

Window 1: Somebody I used to know: A Memoir – a book about new opportunities

“I like to concentrate on what I can do, not what I can’t do, but sometimes we need your help to do this. ... I’m not suffering, I’m living with dementia.”

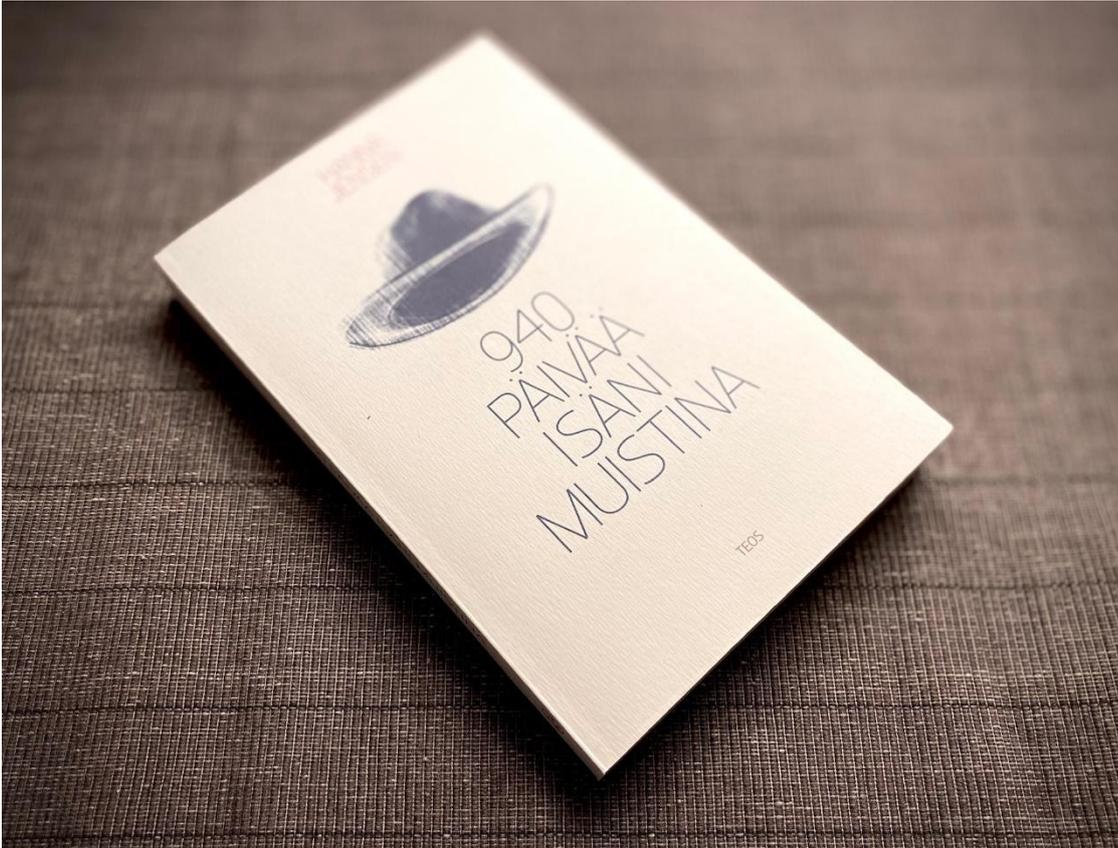
Mitchell, Wendy: Somebody I used to know: A Memoir

In her book, Wendy Mitchell writes about being diagnosed with early onset Alzheimer’s at the age of 58 while she was still working. Her life is inevitably changing, and Wendy discovers a coping method in writing. She sets up a blog with the purpose of writing down her memories. Gradually, the blog gains popularity, and soon Wendy finds herself accepting new challenges. She is invited to speak across England, starts to use social media, and moves from a large city to a small village. Before her diagnosis, she would never have dreamed of doing all these things. She overcomes everyday difficulties with the help of her daughters and her good humour.

With her book and her blog, Wendy Mitchell wishes to increase awareness of not only the everyday challenges of people with dementia but also of the new opportunities available to them. The book evokes plenty of thoughts on how we all could face the challenges that life brings with it: *“Everyone’s Christmas is three Christmases in one: the festivities of the past, present and future. For me, the past has disappeared and the future is too frightening to think about. For me, only the present Christmas remains.”* This paragraph may seem wistful at first but may actually describe a skill that many of us are striving to learn, the ability to stay in the present.

Wendy Mitchell still actively updates her blog, allowing a glimpse into her life in a village in England.

<https://whichmeamitoday.wordpress.com/>



Window 2: 940 days as my father's memory – a book about the surprising nature of dementia

“Under the surface, I started to see the man he was before the world and his parents had the time to influence him, making him into someone different from who he would have been. He often seemed like a boy, because he lacked those gestures, behavioural norms and appearances that adults tend to exhibit. He was free, straightforward, real.”

Jensen, Hanna: 940 päivää isäni muistina (940 days as my father's memory)

Hanna Jensen's book starts with her realising that her father's behaviour has changed. Soon after, her father is diagnosed with Alzheimer's disease which has already reached the moderate stage. The diagnosis of dementia took the author by surprise, and her background in journalism drove her to look for information on the condition. In particular, she wanted to find more about the experiences of the loved ones of people with memory disorders. This inspired her to write a book describing the period of more than three years she spent as her father's carer. In addition to her story, the book gives practical tips on how to care for a person with dementia and other advice to support informal carers.

The book is an authentic description of the progress of her father's illness and the challenges it brings to daily life, which are familiar to many who have been in the same position. The author also describes her own insights and her way of adapting to the new situation. The underlying thread throughout the whole book is the author's intent to see and treat her father with respect, as himself, despite the changes caused by his dementia. *“I learned that trying to pull a person with a memory disorder into the world of us healthy people is pointless. They only act illogically from our perspective, not from their own. They should not be put in a situation where they have to be ashamed of their inability to remember. I stopped asking my father: ‘Do you remember?’”*



Window 3: Restaurant of Mistaken Orders – a documentary film about the importance of a dementia friendly society.

“Dementia is so widely misunderstood. Many believe that you can’t do anything for yourself. Dementia can isolate you from society. We want to change society to become more caring or easy-going. So dementia or no dementia, we can live together in harmony.”

Oguni, Shiro: Restaurant of Mistaken Orders

Window 3 reveals a short documentary film about a Japanese pop-up restaurant called the **Restaurant of Mistaken Orders**. This is a restaurant where all the waiters have dementia. The founder of the pop-up restaurant, Shiro Oguni, states that a dementia diagnosis should not define a person, but, rather, a dementia friendly society should allow for their participation.

This bold experiment proves how sufficient support and necessary adaptations allow people with dementia to remain as active participants in society. Working in the restaurant improved the participation of the people with dementia, gave them more respect and helped them to have positive interactions. The customers also felt that their visit to the restaurant improved their view on dementia. Of all the orders in the restaurant, 37% contained mistakes, but the customer satisfaction rate was 99%. The idea led to the British reality TV show **The Restaurant That Makes Mistakes** in 2019.

You can watch the short documentary film **Restaurant of Mistaken Orders** online on YouTube.

<https://www.youtube.com/watch?v=su34Gx-STQk>



Window 4: The father – a film about the many dimensions of reality

“There is something funny going on.”

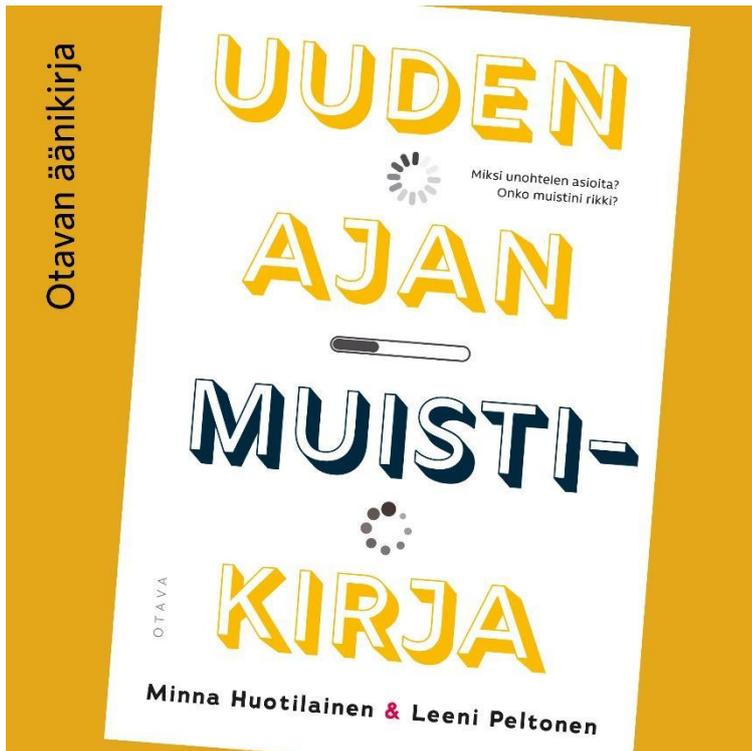
Zeller, Florian: The Father

In this Oscar-winning film based on Florian Zeller’s play, Anthony Hopkins plays the role of a father with Alzheimer’s disease. His daughter is very worried about him, but the father feels like he is coping just fine in his beloved home, and this is also partly true. However, as the movie progresses, we see the home’s decor starting to change, things go missing and visitors change into different people. The film is an excellent depiction of the confusion people with dementia may experience, as it is more difficult for them to discern changes and adapt to them. The situations seem chaotic at times, highlighted by the daughter’s difficulties in understanding her father’s point of view. The viewers are left to wonder whose version of the story is real and what is the final truth of these shared experiences of two different people.

In addition to deteriorating memory, changes in personality and behaviour can occur in relation to dementia. These changes, referred to as neuropsychiatric symptoms, are often difficult for the person living with dementia to recognise themselves. The causes behind these symptoms are varied: they can, for example, be due to changes to the brain caused by the dementia itself, or due to changes in other conditions, or perhaps due to inappropriate medications. The person’s ability to express their own needs may also deteriorate and being misunderstood can cause feelings of frustration. A person with dementia looks for logical explanations for incidents that are difficult to understand. Sometimes, these erroneous interpretations may even seem delusional to others. If the neuropsychiatric symptoms weaken the patient’s condition and ability to cope or make their personal relationships more difficult, the underlying causes should be sought. Often, it is possible to find simple ways to alleviate the situation.

The trailer of the movie The Father is available online on YouTube.

<https://youtu.be/4TZb7YfK-JI>



Window 5: Notebook for a new era – a guide to the world of memory

“Memory is nothing like a computer that allows you to use a certain command to pull up what you need. In this sense, memory is a lot more erratic.”

Huotilainen, Minna and Peltonen, Leeni: Uuden ajan muistikirja (Notebook for a new era)

Uuden ajan muistikirja is a practical and easy to understand non-fiction book about memory. The authors explain that they decided to write the book so that we could all better understand the different aspects of memory, and thereby use it in smarter ways. The book is mainly focused on “normally functioning” memory but has its own chapters for preventing cognitive impairment and about the most common forms of dementia.

Often, when we talk about the impaired memory of those with dementia, we tend to forget that healthy memory is not perfect either. Even though we may think of our memories as accurate, unchanging recordings of events, our mind is constantly editing our memories by choosing which parts to keep and which to erase. Our memories can become coloured, faded or distorted, even if we do not have dementia. On the other hand, events which are emotionally loaded tend to be retained especially well, even for those living with dementia.

The way a person’s memory starts to deteriorate varies depending on the memory disorder in question. The most common form of dementia, Alzheimer’s disease, usually starts with difficulties in learning new things and problems with the episodic memory, whereas the first symptoms of frontotemporal or vascular dementia may not have anything to do with memory at all.



Window 6: Coco – a film about the power of music and memories

“Remember me. Though I have to say goodbye, remember me. Don’t let it make you cry. For even if I’m far away, I hold you in my heart. I sing a secret song to you, each night we are apart. Remember me.”

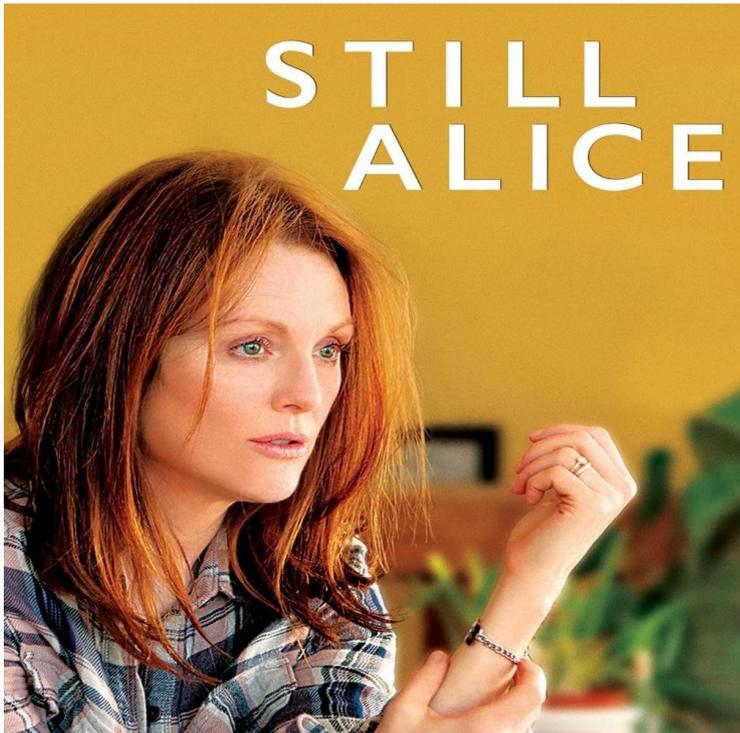
Disney & Pixar: Coco

Coco is an animated film by Disney and Pixar about a 12-year-old Mexican boy, Miguel, who – unlike the rest of his family – loves music. Miguel also loves his great grandma, Mama Coco, who lives with the family and has advanced dementia. Music is prohibited in the family, and the answer to why this is the case, is hidden in Mama Coco’s childhood. At the end, the power of music is the thing that brings the family together.

The film beautifully shows the power music has to awaken old memories, even in people with advanced dementia. Research has shown that some areas of the frontal lobe of the brain are activated by familiar music, and this ability is retained even into late Alzheimer’s. A simple way to test the effect of music is with familiar, seasonal Christmas songs, for example. Which Christmas songs awaken the most memories for you and your loved ones? Listen to or sing these songs together.

Miguel’s song, **Remember me**, can also be watched on YouTube.

<https://www.youtube.com/watch?v=vgpBt5STusE>



Window 7: Still Alice – a book about a career woman’s Alzheimer’s disease

“She simply couldn’t find the word. She had a loose sense for what she wanted to say, but the word itself eluded her. Gone. She didn’t know the first letter or what the word sounded like or how many syllables it had. It wasn’t on the tip of her tongue.”

Genova, Lisa: Still Alice

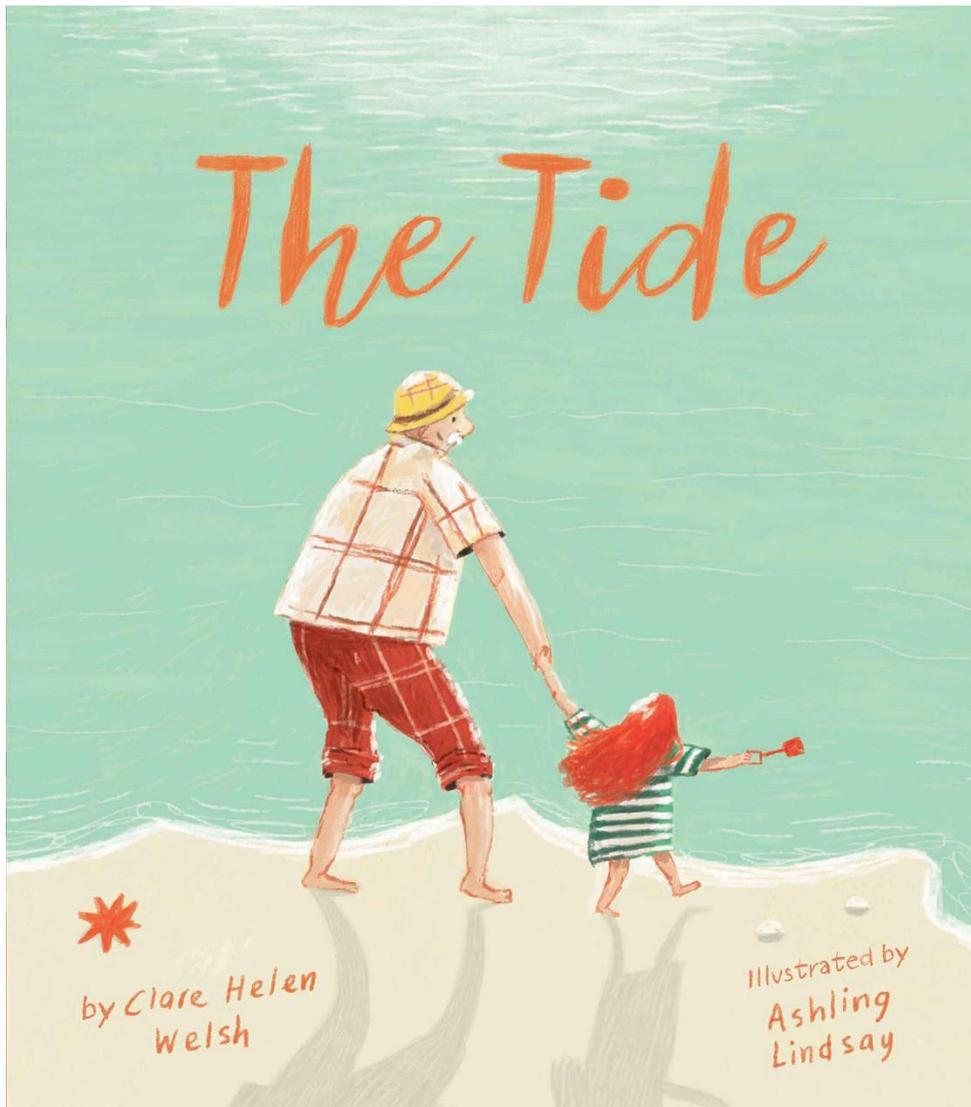
Alice notices that she is forgetting familiar words. She, a professor of linguistics at Harvard, suddenly cannot find the word “dictionary”! Her work pace is slowing down, she needs to use sticky notes to get by and she keeps forgetting appointments. She attempts to explain these mistakes away with her menopause and stress, but finally one day, after having a hard time finding her way back home after a run, she decides to get examined. Alice is just 50 years old when she is diagnosed with early onset Alzheimer’s. The book shows how the disease changes her life and how this affects her loved ones. Shared dreams with her partner collapse, and Alice feels that her partner does not understand her wishes. In a peer support group Alice feels like she is being heard and gives her the comfort and strength to carry on. Alice’s children start to consider their own future, especially when Alice tests positive for a rare, hereditary form of Alzheimer’s disease.

The book describes vividly how the symptoms of Alzheimer’s can vary from day to day. Awareness of this fluctuation of symptoms allows people to enjoy the good days, but their reduced capabilities on the harder days may confuse and even cause frustration. Alzheimer’s may include aspects and symptoms that are hard to understand and accept. It can be easier to process these thoughts in a peer support group, which can also give new perspectives to personal thoughts.

Many loved ones wonder whether Alzheimer’s disease is hereditary. It is rarely strongly hereditary, but an elevated risk of getting Alzheimer’s can be inherited. You can partly help reduce the risk with a lifestyle that protects brain health. Find out more behind window 13.

An Oscar-winning film was also directed based on the book, and its trailer is available on YouTube.

https://youtu.be/oGN9b_KJb_8



Window 8: The Tide – a picture book of a Grandpa’s disappearing memory

“Grandpa’s memories are like the tide,” Mummy explains. “Sometimes, they’re near and full of life. Other times, they’re distant and quiet.”

Welsh, Clare Helen: The Tide

A little girl and her grandfather are spending a day at the beach, waiting for the tide to come in. Many things go just as they used to: they build sandcastles, eat ice cream and get wet in the splashing waves. But where has their lunch disappeared to? Does Grandpa have something to do with it? At the end of the day, they talk about their day together helping Grandpa remember the fun moments that he may have forgotten already...

The book focuses on a preschool-aged child’s experiences of their grandparent’s dementia. The book can help a child understand the symptoms related to memory disorders; after all, children tend to lose things, too, and often need help from others to resolve matters. The book also beautifully depicts how the social skills and emotions of people with dementia s can remain unchanged for a long time, although other symptoms can already be seen clearly.



Window 9: Remember me – a book of a daughter’s experiences of her parents’ dementia

“I’m already sitting in the car, ready to go, when I see my dad frantically waving by the front door. I turn off the engine and get out of the car. On socked feet, dad runs out to give me another hug and to thank me for my visit. I can see fear and panic in his eyes. I look at him with an encouraging smile: ‘Take care, I will see you next weekend!’ My father walks back inside with hunched shoulders. I sit back down in the car, tears stuck in my throat.”

Koivuniemi, Anne-Maarit: Muista minut, vanhempieni Alzheimer (Remember me, my parents Alzheimer’s)

Muista minut – “Remember me” – is a depiction of the personal experiences of a daughter whose parents have Alzheimer’s disease. Both of Anne-Maarit Koivuniemi’s parents were diagnosed with Alzheimer’s when they were 70 years old. Koivuniemi beautifully describes the possibilities that open up when one decides to become an informal carer, but she also shares the feelings of guilt and inadequacy she experiences.

Loved ones often have to consider the ethicality of different decisions, given dementia affects the patient’s awareness of their own symptoms as well as their functional abilities. One such theme is driving and the loss of a driver’s licence, which is a topic that is often revisited on the pages of this book. The same methods do not work for everyone, Koivuniemi states. *“My father is no simpleton, even if he does have dementia. He is highly intelligent and can easily sense if someone is trying to trick him or is being dishonest.”*

The overall message in this book is that dementia is a change that up-ends one’s life, but it is also an opportunity. It does not have to only be distressing or frightening. Koivuniemi herself feels like she became closer to her parents and found out more about their childhood and youth. Giving up driving worked out in the end, too, through compromises and while listening to the father’s wishes.



Window 10: I'm not gonna miss you – a country musician's last song

"I'm still here, but yet I'm gone. I don't play guitar or sing my songs. They never defined who I am. The man that loves you 'til the end."

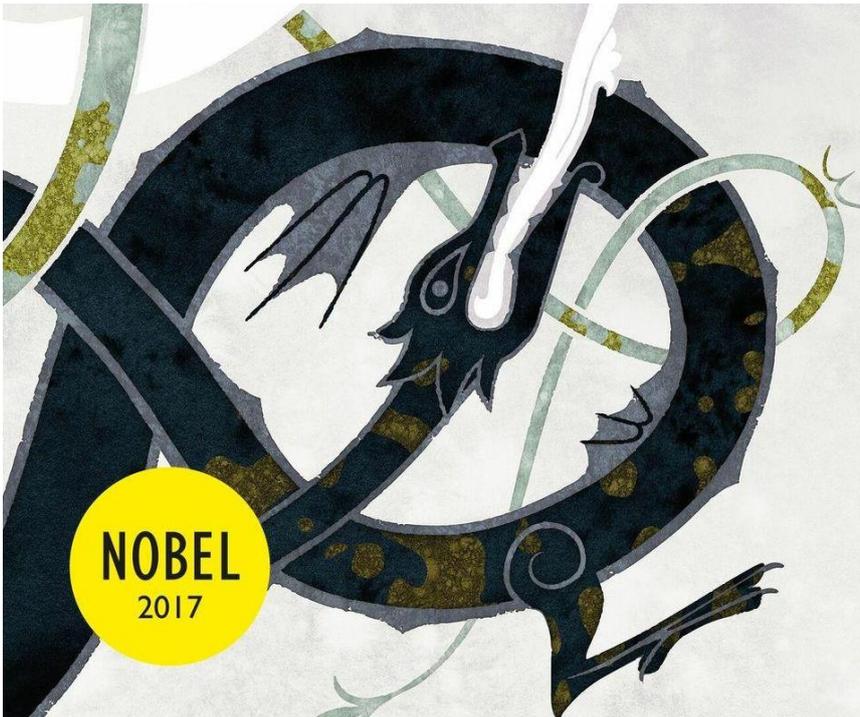
Campbell, Glen: I'm not gonna miss you

When the American country legend Glen Campbell was diagnosed with Alzheimer's disease, he was told to give up his career as a musician. However, with the support of his family and his band, Glen Campbell decided to embark on a farewell sell-out tour that lasted for an amazing 425 days and included 151 concerts. This tour was recorded into a documentary film called **I'll Be Me**. In the film, the country legend's doctor muses about how playing music and going on the tour was a likely factor in helping to maintain Campbell's memory and functional abilities. As his last song, Glen Campbell, his band and his musician daughter record a song called **I'm Not Gonna Miss You**.

Through their own experience, Glen Campbell and his family wanted to show how it is possible to continue living a good life and carry on one's life's work also with dementia. Being diagnosed with dementia does not automatically transform a person into nothing but a "dementia patient". Glen was still Glen. The stigma of dementia is easier to remove when the person's own voice can be heard. It is great that so many public figures have openly spoken about their diagnoses. Any one of us can get a memory disorder. Dementia should not define one's life, but neither should it be a silent taboo.

You can watch the music video of Glen Campbell's last song, **I'm Not Gonna Miss You**, on YouTube.

<https://www.youtube.com/watch?v=U8TsAh-zYFI>



Window 11: The Buried Giant – a novel about the fickle nature of memories

“Yet are you so certain, good mistress, you wish to be free of this mist? Is it not better some things remain hidden from our minds?” ‘It may be so for some, father, but not for us. Axl and I wish to have again the happy moments we shared together. To be robbed of them is as if a thief came in the night and took what’s most precious from us.’ ‘Yet the mist covers all memories, the bad as well as the good. Isn’t that so mistress?’ ‘We’ll have the bad ones come back too, even if they make us weep or shake with anger. For isn’t it the life we’ve shared?’

Ishiguro, Kazuo: The Buried Giant

In this novel, the country has been taken over by a mist that wipes away people’s memories. Others do not seem bothered by this, but Axl finds himself perturbed, and the ageing couple decides to embark on a long hike to find their son. At the start of the tale, they only have vague memories of their son, but these start to become clearer along the way. Are they recovering their old memories or are their shared hopes becoming new memories?

All our memories take new shapes over the course of our lives. We share our memories, listen to those of others and reminisce about the times we have lived together. This may lead to our memories merging together so that we create a collective memory. This often happens when we reminisce about nice things. When we think about more difficult times, it is often easier to spot the differences in our recollections, which may lead to confrontations, even if the truth lies somewhere between these different perspectives.

The novel by Nobel-winning Kazuo Ishiguro can spark philosophical discussions – or you can immerse yourself into the story and forget the world around you for a while.



Window 12: The Mole Agent – a documentary of experiences of loneliness

“I know you asked for objective information, not opinions. I will still share my opinion, because I don’t want to remain silent. The residents at this retirement home are lonely. They don’t get visitors and some have been abandoned here. The worst abuse in this house is loneliness.”

Alberdi, Maite: The Mole Agent

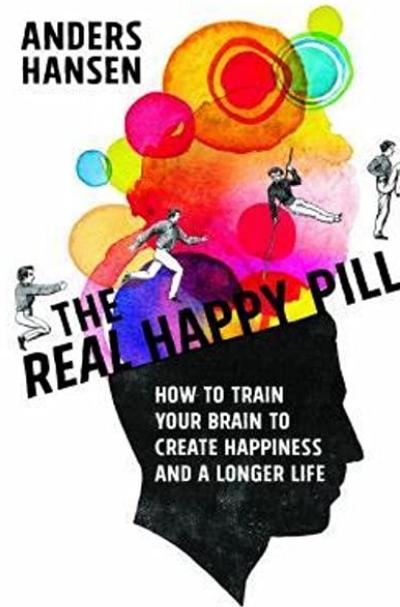
The dramatised documentary film directed by Chilean Maite Alberdi starts when a private detective hires the 83-year-old Sergio as an undercover agent at a nursing home. A daughter of an old lady living in the nursing home suspects that her mother, who has dementia, is being mistreated there, and Sergio moves to the nursing home to find out if this is true. The staff and residents of the nursing home have been told that the new resident, Sergio, is being filmed for a documentary. Sergio solves the case while making friends with the residents in the nursing home. He also has an important message to share with us all.

Three quarters of residents in long-term care in Finland have dementia. The lives of people with dementia are often viewed only from the perspectives of service and support needs. This documentary encourages viewers to consider first and foremost, housing and other needs from the perspective of well-being. The fundamental requirements for well-being do not disappear when a person develops a memory disorder. On the other hand, living with others may not necessarily remove loneliness.

A study carried out in Finland demonstrated that more than a third of elderly people living in retirement homes experience loneliness at least occasionally. Many lonely residents feel that they are physically close to others and yet mentally very distant from them. Loneliness weakens health and physical well-being and is an indicator of an elevated risk of premature death. This is why we should strive to actively reduce loneliness through different measures. The Circle of Friends’ group activities for older people have given good, research-based results. An international RECETAS project is also about to be launched, which aims to review the impact of nature experiences on people’s quality of life and experiences of loneliness.

The trailer of the documentary **The Mole Agent** is available online on YouTube.

<https://youtu.be/rTD-B3wZORg>



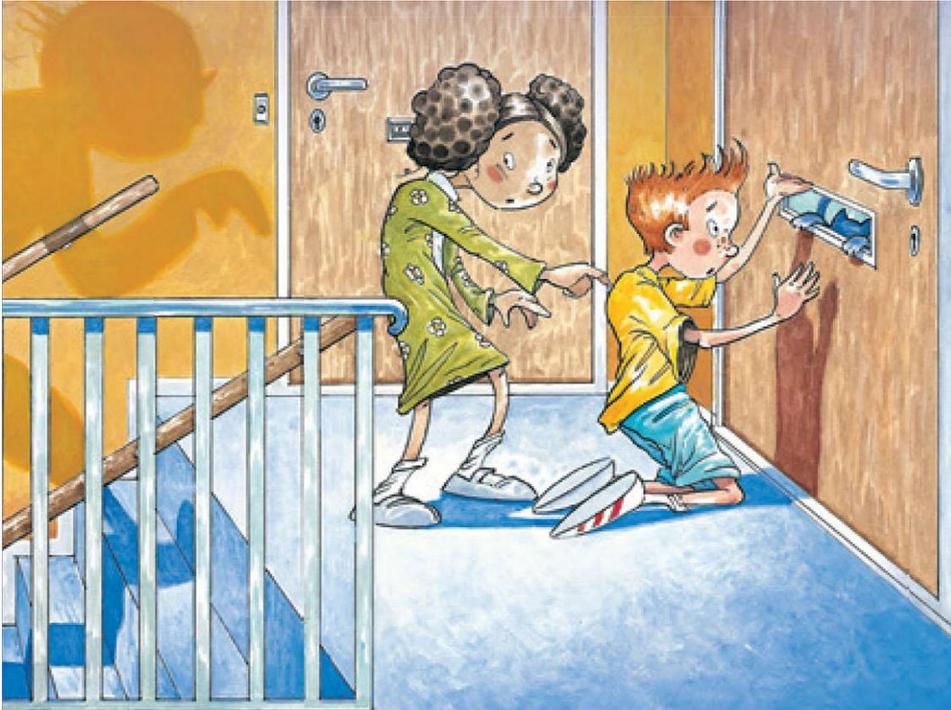
Window 13: The Real Happy Pill: Power Up Your Brain by Moving Your Body – a non-fiction book about the power of exercise

“The memory of most people weakens as years go by, even without a memory disorder. The hippocampus shrinks. The blood supply to the brain becomes impaired. Connections between the different areas of the brain decrease. If you exercise regularly, you can slow down all of these processes. Being physically active literally slows down the aging of the brain and improves memory, regardless of whether the person has a memory disorder or not.”

Hansen, Anders: The Real Happy Pill: Power Up Your Brain by Moving Your Body

Anders Hansen’s book is a comprehensive but approachable look into the positive influences of exercise on different brain functions: stress tolerance, concentration, mood, memory, creativity, and brain development throughout one’s life, as well as the brain’s ability to adapt to modern society’s challenges. Hansen uses examples to present research results in an easy-to-understand format. Readers will be happy to hear that a significant positive impact can be achieved through just small changes.

Over the last decade, we have learned a great deal about the significance of lifestyle in the prevention of, and rehabilitation of those with dementia. The Finnish intervention study to prevent cognitive decline and disability (FINGER) was the first in the world to prove that when aging people adopted healthier lifestyles, their memory and thinking abilities remained better. The study also discovered that these measures were just as effective for people with hereditary risk of dementia. The FINGER study has garnered a great deal of international interest, and the research network now has more than 40 member countries.



Window 14: Cat Missing – a children’s detective story about the changing behaviour of a person with dementia

*“- Do you have a cat? But the man does not answer, he just continues walking.
- Puss... He mumbles to himself. Kevin and Dina look at each other.
- Strange man, Dina says.
- Should we spy on him?
Kevin nods.”*

Bross, Helena: Cat Missing

Kevin and Dina are primary school friends who solve mysteries together. In the book **Cat Missing**, cats start to mysteriously disappear from Dina’s and Kevin’s home town. The friends start to pay attention to an older man and his strange behaviour, and soon they decide to call the police. By working together, the characters manage to save the cats, and it comes to light that the older man is also in need of some help. The book is one book in an easy-to-read **The Mini Mysteries** series, which is a great read for primary school students.

Sometimes, the behaviour of an unknown person may seem confusing or even frightening to others. This may delay them from receiving help they may need, especially if the person has no-one who knows them well. It is worth bearing this in mind, for example, if the behaviour of an elderly neighbour changes, becoming suspicious or fearful. The book is a great way to start talking with children about the possible reasons behind a stranger’s odd behaviour.

As a professional, one does start to wonder whether the older man in the book should have had the chance to continue living at home with some help from home care services – maybe with a cat to keep him company... Nowadays, pets are sometimes used to help rehabilitate people with dementia. Robots that resemble pets have also been developed to support those with memory disorders, and they are in use in several nursing homes.



Window 15: I am somewhere – a documentary of a life with Alzheimer’s.

“Old age, brand new era. Unforeseen, like youth used to be. I am scared, I imagine the terrors of what will become of my life. I try to picture it, prepare myself to face the time when I no longer have the strength to think. But today, I can see the sunrise, and I get up, determined to live, still.”

Rajavaara, Tuula: Olen jossain (I am somewhere)

Olen jossain, “I am somewhere”, is a documentary film directed by Tuula Rajavaara. It is based on the personal experiences of her mother Aili Rajavaara, living daily with Alzheimer’s. The documentary focuses on the life of Aili, who lives alone, and the challenges brought on by the condition, both from Aili’s own and her daughter’s perspective. Aili should, for example, remember to go to eat lunch at Myyrinkoti service home every day, and she should not go to the store without her daughter. Aili also writes down her thoughts as poems.

The documentary film depicts well the practical challenges that the symptoms of dementia can create for a person living alone, as well as some of the concrete solutions available. The services targeted at people with dementia who are living at home need to be developed further. Research has shown that people with dementia can live at home independently or with minor support for several years, if they have people supporting their well-being around them and if their services have been customised to their individual needs.



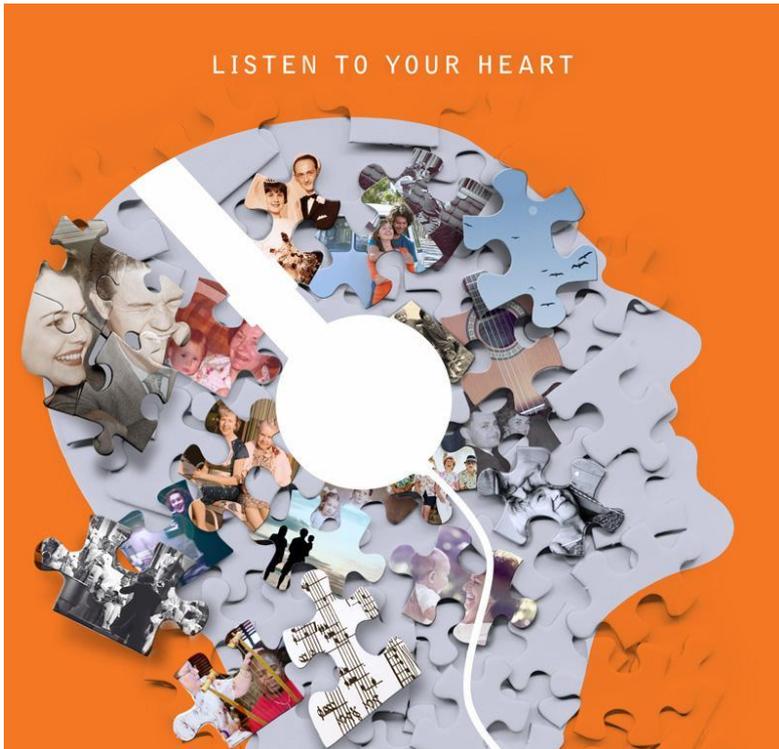
Window 16: What Dementia Teaches Us About Love – a book about humanity

“The edges of the self are soft, the boundaries of the self are thin and porous... how much are we connected to each other and how much are we separated?”

Gerard, Nicci: What Dementia Teaches Us About Love

Personal experiences tend to make people consider illnesses and disorders from a wider perspective. This happened to Nicci Gerard, whose father was diagnosed with dementia. The book is not a traditional case study or a daughter’s personal experience, but rather a more philosophical study of memory disorders. The book does not give straight answers, but, rather, encourages the reader to think about what it means to be human and how this is connected to our memory. Do people lose themselves to dementia? Who are we, if not ourselves? The book has interviews with several people with dementia, their loved ones and professionals in the field. There are as many stories as there are people telling them.

The encounters with people with dementia can press pause on our busy everyday lives and reveal the excessive focus society puts on independence and performance abilities. It is important to face people with dementia with respect, as their fragile shell protects a vulnerable self. People with dementia can also help us learn how to be present in the moment where the encounter itself and expressing one’s emotions are more important than showing off one’s success.



Window 17: Alive Inside – a documentary film about the power of music

“Our healthcare system imagines the human to be a very complicated machine. We have medicines that can adjust the dial. Bloodpressure: we’ll turn that down. Blood sugar: turn that down. We haven’t done anything to touch the heart and soul of a patient.”

Rossato-Bennett, Michael: Alive Inside

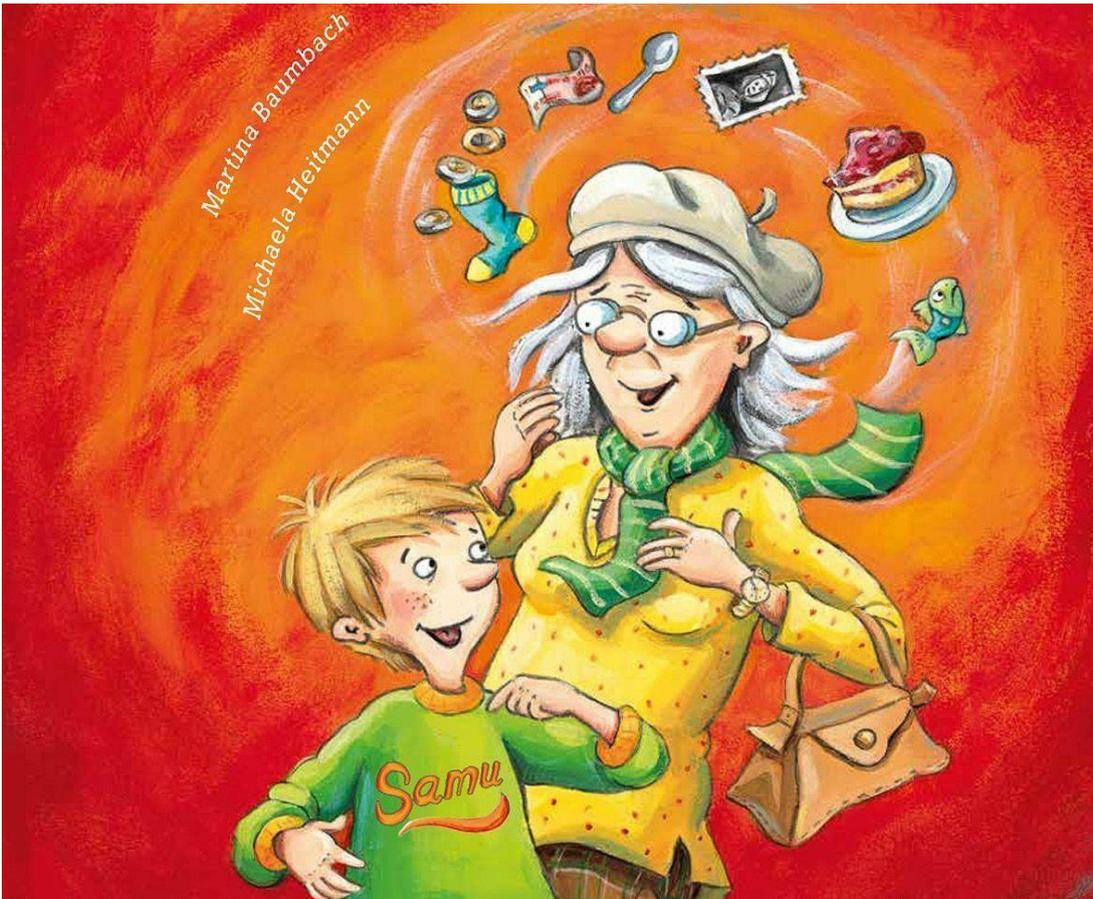
Alive Inside is an American documentary film that studies the progress of the **Music and Memories** project founded by social worker Dan Cohen. The project has a simple goal: to provide all long-term care residents with their own portable music player and personal list of music. The documentary film considers the amazing power of music to inspire people to sing, dance and come together.

Using music in the treatment and rehabilitation of people with dementia has also been studied in Finland in the **Muistaakseni laulan** (double meaning: “I remember I’m singing” & “I sing to remember”) project. The study showed that music coaching, which utilises familiar music and emphasises the social interaction between the person with dementia and their loved one or carer, can improve the person’s mood and quality of life. Singing together also had a positive effect on their linguistic memory, as well as the loved one’s mental well-being.

As dementia progresses, linguistic abilities can also deteriorate. That is why we need to find a new way to communicate and interact. Music is one great way to do this. However, not just any music is good for this; we all have our own personal favourites that touch us and affect our energy and mood. We should all write down the music we prefer, for example as part of our living will. If you had to make a playlist of your life, what songs would you include?

The trailer of the **Alive Inside** documentary film is available on YouTube

<https://www.youtube.com/watch?v=fVkrI1R0XjA>



Window 18: ‘Grandma’s memory is playing tricks’– a picture book of everyday incidents

“I feel like a few more memories fade away every night,” Grandma says with a wistful smile. Nils and Grandma start to look for the missing memories. They go through Grandma’s pillow and duvet and even look under the bed, but there is nothing there, except a candy wrapper and one lonely sock. How can something you cannot even see go missing?”

Baumbach, Martina: Kuddelmuddel in Omas Kopf (‘Grandma’s memory is playing tricks’)

This children’s book by a German author describes a family’s daily life after their Grandma moves in to live with them, when it becomes apparent she can no longer live alone. The story shows how everyday incidents brought on by dementia can look from the perspective of a school-aged child. First, Nils finds the changing behaviour quite funny; Grandma hides her money under her mattress and waves at the people on the TV. The book also handles the more difficult feelings dementia may bring up for a child: sadness that they no longer do things together, worry when Grandma goes missing one night, and anger when Grandma one minute remembers things just fine and then suddenly remembers nothing – as if she is doing it on purpose!

Dementia may change a person’s behaviour in many ways. This changing behaviour may seem strange but treating the person with acceptance can help everyone adapt to the new situation. A child’s open-minded and even curious attitude can sometimes also help adults look at challenging matters with fresh eyes. This book, too, beautifully depicts how a close and warm relationship carries even through dementia: *“It is easy to talk with this boy, Grandma thinks with a smile on her face. She has already forgotten the boy’s name, but it doesn’t matter. Right now, she is still the happiest person in the whole universe.”*



Window 19: Elizabeth is missing – a detective story about the importance of memories of youth

“How do you solve a mystery when you can’t remember the clues?”

Healey, Emma: Elizabeth is missing

Emma Healey’s debut novel is a true thriller! Maud is an ageing woman with a failing memory; she does not remember what she was supposed to buy from the store, her home feels like a strange place, and she cannot always recognise her own daughter. But one thought keeps constantly running through her mind: “Where has Elizabeth gone?” The book alternates between Maud’s youth and her present life. Memories from her youth pop up in Maud’s mind, but no one really believes them to be true. How could she remember such old things, when she can no longer even remember where she set down the cup of tea she just boiled? Nevertheless, Maud remains persistent. In the end, will they finally discover Elizabeth, or maybe someone else was missing all along?

The book is an inventive look into the ways dementia affects the memory. Important events that occurred decades ago may still remain clear in one’s mind, while yesterday’s events have already been wiped from one’s memory. This may seem strange, but there is a logical explanation for this, which is related to the different functions of memory. These are explored in more detail behind window number five. A person with dementia may enjoy talking about their old memories, because reminiscing about them is easier and makes the person feel that their memory is still working well. And they are also completely right when it comes to long-term memory!

A film based on the book was made in 2019, with Glenda Jackson giving a brilliant portrayal of the elderly Maud. The film’s trailer is available on YouTube.

<https://www.youtube.com/watch?v=d2ejTIsfBeA>



Window 20: My Name is Lisa – a short film about dementia from the perspective of a teenager

– Mother: Now is your lunchbreak.

– Lisa: Eeh... You already made me lunch. I had a sandwich 5 minutes ago. I only need one lunch!"

Shelton, Ben: My Name is Lisa

The short film tells the story of a teenager called Lisa, and her mother who has Alzheimer's. The film has no actual storyline, it is more a collection of short, everyday events that gradually reveal the mother's problems with memory and the progression of the disease. The film shows how the roles between the mother and the daughter gradually change. For Lisa, this is a confusing change that she finds frustrating, but, in the end, the viewers get to see her adapting to the difficult situation and even accepting it. The film presents how literature can be used to create good, shared moments including where advanced Alzheimer's is present. In 2007, the film won the YouTube award for the best short film.

It is estimated that 7,000 working age people in Finland have dementia. Their families often have teenage children for whom their parent's illness can be confusing and difficult. Listening to the child's thoughts and facing their concerns with honesty is important, even if there are no answers to all their questions. The family also often needs external support. Teenagers can find peer support through a private Facebook group by the Alzheimer Society of Finland.

The short film is available on YouTube.

<https://youtu.be/ZiRHyzb5SI>



Window 21: The Summer Book – a book about giving things up and the happiness of living

“Wait a minute!” Grandmother said. She was very upset. ‘I’m not through! I know I do everything. I’ve been doing everything for an awfully long time, and I’ve seen and lived as hard as I could and it’s been unbelievable, I tell you, unbelievable. But now I have the feeling that everything’s gliding away from me, and I don’t remember, and I don’t care, and yet now is right when I need it!’ ‘What don’t you remember?’ asked Sophia anxiously. ‘What it was like to sleep in a tent!’ her grandmother shouted.”

Jansson, Tove: The Summer Book

The Summer Book is a story about the last summer an old woman and a young girl spend together on an island. Their daily life and dialogue put the fleeting nature of life and the difficulty of giving things up into words. The old woman no longer remembers her youth, her life seems to be gliding away and her memory fails and becomes weaker. The book’s characters are based on Tove Jansson’s niece, Sophia, and the author’s own mother Signe.

The vulnerability of a person with dementia and the loss of cognitive abilities may be difficult things to face, especially in a society with a weak sense of community. In **The Summer Book**, the island comes across as a safe space, a community where everyone has their place. The grandmother is well-respected. She has plenty of knowledge and skills needed for living on an island. She also has what every little girl wants: time to play together and to answer Sophia’s never-ending questions.



Window 22: Until I Forget – a short documentary film about dementia in a relationship

“What comes, comes, and there is no way to change that. ...Of course it is frightening, too, but... Life is so unpredictable that there is no use in making elaborate plans. Let’s just enjoy this moment. We cannot know about tomorrow.”

Lantela, Meri: Kunnes minä unohtan (Until I Forget)

The short documentary film **Kunnes minä unohtan** (“Until I Forget”) tells the story of Matti, who has Alzheimer’s disease, and his partner, Anja. The viewer gets glimpses into their daily life with moments in the present, memories of old times, and thoughts about the future. Matti and Anja only met in later life when Matti had already experienced loss and grief in his life. After being diagnosed with dementia in 2018, he feared that he would lose Anja too. However, Anja felt that *“it’s not a deal-breaker in this kind of situation”*, and slowly they went from dating to living together. They have continued to build their life together. Their days are mostly filled with daily chores and everyday events, but both seem to appreciate them, as they both are aware of the unpredictable nature of life.

Relationships change over life. Some of them end and may be replaced with others. A long-term relationship can also change, one way or another. Dementia often brings changes to a relationship: roles and division of work can change, familiar routines may need to be replaced with new ones, and communication can change in many ways. The future can bring up many thoughts or even fears. Maybe someone you know has had very difficult experiences. However, every relationship is one of its kind, and so is every person’s experience of dementia.

The Circle of Couples’ activities provide support for couples that are dealing with dementia. The activities are based on extensive research and development work. It has been proven that group rehabilitation improves the information processing of a person with dementia and improves the quality of life of their spouses.

The documentary film **Kunnes minä unohtan** is available on Yle Areena in Finnish.



Window 23: Wrinkles – a stark depiction of daily life in a nursing home

“Like I was saying, there’s nothing in this home. At eight o’clock, it’s breakfast. At noon, we lunch and at seven o’clock, we dine. The medication and the food are our only motivators. It’s the world turned upside-down. The period between meals is dead time. People either sleep or vegetate in front of the tv until the next meal time.”

Roca, Paco: Wrinkles

Wrinkles is an austere comic book by Paco Roca, depicting 72-year-old Emilio’s move to a nursing home. Emilio’s children put their father in long-term care as he can no longer cope at home due to his dementia. Emilio’s new room-mate, Miguel, is the king of cynicism, who constantly jokes about the elderly as society’s burden.

When reading the comic from a professional’s perspective, it strongly feels like it is a manual of grievances. One can only hope that the individual themselves is not told about their diagnosis. Where is the person’s right of self-determination? Where is the respect and appreciation for them? The book is full of terms such as “demented” and “senile”, which one would hope are not in use anywhere anymore. Word choices affect people’s actions and expectations. A person does not become ‘demented’ after being diagnosed with dementia. The book is also a sharp description of the fear of losing one’s independence and dignity. The comic makes the reader think how highly we value independence in our society and about our attitude to needing help.

None of us can know about tomorrow. Have you ever wondered what kind of treatment and care you would like to have? You should bring up these wishes with a loved one or a professional or draw up a written living will.



Window 24: Muistisairaan maailma – a book that gives a voice to people living with dementia

“Alzheimer’s is quite a frightening word. Everyone has some knowledge about how this nebulous, incurable disease changes one’s personality. However, I see no reason to be ashamed of a memory disease. Memory diseases are shrouded in mist and mystery. It is probably because only a few people with memory disorders are actually able to explain what the disorder feels like. It is this silence that defines the matter.”

Seppänen, Liisa: Muistisairaan maailma (The world of a person living with dementia)

In the book **Muistisairaan maailma** (“The world of a person living with dementia”), the main narrative has been given to people of different ages and at different stages of dementia, and their loved ones. They speak openly and boldly about what a memory disorder feels like and about the best ways to cope with it. This is not a traditional non-fiction book, but, according to the author herself, rather a travel journal describing a slow journey towards an unknown destination.

The book describes very well the individual experience of people living with dementia. Some are strongly aware of their symptoms, while others are not. It can be confusing and painful to someone with dementia to start noticing their own symptoms. However, a lack of awareness about one’s own condition can confuse their loved ones and cause confrontations. The symptoms and the person’s awareness of their disease also often change along the way. Dementia is often referred to as a condition affecting the whole family. Some feel that the disease is kinder to the person themselves than their loved ones, but this will not always be the case. The most important thing is that information and support are available to both the individuals and their loved ones.