I want to introduce you to this subject area and ask that you work together to help people with dementia as they experience sensory changes. My hope is that sensory issues will be part of the curriculum of all relevant professionals such as GPs, nurses, allied health professionals and those studying health and social sciences. I hope that care homes and home care partners will recognise when people with dementia have a support need related to sensory issues.

- Agnes Houston MBE

The lived experience of people with dementia is increasingly informing our understanding of dementia and this is especially true in regard to sensory changes. When Agnes received her diagnosis of dementia, she discovered not only was there little support for continued independence, but what support there was had virtually no awareness of the common experience of sensory change.

Talking sense: Living with sensory change and dementia is the result of Agnes' personal journey of discovery and her courageous fight to ensure the voice of people with dementia—who experience sensory change—is heard.

If the world doesn't look, sound, smell, taste or feel as it once did, Talking sense offers much needed advice, support and most of all, hope.

Whether senses are changing due to ageing, as a direct result of dementia or a combination of the two, Talking sense offers the latest information and tips in an easy to ready format to enable understanding and quality of life.

To quote Agnes

"Think dementia, think sensory, think solutions, that's Talking sense!"

Associate Professor Colm Cunningham
'I chose to go on a quest for knowledge to understand what was happening to me. Surely, I was not the only one having these sensory changes.'

– Agnes Houston
Why this book?

I was diagnosed with younger onset dementia of the Alzheimer’s type in 2006. My care afterwards was in the hands of the old age psychiatry service. It consisted of a dementia ‘early onset’ nurse to monitor my medication and my cognitive function.

I found it to be a negative experience, which was all about loss. There was no attention paid to my sensory challenges, no rehabilitation programme and no counselling. I felt as if my care was out of my hands.

I consulted my optician who knew little about dementia. My GP team knew little about the sensory changes associated with dementia. My psychiatrist made time to talk and listened to my experiences but I felt that little practical help was given to me.

Something was missing. It was as if I had been given a diagnosis, was assessed cognitively, medication monitored and left to my own devices. Instead, I chose to go on a quest for knowledge to understand what was happening to me. Surely, I was not the only one having these sensory changes. This prompted me to ask other people living with dementia about their experiences. As a result I produced in 2015 the booklet *Dementia and Sensory Challenges*¹ (funded by the Life Changes Trust in Scotland).
In 2016, I obtained a Churchill Fellowship to travel to other countries to learn more. My findings confirmed the need for this handbook, which we hope will be a starting place for others to discover information on sensory challenges. Among other things, it shows **who** to go to for help, **where** support organisations can be located and **how** to access services and support.

Hopefully, with this knowledge people can avoid the distress and sense of being alone that I experienced.

I want to thank Professor Mary Marshall for her work refining the materials that I have gathered over this time and assisting me to develop my collection into the book you see in front of you today.

**Also for health professionals**

For professionals, I want to introduce you to this subject area and ask that you work together to help people with dementia as they experience sensory changes. My hope is that sensory issues will be part of the curriculum of all relevant professionals such as GPs, nurses, allied health professionals and those studying health and social sciences. I hope that care homes and home care partners will recognise when people with dementia have a support need related to sensory issues.

We need to share knowledge with one another and recognise the interdisciplinary learning in this field. This could include going to conferences and events, which can provide us with the tools we need to be knowledgeable about the senses and dementia and not look at each in isolation. I want people with dementia and their care partners to have the right support at the right time.

Finally, I want to share my 12 years of fact-finding and evidence gathering and most importantly, this includes the knowledge and lived experiences of people with dementia and their care partners around the world.
**The shape of the book**

In each chapter, we briefly describe the senses, the impact of ageing and the impact of dementia. Then we address the sensory problems that can occur. We cover the implications of environmental design and interior finishes with some tips on self-management for the person with dementia and advice for families and care partners. Throughout the book we include the experiences of people living with dementia.

Later in the book we provide details of support and advice organisations and there is a ‘Further reading’ section featuring references (endnotes) from throughout the book.

**Your feedback**

This is the first edition of this book and we welcome stories and suggestions for the second edition. You can do this by going online and visiting dementiacentre.com or emailing publishing@hammond.com.au

Before we move on to the chapters on senses, we’ve provided an overview of dementia and its impact. Sensory changes are not mentioned specifically in this brief section as they are the main focus of the rest of the book.

**What is dementia?**

Dementia describes a range of progressive disorders that affect the brain. It is experienced by people of all ages although it is more common in older age, where it may be accompanied by age-related issues.

The brain is the control-centre for everything we do, with messages travelling to and from the body. As a result, if the brain is affected by dementia, our daily lives will also be affected.

Research has taught us that different human activities and functions are controlled or influenced by different parts of the brain, for example:

- the frontal lobe is involved with planning and behaviour
- the temporal lobe relates to memory
• the limbic system in the brain interacts with sleep and hunger.

**Types of dementia**

Each type of dementia impacts the brain differently which means the experience of dementia is highly individual but with some similar aspects.

Alzheimer’s disease is most common and is usually characterised by a gradual but persistent decline in cognitive functioning. Vascular dementia is next most common and usually involves a stepped cognitive decline due to a series of vascular events that affect blood circulation in the brain. Lewy body disease is another type of dementia caused by the death of nerve cells in the brain. Symptoms can be characterised by fluctuations in mental state including periods of extreme confusion and hallucinations. Falls may also be common.

Other forms of dementia include frontotemporal dementia (formerly known as Pick’s disease), Huntingdon’s disease, alcohol-related brain damage, HIV and AID's-related dementia and many other diseases that cause symptoms of dementia.

While the experience of dementia is different for each person, and the different types also vary in impact, dementia is almost always a progressive condition, with increased symptoms over time.

**The human impact of dementia**

While these more clinical descriptions of dementia (above) help us understand what it is, what it does and how it can vary, it is most important to remember the very human side to living with dementia and the affect it can have on our lives.

**Problems with memory**

Memory impairment occurs frequently with dementia and can impact many aspects of life, from remembering a name, knowing where you are or what season of life you are in. People with dementia will often lose their short-term memory.
more quickly, and so are more likely to rely on their long-term memory. This could mean, for example, that a bereaved person with dementia may believe that his or her spouse or partner is still alive (or has only just died), or mistakes a child for their spouse, or that they are living 30 or 40 years in the past.

Depending on the stage of dementia, memory changes might also mean the person with dementia doesn’t recognise family or friends and might not identify familiar places or usual routes. The person may forget that he or she needs to wear glasses and may not remember what they’ve done today.

**Finding it hard to plan, organise and solve problems**

Challenges may occur in getting organised to prepare a meal, make a cup of tea, get ready for the day or go out for an appointment. Simple problems may become overwhelming such as getting the TV remote to work, hanging the washing on the line or working out what train or bus to catch to arrive somewhere on time. The dozens of little neural connections that otherwise allow these activities to occur are interrupted because dementia has damaged the brain and impaired memory.

While we know that every person with dementia is different, it is common for more complex activities—such as family finances—to become difficult in the earlier stages of dementia, while more basic activities such as bathing and dressing are challenging in the moderate and later stages of dementia.

**In summary**

- Dementia is a term describing a range of progressive conditions that affect the brain.
- Dementia is more commonly a condition of older age but younger people do also live with dementia.
- Memory problems, sensory changes, difficulties with problem solving and challenges with planning are some of the common impacts of dementia.
A person with dementia may have vision difficulties because of changes to their sight resulting from ageing or another health condition. Having dementia may add to the challenge of living with these sight changes.

Or the person’s eyes may be healthy but their brain has trouble interpreting what is seen due to the impact of dementia. Let’s learn more about vision, dementia and sensory changes.

How sight works
Our eyes provide us with vision—the ability to receive and process visual detail—as well as enabling several photo or light response functions that are independent of vision. We can think of our eyes as capturing images and pictures of the world around us and then sending these to the brain. Your brain then processes and interprets what your eyes are seeing.

The process of ‘seeing’ involves many different stages, but in order to work out what the image means, sometimes our brain uses shortcuts. This means some of our vision processing by the brain can be based on expectations of what will be seen, as well as information from our other senses. Thoughts and memories also come into play, e.g. ‘Have I seen this image before?’ As we bring all this together, we then come to recognise the image and its meaning.

‘Most people who receive a diagnosis of dementia are aware they may experience memory problems. But they are often surprised when they begin to encounter ‘unexplained’ sensory changes...’
When this process goes wrong, such as when the brain is damaged by dementia, we can experience what experts call visuo-perception difficulties.

**The impact of ageing**

One of the causes of sight impairment is ageing. Age-related changes to the eye include:

- seeing things less sharply, e.g. needing more light and good contrast
- colour being less vivid
- needing more time to adapt to changing light levels, e.g. going from outside to indoors
- the visual field getting smaller and the loss of peripheral vision
• problems with depth perception
• shadowing from small shapes floating in the visual field (floaters)
• sensitivity to glare.

There is also an increasing chance of having eye conditions such as macular degeneration, glaucoma and cataracts. The images below shows how these conditions can affect your visual field.

In middle age, many people experience presbyopia, which is an age-related decrease in the ability to see objects that are near. This can be remedied with glasses.

People who have younger onset dementia will also go through these changes as they age but the brain’s ability to cope with these impairments can be affected.
The impact of dementia

Having dementia can make living with sight impairments much more difficult, as well as causing other sight difficulties. The Royal National Institute of Blind People (RNIB) in the UK has a leaflet called Dementia and Sight Loss\(^2\), which makes the useful point: ‘Sight loss is typically under-diagnosed in people with dementia because one condition can mask or be mistaken for another.’

The leaflet describes the problems that can arise which include:

- becoming withdrawn or uncommunicative
- being clumsy or falling more
- having visual hallucinations
- holding things up close
- feeling confused and disorientated
- being startled by noises or people approaching.

It is crucial that people with dementia actively seek advice on how to improve vision. Regular eye checks and the right spectacles may make all the difference.

Some people with dementia experience a narrowing visual field, making it harder to see objects at the edge of your eye. This is called your peripheral vision\(^3\). For this reason, it helps to approach someone with dementia from the front, in full view and ensure you leave time for the person to process the fact that you are there as the image goes from eye to brain and back.

Dementia and vision problems

Vision problems in dementia are sometimes referred to as ‘brain blindness’. This is where despite an ophthalmologist (or hospital eye specialist) advising that there are no sight problems, the person still cannot see properly. In this case the issue is not with vision but with the person’s perception of what they are seeing. This means that the brain’s ability to process or find the right match for the picture is impaired or sometimes it just takes longer to find the right match.
I find going into lifts almost impossible, especially if they have a large mirror. I see a big hole instead of the floor and the mirror just adds to my confusion and distress.—Agnes

A confusing lift with a floor that can look like a hole and a mirror that disorients.

So, as you have read, people with dementia can have visual difficulties caused by the brain but still have healthy eyes. It is easy to understand how this may lead the person with dementia to speak or act in a way that does not make sense to others.

Here are some words professionals use in relation to dementia and vision challenges:

- Misperception: The person sees something and the brain tries to make sense of it, but may not perceive what is actually there, e.g. a black mat on the floor which the brain ‘sees’ as a black hole, or blue flooring in the bathroom which the brain ‘sees’ as water.
• Misidentification: Damage to different parts of the brain can lead to problems identifying specific objects and people. This can mean mistaking an object for something else and finding it alarming, such as thinking a coat stand in your hall is a person and being concerned there is a stranger in your home.

Misperception and misidentification are different from hallucinations (see later in this chapter). Hallucinations are where someone sees, hears, smells, tastes or feels things that don’t exist outside of their mind.

Posterior cortical atrophy
Posterior cortical atrophy (PCA), also known as Benson’s syndrome, is a rare form of Alzheimer’s disease. This condition causes shrinkage (atrophy) of the posterior cerebral cortex in the brain, resulting in the progressive disruption of a person’s complex visual processing. People with PCA generally experience:

A mannequin or coat stand may be misidentified as a person.
• difficulty recognising familiar objects and faces
• increased sensitivity to bright lights or shiny surfaces
• double vision and difficulty seeing in fading or low light conditions
• difficulty judging distance/speed/perspective—this can cause problems with stairs, the speed of traffic, reaching out for things or putting things down on surfaces
• stationary objects may appear to move.

Vision and vascular dementia
A stroke or vascular accident can cause someone to have problems with vision. The most severe form of this is hemianopia (see below) where the peripheral visual field is reduced by half, and on a particular side. It can be frightening if you have dementia and cannot understand what is happening. It is helpful for care partners to approach from or stand on the side of the person’s good vision. In some cases, the person with dementia might not be aware of changes to their vision.

Hemianopia causes loss of sight on one side.
**Visual hallucinations and dementia**

Visual hallucination can be as simple as seeing flashing lights or as complex as experiencing animals or people in bizarre situations. Some hallucinations do not make the person feel anxious or threatened whereas other hallucinations can be frightening and the person may react accordingly. Some people with dementia have reported that they have vivid dreams and when they wake up, the dreams remain a reality.

Charles Bonnet syndrome is a type of visual disturbance where people with partial or severe blindness experience visual hallucinations. CBS hallucinations are only caused by sight loss. You don’t need to have dementia to experience these. They are caused by a lack of visual information to the brain and as a result the brain then fills in the gaps with its own images. This usually improves over time.

**How to respond**

If the person with dementia is experiencing hallucinations, carer support both at the time and when visiting the GP is important. Some helpful ways to respond to hallucinations include:

- remaining calm
- using language that is reassuring in a familiar setting (such as sharing a cuppa), e.g. ‘Although I cannot see what you see, would you mind describing what you see?’
- changing location which can sometimes make the hallucinations disappear
- listening carefully to what you hear and record this on paper
- checking with the pharmacy in case the hallucinations are a side effect of medication
- always consulting the person’s GP.
Talking to the GP
When visiting your doctor to discuss hallucinations, the advice below can help make it a successful visit. It is adapted from Alzheimer’s Society fact sheet 527LP7 (Dementia Australia also provides a range of fact sheets):

If you are visiting a GP about a person’s hallucinations then consider providing notes about:

- what the person saw or sensed
- what time of day it occurred and whether it was after some event such as a nap, meal or exercise
- where it happened and how long it lasted
- how the person responded, e.g. were they distressed? What words did they use to describe the experience?
- medication the person is taking and the dosage (including over the counter supplements)
- the person’s medical history including any previous sight or sensory conditions
- the person’s use of alcohol or other recreational drugs.

Anaesthesia, dementia and hallucinations,
Anaesthesia needs to be given with great care as people with dementia can have reactions resulting in hallucinations. Edward McLaughlan was administered an anaesthetic, commonly recommended for people living with dementia, and he experienced hallucinations. He painted one to capture the image which he called the Dortmund Dog—you can see it in his art collection8.

Anaesthetic use generally where a person has dementia can be a problem. The effects of the drugs can last several weeks and during that time the person may experience increased confusion, an increase in sensory impairments, slower information processing and sleep disturbances9.
The eye and circadian rhythms

The eye has a second function, which is to receive light to operate our body clock. In our eyes we also have non-visual detectors (ganglion cells), which send signals to the part of the brain concerned with circadian rhythms or the body clock.

When you have dementia you may find your body clock is not working so well and you are awake during the night and sleeping during the day. It is important to get enough daylight or really bright light for the body clock to work. You may need to organise your day to make sure this happens.

A helpful book is *Enlighten: Lighting for older people and people with dementia* by David McNair, Richard Pollock and Colm Cunningham which explains this fully as well as giving a lot of information about how to make places light enough for the ageing eye and for people with dementia.

Design implications

Age-related sight problems may require many design changes:

- Double the usual levels of light (wherever possible maximise the use of natural light since it is usually much brighter).

- Ensure good contrast. If something does not contrast sufficiently, then it is invisible. This can have severe consequences, such as a person missing the seat of the chair or the toilet seat, when sitting down.

- Do not rely on colour for orientation. If an older person’s ability to see colour is impaired, and their memory is too, it is not reasonable to expect them to be able to find their way using colour cues. If colour is to be used in any meaningful way, it needs to be vivid.
If the impairment is related to perceptual problems caused by dementia, then there are some adaptations to the environment which may be helpful:

- Ensure the floor is the same ‘tone’ throughout (see the explanation of Light Reflectance Value in the ‘Appendix—contrast in tone’).
- Avoid speckled or sparkly flooring as this may be seen as litter or dirt, or as if it is moving.
- Avoid elaborate patterns on the floor which may be seen to be moving.
- Avoid swirls, vertical strips, and complicated patterns in fabrics which may be misinterpreted.
Assessments

The first step for most people with vision impairment is to visit a high street (local) optician (optometrist) or GP. The GP will then arrange for more specialist eye assessments by an ophthalmologist or neuro-opthamologist.

Neuro-opthamology is a specialist branch of medicine concerned with visual and eye movement problems related to the nervous system. Neuro-opthamology teams assess, diagnose and manage disorders of the eye.
After an assessment by an ophthalmologist, in the UK, you can also be placed on the vision impairment register by contacting your local council. There are two registers—one for sight impaired and another for severely sight impaired.

Depending on which register you are on you could be eligible for a range of concessions and you can also have an assessment of your needs undertaken by the local health and social care team. You can also request a low vision assessment to access aids to make the most of your remaining vision. This service varies according to your geographic location, e.g. it can be provided by hospitals, local authorities or charities.

In Australia, people who are assessed as blind or vision impaired may be eligible for a range of benefits issued by Centrelink as well as a number of state-based supports.

**Available services**

In the UK, the Royal National Institute of the Blind (RNIB) employs Sight Loss Advisors who can help you to find the right person to talk to in your area.

If you are a veteran of Her Majesty’s armed forces and you have a vision impairment (at any time in your life), you can contact Scottish War Blinded and ask to be assessed to receive added assistance and rehabilitation to maintain your skills. This organisation provides outreach services and support including:
grants for equipment, funded respite care, home modifications, sports, recreation and fitness facilities. Royal Blind, a Scottish charity, provides specialist residential facilities for older people with a visual impairment in Scotland.

Some similar services are provided by organisations such as Blind Veterans UK, Blinded Veterans Association (US) and Blind Military Veterans Australia.

You can discuss these services with your GP who can then make inquiries or referrals on your behalf.

**Self-management and care partners tips:**

- Schedule appointments with optometrists for eye check-ups.

- Put processes in place to help with dementia symptoms. This might mean having a conversation with your optometrist about dementia and the person’s specific personal needs so that both the optometrist and the person with dementia have a positive experience.

- Check regularly that glasses are clean.

- Encourage the person to wear their correct spectacles for reading or distance.

- Label each glasses case for easy identification.

**Getting vision help—step by step**

- Go to the optician, commonly known as an optometrist. Take a list of your medications and your glasses.

- Tests will be carried out to optimise vision. If symptoms persist a letter will be sent to your GP.

- You might then be referred to a specialist for more in-depth tests.

- If the ophthalmologist decides it is necessary, he/she will ask permission to consult with other specialists involved in your care.

- After this consultation a diagnosis is made.