at hand before I felt well-equipped enough to create the simplified version. My own personal gain is that this method of working has proven to be both useful and inspiring, even in my other work.

This book is divided into three parts. In the first part, I will explain what dementia is, which illnesses can cause dementia, how dementia diagnoses are carried out, how dementia is different from the normal ageing process, and where we stand in the search for curative treatment. I hope that this part will also provide some insight into how it can be to have dementia.

 In the second part, I will consider the main theme of the book, namely how dementia can be prevented, both by ourselves as individuals and by adjustments in public health measures in wider society. I will describe the connection between individual lifestyle factors and dementia risk, why such a connection exists, and how one can influence this risk.

 In the third and final part, I will gather the threads and present several sides of the story. Prevention of dementia is a positive message, but it also comes with some difficult ethical questions. The road from scientific results to the real world is often long. I hope that whoever is reading this will be left with a multifaceted picture, and that you will find this to be relevant to the world in which you live.

**PART 1**

**CHAPTER 1: SIX STORIES ABOUT DEMENTIA**

It started five-six years ago. Or was it ten years? Fifteen? Brief moments when the world was incomprehensible. Time and place was unrecognisable, like a shapeless jelly.

 His consciousness would fumble for points to grab onto, for hooks of recognition. His gaze would become distant, searching. Then it would pass, and the world was intelligible again. Per had just turned 82. He shrugged his shoulders and thought that this was just what it was like to get old. Those closest to him also thought the same. Nothing to worry about. “That happens to me sometimes as well,” they might say.

 But it got worse. It creeped in slowly, impacting life more and more. The periods in which the world was incomprehensible grew longer. Restoring order grew more demanding. Per noticed that he was asking the same things. Not once, or twice, but more than he could bear to count. His wife and children would comment on this. Often playfully, sometimes with irritation.

 Paying attention became difficult. Where once he took the lead and spoke, he now sat back, withdrawn, observing. Things that happened didn’t stick in his memory. The practical things in life became more cumbersome. He had never been a handyman, but now even simple tasks demanded more time, intense concentration. And yet, the result was bad, and afterwards he was exhausted. Small, simple, banal tasks. It was humiliating.

 Now it started going faster. Per needed help with more. Getting dressed, making food, cleaning. He was scared to be alone. At home and outside. He would get lost even on routes he knew well. Those closest to him were worn out and despairing, and they sometimes lost heart. Even though he experienced these events as hazy, he noticed their frustration. This made him anxious. He was completely dependent on them and the assistants from the local authority. One day, the resources were depleted. His family were exhausted, the assistants from the local authority had run out of what they could offer him, and he felt like he was losing his grip on reality. A nursing home was suggested. Many times. By his family, by the assistants from the local authority. He fought against it, but eventually gave in. On the way, he lost his trust in those closest to him. At times they were enemies, part of a conspiracy.

Karin (65 years old) was not herself. She, who was the most meticulous in the family, who always grumbled over the fact that her husband would wear the same shirt three days in a row, was now utterly indifferent to how she came across. How she dressed, how she acted. She, who cared about almost everything, who felt the unhappiness of others and did something about it, was now cold and unfeeling, hurting those closest to her and random passersby with inappropriate words and actions. Sexualised language and swearing was commonplace.

 She was unrecognisable. The strange thing was that she seemed content with the change. She couldn’t see anything wrong with the way she was behaving. On the contrary, she believed that other people were to blame, that they were the ones who had changed. She found it difficult to get going, but she was able to manage most practical things like she could before. Karin drove a car, had a command of the practical, but didn’t care about speed limits, road signs and lights. She made food, but the same dishes again and again. Not one meal without sweet biscuits.

 Karin was at the end of her working life. The end was painful and humiliating. Tasks were gradually taken away from her, and in the end her employer stopped her from coming to the workplace.

 What was happening here? Everyone – those closest to her, her employer, the health service – tried to search for an answer. Was it a psychiatric illness? A psychosis? Was it a family conflict? Whose version of reality was the right one? When the diagnosis came, the search for answers had been underway for several years.

Ola (79 years old) couldn’t go for walks like he used to. His feet couldn’t keep up with him. He was more unsteady. His steps, once long and confident, were now hesitant and uncertain. It was a loss for him, those long walks in the forest that had been so important in his life now reduced to strolls in his nearby neighbourhood. But this was something he had to live with. Getting old means getting used to loss, he thought. What was worse were the strange episodes that came as though thrown at him. He felt like he was losing his grip, that the world suddenly turned to chaos. He couldn’t follow conversations, got confused about what time of the day it was, and he even had problems recognising members of his own family. And then suddenly, the confusion would pass. The world would fall into place again. It could last for hours, and he couldn’t predict when it would start or end.

 Other strange things happened. Ola saw things that weren’t real. Faces of people he knew, some of them well, could appear as part of a piece of furniture. He could look out of the window and see groups of people approaching, but his wife couldn’t see them. He comforted himself with the fact that the things he was seeing weren’t real, but he still found it frightening. His sleep had gotten worse. Or rather, he would sleep through the night, but wake up feeling exhausted. As such, he would nod off throughout the day. He and his wife had been sleeping in separate rooms for several years because he was such a restless sleeper. He would gesticulate, kick and shout, and his wife felt that it was no longer safe to sleep in the same bed. A shame, he thought, but this was also something he could get used to.

 As time went on, the chaotic episodes became longer and more frequent. The difference between what was real and what was not became unclear. The hallucinations became more frightening. Ola wasn’t able to comfort himself by thinking that it was just his brain playing tricks on him. The worst thing was the ups and downs. He appreciated the periods when he had control, but the fear of the next episode of confusion got worse and worse. The fight to regain control became harder and harder. At the same time, he found it more and more difficult to walk. He was more unsteady, and those life-giving walks outside became shorter and less frequent. He felt depressed. Every day was a greater effort than the last. It was difficult to look forward to the things he had once appreciated, such as spending time with his children and grandchildren.

Three years ago, Mari (81 years old) had an experience that changed her life from one hour to the next. The strength in half of her body disappeared, her face was lopsided, and she felt numb. It was difficult to find the words she wanted to say. The doctor told her that she had had a stroke. He believed that she would be able to get fit again. After the initial shock, it was good to have something to work towards. Mari worked tirelessly. Her strength slowly came back, her face returned to its usual shape, and she could make herself understood. Around a year after the stroke, life was back to how it was before – almost. She was slower to understand things. It took her longer to understand what people meant. It was difficult to pay attention. And she struggled more with practical tasks she could previously do without thinking about. A new mobile phone had to be returned.

 A year later, Mari had another stroke. Smaller than the first. Her face was now only slightly lopsided, and she was a little clumsier when using her hands. Since then, she had experienced a few short episodes where she felt unsteady, unwell and dizzy, but this passed after a few days. What didn’t improve, but rather gradually became worse, was her memory and the slow pace at which she now did everything. She became dependent on lists to remind her of what she had to do each day, and she gradually had to give up several everyday tasks.

Einar was way too young, just turned 47 years old. Nobody considered the possibility. His children went to school. Future plans were made. Life moved onwards and upwards. Then the brakes were put on. Something was wrong. He noticed it at home, at work, out with friends. He couldn’t follow things and had to put in twice the effort to complete tasks, whether it be supervising colleagues, playing with his children or maintaining his role as the centre of his group of friends. The diagnosis was a bolt from the blue, but at the same time a kind of relief. Something to grab onto, something to work with. A project for the whole family. Einar forgot things and had to ask again. He got confused about how old he was, and he wasn’t able to navigate like he could before. Where once he helped, he now needed help. Still, this new life did eventually become manageable. The greatest challenge was that he had an illness that belonged to a different stage of life, a different age group. This impacted the kind of support he received and the kind of help he could be offered. It was frustrating. More frustrating when the illness developed and his needs became greater.

Eline knew she was in the final stages of life, closer to 100 than to 80. She had been active for a long time, but things started getting more difficult after she turned 85. Her sight deteriorated, and glasses didn’t help much. Her hearing became impaired, but she rarely used her hearing aid. Unsteadiness and dizziness made the world smaller, but her walking frame was used reluctantly. There was also a persistent failure of her cognitive skills. Eline couldn’t remember what had happened ten minutes ago, even though she could remember in detail events from her early adult life. She couldn’t find the words she wanted to say. She struggled to recognise faces. It was difficult to concentrate and pay attention, especially if several things were happening at the same time.

 Eline needed more help to keep her house in order, find clothes and plan her shopping.

 She was grateful for a long and mostly good life. She accepted that old age came with loss of skills and functions. It was sad, but she would just have to live with it.

The illnesses that cause dementia are different. The people who contract dementia are different.

 Dementia impacts first and foremost the person who has it and those who are closest to them – their relatives. But in addition to this, dementia is one of the greatest challenges society and the health service are faced with. The most important thing is to ensure that those who have dementia receive the best possible individually tailored support, from early symptoms to the point at which they require twenty-four hour care. After that, society – and that includes each and every one of us – must work towards reducing the chance of dementia. We are expecting a drastic increase in incidents of dementia over the next few decades. By influencing risk factors over the course of our entire lives, we can reduce this increase. This is first and foremost what this book is about.

**CHAPTER 2: WHAT IS COGNITION AND WHAT IS NORMAL?**

Cognition and cognitive impairment are terms that will be used all the way through this book. What does cognition and cognitive impairment mean? And what changes in cognition can we expect as part of the normal ageing process?

Cognition is the brain’s ability to receive, process, store and express information and actions. It can be difficult to understand what this involves. I think it is easiest to illustrate these terms through some examples. There are thick textbooks that have been written about a whole range of cognitive functions. I will shine a spotlight on a few of them. The cognitive functions we most often speak about in relation to ageing and dementia are memory, orientation, attention, language and the ability to plan and carry out an action (executive function).

*Memory* can be divided into several subgroups. We distinguish between remembering something that happened a few hours or days ago (short-term memory) and remembering events from several years ago (long-term memory). Another distinction is between immediate recall, such as remembering a phone number just after you have heard it, and delayed recall, such as remembering the number after ten minutes. With dementia, and particularly with Alzheimer’s disease, it is most often short-term memory or delayed recall that is impaired. You might ask things again and again because you can’t remember the answer you were just given. Procedural memory is the knowledge to carry out an activity which, with time, becomes automatic. It can be cycling, tying your shoelaces or driving a car. The procedures, or skills, can be difficult to learn, but once they have been learned, we carry them out almost automatically, without thinking about it. It is strange to think about how long we struggled to learn to tie our shoelaces as children. Now, we tie our shoes while at the same time effortlessly engaging in conversation. This type of memory deteriorates slowly over the course of the dementia illness. This is also the same for semantic memory, general knowledge, such as the capital of France or the queen of Denmark. A commonly-used memory test is to show picture or word charts, then ask the person to repeat as many words or objects as possible after a few minutes have passed. This is how we can test delayed recall.

*Orientation* can be divided into three sections: time, place and situation. Orientation in time can be tested by asking which year, month, date or day it is. When testing orientation in space, we ask if the person knows where they are and which direction they would have to walk in order to get to a different place. It is common to have problems with orienting oneself in time before orienting oneself in place. The third type of orientation concerns one’s own situation. This is an impairment that arises in the later stages of dementia, and that concerns how one experiences oneself in relation to one’s surroundings. It can, for example, take the form of not realising that it is your own reflection in the window on a dark winter’s night, but rather thinking that it is an intruder.

*Attention* is about being able to focus on something and shift focus between different things. In some contexts, this is called concentration. When someone with dementia can no longer drive a car, it is often a result of impaired attention. This usually happens long before one forgets how to practically drive a car (procedural memory). A common attention test is to ask someone to name the months of the year or the days of the week starting at the end and working backwards. Another test is to ask if they can draw a line from the number one to the first letter of the alphabet and then continue the line, alternating between numbers and letters in ascending order: 1-A-2-B-3-C, etc.

*Language* is complex, and impairment can take many forms. A common distinction is between the ability to express oneself in a way that others can understand, and the ability to understand what others are saying. With dementia, both the ability to express oneself and to understand what others are saying can be impaired. If it is difficult to understand what a person with dementia is saying, then the person in question often struggles just as much to understand what you are saying. That is why it is important to use simple, concrete language when talking to someone who has language difficulties as a result of dementia. With several dementia-related illnesses, particularly Alzheimer’s, an early symptom is that one forgets what things are called. “I know exactly what it’s called, but I can’t find the word.” Later, one can have problems putting words in the right order. In the later stages, language might consist only of word salad, or language disappears completely and the person communicates by sounds alone. Examples of language assessments are asking the person to name a series of objects, or to repeat slightly complicated sentences.

The final cognitive function I wish to discuss is the king or queen of all functions, namely *executive function*. This function underpins all the others and is necessary in order to translate the other cognitive functions into ideas or actions. Executive function encompasses everything from having an idea to translating it into actions or thoughts. It includes the ability to plan, initiate and be flexible. This often happens subconsciously, but with normal executive function we are still able to adapt plans to changes that occur. Sometimes one must stick with and implement the plan one has made, and other times one must change a plan, or slow it down. This can be illustrated by an oft-used executive test which consists of showing a chart on which the names of colours are written: red, yellow, green, blue. However, the words are printed in a colour different to that which the word means, for example the word “red” might be printed in yellow. The task is to say the colour, not the word. Here, one has to slow down the plan or the impulse to say what is written, and facilitate the impulse to say the colour. This is more difficult than it sounds, especially when the test has been going on for a while.

Most of us will find that some of the functions described above will deteriorate as we get older. What is normal? What can be expected as part of the normal ageing process, and what is a sign of illness? It is said that, cognitively speaking, we peak when we are around 25 years old, and from then on it all goes steadily downhill. This is only partly true.

 When we feel that some cognitive functions deteriorate with age, it has roots in reality. Episodic memory, which I have described above as delayed recall, becomes worse when we get older. It is more difficult to remember precisely what happened yesterday or a few days ago, precisely when it happened and in what context it happened. We use reminders more often in order to remember what we have to do. We get worse at remembering names, or naming, as I mentioned above. More and more often we feel that words are on the tip of our tongue, but we can’t get them out. It could be a person we know in passing, or the name of an object we rarely engage with. Some people use strategies to help with this, such as going through the alphabet in order to remember a name when they reach the right letter. H…Harald, that’s it, yes. Short-lived moments of confusion – when one struggles to tidy one’s thoughts – happen more and more often with old age. The confusion is brief and disappears as quickly as it came. The ability to carry out complex or intricate tasks becomes somewhat impaired. This is similar to what I have described above as executive function.

But is it the case that all cognitive function follows an unavoidable downward curve? Is there nothing that stays the same, or that improves, even? Not to worry – our cognitive future is not entirely bleak. Some things do not deteriorate with age until one is extremely old, and in some areas cognition can improve long into old age. The world’s oldest person, Jeanne Calment, was given repeated cognitive tests from when she was 118 years old. Not only were there no signs of dementia, but her cognitive function improved over the course of the test period.

 General knowledge remains stable and can be improved, especially if we have the time to do so. Language is not greatly impacted by normal ageing, and the ability to reflect often improves. Memory or knowledge of one’s own life gets better with age, and there is a lot of research that points to the fact that vague concepts such as wisdom are strengthened when one gets older. A concrete thing that we get better at with old age is solving crosswords.

Sometimes that which appears to be a clear impairment of cognitive function can be more complex if the phenomenon is examined more closely. Most people agree that response time – the time it takes to carry out a simple task – steadily declines after we turn 25. Newer scientific investigations have confirmed this, but research has also been conducted into what lies behind this lengthening of response time that we experience as we grow older. It turns out that it is not first and foremost the brain that reacts more slowly when we get older, but rather that we take fewer chances and think a little longer about things in order to achieve a better result. In addition, our senses and musculoskeletal system work a little slower. It takes a bit longer to transfer visual impressions to the brain, and the finger that pushes the button reacts a little later. Newer studies have shown that, taking these things into account, the difference in brain response time between a twenty-five-year-old and a sixty-year-old is not especially big.

Some of the same changes in cognition that happen as a result of the natural ageing process are similar to the changes that are early symptoms of dementia. This can include problems finding the right word, remembering precisely what happened yesterday, or carrying out complex tasks. In other words, there is no fundamental qualitative difference between what can be experienced as part of the normal ageing process and what happens when one contracts dementia. It is the degree of the symptoms and the extent to which they impact everyday functioning that is decisive, and not least how quickly these changes happen. It is also important to note that dementia is not the only cause of cognitive impairment. Other illnesses and use of medicines could contribute to cognitive impairment without the development of dementia. What about the opposite? Are there things that can improve cognition and slow down the negative effects of ageing? Yes, there are. I will come back to this several times throughout this book.

**CHAPTER 3: WHAT IS DEMENTIA?**

Before, when an older person had poor memory or became confused, we would call it arteriosclerosis or senility. We might still say this, or else we might say that someone has Alzheimer’s. Dementia is connected to both arteriosclerosis, senility and Alzheimer’s. Arteriosclerosis means that the arteries become narrower, which can lead to dementia. Senility simply means that someone is old – over 65 is the usual cut-off point – and dementia is, of course, more common the older one gets. Alzheimer's disease causes dementia. But dementia is also much more than this. Even though Alzheimer's disease is by far the most common cause of dementia, dementia can be caused by more than 300 different illnesses.

In other words, dementia is a generic term used to describe many different conditions, and the definition of dementia is quite simple. There must be a cognitive impairment to one or several areas, the impairment must weaken the skills needed to function in everyday life, and there must be no other explanation for the condition.

 The most common cognitive impairment is poor memory, particularly when it comes to things that have happened recently, but there can also be problems orienting oneself in time, such as knowing what day, month or year it is or how old one is. Some people can have problems finding their way in places they used to know very well. Others can have difficulties finding the right words or have problems with their attention.

The deterioration of everyday functions can include difficulties using tools or technological devices that one previously had command of, or finding that tasks that were once unproblematic have become difficult. Many people think that it is demanding to keep up with the fast pace of technological progress. A new mobile might have functions you neither understand nor feel you have any use for. Buying and selling things online might be difficult to understand. These are challenges experienced by many people who age normally. The deterioration of everyday functions with regards to dementia, however, includes tasks that one previously had command of, but that have now become difficult. It could be that the TV remote we’ve used for years has now become incomprehensible. Tools used for repairs or for making food, which we previously used without thinking about it, now lie there, unused.

 Sometimes, the symptoms that look like dementia can actually be caused by other illnesses. This is particularly true of depression or delirium (acute confusional state), both of which can cause cognitive impairment and deterioration of everyday functions. It is important to rule out these illnesses because both can be cured, unlike dementia.

Nowadays, 101,000 people in Norway have dementia. Dementia is extremely rare before the age of 70, but the older one gets, the higher the chance of contracting it. 5 percent of those aged 70-75 have dementia, but among those over the age of 90, more than half have dementia.

 In the coming years, many more people will contract dementia. In thirty years, in 2050, the number will be more than double, to 236,000. This is most likely the greatest challenge the Norwegian health service is faced with. Many wonder why there will be such a steep increase. Are the higher incidences of dementia a result of how we live, of pollution, stress or infections?

 The explanation is much simpler than that. Many more people will contract dementia because we are living longer. When I soon turn 60 years old, I can expect to live five years longer than my father could when he turned sixty, while my son will have the prospect of living five years longer than me when he turns the same age. In 2060, there will be twice as many people over the age of 70, three times as many people over the age of 80, and five times as many people over the age of 90 if we compare it to today. You don’t need to be good at maths to understand that this will also mean many more people with dementia.

 But even though dementia numbers are rising, the chance of getting dementia on an individual level is actually lower today than it was 20 years ago. The proportion of those with dementia among the elderly is going down. We don’t know for sure why this is the case, but it most likely has to do with changes to the ways in which we live. Those who grow old today have more education and better cardiovascular health than those twenty years ago. This is wonderful news. By influencing the way in which we live, we can perhaps prevent or delay dementia. The main part of this book will deal with exactly that.