



TOGETHER AGAINST DEMENTIA

A guidance for caregivers, care providers and for people with dementia.



Tunstall



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Preface by Emil Peters

TUNSTALL CEO

WHY A FOCUS ON DEMENTIA IS SO IMPORTANT

In the time it takes for you to read this booklet, 42,000 people will have started to develop dementia. This is a startling figure. This significant life changing disease occurs at a rate of one new case every 3.2 seconds.*

This is why a focus on dementia is essential. As the global population increases, so does the number of people living with this disease. In 2022, it was estimated that over 55 million people worldwide had dementia. This number is expected to almost double every 20 years, reaching 78 million in 2030 and 139 million in 2050. 2030 is less than seven years away, and so we must take action now.

Alzheimer's Disease International (ADI): "Already 60% of people with dementia live in low- and middle-income countries, but by 2050 this will rise to 71%. The fastest growth in the elderly population is taking place in China, India, and their south Asian and western Pacific neighbours."

Dementia is a major public health challenge that affects millions of people worldwide. It's not just the person with the disease who is affected; families, caregivers, and society also feel the impact. The high cost of care can be a significant burden on families and economies. That's why it's so important to focus on dementia and promote awareness, understanding, and

support for those affected. We need to advance research and innovation in dementia care and work together to develop public policies and advocacy efforts that improve dementia care and support globally. By doing so, we can make a real difference in the lives of people with dementia and their families.

For people with dementia, it can be tough to cope with the loss of independence and changes in behaviour and personality. That's why dementia care and support must be holistic and address not just the medical aspects but also the psychological, social, and environmental aspects of the disease. By taking a compassionate and understanding approach, we can make a real difference in the lives of those affected by dementia.

One of the ways that we at Tunstall can help to meet the global dementia challenge is through technology innovations.

Technology innovations can provide valuable support for people with dementia and their caregivers, helping to promote safety, independence, and socialisation, as well as reducing stress and improving quality of life. Essentially, helping to maintain as much of the whole person for as long as possible, providing choice for how a person lives their life, regardless of their dementia diagnoses. Technology innovations can be a key contributing factor to the critically important holistic approach that is required.

**numbers sourced from ADI - <https://www.alzint.org/about/dementia-facts-figures/dementia-statistics/>*



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I'm incredibly proud that the Tunstall team has such a powerful role to play in helping people with dementia live their best lives possible, and in helping the people who care for them to feel supported and enabled. It's a role that we take seriously and approach with passion.

TOGETHER
AGAINST
DEMENTIA





1

THE DEMENTIA CHALLENGE

The dementia challenge

Dementia has many challenges for healthcare systems. Understanding the effects on patients and families, along with resource use and costs, is crucial for planning care and creating public policies to reduce the economic impact on society and healthcare systems.

Figures from Alzheimer's Disease International tell us that the global cost of dementia is estimated to be US\$ 1.3 trillion and is expected to rise to US\$ 2.8 trillion by 2030*. Currently there are over 55 million people worldwide living with dementia. The number of people affected is set to rise to 139 million by 2050, therefore increasing the cost and the challenge of this disease.

Dementia care costs can be split into direct medical costs, direct social (non-medical) costs and informal care costs.

Direct medical care costs account for roughly 20% of global dementia costs, while direct social sector costs and informal care costs each account for roughly 40%. The relative contribution of informal care is greatest in the African regions and lowest in North America, Western Europe and some South American regions, while the reverse is true for social sector costs.**

In 2019, informal dementia carers spent over 89 billion hours providing support with activities of daily living – about 5 hours per day per person with dementia. Informal care provision – the bulk of it provided by women

(about 70%) – is particularly high in countries with low resources where there is a scarcity or lack of formal support services for dementia.

Dementia severity is an important driver of cost and the proportion of mild, moderate, and severe dementia cases living in a country can influence the cost estimates. The annual per-patient costs increase steadily with increasing dementia severity, ranging from US\$16000 for mild dementia, US\$27000 for moderate dementia to US\$36000 for severe dementia.

Research shows that most people currently living with dementia have not received a formal diagnosis. In high income countries, only 20-50% of dementia cases are recognised and documented in primary care. This 'treatment gap' is certainly much greater in low and middle income countries, with one study in India suggesting 90% remain undiagnosed. If these statistics are extrapolated to other countries worldwide, it suggests that approximately three quarters of people with dementia have not received a diagnosis, and therefore do not have access to treatment, care and organised support that getting a formal diagnosis can provide. *

* <https://www.alzint.org/about/dementia-facts-figures/dementia-statistics/>

** <https://apps.who.int/iris/bitstream/handle/10665/344707/9789240034624-eng.pdf>



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WHAT IS DEMENTIA?

What is dementia?

Dementia is a condition where mental skills are weakened due to pathological changes in the brain. It is the overall term for a large number of disease states, all of which lead to a permanent weakening of the brain's functions. The term comes from Latin meaning 'away from the mind'. Although we do not know why dementia occurs, it is always due to pathological changes in the brain.

Alzheimer's disease is the most common cause of dementia, affecting at least half of all people with dementia. However, there are over 100 forms of dementia*; let's take a look at some of the different dementia disease states...

ALZHEIMER'S DISEASE

Alzheimer's disease is the most common type of dementia. It affects memory, especially short-term memory, and makes it harder to remember names or do everyday tasks. As the disease progresses, it can also change a person's emotions, personality, and behaviour, causing them to become irritable, passive, or withdrawn.



Alzheimer's disease is caused by two proteins, Beta-amyloid and Tau, that deposit in the brain as plaques and tangles. These deposits are unique to Alzheimer's disease and affect the areas of the brain that control memory, causing memory problems. There is currently no cure for Alzheimer's disease, but medication can help reduce the symptoms temporarily.

In Alzheimer's disease, the brain is progressively affected, starting with the front of the brain which is the area responsible for memory and logic. Later, the disease begins to destroy the centre that regulates our emotions and results in strong mood swings. One of the last stages is the effects on long-term memory (occipital lobe), which ends up being so bad that even close family members and loved ones may no longer be recognised. At the end stage, the cerebellum is affected, which regulates the heart and the ability to breathe, and sadly this leads to death.

VASCULAR DEMENTIA

Vascular dementia is caused by damage to the brain's blood vessels, such as calcification, blood clots, bleeding, or lack of oxygen. This damage



can result in memory loss, confusion, and difficulty with thinking and communication. A person may have one or more strokes before developing dementia, which can cause sudden paralysis or speech difficulties. While for some people the symptoms develop suddenly after a stroke, for other people symptoms may develop gradually over time without any prior strokes.

Vascular dementia symptoms differ from person to person and depend on which areas of the brain are affected. Symptoms are often caused by damage to the deep structures of the brain. This makes a person's ability to think to become slower, they become more apathetic and develop concentration problems, and difficulties in finding words and solving more complex tasks.

People with vascular dementia may experience symptoms of depression and emotional instability, such as uncontrollable laughing or crying, even in situations that don't warrant such a response.

Although there is no cure for vascular dementia, medications such as blood pressure, blood-thinning, or cholesterol-lowering drugs may be prescribed to help manage the symptoms

and prevent the disease from progressing further.

Vascular dementia damages the brain's blood vessels, causing memory loss, confusion, and emotional instability, with symptoms varying based on which parts of the brain are affected.

FRONTOTEMPORAL DEMENTIA

Frontal lobe dementia is also called frontotemporal dementia (often abbreviated FTD). It is the term for a group of brain diseases that affect the frontal lobes and the front part of the temporal lobes. It is the fourth leading cause of dementia and accounts for somewhere between 5% and 10% of all dementia cases.

The diseases often cause major changes in the personality with behavioural disturbances, the ability to speak (aphasia) and psychiatric symptoms. The disease means that inhibitions and situational awareness gradually disappear, and that the person with dementia becomes impulsive and reckless. People with frontal lobe dementia can also show indifference towards social norms and other people. Unlike Alzheimer's disease, memory function in people with Frontotemporal dementia is often relatively good well into the course of the disease. This type of dementia can be seen in both younger and older people.

Frontotemporal dementia has no cure or drugs that slow the disease, but early support and specialised social education and environmental adaptations can help manage disturbances in behaviour and psychiatric symptoms for patients and their families.

Frontal lobe dementia, or frontotemporal dementia (FTD), is a group of brain diseases affecting the frontal and temporal lobes that

cause personality changes, impulsive behaviour, and speech problems.

LEWY BODY DEMENTIA

Lewy body dementia is a slowly progressing brain disease that particularly affects older people. The cause of Lewy Body dementia is not known. No hereditary forms of this disease have been found (yet). The biggest risk factor for the disease is age.

In Lewy Body dementia, a special protein is deposited inside the nerve cells in the brain and forms the so-called Lewy bodies, which have given the disease its name.

In Lewy Body dementia, the dementia symptoms appear before or at the same time as possible Parkinson's symptoms such as slow movements, muscle stiffness or tremors. The dementia sufferer's attention and sense of direction are often affected. The symptoms are like those of Alzheimer's Disease. The special thing about Lewy Body dementia is that the person's attention span can be very fluctuating, with the severity of the symptoms fluctuating not just over days, but also within minutes.

The person's ability to plan, overview and orientation is affected. Lewy Body dementia also means that the sufferer tends to see visions.

Lewy Body dementia cannot be cured, but medication can temporarily reduce the symptoms of dementia. The drugs work by slowing down the breakdown of the signal substance acetylcholine, which the brain cells use to communicate. The medicine improves the brain's ability to recycle its own signalling substance, acetylcholine. However, the medicine does not work on all patients with Lewy Body dementia. Medical treatment cannot stand

alone either. Some patients need treatment for Parkinson's symptoms.

Advice, as well as practical support and relief in everyday life, are the most important elements of the treatment. Most patients with Lewy Body dementia have difficulty tolerating antipsychotic medication, which can make it difficult to treat their visual hallucinations.

Lewy body dementia affects older people and is caused by protein deposits in the brain; symptoms include memory loss, Parkinson's-like movements, and visual hallucinations.

RARE DEMENTIA DISEASES

Alcohol-related dementia

Alcohol abuse may cause dementia, but it's not well-defined whether it's due to alcohol itself or unhealthy lifestyle habits, and it's uncertain whether the harmful effects are permanent or can be reversed with long-term abstinence.

Korsakoff's psychosis

Korsakoff's psychosis is a chronic dementia disease in which the patient has pronounced memory problems. It is caused by damage to the deep structures of the brain as a result



of thiamine deficiency. This deficiency state is seen almost exclusively in alcoholics who have not eaten for a long time. The memory is characterised by ‘gaps’, and the patient often unconsciously fills in the memory gaps with explanations or stories that sound reliable. The condition usually does not worsen once the acute phase is over.

Huntington’s disease

Huntington’s disease is a distinctly hereditary disease. In Huntington’s disease, there is often a mixture of neurological and psychiatric symptoms, including dementia in the late stages. The symptoms can vary from person to person, but there are usually varying degrees of involuntary throwing movements (chorea), unsteady gait and possibly more twisting movements (dystonia).

Dementia is not seen in everyone with Huntington’s disease. It develops slowly and only later in the process. In addition, delusions and depression may occur.

AIDS dementia

AIDS dementia is rare today because treatment for AIDS has significantly improved.

Creutzfeldt-Jakobs disease

Creutzfeldt-Jakob disease (CJD) is a rare and fatal degenerative brain disorder that affects the nervous system and causes rapid deterioration of cognitive and motor functions, leading to dementia and eventually death. It is caused by an abnormal protein called prion that accumulates in the brain, leading to damage and death of nerve cells. There are different forms of CJD, including sporadic, genetic, and acquired forms, such as variant CJD that is linked to the

consumption of contaminated meat products known as ‘mad cow disease’.

Multiple sclerosis and inflammation

Multiple sclerosis is a disease in which the body creates an inflammatory reaction which destroys the insulation around the nerve fibres. Multiple sclerosis can progress to dementia. There are also other rare inflammatory diseases that can affect the brain and cause dementia.

Poisonings

Certain heavy metal poisonings, including lead and mercury, and long-term exposure to organic solvents can cause memory and concentration impairment as well as dementia. In the case of what is called solvent dementia (painter’s syndrome), the condition stops worsening as soon as the person is no longer exposed to the organic solvents.

Metabolic diseases

These diseases are rare causes of dementia. There are different types of the body’s metabolic processes that can affect the brain, so that it produces dementia symptoms. It is not only diseases of the overall metabolism, which are controlled from the thyroid gland, that can cause dementia.

It can also be disturbances in the amount of calcium ions in the blood (a rare condition). For example, lack of vitamins B1 and B12, either because you get too little vitamin in the diet or because the vitamins cannot be absorbed by the body, can lead to damage to the spinal cord, which causes sensory disturbances in the legs as well as memory and concentration impairment.





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10 WARNING SIGNS OF DEMENTIA

10 warning signs of dementia

The American Alzheimer's Association has prepared a list of 10 warning signs for Alzheimer's disease. However, the 10 signs are so broadly formulated that they will also apply to most other dementias.

We all change as we grow older. It may become a little more difficult to learn new things and tasks may not be done as quickly as before. However, it is important to distinguish between normal aging and disease. If you experience significant changes in e.g. memory or behaviour, it is important to see a doctor, be examined and find out what the cause is.

Even if you notice one of the 10 warning signs in yourself, it does not mean that you are about to develop dementia. It's completely normal to forget a single appointment, to not be able to find your keys and wallet on the way out the door. Using reminders to keep track of your appointments and purchases is also completely normal. You may experience moments when you cannot think of a particular word. You may also have experienced standing and looking into the fridge and actually can't remember why. We've all been there!

The main point is that all of this is completely normal and it's important to remember this when reading through the 10 warning signs in this eBook. However, if several of the problems appear more frequently than usual - or clearly worsen, it may be time to make an appointment with the doctor.





1. Memory loss:

One of the most common early signs of dementia is forgetting recently learned information. While it's normal to forget appointments, names, or telephone numbers, those with dementia will forget such things more often and not remember them later.



2. Difficulty performing familiar tasks:

People with dementia often find it hard to complete everyday tasks that are so familiar we don't usually think about how to do them. A person with Alzheimer's may not know the steps for preparing a meal, using a household appliance, or participating in a lifelong hobby.



3. Problems with language:

Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease often forgets simple words or substitutes unusual words, making his or her speech or writing hard to understand. If a person with Alzheimer's is unable to find his or her toothbrush, for example, the individual may ask for 'that thing for my mouth'.



4. Disorientation to time and place:

It's normal to forget the day of the week or where you're going. But people with Alzheimer's disease can become lost on their own street, forget where they are and how they got there, and not know how to get back home.



5. Misplacing things:

Anyone can temporarily misplace a wallet or key. A person with Alzheimer's disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl.



6. Problems with abstract thinking:

Managing finances can be hard when the task is more complex than usual. Someone with Alzheimer's disease could forget completely what the numbers are and how to use them.



7. Poor or decreased judgment:

No one has perfect judgment all the time. Those with Alzheimer's may dress without regard to the weather, wearing several shirts or blouses on a warm day or very little clothing in cold weather. Individuals with dementia often show poor judgment about money, giving away large amounts of money to telemarketers or paying for home repairs or products they don't need.



8. Changes in mood or behaviour:

Everyone can become sad or moody from time to time. Someone with Alzheimer's disease can show rapid mood swings, going from calm to crying to anger-for no apparent reason.



9. Changes in personality:

People's personalities ordinarily change somewhat with age. But a person with Alzheimer's disease can change a lot, becoming extremely confused, suspicious, fearful, or dependent on a family member.



10. Loss of initiative:

It's normal to tire of housework, business activities, or social obligations at times. The person with Alzheimer's disease may become very passive, sitting in front of the television for hours, sleeping more than usual, or not wanting to do usual activities.



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WHEN MY HUSBAND GOT DEMENTIA

A personal story - when my husband got dementia

Barthe Risom Holst with her husband, Ebbe Holst.

Barthe Risom Holst is an active 70-year-old who is, among other things, vice-president of the DaneAge Association (Ældre Sagen Them), where she is also a dementia manager. She volunteers at a local thrift store, and she enjoys being an art consultant at Midjyllands Kunstcenter in Denmark several hours a week.

Barthe Risom Holst is married to Ebbe Holst, who is living with dementia. He lives at Ådalen, which is a dementia unit in connection with Funder Plejecenter, in Silkeborg. He has lived here since December 1, 2014, which is a day that Barthe Risom Holst still clearly remembers: “I don’t want to be his nurse, but his wife, and I had to send him to a nursing home – even though I had promised him not to. It’s the hardest decision of my life.”

The day they drove to the nursing home, Ebbe Holst asked if he was going to a nursing home when they saw the large sign ‘Funder Plejecenter’. Barthe tell us “I just said no, we’re going to live in a house over there and I pointed. It’s hard to lie, but I do it for his good. So that he doesn’t get upset.

The first signs of dementia...

Ebbe Holst worked for many years with computers. He is 10 years older than his wife, so he left the labour market long before her. But he was very active, so he looked after both the house, the garden, washing and shopping. In

addition, he worked with websites in his spare time. Together with Barthe Risom Holst, he also had an interest in amateur theatre, camping, as well as their holiday, home on Bornholm. Sailing was also a common passion that they cultivated (including in the Mediterranean). It was on a canal voyage in the South of France that the first signs of a dementia disease appeared. In 2009, the couple went sailing with a team of friends. Suddenly Ebbe Holst did not want to steer the boat and he was uncomfortable with the locks, even though he was an experienced sailor.

Later in the same year, they visited their holiday home. Ebbe was driving the car on a route he was familiar with but had suddenly lost his way and drove in the wrong direction. He had trouble remembering the activities they had agreed on for their holiday.

I don’t want to be his nurse, but his wife, and I had to send him to a nursing home – even though I had promised him not to. It’s the hardest decision of my life.

Seeking medical help

The following year, the forgetfulness increased – and the arguments so often that Barthe Risom Holst chose to talk to her own doctor about it. She was told that Ebbe Holst himself would have to be involved if action was to be taken. He then went to the doctor himself but could not remember what they had talked about. Therefore, Barthe Risom Holst went with her husband to the doctor. Here they agreed to contact Odense University Hospital (OUH).

Ebbe had to undergo blood tests, spinal cord tests, CT, and MRI scans. Finally, a meeting with a neuropsychologist. All of this resulted in the diagnosis of Frontal lobe dementia on the right side.

Ebbe Holst was immediately prescribed mood-stabilising medication when he became very upset and angry at the effects the disease was having on his life.



Moving to a new house

As the challenges of Ebbe's illness grew progressively worse, the couple made a difficult decision to sell their home. The couple wanted to move closer to their daughter, son-in-law, and grandchildren.

After the move, it became necessary for Ebbe to receive additional support and for Barthe to have some help with the increasing caring responsibilities for her husband. Ebbe was given a place in a respite care facility that specialises in caring for people with dementia. While this was a difficult transition initially, after the first few visits, Ebbe settled in very well and was happy. The move also gave Barthe the time she needed to be herself and get out of the house.

Managing everyday life

Ebbe still wanted to help in everyday life – for example, setting the table. But he was annoyed by the fact that he couldn't remember where things were. To support her husband, Barthe labelled the kitchen cupboards with numbers so she could easily direct Ebbe and enable him to still feel some normality.

For many years of her normal working life, Barthe worked a lot with dementia equipment. She therefore knew of a stove guard that can turn off the stove if you forget. She was therefore given a stove guard so that no accidents occurred if the stove was not turned off. With the stove guard installed, the stove could be used as before, so no new routines had to be learned. Something that becomes more difficult the older you get – and especially the more advanced the dementia disease is.

Ebbe continued to walk the couple's dog every day, but gradually it was the dog that walked him. He could no longer find his way.

Eventually, the effects of Ebbe's dementia meant he started to have difficulties with using the bathroom and Barthe had to convince him it was time to use specialist underwear. Sleep was also affected, and Barthe found her husband no longer slept at night but took short naps instead. Often, he would wake her throughout the night and start conversations about all sorts of things that he had just been thinking about. At this stage it became necessary to increase the respite care from two nights to three nights per week.

As other everyday activities became impacted, such as switching on the TV, the caring responsibilities for Barthe increased and the couple became more isolated, only seeing each other which Barthe felt made her husband bored.

Due to the development of Ebbe's illness, Barthe was hardly out of the house for two years.

The hardest decision

In 2014, as Ebbe's condition worsened, Barthe had to assess how much she could handle. She spoke to friends and specialist support agencies about the actions she could take to ensure Ebbe received the care he needed. There were three care home options for Ebbe, and while this was the hardest decision Barthe had ever made, she decided that she must give her husband the care he needs in a nursing home setting.

Barthe and her support team were very careful with moving Ebbe's furniture and belongings into his new home. It was important that Ebbe was familiar with some elements of his surroundings. Friends helped with the move to provide even more stability and support with the transition.

On the day that Ebbe moved, he was welcomed in such a way that Barthe felt like she quickly became redundant. However, she was very careful to ensure this new living arrangement felt like their home, together. Barthe says: "He thinks we still live together, so I never say 'goodbye' or 'hello'. At most, I have to go shopping, and then he quickly forgets about me again – and suddenly I'm here again. He should not have the feeling that I am leaving him".

Barthe told us: "Of course. He must feel his best in his final days with dementia. I put a lot of effort into taking care of him, but also of myself. Because if I break, I can't be there for him. And Ebbe has been a great man for me. My best friend and husband. We've known each other for 37 years".

Sadly, Ebbe passed away in 2021. We extend our deepest condolences to his wife, Barthe, and express our sincerest gratitude for allowing us to share this deeply personal story with you. Barthe and Ebbe's story resonates with millions of dementia patients worldwide.

He thinks we still live together, so I never say 'goodbye' or 'hello'. He should not have the feeling that I am leaving him.



5

CARING FOR SOMEONE WITH DEMENTIA

Caring for someone with dementia is more than just medication

It is important to remember that people with dementia are still people. While the disease affects the brain and its functions, behind the illness there is still someone's partner, parent, sibling, friend or loved one.

In the early stages, dementia is first and foremost a great challenge for the person living with dementia, but gradually their family are also affected by the changes that occur. Caring for people with dementia requires great empathy and empathy on the part of the family. And that can mean new ways of doing things – and finding new ways of being together.

Communication, care and respect are key words when interacting with people who have dementia. Whether you're a healthcare professional or a family member, it is important to always keep this in mind. Alzheimer's Association's director, Nis Peter Nissen tell us that we must "see the person behind the disease".

Dementia means the brain doesn't process information as it should, which means the person living with the condition becomes unable to do things they once could. This can be extremely frustrating for both the individual and to someone caring for them., and it can be hard to always **see the person behind the disease**.

People living with dementia are in the process of change. The focus should be on things the person can still do, and which create joy and energy. The condition represents a new stage of life, and a way of living that adapts to the gradual changes brought by dementia.

When someone is diagnosed with dementia, it is not something to be kept secret. Quite the opposite, in fact! By sharing with family, friends, and any other relevant person, you can create an environment where the person is better supported and there is understanding. With so many people diagnosed with dementia, this is not something that should be a taboo subject and we must break down the stigma.

CARING FOR PEOPLE DEPENDING ON THEIR NEEDS

The English sociologist, psychologist, and professor Tom Kitwood (1937-1998) researched dementia care and developed a value base and a philosophy of care. With this work, he has inspired many to work with a new culture in dementia care.

Through his research, Tom Kitwood emphasised five psychological needs which are essential in all people. These essential needs were brought together as the 'Kitwood Flower' model. This model is often included in the training given to people working in dementia care.



The Kitwood Flower

1. Comfort

All people need comfort and relief from pain and sorrow in the form of tenderness, presence, and security.

2. Identity

All people need to see and reflect themselves in others – it is important to be able to maintain one's identity and continue to be who one is.

3. Occupation

All people need to occupy themselves with something meaningful, as it gives content to everyday life and strengthens our self-esteem.

4. Inclusion

All people need to join communities and participate in meaningful activities to experience satisfaction and quality of life.

5. Attachment

All humans are social creatures who need connection with someone. It gives a sense of security.

If the five psychological needs are met, the feeling of being loved is also met. That is why love is seen as the central part of the 'Kitwood Flower'.



Alzheimer's is a common type of dementia caused by two proteins that deposit in the brain, leading to memory loss, personality changes, and eventually affecting vital functions.



If you are a professional...

For professionals who work with people affected by dementia, there can be many challenges. Knowledge of Tom Kitwood's psychological needs can be an aid to the effort and a structured approach to dementia care.

According to the Danish National Knowledge Center for Dementia, person-centred care implies that professional caregivers should ensure they:

- Value the person with dementia as a unique and equal person despite the mental challenges.
- Organise individual care and treatment, which is based on the special features of each individual person.
- Try to understand what is best for the person with dementia from their perspective.
- See the person with dementia as an active collaborative partner.
- Strive to involve the person's social network in care.

If you are a relative...

As a relative, a lot can be done to ensure that the person with dementia maintains their dignity, identity, and sense of self-worth. The disease affects the ability to articulate and understand others. It is therefore important to take the time to listen and understand how to communicate.

In the story we share giving a personal insight, Barthe Risom Holst shared the things she did to help her husband maintain as much of himself and his personal dignity as possible. She told us the effort she made to include her husband in normal daily life. A good example is that her husband would like to help with the daily chores. She therefore put numbers on the

kitchen doors, so that she could easily direct him. Then her husband could still help set the table when they had to eat. And he didn't feel humiliated that he couldn't remember where those plates were.

Helping a loved one with dementia feel productive and involved even at home is a key part of dementia management. To help make your loved one feel a sense of accomplishment even in the comforts of their own home, engage them in any of these five activities:

Untying knots

Untying knots can be very therapeutic for people with dementia. The activity engages their motor skills without exerting too much physical effort. Having a loved one with dementia undo knots on a piece of rope also has emotional benefits. You'll see right away that upon finishing the task, they'd have a sense of accomplishment which can boost their self-esteem.

TIP: When choosing a rope, make sure it has a fairly large diameter and is soft to the touch.





Keep the knots simple—don't make them too hard to unravel.

Sorting and folding laundry

Another stimulating task that you can involve people with dementia in is sorting and folding laundry. It might sound like an easy chore to many of us, but to someone with dementia, it's a way for them to keep busy and have a sense of accomplishment. Those with dementia often want to feel like they're still contributing to the household. Sorting and folding laundry accomplishes that. Plus, your clothes get sorted—it's a win-win situation!

Other similar activities you can try with someone who has dementia that involves sorting are: pairing socks, sorting cutlery and crockery, organising drawers.

TIP: When someone with dementia is doing the laundry, give them items that are relatively easy to fold like hand towels and socks. If you ask them to help you sort knives and forks, be cautious when it comes to knives and other sharp items.

Creating a box of memories

Helping your loved one create a box full of their mementos and souvenirs is a great way to keep them connected with their past.

Sit down with your loved one and talk to them about what they used to do back when they were younger.

You can then help them go through the house and fill a box with items that either remind them of those times or actual keepsakes from the past.

Say your loved one has a passion for painting, you can help them fill the box with brushes, paint pots, and water wells. If they were career-oriented in their youth, you can put items in the box that remind them of their career—office supplies like pens, paper clips, envelopes, and folders.

If the person with dementia was an avid cook back in the day, you can help them make a recipe box. Type out recipes on hard-stock cards and ask your loved one to sort and keep them in a nice wooden box.

Photographs, music, and other mementos are all perfect as well. You might be amazed by the stories that surface with each piece.

TIP: You can even engage in a bit of arts and crafts with your loved one by helping to design the actual box they'll keep their memories in.

Playing their favourite songs

Music is a good way to stimulate anyone's senses. This also holds true for those with dementia.

Set aside some time to talk to your loved one about their music preferences. Ask them about the music or sounds they enjoy listening to.

You can look for their favourite songs on apps like Apple Music and Spotify. You and your loved one can sit and enjoy the music together.

Doing this can help them feel at ease and may even help them recall happy memories.

TIP: Be mindful of the music's volume, especially if your loved one enjoys upbeat songs.

Cooking and baking

Like sorting clothes, cooking or baking simple dishes in the kitchen can help your loved one feel a sense of accomplishment. Working in the kitchen is also a good way to have someone with dementia to excite their motor and sensory experience.

The kind of kitchen duties you let your loved one perform should be on a case-by-case basis. If they're more able, you can have them peel, chop, or mix ingredients. For those who aren't so agile, they can be given other tasks like pouring or measuring.

TIP: When in the kitchen with someone who has dementia, it's best to let them do as much as possible while ensuring their safety. Have them wear oven mitts and an apron. If something needs to go in or out of the oven, make sure you're there to assist.



- Try to establish a personal relationship with the person with dementia.
- Create a supportive environment around the person.

CARING FOR THOSE WHO CARE

If you are a caregiver for someone with dementia, it is easy to become so focused on the needs of the person you are caring for that you neglect your own needs. However, taking care of yourself is just as important as taking care of your loved one.

Avoid burnout

Caregiving can be physically and emotionally exhausting, and without proper self-care, a caregiver can quickly become burnt out. Burnout can lead to feelings of resentment, frustration, and even depression, making it harder to provide effective care to your loved one. Here are some tips to help with this:

- Set limits and communicate them to others – be realistic about how much time, energy and effort you can commit to as a caregiver.
- Ask for help when needed – reach out to family, friends, medical professionals and specialist organisations.
- Take care of your physical and mental health by getting enough sleep, eating well, exercising, and seeking support if needed.

Maintain good physical health

Neglecting your own physical health can lead to a range of health problems, such as high blood pressure, diabetes, and obesity. As a caregiver, it is important to stay healthy so that you can continue to provide care to your loved one. Some examples of the things that help you to stay physically well:

- Stay physically active – walking and getting fresh air is a great start and is a good activity for a person with dementia too. Enjoy getting out into nature.
- Eat a healthy and balanced diet with plenty of fruits, vegetables, lean protein, and whole grains.
- Get enough sleep – aim for seven to eight hours a night and establish a sleep routine. Rest and routine are also great for dementia patients, although it can become more difficult to ensure enough sleep as the disease progresses, which is why we will refer you back to the points under avoiding burnout and asking for help.

Maintain good mental health

Caregiving can be stressful and emotionally challenging, leading to feelings of anxiety and depression. Taking care of yourself can improve your mental health and help you better manage the emotional demands of caregiving. Some ideas for how you can ensure good mental health:

- Take care of yourself by doing things you enjoy and that help you relax.
- Connect with others and seek support when needed.
- Practice mindfulness techniques regularly to reduce stress and promote relaxation.

Set a good example

Taking care of yourself sets a good example for your loved one, showing them the importance of self-care and healthy habits.



Maintain relationships

Caregiving can be isolating, but maintaining relationships with friends and family members can help combat feelings of loneliness and provide a source of support. It's important to maintain your relationships with friends and family members because they can be a valuable support network for you:

- **Be proactive:** Take the initiative to reach out to friends and family regularly. Let them know about your caregiving responsibilities and your loved one's condition and make plans to get together when possible.
- **Be flexible:** Understand that your caregiving responsibilities may limit your availability for socialising but try to be as flexible as possible. Consider inviting friends and family over to your loved one's home or finding activities that can be done together.
- **Be honest and realistic:** Be honest with friends and family about the challenges you are facing as a caregiver, but also be realistic about your limitations. Don't be afraid to ask for help or support when needed and try not to overextend yourself.





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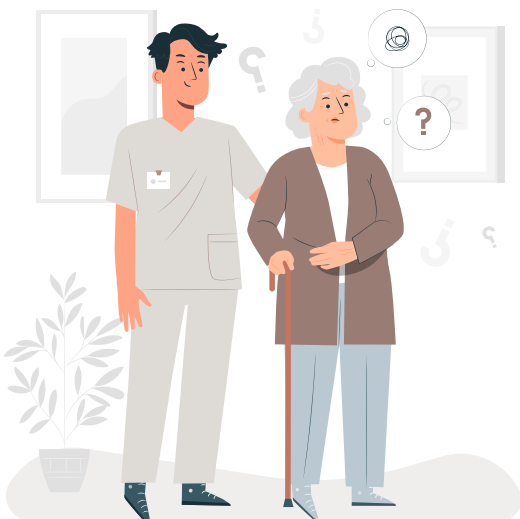
WHEN SOMEONE YOU LOVE HAS DEMENTIA

When someone you love and care for has dementia

Help is needed when someone you love and care for has dementia. It's important to see help and support as vital and not as a sign of failure. These services are there for you to use. By accepting help and support, it can help you to learn how to best live your new life with dementia.

Many people are likely to resort to the internet in the first instance and there are several useful websites for this purpose. It is also likely that help is available through local organisations where you live. There are various aids for several stages of dementia too.

Remember, the type of support you need may not just be for managing this illness, you may need to consider things like legal and financial assistance, as well as support for anyone who is a caregiver to a person affected by dementia. Take time to carefully consider and ask for all the support that is needed – having dementia should not limit life when so much support is on offer.



SAFETY AIDS

In the beginning, the effects of dementia are first and foremost felt by the person living with the condition, but the family is also increasingly affected by the changes that occur.

It requires great empathy to take care of people with dementia – and over time, there will be a need for technological aids. When the disease is in its early stages, mobility is often unaffected and being able to go for a walk can help to preserve wellbeing and personal freedom, particularly as they may no longer be able to drive. Continuing with activities of daily living such as cooking can also be beneficial, and technology can help to make these activities safer and therefore prolong them.

Here are some safety aids that are available...

GPS

The lack of orientation is naturally a cause for concern. Therefore, you may want to consider getting a GPS transmitter. A GPS tracker is available with and without an alarm button – and a GPS is typically small and light, so it is easy to carry in your pocket.



A GPS can be used to contact to a control centre. Here, alarm operators can log in to a computer system where they can follow the person's movements if needed. The system is only logged in when an alarm is given from a GPS transmitter or if the control centre is notified about it.

GPS transmitters are fairly accurate, but a basement room or a dense forest will present challenge in relation to the position. In such cases, however, it will be possible to trace which route the person has taken and confirm the last known place of the individual.

When investing in GPS transmitters, it does not mean that you have a dementia protection system. A modern and secure system consists of a wide range of products that can be targeted at the individual. As the person's situation changes during the course of the disease, it is extremely important that a thorough analysis of their skills is carried out on an ongoing basis. For example, equipping people with dementia with GPS could have disastrous consequences if they are unable to assess traffic – and therefore risk going out in front of the cars.

GPS transmitters should only be used by people who are able to go out on their own. It's important to keep the GPS transmitter charged for safety. Talking to a local specialist can help choose the best equipment for safety and provide assistance when the disease progresses.

Stove guards

A stove guard is a useful tool for people who may forget to turn off the stove. It should be chosen to allow normal stove use, as it's harder to learn new routines as you age or as dementia progresses.

Smoke detector

Most of us have smoke alarms to protect our homes. But there are also smoke alarms that are available as part of a telecare system that will automatically alert a manned control centre if activated, so if the person living with dementia is unable to react to the alarm, help can be sent.

Identity card

When the person with dementia is still moving around on their own, an ID card may be a good idea. The ID card may contain the name, phone number of a contact person, and information that the carrier of the ID card has dementia. For example, the ID card can be a wristband so that helpful people can easily get to the contact information.

AIDS FOR SUPPORT AND SECURITY

In addition to the safety aids, there are also products that can make it easier to live with failing memory and sense of place. Here are a few examples:

Phones

Easy-to-use phones are available with both number and photo keypads, so it's easy to dial selected numbers. Mobile phones can also have a built-in GPS tracking function that makes it possible to locate the person carrying the phone.

Duvets

There are specially developed duvets that are soothing and sensory stimulating. For example, they can help reduce anxiety and restlessness – and therefore provide better sleep.

Tight-fitting jackets

Many people with dementia can experience a sense of security when they wear slightly heavy and tight-fitting clothes. The weight and pressure provide a clear body sensation and provide optimal sensory stimulation that can reduce anxiety, hyperactivity, and stress.

Digital photo frames with sounds

Digital photo albums can help people with dementia recognise people from the pictures. They are available in different versions, where images can be inserted, and a short message can be recorded for each image.



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**HOW DOES TUNSTALL
SUPPORT PEOPLE
WITH DEMENTIA?**

How does Tunstall help to support people with dementia?

Technology innovations can provide valuable support for people with dementia and their caregivers, helping to promote safety, independence, and socialisation, as well as reducing stress and improving quality of life.

Essentially, helping to maintain as much of the whole person for as long as possible, providing choice for how a person lives their life, regardless of their dementia diagnoses. Technology innovations can be a key contributing factor to the critically important holistic approach that is required.

Supporting People with Dementia and their Carers

Technology can facilitate the delivery of care at home, enabling people with dementia to stay in familiar surroundings for as long as possible, helping them to enjoy a better quality of life for longer, as well as offering invaluable support to carers. When residential care becomes the most appropriate environment, technology can help



to provide improved levels of care, supporting staff and protecting the safety and dignity of residents. As more is understood about dementia in its various forms it is clear that enabling technology has the potential to make a significant and positive difference to the lives of people with dementia, and the ability of our health and social care systems to support their needs effectively.

Solutions to Support Dementia

Tunstall offers a range of connected care and health solutions, which use advanced technology to provide enhanced care and support for people with dementia. Solutions are tailored to the needs of the individual and their circumstances, are designed to evolve over time as the users' requirements change.

You can find more information about our solutions on:

- Group website: www.tunstall.com
- Australia website: www.tunstallhealthcare.com.au

Why Tunstall?

Tunstall has been at the forefront of technology innovation for the health, housing and social care markets for over 65 years. Its pioneering software, hardware and services enable providers to deliver integrated, efficient and person-centred care in the community, and empower people to live independently and with an improved quality of life.

Tunstall works with social care providers, healthcare services, housing and retirement living providers and charities in 18 countries, improving the lives of more than five million people, including those living with dementia, learning disabilities, physical disabilities and long-term health conditions.

As technology advances and solutions become increasingly digital and cloud-based, we will work closely with our customers and partners to enable them not just to react to events, but to predict and even prevent them, using data-driven insights. Our focus is on creating a more connected world that fulfils the potential of technology to offer intelligent care and support and give people greater choice and control about how they live their lives.


**TOGETHER
AGAINST
DEMENTIA**

This eBook has been produced with support from the experts within our organisation, and using expertise from the partnership we have with local health and care services and charitable organisations. This eBook has been written in English and has been translated into Finnish, French, German, Spanish and Swedish.

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TUNSTALL AGAINST DEMENTIA



Dementia can be a daunting diagnosis, but it doesn't mean that life is over. However, navigating this chapter requires a positive and proactive attitude, as well as the right resources to maintain independence and quality of life for as long as possible.

Our mission is to provide practical and useful information to those caring for someone with dementia, as well as those directly affected by the disease. We hope this eBook can be a tool to improve the lives of everyone impacted by this condition.