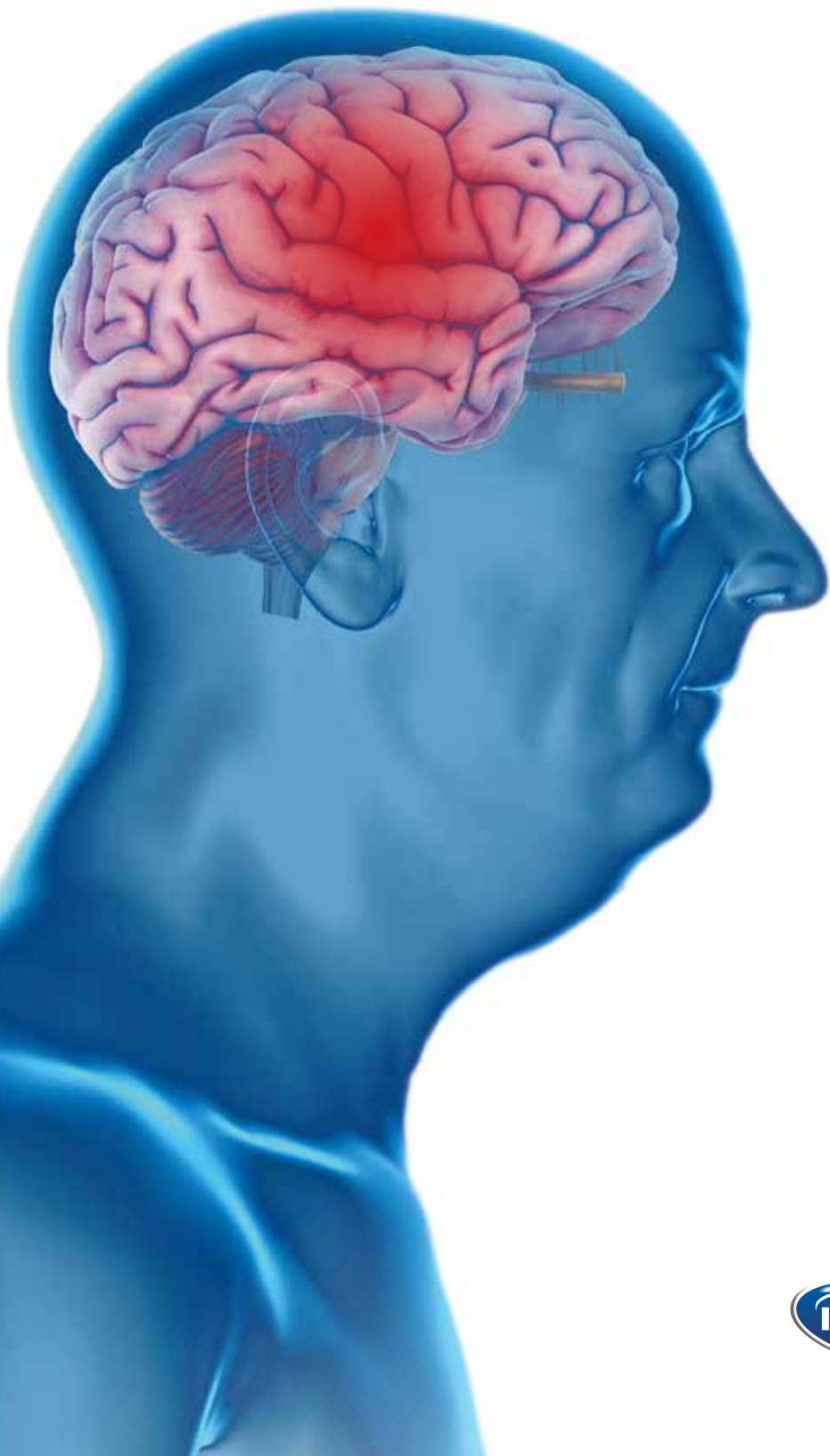


Dementia

Clinical Guide



Yes, you can.®

Main author

Rhona Moot

Occupational Therapist,
Clinical Specialist, Europe

Contributors

Megan Bennett

EMEA Marketing Communications
Specialist, Europe

Sian Philpin

EMEA Marketing Communications,
Europe



Contents

Introduction	4
Chapter 1	
Manifestation of dementia	6
Chapter 2	
What is dementia?	12
Chapter 3	
Types of dementia	18
Chapter 4	
Dementia care models	32
Conclusion.....	42
References	44



Our brain is the
**most complex
organ in our body**

responsible for every
conscious and
subconscious action
we make

Introduction

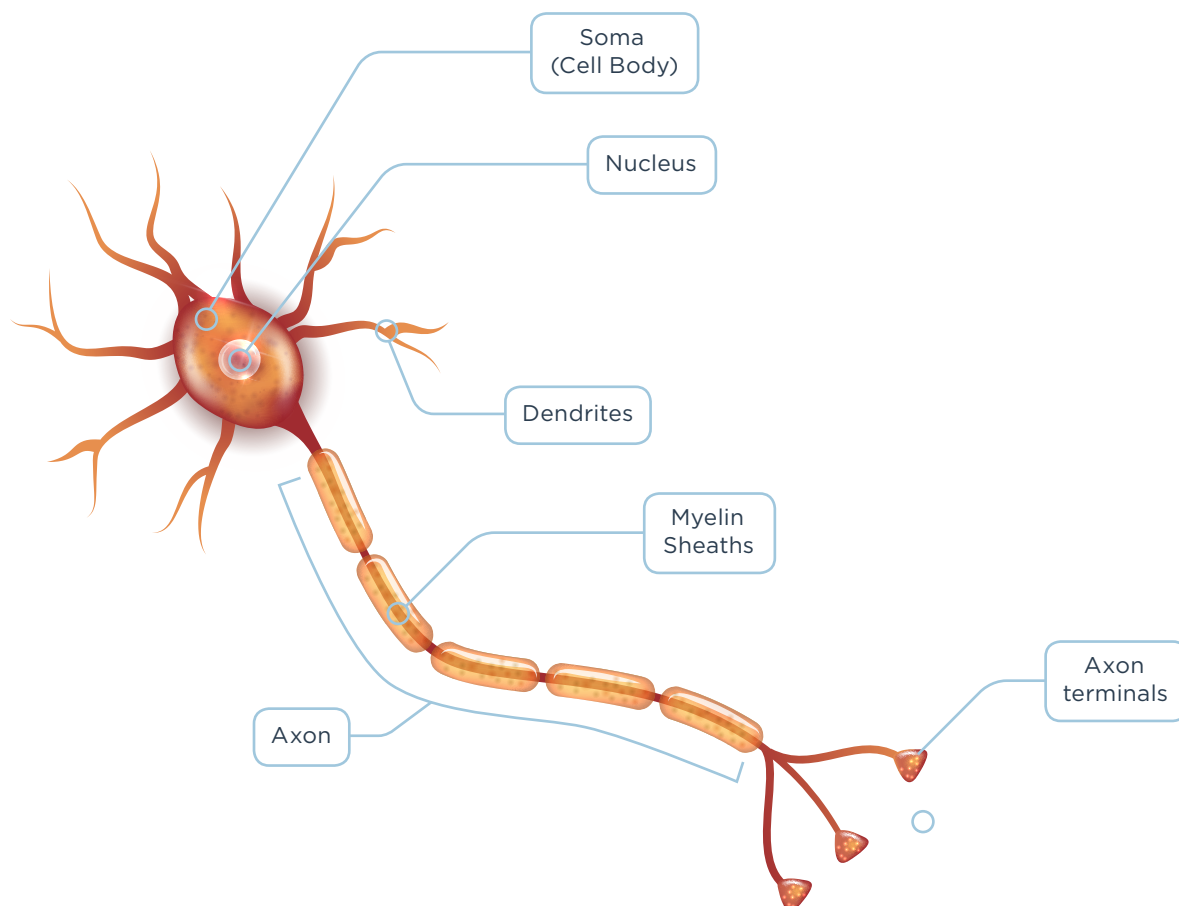
The brain and how it functions

► Our brain is the most complex organ in our body; it is our body's control centre, responsible for every conscious and subconscious action we make.

Our brain is made up of different parts, each of which has a different function. Sometimes, parts of our brain work independently in order for us to perform a particular task, but for more complicated actions such as memory, language and vision, all the different parts of our brain work together.

Our brain contains billions of tiny nerve cells called neurons.

Neurons act as chemical messengers, transferring chemical signals from our brain to our body, to activate various bodily functions



Pre-synaptic

The neuron which carries the chemical signal is referred to as the pre-synaptic neuron, while the neuron which receives the signal is known as the post-synaptic neuron.

Re-uptake pump

Synaptic vesicle

A synapse occurs when two neurons come close enough together without touching, but can give signals from one to the other.

Neurotransmitter

Chemical signals, otherwise known as neurotransmitters, are passed between neurons in the form of a synapse.

Synaptic cleft

The small space between the neurons in which signals are transferred is called the synaptic cleft.

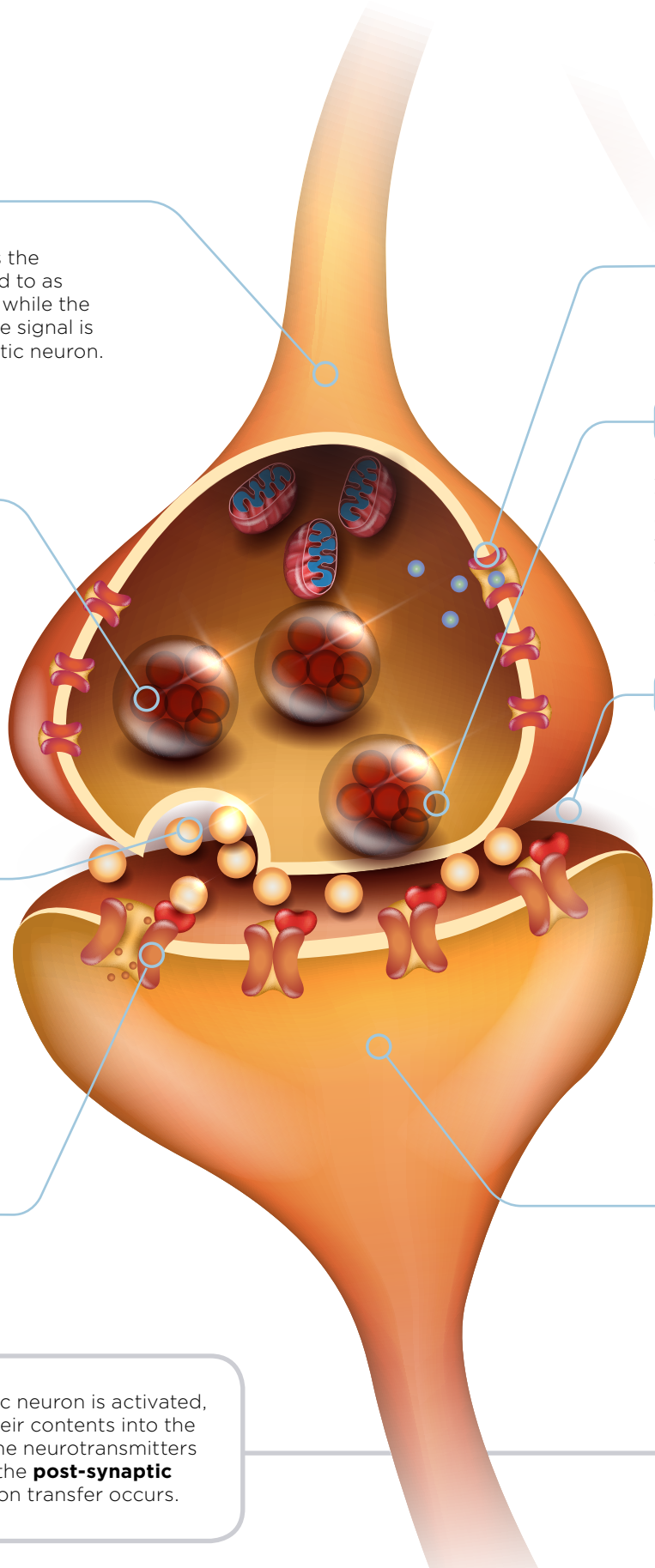
Vesicle fuses with cell membrane

Within the pre-synaptic neuron, tiny sac-like structures called vesicles hold thousands of neurotransmitters.

Receptor

Post-synaptic

When the pre-synaptic neuron is activated, the vesicles release their contents into the synaptic cleft. Here, the neurotransmitters bind to **receptors** on the **post-synaptic** neuron, and information transfer occurs.

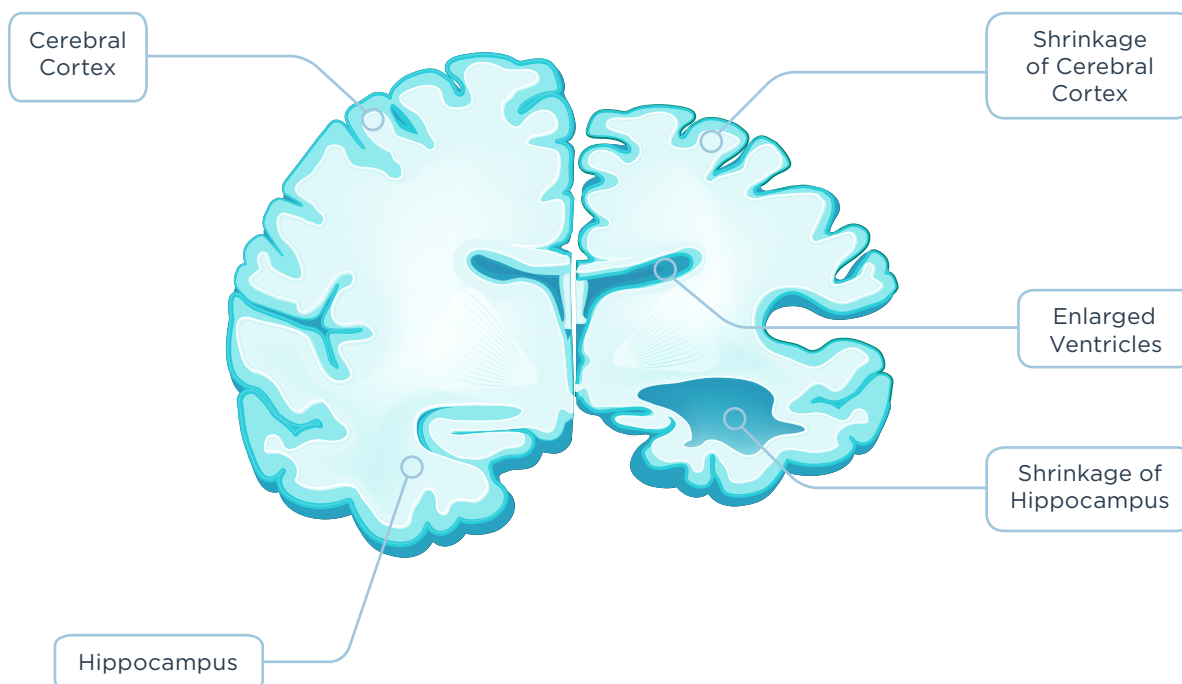


Manifestation of dementia

1

► Dementia occurs when neurons are no longer able to transfer chemical signals from one to the other, when this happens the neurons die off. As neurons die, changes in the brain start to occur including what's known as atrophy (wasting).

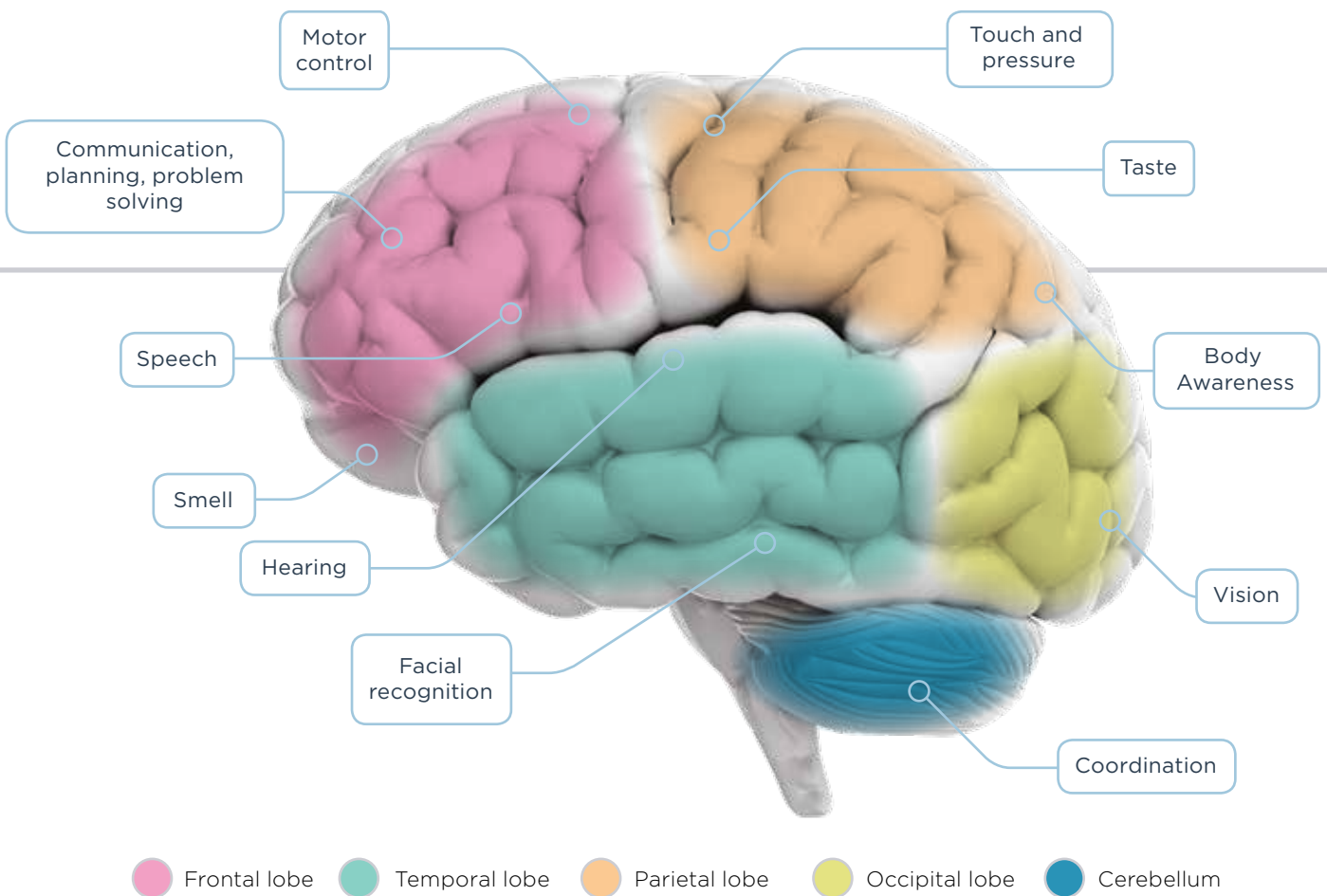
This atrophy or wasting causes the brain tissue to shrink and eventually die, as can be seen in this example of a healthy brain and one that has been affected by Alzheimer's disease.



The brain is a hugely interconnected organ, but three major areas can be identified, **the cerebrum, the cerebellum and the brainstem**. The brainstem found at the base of the brain connects the brain with the spinal cord. The brain stem contains the medulla, pons and midbrain and is responsible for autonomic body functions such as heart rate, breathing and digestion.

The cerebellum or (little brain) as it is also known, is responsible for attention, language and emotional functions (such as fear and pleasure) as well as the processing of procedural memory. The primary role, however, is in the regulation of posture and balance. Although it accounts for 10% of the brain's volume, the cerebellum contains over 50% of the total number of neurons in the brain; it integrates nerve impulses from the inner ear and from proprioceptors in the muscles.

The cerebellum contains over
50%
of the total number of neurons in the brain



The cerebrum, also known as the forebrain, is the most highly developed part of the brain. It makes up 75% of the brain in volume and 85% in weight and is divided into two distinct hemispheres, left and right and is characterised by its lined appearance. These lines or folds increase the overall surface area of the cerebrum, increasing the amount of grey matter and the quantity of information that can be processed in the cerebrum. Its grey colour is attributed to neurons found in this part of the brain. Neurons in the cerebrum lack insulation (or Myelin).

Without insulation, the neurons have a greyish appearance, neurons which are insulated via a myelin sheath, appear whitish, hence where the terms grey and white come from.

As mentioned the cerebrum consists of two hemispheres, left and right, which control opposite sides of the body, i.e. the right hemisphere controls the left side of the body and vice versa. Both right and left hemispheres are broken down into four lobes, the frontal lobes, the temporal lobes, the parietal lobes and the occipital lobes, each of the lobes are responsible for different functions.

Four lobes of the brain

a

Frontal lobe

► **The frontal lobe is considered our emotional control centre and home to our personalities.**

There is no other part of the brain where damage can cause such a wide variety of symptoms (Kolb & Wishaw,1990).

The frontal lobes are responsible for higher executive functioning such as thinking, memory, planning, decision making, spontaneity, problem solving, emotion, impulse control, behavioural control, judgement, initiation, language, plus social and sexual behaviour. Therefore, in frontotemporal dementia; personality changes are often the first signs of the disease. One of the most common characteristics, however, of frontal lobe damage

is difficulty in interpreting feedback from the environment and spatial orientation, including awareness of one's own body in space, also known as proprioception.

The frontal lobes also contain the primary motor cortex, the region of the brain responsible for voluntary movement. Disturbance of motor function can be characterised by loss of fine motor movements, such as movement of the fingers and hands, but it can also affect the strength of the arms (Kuypers,1981). Patients with frontal lobe damage also commonly exhibit little spontaneous facial expression, suggesting the role of the frontal lobes in facial expression (Kolb & Milner,1981).

b

Temporal lobe

► **Based either side of the temples, it is the area of the brain dedicated to processing sensory information, memory, understanding language, facial recognition, hearing, vision, speech and emotion.**

The temporal lobe contains the auditory cortex. When we listen to and understand speech, sounds are processed in the auditory cortex, signals are then passed through the temporal lobe, where the meaning of the words are processed.

The outer part of each temporal lobe is where we store general knowledge, which is a type of memory known as semantic memory. Our semantic memory allows us to recognise familiar sounds and words processed by the auditory cortex so that we can understand what it is we are hearing (e.g. words, laughing, baby crying, dog barking).

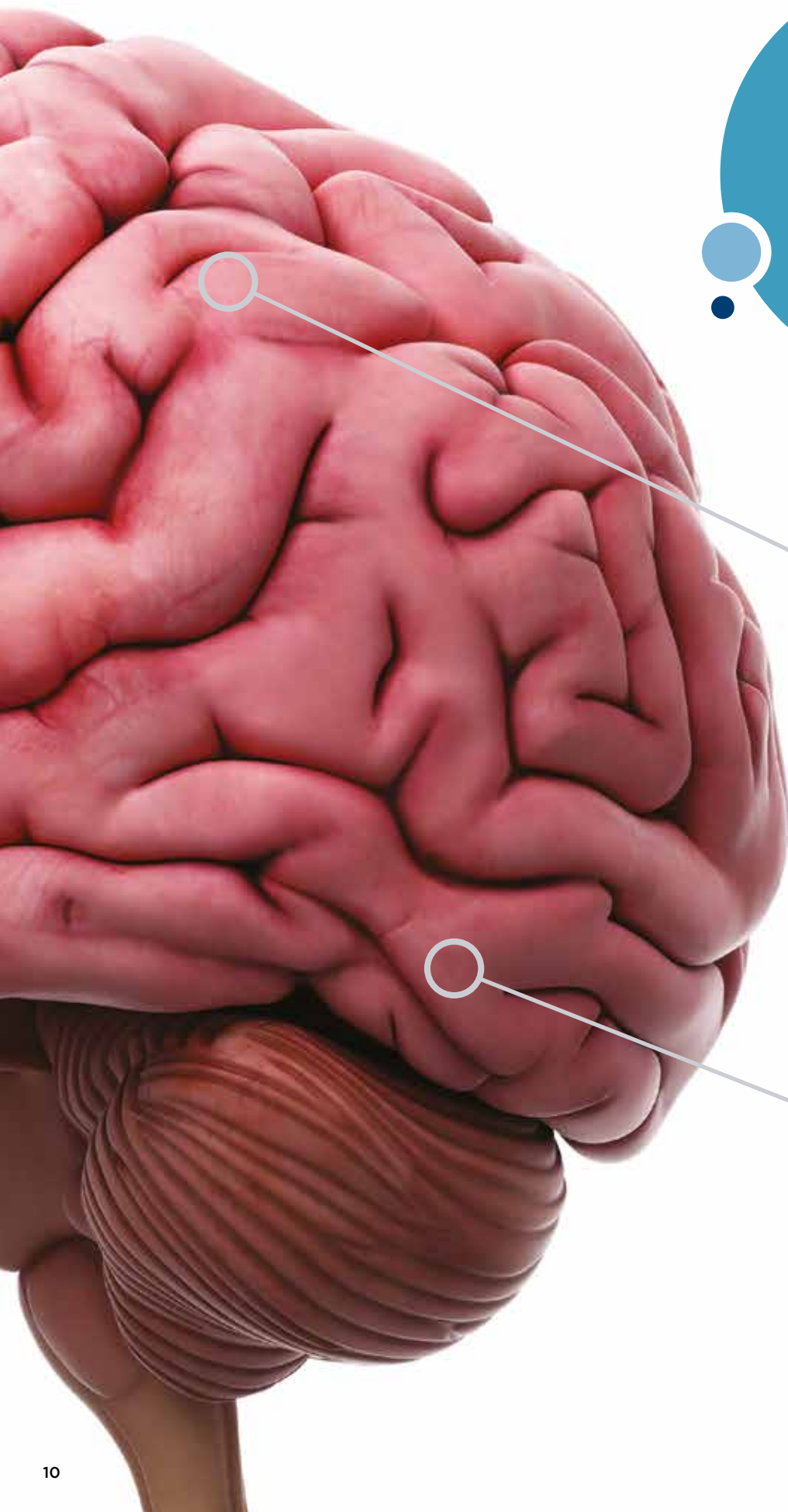
Our memory is closely linked to the hippocampus, a region of the brain also found in the temporal lobe. The hippocampus is essential for memory, learning and emotion. The things we remember, for example, faces, facts and places are all recalled by different types of memory. Episodic memory is our memory of events at a particular time and place. For example: 'I ate eggs for breakfast this morning in my kitchen'. These memories are specific to each of us and can have an emotional aspect.

Semantic memory is our general knowledge about objects, word meanings, facts and people. For example: 'Eggs have a shell and are laid by hens', procedural memory is our memory for skills we have learned. Examples include tying shoelaces, brushing our hair or riding a bike.

Personality changes

are often the first signs of the disease

Our memory is closely linked to the Hippocampus



It is thought that most vision involves some memory, so researchers believe that the role of the occipital lobe has more to do than just with vision

Four lobes of the brain (continued)

Parietal lobe

► **Responsible for integrating sensory information, including touch, temperature, pressure and pain as well as object classification,** spelling, knowledge of numbers and visuospatial processing.

Damage to the left parietal lobe can result in right-left confusion, difficulty with writing (agraphia) and mathematics (acalculia). It can also produce disorders of language (aphasia) and the inability to perceive objects normally (agnosia).

Damage to the right parietal lobe can result in neglecting part of the body or space (contralateral neglect), which can impair many self-care skills such as dressing and washing. Right side damage can also cause difficulty in making things (constructional apraxia), denial of deficits (anosognosia) and drawing ability.

c

Occipital lobe

► **Located at the rearmost point of the brain and is dedicated to vision.** Vision is a highly complex process and involves many different methods, which include mapping the visual world, determining colours, assessing distance, size and depth; identifying familiar faces and objects; the transmission of visual information to other parts of the brain and receiving raw visual data via the retinas of the eyes.

It is thought that most vision involves some memory, so researchers believe that the role of the occipital lobe has more to do than just with vision.

Scanning the visual field, for example, involves you being able to recall what you saw only a few seconds earlier. The occipital lobe works in combination with other parts of the brain to transmit visual information so that different parts of the brain can create a memory, assign meaning to visual stimuli and craft an appropriate motor or linguistic response.

d

2

What is dementia?

► **Dementia is an umbrella term for progressive degenerative brain syndromes which affect memory, thinking, behaviour, emotion, problem-solving, perception and language (ADI 2010).**

The fundamental causes of dementia are not yet known, and no cure has yet been found, however, dementia impacts on an individual's life to such an extent, that it interferes with a person's ability to perform daily life activities.

Although dementia predominantly affects people in older age, it is not a natural part of ageing. As mentioned, the experience of dementia is subjective and unique to everyone; it is determined by several factors including the area of the brain affected and the thoughts, feelings and behaviour of the individual, within their social context.

Dementia is defined by the World Health Organisation (WHO) as:

“ A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple cortical functions, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded by, deterioration in emotional control, social behaviour or motivation”.

Impairments

a

▶ **Generally, dementia develops slowly, and in the early stages of the disease symptoms are not always obvious.** Progression of the illness is often separated into early stage (mild), mid-stage (moderate) and late stage (severe) when the individual becomes reliant upon others for all their daily care needs. Classifying dementia in this way can be helpful when providing an outline of typical symptoms and a degree of difficulties associated with the disease progression. However, not all forms of dementia can be characterised by such distinct stages, the degree of disability encountered at each stage will depend on the individual, the part of the brain affected and their unique set of circumstances, as already described.

Below are the range of symptoms people with dementia may experience:

Cognitive Impairment

- ▶ Memory
- ▶ Confusion
- ▶ Concentration
- ▶ Disorientation
- ▶ Language
- ▶ Learning capacity
- ▶ Judgement
- ▶ Thinking
- ▶ Comprehension
- ▶ Calculation
- ▶ Time perception

Behavioural Manifestations

- ▶ Personality, behavioural and mood changes
- ▶ Apathy
- ▶ Anger
- ▶ Anxiety
- ▶ Sleep disturbance
- ▶ Delusions
- ▶ Hallucinations
- ▶ Physical aggression
- ▶ Depression

Functional Limitations

- ▶ Self-care
- ▶ Activities of daily living
- ▶ Balance and gait
- ▶ Motor skills
- ▶ Visuo-spatial difficulties
- ▶ Disinhibited social behaviour

Not all forms of dementia can be characterised by such distinct stages

Possible risk factors

b

▶ Although currently there is no cure for dementia, researchers have identified several risk factors contributing to the disease, including cardiovascular issues, lack of physical exercise, diet, a mental rut, social isolation, hearing loss and sleep problems to name a few.

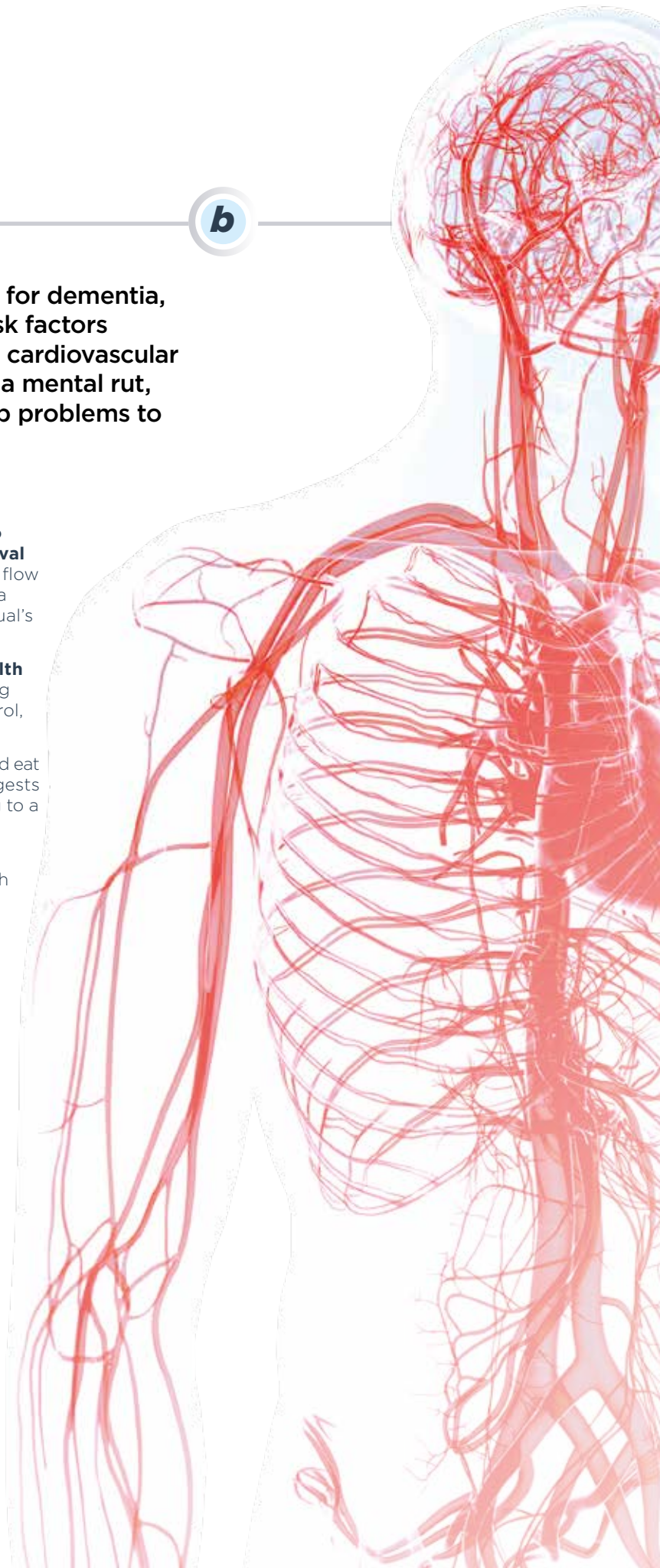
▶ **The brain is nourished by one of the bodies richest networks of blood vessels. Blood carries oxygen, nutrients and other essential minerals to brain cells (neurons) which are vital for cell survival and function.** Anything that reduces or blocks the flow of blood within the body and to the brain, such as a stroke (CVA) or heart disease, increases an individual's risk of dementia.

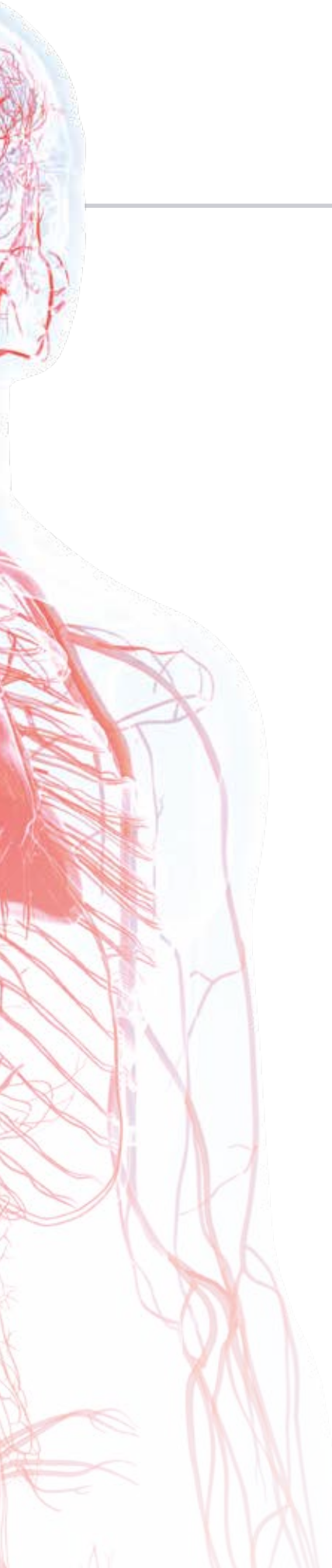
▶ **Taking measures to ensure one's vascular health can help to reduce the risk of dementia.** Managing conditions such as high blood sugar, high cholesterol, obesity and high blood pressure, is paramount.

Therefore, experts advise to stop smoking, exercise, and eat a balanced, healthy diet. Best current evidence suggests that heart-healthy eating patterns, such as adhering to a Mediterranean diet may help protect the brain.

This diet includes relatively little red meat and emphasises whole grains, fruits and vegetables, fish and shellfish, nuts, olive oil and other healthy fats.

Engaging in mentally stimulating activities has also been proven to help slow the rate of cognitive decline





► **Regular physical exercise may also help lower the risk of some types of dementia.** Evidence suggests exercising may directly benefit the brain cells by increasing the blood and oxygen flow and may also enhance the brain's ability to generate new cells.

Engaging in mentally stimulating activities has also been proven to help slow the rate of cognitive decline and help prevent behavioural problems, more so than some medications.

► **Social isolation or a lack of social contact has also been connected to the development of dementia.**

Among older adults outside of nursing homes or other institutions, nearly a third live alone.

Without a job, nearby family or other regular opportunities to socialise, people quickly become isolated which can have a detrimental effect cognitive health.

► **Deafness or difficulties hearing is extremely common amongst the elderly;** however, it is only in the last decade or so that it's been recognised as a possible risk factor due to its association with social isolation, stress and links to depression.

Studies have shown that it influences cognitive health, perhaps by cutting sensory input to the brain.

Furthermore, people who don't get their vision checked or have untreated visual loss could be at higher risk of cognitive decline.

Sleep apnoea and/or disrupted sleep have shown to increase the risk of Alzheimer's in later life, part of the reason being that apnoea disrupts the flow of oxygen, meaning parts of the brain may not be properly nourished. Sleep apnoea has also been strongly linked to higher risk of stroke. Evidence shows that sleep is the time when our bodies are most able to get rid of amyloid proteins, made in the brain which can contribute to Alzheimer's disease. Everyone's body makes amyloid proteins, but the reason we don't all have Alzheimer's is that we may be able to get rid of this protein more effectively compared to those with this disease.

Reversible causes of dementia

C

► Up to one in five cases of dementia are caused by potentially reversible conditions such as hypothyroidism, vitamin B12 deficiency and Lyme disease.

Many conditions can mimic dementia, these include healthy ageing, depression, delirium and Mild Cognitive Impairment (MCI).

Many conditions can mimic dementia

i

Mild Cognitive Impairment (MCI)

► Clinically defined by “an impairment in one or more cognitive domains for age (memory, attention, language) but do not meet criteria for dementia” (Petersen et al. 1999).

MCI can be differentiated from dementia as it does not significantly interfere with a person's daily functioning.

It is, however, considered a precursor of dementia, particularly Alzheimer's Disease (AD), but to make it clear not everyone who has MCI will develop dementia. Symptoms of MCI are generally brought on by some medications or other factors, for instance, a vitamin deficiency, so contacting your GP is imperative.

ii

Young or early onset dementia

► **Dementia itself does not only affect those over the age of 65. Young or early onset dementia is the name given to dementia affecting those in their 40s-50s.**

These individuals are usually maintaining an independent life, in employment and supporting their own families.

Typical symptoms of young or early onset dementia are problems with mobility, movement, balance or coordination. A genetic link is believed to exist, it is estimated that 10% of individuals with young or early onset dementia may have inherited it from a parent.

Globally depressive disorders affect
10%-20%
of the elderly population

iii

Non-cognitive symptoms of dementia

► **Also referred to as Neuropsychiatric or Behavioural and Psychological Symptoms of dementia (BPSD) these non-cognitive symptoms include: delusions, hallucinations, depression, anxiety and apathy, plus a range of behaviours such as aggression, wandering, disinhibition and agitation.**

It is thought that these behaviours may occur in up to 90% of people with Alzheimer's Disease (AD). Depression and anxiety are commonly associated with dementia, but may be difficult to diagnose due to overlapping symptoms which can often result in misdiagnosis.

The presence of depression associated with dementia usually appears in the elderly. Globally depressive disorders affect 10%-20% of the elderly population. Furthermore, depression can sometimes be precipitated or exaggerated by medication taken for other conditions. The true extent of dementia misdiagnosis is unclear; however, it has been suggested that early admission to long term care facilities could in many incidences be prevented if the correct diagnosis of depression had been made rather than that of dementia.

When a diagnosis of dementia has been made, many other symptoms are often disregarded and are thought to be part of the dementia process. This has led to people with dementia receiving insufficient pain-relieving medication in some instances, or pain being entirely overlooked and instead considered a behavioural issues.

3

Types of dementia

a

Alzheimer's Disease (AD)

▶ Alzheimer's Disease (AD) is the most common type of dementia accounting for 60%-80% of cases. It is the most researched of all the different types, and therefore the best understood to date. It was first described by German psychiatrist Alois Alzheimer over 100 years ago.

Common symptoms of Alzheimer's Disease include:

- ▶ Difficulty remembering recent conversations, names or events
- ▶ Apathy
- ▶ Lack of motivation
- ▶ Depression
- ▶ Word finding difficulties
- ▶ Poor judgment
- ▶ Disorientation and confusion
- ▶ Behaviour changes such as mood swings,
- ▶ Hallucinations
- ▶ Mobility problems.

Alzheimer's Disease,
accounts for
60%-80%
of dementia
cases

What causes Alzheimers Disease? ▾

► **AD is caused by the accumulation of the protein beta-amyloid outside of the neurons (brain cells) and the accumulation of an abnormal form of the protein tau inside the neurons.**

i Amyloid is a protein naturally produced by the body. In a healthy brain amyloid fragments are broken down and eliminated, however, in AD the fragments clump together to form insoluble plaques which block the transfer of information between the neurons, leading to cell death.

The presence of the protein tau in the brain helps to keep the flow of essential nutrients within the neurons flowing in a straight line.

However, for some reason in AD, the tau collapses and becomes tangled, blocking the transport of nutrients and other essential molecules inside the neurons. Neurons are dependent upon nutrients and other crucial molecules for survival, without them they cannot function and eventually die.

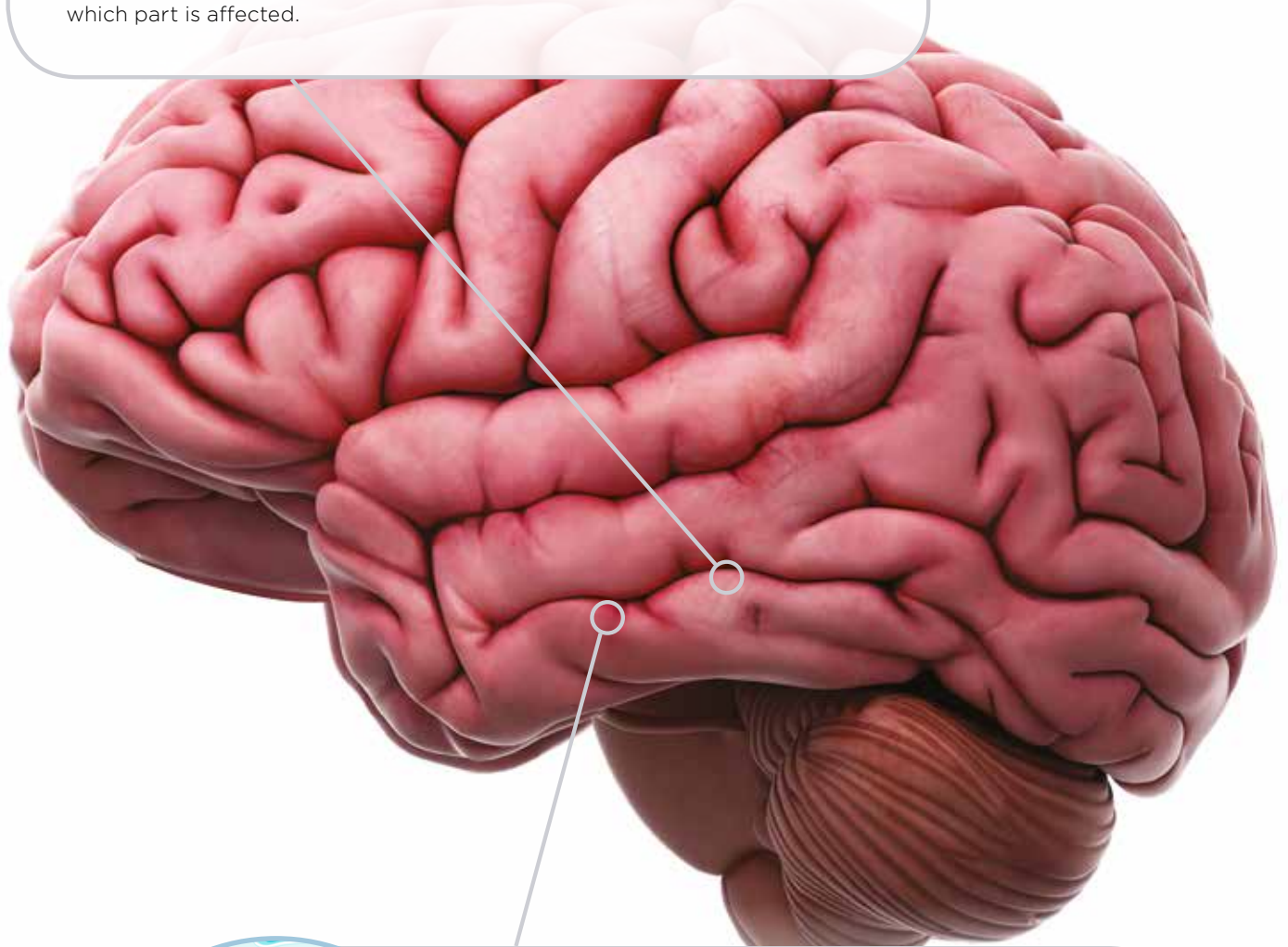
How does AD affect the brain? ▾

ii

► **In AD, the first area of the brain damaged is the hippocampus and its connecting structures. As the brain is symmetrical, you have two hippocampi. They are located just above the ears, about an inch-and-a-half inside the head.**

The hippocampi are small, curved formations that are involved in the creation of new memories, as well as learning and emotions. The exact impact of damage to the hippocampi varies depending on which part is affected.

Research suggests that damage to the left hippocampus affects the recall of verbal information, while damage to the right hippocampus results in problems with visual information.



► **The hippocampi play a critical role in the formation, organisation, and storage of new memories as well as associating certain sensations and emotions with memories.**

Research has also shown that different regions of the hippocampi play an essential role in the formation of certain types of memory. For example, the rear of the hippocampi is involved in the processing of spatial memories, (i.e. where a place is located, how to plan a route or to remember where a specific event took place).



► **When the hippocampi become damaged a person with AD may struggle to remember what they did earlier that day, what they have just said, or they may repeat themselves in conversation.**

Often individuals will continuously ask the same question, but when confronted will deny their repeated line of questioning.

Individuals with AD also tend to make up or give inaccurate responses to questions. In general, deficits in episodic memory (i.e. when or where something took place) are prominent from disease outset. More severe memory impairment affecting long-term memory and language, also known as semantic memory, emerges later in the disease.



► **Difficulties with language can cause word finding difficulties, a reduction in the person's vocabulary, fluency issues when speaking and difficulties comprehending what someone is saying.**

As the disease worsens problems identifying familiar places, family members and friends may present, which can be extremely distressing not only for the individual but also their families.



► **In AD another part of the brain known as the amygdala can also be affected.**

The amygdala is responsible for the processing of emotions, survival instincts and

memory, so a person with AD may often recall emotional aspects of a memory rather than the actual factual content of the memory itself.



► **Other problems relating to memory may include issues with procedural memory.**

An individual may lose their ability to put their clothes on in the right order, forget how to make a cup of tea, or forget how to use everyday household objects. Visuospatial dysfunction may also manifest itself through impaired driving ability or cause the person to get lost in well-known environments.

Problems with mathematical calculations may impair the individual's ability to use money and balance their finances, while executive dysfunctions may result in issues with problem-solving, reasoning, decision making and judgement. The individual may become increasingly vulnerable and lose their ability to live alone.

► **The long-term memory of someone with AD is not generally affected until the most severe stages of the disease, hence why many can still recall memories of their childhood.**

The reason for this is that long term memories are not stored in the hippocampi. The hippocampi can be described much like a shipping centre, where new memories are sent and received, registered and temporarily stored before being sent off to the brain's cerebral cortex where long-term memories are stored. Due to the progressive nature of the disease, damage caused by AD will eventually spread throughout the whole brain. The cortex overall becomes thinner, which means that memories from long ago are also lost. The brain gradually shrinks, rendering the person entirely dependent upon others for all care needs.

Other behavioural symptoms related to AD include agitation, apathy, wandering and sleep disturbance. Sundowning is a phenomenon which commonly affects those with AD.

Individuals may experience a problem with restlessness, agitation, irritability or confusion that worsens as daylight begins to fade. Sundowning can continue into the night and may affect sleep patterns or make it difficult for someone with AD to fall asleep and even stay in bed. The actual cause of sundowning is not understood, but it is believed to be related to changes within the brain that affect the person's biological clock, leading to confused sleep-wake cycles.

Many of the behavioural and psychiatric symptoms experienced by those with AD are treatable. It's essential that carers are given appropriate support and that proper medical interventions are offered to those with AD.

b

Vascular dementia

▶ **The second most common cause of dementia is Vascular dementia. It is estimated to account for approximately 10% of all dementia cases.**

Vascular dementia is caused by the reduction in blood supply to the brain. For the brain to remain healthy and function properly, brain cells need a constant amount of blood which carries oxygen and nutrients. Blood is delivered to the brain through a network of vessels called the vascular system. If the vascular system within the brain becomes damaged (i.e. the blood vessels leak or become blocked), then blood cannot reach the brain cells, and they eventually die.

Vascular dementia symptoms can vary widely, depending on how severe damage to the blood vessels are and the part of the brain affected. Unlike Alzheimer's disease (AD) memory loss may or may not be a significant symptom in Vascular dementia, but this is dependent upon the specific area(s) of the brain where blood flow has been restricted.

A growing number of experts prefer the term 'Vascular Cognitive Impairment (VCI)' rather than "Vascular dementia" because they feel it better expresses the concept that vascular thinking changes, can range from mild to severe.

Symptoms of vascular dementia include:

- ▶ Impaired judgment or ability to make decisions, plan or organise
- ▶ Problems with short-term memory (but not as common as with people with AD)
- ▶ Wandering or getting lost in familiar surroundings
- ▶ Laughing or crying at inappropriate times
- ▶ Trouble concentrating, planning, or following through on activities
- ▶ Trouble managing money
- ▶ Inability to follow instructions
- ▶ Loss of bladder or bowel control
- ▶ Hallucinations or delusions
- ▶ Confusion
- ▶ Disorientation
- ▶ Trouble speaking or understanding speech
- ▶ Vision loss
- ▶ Slowness of thought
- ▶ Mood or behavioural changes

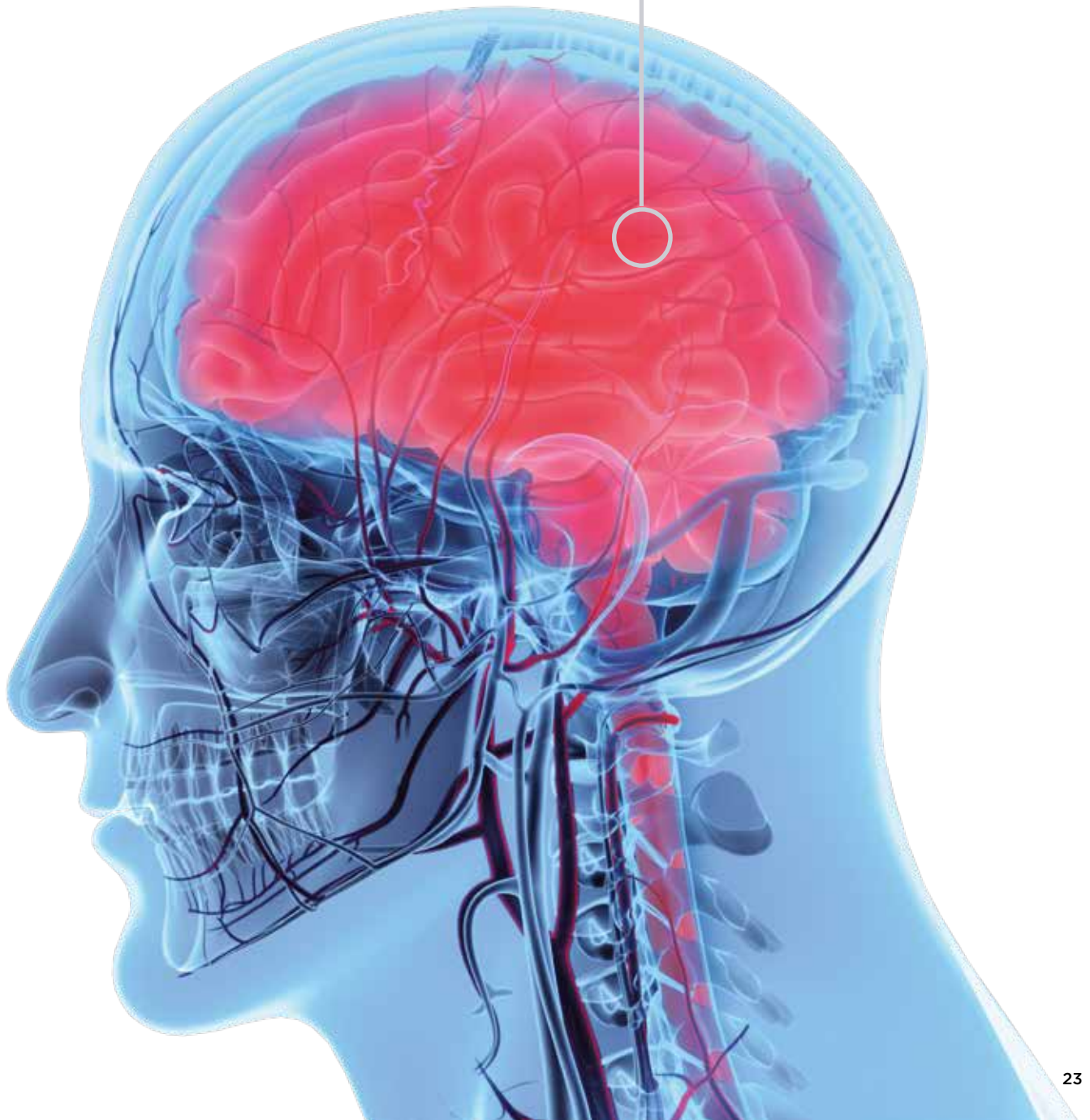
▶ **Clinical factors thought to be associated with an increased risk of Vascular dementia include age, lower levels of education, cortical atrophy, previous cerebrovascular events (such as CVA or stroke), atherosclerosis (narrowing of the arteries) hypertension (high blood pressure) and Diabetes mellitus.**

The association between hypertension and cognitive impairment has been widely investigated. Most studies have found a significant association between elevated blood pressure and the occurrence of dementia 10 to 15 years later.

The underlying mechanism by which cerebrovascular risk factors lead to cognitive impairment and dementia is not yet fully understood.

Vascular dementia is caused by the reduction in blood supply to the brain

► **When the blood supply to the brain is interrupted by a sudden blockage or a leak, this is called a Cerebral Vascular Accident (CVA)**, more commonly known as a stroke. When the parts of the brain responsible for memory, thinking, or language are damaged, due to lack of blood supply, the person may have difficulty remembering, thinking or speaking, all symptoms of vascular dementia.



Vascular dementia

► There are a number of different types of vascular dementia which are outlined in the following pages:

Types of Vascular dementia

i

Post-stroke dementia

► **When blood flow in a large blood vessel in the brain is suddenly and permanently cut off this is known as a Stroke or CVA. Most often this happens when a large blood vessel becomes blocked by a blood clot.**

Much less often it is because a blood vessel has burst and bled into the brain. This sudden interruption in the blood supply starves the brain of oxygen and leads to the death of large volumes of brain tissue. Stroke predominately causes the death of tissue on one side of the brain, and this can result in various cognitive impairments including problems with planning, concentrating, thinking or memory. Also, the person may be left with weakness down one side of the body or problems with vision or speech.

Not everyone who has a stroke will develop Vascular dementia, but research estimates that about 20 per cent of people who have had a stroke will go on to develop post-stroke dementia within the following six months. A person who has had a stroke is at increased risk of having further strokes in the future. If this happens, the risk of developing dementia is higher.



**20% of
people**

who have had a stroke
will go on to develop
post-stroke dementia
within the following
six months

ii

Single-infarct and multi-infarct dementia

Single-infarct and multi-infarct are the two types of vascular dementia that are caused by one or more smaller strokes. These types of strokes happen when a blood clot blocks a large or medium-sized blood vessel. The stroke may be so minor that the person doesn't notice any symptoms.

Alternatively, the symptoms might only be temporary, lasting perhaps a few minutes because the blockage clears. Medically, if symptoms last for less than 24 hours, it is known as a 'mini-stroke' or Transient Ischaemic Attack (TIA). If the blood supply is interrupted for more than a few minutes, the stroke will lead to the death of a small area of tissue in the brain. This area of damage is known as an infarct.

Sometimes just one infarct forms in an essential part of the brain, and this causes dementia known as single-infarct dementia. Much more often, a series of small strokes over a period of weeks or months lead to several infarcts spread around the brain. When this happens, it is referred to as multi-infarct dementia.


Subcortical dementia

Diseases of the small blood vessels found deep within the brain cause subcortical dementia, many of the symptoms of subcortical vascular dementia are different from those of stroke-related dementia. Small vessel disease often damages the bundles of nerve fibres that carry signals around the brain, known as white matter. The small vessels develop thick walls and become stiff and twisted, meaning that blood flow through the vessels becomes restricted.

As narrowing affects more and more small blood vessels, more of the brain becomes damaged, and the person will experience a gradual loss of abilities. Brain cells carrying messages to the frontal lobes of the brain are affected, therefore, a person with subcortical dementia will often have slowed thinking and problems with executive functions.

This type of dementia is characterised by the insidious onset of symptoms including psychomotor slowing, memory impairments, changes in speed, and neuropsychiatric features such as depression and apathy. Neurological features include parkinsonism, ataxia, and urinary incontinence.





Symptoms of mixed dementia may present similarly to those of Alzheimer's disease, vascular dementia, or they may be a combination of the two

d

Mixed dementia (Vascular dementia and Alzheimer's disease)

Mixed dementia generally means that both Alzheimer's disease (AD) and Vascular disease are thought to have caused dementia.

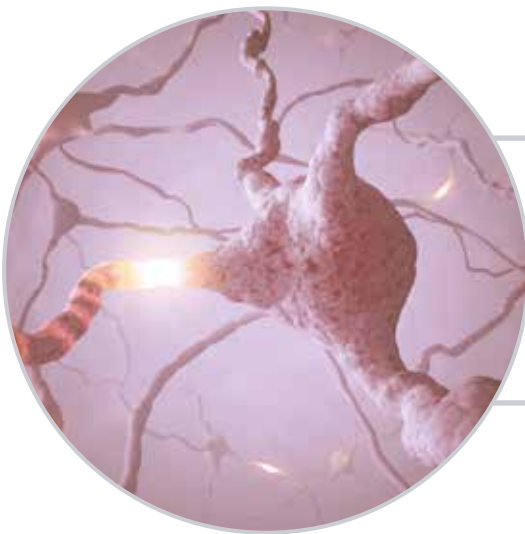
Symptoms of mixed dementia may present similarly to those of Alzheimer's disease, vascular dementia, or they may be a combination of the two.

As with all types of dementia, there is currently no cure, however, by controlling the underlying cardiovascular disease which affects blood supply and by controlling high blood pressure, high cholesterol and heart disease, it may be possible to slow down the progression of vascular dementia.



Dementia with Lewy body

Lewy bodies, named after the Neurologist Doctor Frederich H. Lewy who first identified them in 1912 are small, circular deposits of a protein known as alpha-synuclein. This protein is found widely in the brain, but its normal function isn't yet known.

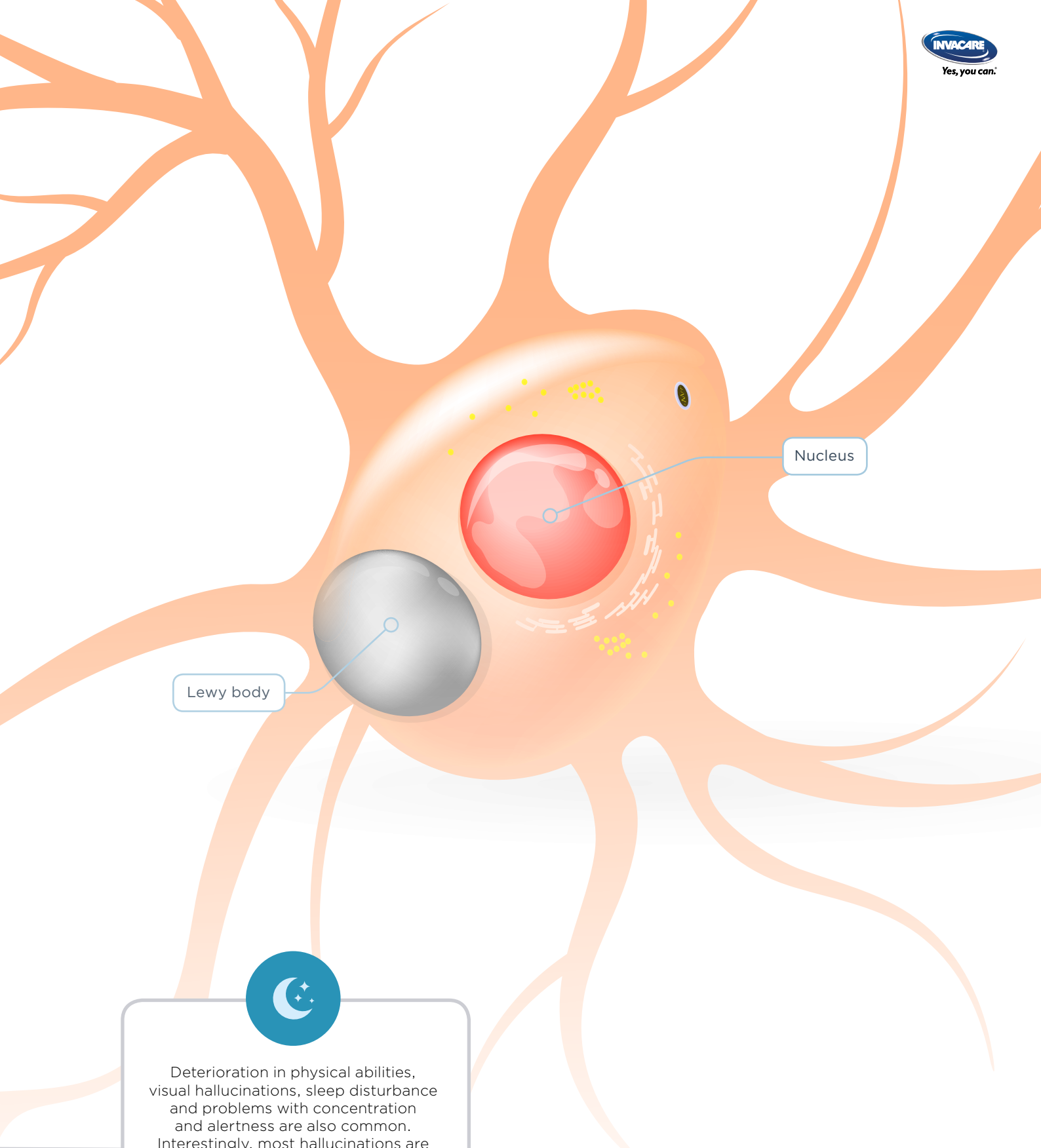


Lewy bodies prevent cells from communicating with each other by disrupting the transfer of critical chemical messages between them, which eventually leads to cell death.

The most commonly reported symptom **is difficulties with movement**



Dementia with Lewy bodies can affect any part of the brain, so people present with a range of symptoms. The most commonly reported symptom is difficulties with movement, similar to that of Parkinson's disease. The reason for this is thought to be the presence of Lewy bodies in the brain stem, which is responsible for balance and postural control.



Lewy body

Nucleus

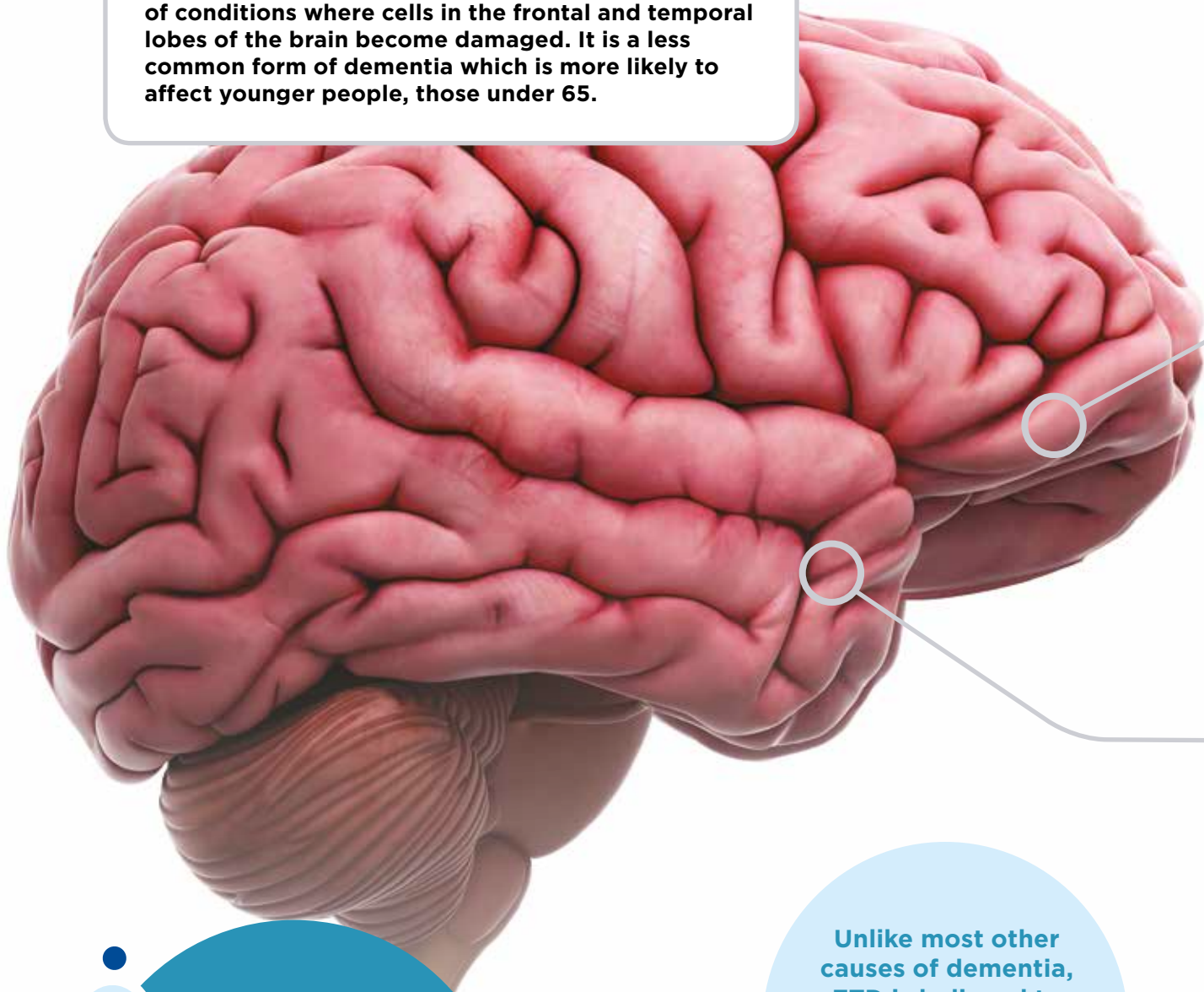


Deterioration in physical abilities, visual hallucinations, sleep disturbance and problems with concentration and alertness are also common. Interestingly, most hallucinations are reported to be of people or animals. It is believed that hallucinations are triggered when cells involved in the processing of visual information become damaged; this can result in people misperceiving things they have seen.

Individuals experience vivid dreams which they tend to act out while sleeping. Studies have shown that exercising during the day, and or reducing day time napping can help with some of these sleep disturbances.

Frontotemporal dementia

Frontotemporal dementia (FTD) or Pick's disease as it is sometimes referred to, is the name for a range of conditions where cells in the frontal and temporal lobes of the brain become damaged. It is a less common form of dementia which is more likely to affect younger people, those under 65.



Frontal Temporal dementia is thought to occur when abnormal forms of specific proteins, including the protein tau involved in Alzheimer's Disease (AD), build up in nerve cells

Unlike most other causes of dementia, FTD is believed to have a family link, but the extent of this is not fully understood

The frontal and temporal of the brain control behaviour, emotional responses and language. There are two main types of Frontotemporal dementia, the most common types are:

Behavioral Variant Frontotemporal dementia (BVFD)

With Behavioral Variant Frontotemporal dementia (BVFD) there is early damage to the frontal lobes, this means that people experience changes in personality and behaviour. In the initial stages, this can be very subtle and difficult to detect, but as the disease progresses symptoms may develop to include loss of inhibition, for example, when someone starts to behave in a socially inappropriate manner or act on impulse such as making tactless or inappropriate comments.

Loss of apathy is also common - when someone loses interest in people or things. Some individuals may lose the motivation or their sense of sympathy or empathy which can make the person appear selfish and unfeeling.

Other commonly reported symptoms of the behavioural form of FTD are repetitive, compulsive or ritualised behaviours, this can include repeated use of phrases or gestures, hoarding and obsessions with timekeeping, or oddly craving or bingeing on sweet or fatty foods.

Primary Progressive Aphasia (PPA)

In the other type of FTD, known as Primary Progressive Aphasia frontotemporal dementia (PPA), there is early damage to the temporal lobes of the brain, which predominately causes issues with language. PPA can be further broken down into two subclassifications: Semantic dementia (SD) or progressive nonfluent aphasia (PNFA). The first symptoms of SD are usually very subtle changes in word finding or word comprehension.

This is thought to be due to loss of semantic knowledge - our understanding of what things are or their meaning. People may initially complain that they have a memory problem or that they forget words. However, unlike in Alzheimer's disease, day-to-day memory for events or surroundings are not usually affected in the early stages of SD, but, these changes can occur as the disease progresses.

The first symptoms of PPA are usually a subtle change in the ability to produce speech. At first, this might only be in certain circumstances such as when speaking on the telephone or when speaking in public, but may progress to include using the wrong words to describe something.

Unlike SD, understanding speech in the early stages is not usually affected; however, this may change as the disease progresses. In the latter stages issues with planning and problem solving may appear, as well as some non-language related symptoms such as changes in behaviour and difficulty remembering things. As more areas of the brain become affected symptoms of the different types of dementia can start to overlap.

Frontal Temporal Dementia is thought to occur when abnormal forms of specific proteins, including the protein tau involved in Alzheimer's disease (AD), build up in nerve cells. Unlike most other causes of Dementia, FTD is believed to have a family link, but the extent of this is not fully understood.

4

Dementia Care Models

A ‘model of care’ can be loosely defined as: something which provides ‘the best practice care and services to an individual as they progress through the stages of a condition, injury or event’.

In simplistic terms, any care model aims to ensure that a person receives ‘the right care at the right time, delivered by the right people in the right place’.

Traditional models of dementia care focus on the medical model, which assumes that dementia is a disease caused by organic problems and should be treated and managed medically. The symptoms of dementia, however, are wide and varied, there is no ‘one size fits all’ model of care for dementia. The experience of dementia is subjective and unique to each individual and is determined by several factors, which include neurological damage, but more so the thoughts, feelings and behaviour of the individual within their own social context. Dementia care requires a broader focus, extending to family members, caregivers and support networks. Any dementia care model must take a holistic and person-centered approach to caring for people with this condition.

Thomas Kitwood, a pioneer and influential figure in the management of dementia, based his work on the concept of person-centered care and wellbeing. Kitwood developed a model outlining the factors he felt influenced the life experiences of people with dementia. He stressed that while we cannot escape the fact that an individual has dementia, and that this will impact on how they act and respond to people, things and what they can and cannot do, the individual should not be defined by having dementia.

Key to Kitwood’s concept of person-centered care is the idea of personhood, which reminds us that people with dementia are still thinking and feeling individuals, who have different identities, personal histories, experiences, likes and dislikes. This emphasises the need to respect, value and celebrate what individuals can do rather than define them by their dementia. Doing the latter only reinforces the medicalisation of that individual, relegating them to ‘demented body’ status.

Kitwood’s view is that failure to recognise personhood and the negative impact of inappropriate caregiving results in what he calls ‘malignant social psychology’. This includes labelling those with dementia, causing disempowerment, infantilisation, invalidation and objectification.

Kitwood explains that malignant social psychology arises because people with dementia are seldom visible or acknowledged in society, which undermines the personhood of these individuals.

Even when a person seems to have lost a significant part of what made them unique owing to dementia, core elements of their identity will remain. These characteristic gestures and personal ways of doing things are what keeps alive the sense of the individual they once were, even if the more sophisticated levels of that individual have been removed. This has important implications for the management of dementia. A person’s sense of self and self-respect can be fostered through reinforcing any remaining elements of conscious self-identity. Less conscious elements in a person’s identity can be preserved through physical surroundings, such as within the home, or room within a care setting, to retain physical links with their past, which helps to support a sense of personhood.

Kitwood identified several fundamental psychological and social human needs which must be better for all of us to maintain a good sense of wellbeing.

He developed a dialectical model of dementia, which shows that when caring for and supporting people with dementia, we must remember six primary psychological needs: **love, comfort, identity, occupation, inclusion and attachment.**

Love: everybody needs to be loved and to love someone. Being loved and accepted is part of our need for survival from when we are born. Love can range from loving a person, an activity, a favourite meal/food, to loving god and feeling self-love.

Comfort: feeling comfort is our need to be warm, dry and clean, having a full stomach and not feeling thirsty. Comfort might also mean having quietness when we need it, being free of pain, having the freedom to move, a sense of closeness, or being able to bond with others.

Identity: we all require personal identity from the clothes we choose to wear, the food we prefer and the way we like our hair. These are all identifying factors that help us and others identify with who we are.

Occupation: most of us want to be occupied with something to feel that we have worth and purpose in life. From being involved in daily activities, to engaging in planned activities, it's essential that the person can occupy themselves with meaningful things.

Inclusion: inclusion means that we want to be a part of something. If we feel left out it makes us feel bad. People living with dementia may lose track of conversation easily, being mindful of their feelings of inclusion is essential.

Attachment: our connections in life are also crucial to our feelings of wellbeing. Everyone wants to feel connected to something, or someone, often a combination of both. We also need to form wider attachments in our community or groups.

Dementia Care Mapping

In 1993 Kitwood and his colleague Dr Kathleen Bredin, developed an observational tool called 'Dementia Care Mapping' or (DCM), to evaluate the quality of care provided in formal care settings, such as care homes. Kitwood described many ways that personhood might be undermined in care settings. He acknowledged that these depersonalising tendencies often occur because of lack of specialised dementia education amongst healthcare workers.

Kitwood and Bredin designed their DCM approach to empower staff teams to engage in evidence-based critical reflection, to improve quality of care for people living with dementia at an individual, local and organisational level. DCM involves systematic observation, analysis and reporting on each individual within the care setting, in order to optimise that individual's wellbeing over a 24-hour period. Small things that engender happiness or distress for the individual are highlighted in the process of mapping and this can be built upon to ensure that they can experience wellbeing more often during their day.

DCM can also indicate where change can be made that will improve levels of wellbeing for the whole group of people living within the care setting, as well as helping to identify training needs and opportunities for staff. It can help identify staff skills that support and promote levels of wellbeing, as well as helping to tailor training and staff development programmes.

Relationships with others has significant impact on personhood. Kitwood and Bredin believe that the personhood of individuals with dementia needs to be continually replenished; their selfhood frequently evoked and reassured. Staff within the care setting, therefore, play a key role in helping to sustain personhood for those within their care. The further the dementia advances, the greater the need for 'person-work.' The role of the staff member becomes essential in holding the pieces together 'to become the memory'. Kitwood and Bredin believe that this may be understood as the true agenda of dementia care.

Alternative approaches to the institutional hierarchical medical model of care, with greater emphasis on resident choice, have thankfully become more prevalent over the past decade, thanks to the work of Thomas Kitwood. Examples include the Eden Alternative, the Green House Project, the Planetree model and the Wellspring model. These models advocate for a shift from institutional models of care to person-directed values and practices that put the person first, as promoted by Kitwood.

The Eden Alternative®

The Eden Alternative, founded by Dr William Thomas in the early 90's, is structured around the unique needs, preferences and desires of each person. Through this approach, decisions and actions around care honour the voices and choices of care recipients and those working most closely with them. Core person-directed values present in the Eden alternative approach include choice, dignity, respect, self-determination and purposeful living.

As a comprehensive culture change model, The Eden Alternative focuses on creating Elder-centered communities wherever elders live and thrive on close and continuing relationships, meaningful interactions, opportunities to give as well as receive and a rich and diverse daily life. As a principle-based philosophy, The Eden Alternative empowers care partners, whether they are family members, professionals, or volunteers, to transform institutional approaches to care into the creation of communities where life is worth living.

The Eden Alternative aims to revolutionise the experience of home by bringing well-being to life.

“Well-being is a much larger idea than either quality of life or customer satisfaction. It is based on a holistic understanding of human needs and capacities. Well-being is elusive, highly subjective, and the most valuable of all human possessions.”

**Dr. William Thomas,
What Are Old People For?**



The Domains of Wellbeing are:

- ▶ **Identity:** Being well-known, having personhood and individuality; wholeness; having a story.
- ▶ **Growth:** Development, enrichment, expanding, self-actualisation.
- ▶ **Autonomy:** Choice and self-determination; freedom from the arbitrary exercise of authority.
- ▶ **Security:** Freedom from fear, anxiety and doubt; feeling safe; having privacy, dignity, and respect.
- ▶ **Connectedness:** Belonging; feeling engaged and involved; having close, meaningful relationships.
- ▶ **Meaning:** Purpose; activity that speaks to one's personal values; rituals, recognition and self-esteem.
- ▶ **Joy:** Happiness, enjoyment, pleasure, contentment.

Three plagues of ageing

To achieve genuine holistic care, healthcare providers must first eliminate what Thomas calls the **'three plagues of ageing'**:

- ▶ Loneliness
- ▶ Helplessness
- ▶ Boredom

The aim of the Eden Alternative is to transform long-term care and enliven the environment with children, animals and plants, to create an atmosphere reminiscent of home. Thomas believes that every creature has a habitat in which it thrives and one in which it withers and that human beings wither in institutions such as nursing homes.

Person-directed care is defined as a model of care that is an ongoing, interactive process between elders and caregivers that honour the elder's dignity and choices in directing his/her daily life. The Eden Alternative stresses that elders do not live in the staff's workplace, but rather the staff work in the Elders' homes.

The Eden Alternative focuses on moving away from the institutional hierarchical medical model of care into a constructive culture of 'home' where elders direct their own lives.

The 10 principles of the Eden Alternative®:

1

The three plagues of loneliness, helplessness and boredom account for the bulk of suffering among our elders.



2

An elder-centered community commits to creating a Human Habitat where life revolves around close and continuing contact with people of all ages and abilities, as well as plants and animals. It is these relationships that provide the young and old alike with a pathway to a life worth living.



3

Loving companionship is the antidote to loneliness. Elders deserve easy access to human and animal companionship.



An elder-centered community creates the opportunity to give and receive care. This is the antidote to helplessness.

4

5

An elder-centered community imbues daily life with variety and spontaneity, by creating an environment in which unexpected and unpredictable interactions and happenings can take place. This is the antidote to boredom.



6

Meaningless activity corrodes the human spirit. The opportunity to do activities we find meaningful is essential to human health.



Medical treatment should be the servant of genuine human caring, never its master.

7

8

An Elder-centred community honours its elders by de-emphasising top-down bureaucratic authority, seeking instead to place the maximum possible decision-making authority into the hands of the elders or those closest to them.





Creating an elder-centered community is a never-ending process. Human growth must never be separated from human life.

9

Wise leadership is essential for any struggle against the three plagues.

10



Person-directed care encourages both elders and their caregivers to express choice and practice self-determination in meaningful ways at every level of daily life.

As previously mentioned, values that are essential to this philosophy include choice, dignity, respect, self-determination and purposeful living. These values also are at the core of desirable medical care and are embraced by many medical providers, yet practices that conflict with these principles are common in the long-term care settings. Examples include awakening residents at times that are determined by staff convenience, modifying residents' diets without discussion and inflexible meal times and medication pass times.

In addition, care plans are commonly created without truly understanding a resident, their history or previous occupation, their recreational and personal preferences, wishes regarding life-sustaining treatment, and other likes and dislikes. A hallmark of the Eden Alternative, which make this approach so applicable to the care of those living with dementia, is that staff are consistently assigned to the same elders. In that way each elder is well known to their respective staff member, close relationships can, therefore, be forged and staff don't need to be taught each time how to work with a specific resident. Care becomes consistent, which is especially important with people living with dementia.

Conclusion

This booklet was designed in no way to be an expert document on dementia, rather it was designed to promote and encourage insight into a range of disorders, which in their severest form can adversely affect the everyday functioning of an individual to the point where they become completely dependent on others for all their care needs.

Currently there is no cure for the various types of dementia. This booklet describes four types; however, this list is not exhaustive. There are many other forms of dementia, each of which affect the brain and the psychological functioning of an individual in different ways dependent on the region of the brain affected.



As health care providers, carers, family members, friends or even those who have received a dementia diagnosis, the hope is that this booklet will assist you in establishing a basic level of understanding surrounding dementia, why it occurs, how it affects the brain, the different types and how we, from a societal perspective, should be caring for those with dementia.



References

- ▶ Advanced Dementia Practice Model, Alzheimer Scotland, 2015
- ▶ Alzheimer's Association® Dementia Care Practice Recommendations. The Gerontologist (2018) Feb, Volume 58, number S1
- ▶ Andersen CK, Wittrop- Jensen KI, Lolk A, Andersen K, Kragh-Sorensen P (2004) Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia Health and Quality of Life Outcomes, 2:52
- ▶ Barba, B. E., Tesh, A. S., & Courts, N. F. (2002). Promoting thriving in nursing homes: The Eden Alternative. Journal of Gerontological Nursing, 28(3), 7-13
- ▶ Brooker D (2005) Dementia Care Mapping: A Review of the Research Literature. The Gerontologist Vol. 45, Special Issue I, 11-18
- ▶ Brownie S, Nancarrow S (2013) Effects of person-centered care on residents and staff in aged-care facilities: a systematic review. Clinical Interventions in Aging: 8, 1-10
- ▶ Brownie S, Scholarly paper A culture change in aged care: The Eden Alternative™ AUSTRALIAN JOURNAL OF ADVANCED NURSING Volume 29 Number 1
- ▶ Burgess J (2015) Improving dementia care with the Eden Alternative. Nursing Times; 111: 12, 24-25
- ▶ De Vriendt P, Cornelis E, Desmet V, Vanbosseghem R, Van de Velde D (2018) Quality in dementia care: A cross sectional study on the Bio-Psycho-Social competencies of health care professionals. PLoS ONE 13(2): e0191440
- ▶ Dewing J (2008) Personhood and dementia: revisiting Tom Kitwood's ideas International Journal of Older People Nursing 3, 3-13
- ▶ Fazio S, Pace D, Flinner J, Kallmyer B (2018) The Fundamentals of Person-Centered Care for Individuals With Dementia Gerontologist, 2018, Vol. 58, No. S1, S10-S19
- ▶ Feija D, Schaap, Geke J, Dijkstra, Evelyn J, Finnema & Sijmen A. Reijneveld(2017): The first use of dementia care mapping in the care for older people with intellectual disability: a process analysis according to the RE-AIM framework, Aging & Mental Health
- ▶ Grand JHG, Caspar S, MacDonald SWS (2014) Clinical features and multidisciplinary approaches to dementia care. Journal of Multidisciplinary Healthcare 2011:4 125-147
- ▶ Hort J, O'Brien T, Giantti G, Pirttila T, Popescu BO, Rektorova I, Sorbi S (2010) EFNS guidelines for the diagnosis and management of Alzheimer's disease European Journal of Neurology 17: 1236-1248
- ▶ Iliffe S, Manthorpe J (2017) Editorials Dementia: Is the biopsychosocial model vindicated? British Journal of General Practice August 2017 344-345
- ▶ Introduction to Dementia Care Mapping™ (DCM™) University of Bradford School of Dementia Studies last updated Feb 2015
- ▶ Kaufmann EG, Engel SA (2014) Dementia and wellbeing: A conceptual framework based on Tom Kitwood's model of needs. Dementia 0 (0) 1-15
- ▶ Keady J, Jones L, Ward R, Koch S, Swarbrick C, Hellström I, Davies-Quarrell V, Williams S (2012) Introducing the bio-psycho-social-physical model of dementia through a collective case study design Journal of Clinical Nursing, 22, 2768-2777
- ▶ McAllister A, Beaty JA (2016) Aging well: Promoting person directed care. Journal of aging science Vol 4 issue 3 1-7
- ▶ Mitchell G, Agnelli J (2015) Person-centred care for people with dementia: Kitwood reconsidered. Nursing Standard. 30, 7, 46-50
- ▶ Sachdev PS, Mohan A, Taylor L, Jeste DV (2015) DSM-5 and mental disorders in older individuals: an overview Harv Rev Psychiatry; 23(5): 320-328
- ▶ Sadowsky CH, Galvin JE (2012) Guidelines for the Management of Cognitive and Behavioral Problems in Dementia. JABFM May-June vol 25 No 3 350-366
- ▶ The Eden Alternative Domains of well being™ White paper (2012) Revolutionizing the experience of home by bringing well being to life
- ▶ The Eden Alternative™, it can be different www.edenalt.org
- ▶ Vikstrom S, Sandman P, Stenwall E, Boström A, Saarino L, Kindblom K, Edvardsson D, Borell L (2014) A model for implementing guidelines for person-centered care in a nursing home setting. International Psychogeriatrics page 1 of 11
- ▶ Williamson T (2015) Dementia, rights and the social model of disability. The journal of Dementia Care September, Vol 23 No 5 12-13
- ▶ **www.alzscot.org** Delivering integrated dementia care: the 8 pillars of community support

- ▶ www.alzscot.org/delivering-integrated/dementia/care/the-8-pillars-of-community-support
- ▶ <http://www.sherbrookecommunitycentre.ca/sherbrooke-difference/the-eden-alternative-philosophy/>
- ▶ <https://qbi.uq.edu.au/brain/brain-anatomy/what-neuron>
- ▶ <https://www.aarp.org/health/dementia/info-2018/dementia-risk-factors.html>
- ▶ https://www.alz.org/alzheimers-dementia/research_progress/earlier-diagnosis
- ▶ <https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/vascular-dementia>
- ▶ https://www.alzscot.org/assets/0000/4613/FULL_REPORT_8_Pillars_Model_of_Community_Support.pdf
- ▶ <https://www.brightfocus.org/alzheimers/article/alzheimers-and-dementia-whats-difference>
- ▶ <https://www.brightfocus.org/alzheimers/article/history-alzheimers-disease>
- ▶ <https://www.brightfocus.org/alzheimers/article/treatment-vascular-dementia>
- ▶ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4562208/pdf/nihms665391.pdf>
- ▶ <https://www.neuroskills.com/brain-injury/frontal-lobes.php> <https://www.rcpsych.ac.uk/workinpsychiatry/faculties/oldagepsychiatry/newsletters/enewsletterjanuary2016/dementiaandrights.aspx>
- ▶ <https://www.newscientist.com/article/dn9969-introduction-the-human-brain/>
- ▶ <https://www.nhs.uk/conditions/vascular-dementia/>
- ▶ <https://www.spinalcord.com/occipital-lobe>
- ▶ <https://www.verywellmind.com/what-is-the-hippocampus-2795231>

Invacare International GmbH
Benkenstrasse 260
4108 Witterswil
Switzerland
Tel: +41 61 487 70 70
hqeurope@invacare.com
www.invacare.eu.com
© 2019 Invacare International GmbH

All rights reserved.
All information quoted is believed
to be correct at time of print.

Dementia Clinical Guide
Introduction - EU - 10/2019

