

Community Support Essentials



Talking Sense

LIVING WITH SENSORY CHANGES AND DEMENTIA

AGNES HOUSTON WITH JULIE CHRISTIE

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Important: Dementia care knowledge and research is continually changing and as new understanding develops, so to does the support provided for people with dementia. All care has been taken by the authors and publishers, as far as possible at time of publication, to ensure information is accurate and up-to-date. You can contribute to future editions of this book by going to dementiacentre.com

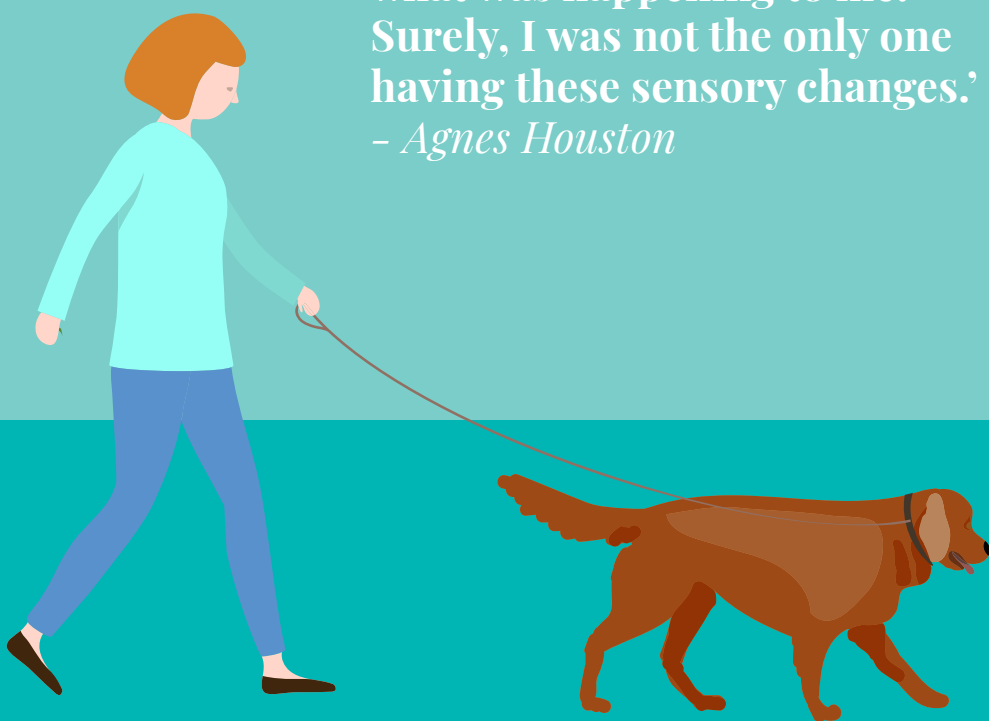
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HammondCare's Dementia Centre is committed to providing excellence in dementia care. Older and younger people living with dementia deserve services that are designed and delivered based on evidence and practice knowledge of what works. This is achieved through providing research, training and education, publications and information, consultancy and conferences. Thank you to everyone who supported the publication of *Talking sense: Living with sensory changes and dementia*.

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‘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*



Introduction



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 AIDs-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.



01 Vision

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.

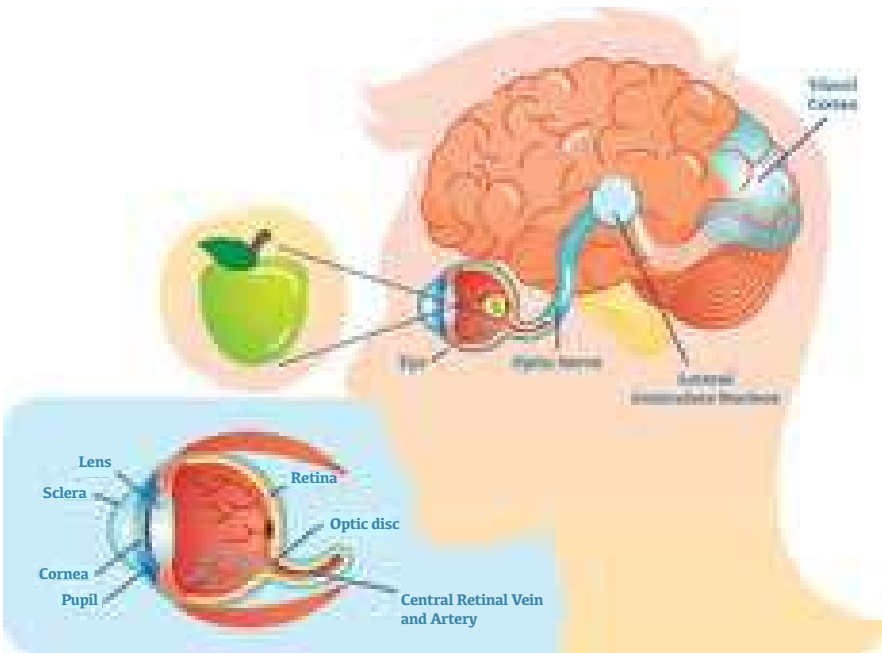
Or the person's eyes may be healthy but their brain has trouble interpreting what is seen due to the impact of dementia. Let's learn more about vision, dementia and sensory changes.

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...’



The eye and brain working together in the sense of sight.

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.



The view with cataracts (top left), glaucoma (top right) and macular degeneration (bottom left).

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 vision³. 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 challenges⁴:

- **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.



A mannequin or coat stand may be misidentified as a person.

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 mind⁵.

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 experience⁶:

- 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 Cunningham¹⁰ 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.



This toilet with good contrast for the seat and rails (left), is preferable to the all white, low contrast toilet (right).

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.



This shiny floor almost looks like a swimming pool!



This floor is too busy with patterns, colours and shadows.

Self-management of vision impairment

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-ophthalmologist.

Neuro-ophthalmology is a specialist branch of medicine concerned with visual and eye movement problems related to the nervous system. Neuro-ophthalmology 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.

02 Hearing

Both hearing impairments and dementia increase in prevalence as people age, meaning the person with dementia may have the challenge of age-related hearing loss as well as auditory issues associated with dementia.

Our ears have two jobs: the first is hearing and the other is maintaining balance.

Hearing occurs after sound vibrations cross the eardrums to the inner ear (see below). The outer ear is the part we can see and it acts like a funnel trapping sound and directing it to our eardrum. The middle ear passes these vibrations on through tiny bones and the vibrations reach the inner ear. Here they are changed into nerve signals and then carried to the brain by the auditory nerve. We can listen to specific sounds by choosing to focus on these even while there is other sound.



Balance (equilibrium) is controlled in the inner ear where fluid and small hairs stimulate the auditory nerve. This helps the brain maintain balance and we will cover this aspect more fully in Chapter 4 ‘Position sense and balance’.

Impact of ageing

As we age the structures inside the ear start to change and ear function declines. The ability to hear sound decreases—with hearing impairment among older adults common and the rate of impairment increasing with age.

If our ears don’t capture all of the sound around us, we then don’t have all of the information we need to interpret it accurately. Hearing impairment can alter a person’s ability to understand speech, while a progressive loss of hearing (presbycusis)—especially for higher pitched sounds—can occur. Hearing aids can help, as can clearing the ears of a build up of wax, a not uncommon cause of temporary hearing impairment (but don’t put anything in your ear!).

Another impact of ageing is that some people may also start to have problems maintaining balance.

Impact of dementia

If you already have hearing impairment and develop dementia, you could face a complex cross-over of symptoms. As you seek to develop strategies or ways of coping, a peer support group can help. It is good to talk to others experiencing similar challenges and to be aware of the risk of social isolation. For example, when you go into social occasions let people know the best way to support you.

It’s important, where possible, that having dementia does not lead to stopping the use of hearing aids or being assessed for hearing impairment and being prescribed hearing aids¹¹.

Some common impacts of dementia that are reported include heightened sensitivity to sound and being unable to filter out background noise such as the TV being on while trying to have a conversation. Let’s look at how dementia interacts with some specific conditions.

Hyperacusis and tinnitus

Hyperacusis is a debilitating hearing disorder which causes increased sensitivity to certain sounds. It may include an inability to tolerate some everyday sounds, which become an unpleasant experience. Living with this condition is not easy and is particularly difficult if combined with dementia. An impaired ability to filter out unwanted sound may develop and can make life very challenging in situations where there is a lot of sound, such as cafés.

I was with my friend in a coffee shop and could feel myself getting more and more furious. I didn't know it at the time but it was the noise. It made me want to scream.

Kathy, a person living with dementia

Tinnitus is the term for the sensation of hearing a sound in the absence of any external sound. A person with dementia may find this particularly distressing and confusing. The British Tinnitus Association has good advice on their website¹² for both hyperacusis and tinnitus:

- Free phone apps, which are available for download, provide a decibel meter for measuring sound levels. This is useful for informing you if noise levels around you are above the recommended safe level.
- To prevent the pain and distress caused by noise you can buy earplugs from local pharmacies or get noise-cancelling headphones.
- You can listen to your own music using headphones or earphones.
- Be bold—request loud music to be turned down in restaurants or ask for a quiet area—explain why. Pointing out that it may be harming the staff too is often effective!
- Some supermarkets now have quiet times for shopping. You can ask your local supermarket if they do this. If they don't, you can ask them to consider this or you can shop somewhere that does offer this service.



Changes to hearing can be a challenge to communication.

If you think you have hearing or balance problems go to your GP. You can ask to be sent for a hearing test if the symptoms continue. Ask to be referred to an audiologist or the hospital audiology clinic.

If you have sensitivity to loud noises ask for the Uncomfortable Loudness Level (ULL) test. This is not done as standard—you must request this. Once you have a diagnosis, you can then take steps to manage the condition.

As mentioned, any problems with hearing are more difficult if you have dementia and you may find yourself quickly becoming overwhelmed or angry. That is why being aware of these sensory changes and talking to others may help.

Auditory hallucinations

Some people with dementia can also hear things that are not there: auditory hallucinations. This can sometimes be comforting or even enjoyable for the person concerned. (The following examples are from Alzheimer's Society's Talking Point forum—used with permission).

‘My grandmother has dementia and we’ve noticed a few times that she has mentioned she can hear music and then shares the song lyric. She is not really a musical person and has never been known to have a little sing-a-long. The kinds of songs she claims to hear are not ones that may have just been on a TV advert or on the radio so it doesn’t seem plausible that she has heard these songs in the background.’¹³

Auditory hallucinations can, unfortunately, also cause anxiety or upset to the person.

‘My partner would often complain of hearing music at night after we had retired to bed. He couldn’t settle as he had to keep checking that the TV and radio were switched off. It made him unsettled and we often wouldn’t get any sleep, even when I explained that there wasn’t any music on in the house.’

Auditory hallucinations can also have care partners scratching their heads as to where the person with dementia is hearing what they report.

The result of a common auditory hallucination with my wife was her reporting that the weather forecaster had just said that it was going to rain, snow, freeze, hurricane, brilliant sunshine... No idea why she was fixated on weather forecasts, as it did not worry her I just let it go. She did not remember any threat of impending disaster.¹³

Design implications

Ensuring that rooms are quiet is the most helpful design modification you can make for someone with a hearing impairment. Reverberation is a frequent problem but less of a problem in smaller rooms.

Noise needs to be absorbed by soft surfaces (carpets, curtains, fabric on furniture) or even acoustic panels. These can be in the walls or ceiling and are now available with pictures on them so they look like art.

Noise is more distressing if the source is not clear (background noise) or is beyond your control. If possible, bedrooms and living rooms should not be adjacent to busy roads or railway lines and it can be helpful to consider double-glazing.

Multiple sources of noise such as the washing machine, vacuum cleaner, radio, TV and loud conversation—all at the same time—will be very distressing to someone with a hearing impairment and worse still for someone with dementia as well.

The book *Music remembers me: Connection and wellbeing in dementia* has some very helpful general sections on noise, sound levels, daily activities and living with dementia.¹⁴

Mrs Johnson was a long-standing member of her church and always enjoyed meeting old friends after the service over a cup of coffee in the church hall. This was especially important when she developed dementia which affected her confidence in other social situations. However, she became increasingly agitated because it was a big, noisy room with no sound absorbing materials. Lots of people talking, the clatter of cups and cutlery, chairs scraping on the floor all overwhelmed her.

Self-management and care partners tips

- Be aware of the importance of ear health.
- Never put anything into your ear to clean it.
- Arrange annual hearing tests by an audiologist.
- If you use hearing aids, check the batteries and clean the tubing. If you cannot do this arrange for someone to help with this task.
- If you have problems with hyperacusis or tinnitus ask your audiologist if they have a rehabilitation course available.

‘Multiple sources of noise such as the washing machine, vacuum cleaner, radio, TV and loud conversation—all at the same time—will be very distressing to someone with a hearing impairment and worse still for someone with dementia as well.’

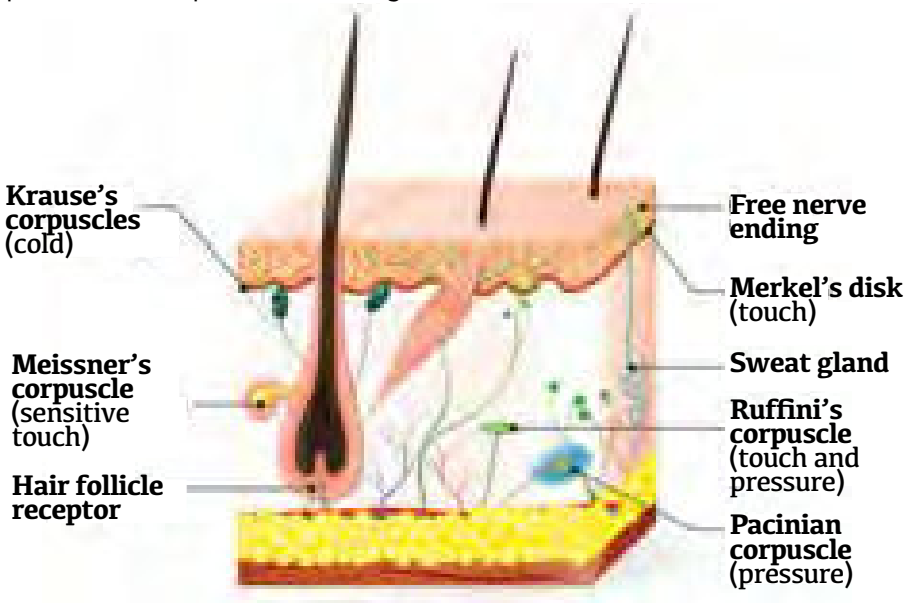


03 Touch

While dementia may mean the experience of touch changes and sometimes becomes challenging, every person needs positive experiences of appropriate touch.

In English and other languages, touch has many meanings. The most commonly recognised is to cause or permit a part of the body, especially the hand or fingers, to come into contact with an object or person so as to feel, disturb or move. We often use our hands to touch others and it is our skin which hosts tactile receptors.

The somatic sensory system is responsible for the sense of touch. The system has nerve receptors that help you feel when something is in contact with your skin. You also have specialised nerve receptors that transmit information about pain and temperature changes.



Tactile receptors on the skin communicate with the brain.

Importance of touch

Touching and feeling is thought to be the sense which is most developed in the mother's womb. It is a sense which requires direct contact to understand an object or the environment. At the slightest touch, millions of tactile sensors throughout the body send countless messages to the brain.

In the case of darkness, blindness or impairment of vision, touch can help us to position ourselves in relation to other people and things (spatial orientation).

The sense of touch is deeply embedded in us, from the moment we are born and when our mothers hold us. This stays with us throughout our lives as we experience comfort, love and a multiplicity of positive emotions from the appropriate touch of someone else. Of course, we understand that, regrettably, touch is not always pleasant, and sometimes it is the previous experience of unpleasant touch that can affect our feelings about later occasions of touch.



A brief touch of hands reinforces friendship and care between pastoral carer Anna and aged care resident Simon.

It is worth highlighting the difference between intentional, caring touch with our hands and the more general touch that occurs when other parts of the body come into contact with things.

Caring touch can trigger the brain to release endorphins and serotonin, which are natural chemicals that suppress pain and depression. It can be helpful to massage a person's hand while waiting for pain medication to work. Pets can provide much needed touch sensations for the 'touch hungry'.

Impact of ageing

We all lose a few touch receptors over the course of our lives¹⁵. Ageing can also cause alteration in the sensory experience of pain. Nevertheless, touch remains an active sense in late life even when someone has dementia.

People who have diabetes can get neuropathy (nerve damage) which can cause hypersensitivity to touch. They can, for example, find taking a shower painful or even the touch of a blanket uncomfortable.

Impact of dementia

Over sensitivity (hypersensitivity) or reduced sensitivity (hyposensitivity) to touch are both problems that can arise from dementia. Hypersensitivity is most likely to arise in the mouth, fronts of hands, soles of feet and genitalia¹⁶. Other parts of the body can become hyposensitive with people reporting less sensation in these areas.

Sometimes, this can lead to a diminished sense of pain which can be hazardous, e.g. Ross (as can be seen in a film¹⁷ produced by the Life Changes Trust) cannot feel hot water and his wife has to stop him putting his hands in very hot water.

People with dementia can react negatively to some kinds of touching and, as mentioned, this may relate to past trauma, which they are unable to explain. They may also misinterpret touch or be extra sensitive to it. However, it is crucially necessary to experience positive touch because it can offer

so much comfort and reassurance. The important point is to respect the person's space and personal wishes.

Phillip is a farmer who lived at home until he was admitted to a mental health assessment unit. His family had to call for help as he became increasingly angry and more than once had lashed out at his wife. Everyone was very distressed about this including Phillip, who wasn't able to explain why he felt so angry and stressed. After a period of assessment, Philip was diagnosed with Lewy body dementia. He continued to be agitated on the ward and would, on occasion, respond to the approaches of others with violence and shouting out. The staff took the time to find out about Phillip's life at home. His family worked with the team and revealed the close relationship that Phillip had throughout his life with the working dogs on the farm. It wasn't practical to have a dog on the ward but instead they obtained a life-sized toy of a collie dog for Phillip. To everyone's surprise he responded with joy when he saw the dog. Phillip was perfectly calm as long as he had his hand on the dog's head or had the dog on his lap.



The friendly presence of a pet can bring calm and comfort.

Some people may be hypersensitive to some kinds of touch, like Freda below.

The home care partners that visited Freda were not looking forward to their visit as today they had to help Freda with her shower. Freda never wanted to take a shower and everyone ended up upset when Freda cried and shouted. They couldn't make her understand that she needed to attend to her personal hygiene.

Freda's family struggled with this as she always loved a shower and was very particular about her appearance and dress before she was diagnosed with Alzheimer's disease. What they didn't know was that Freda's skin felt hypersensitive and her shower water now felt like tiny needles. She became very upset and the whole experience was upsetting and painful for her.



Hypersensitivity can make everyday experiences unpleasant.

Design implications

Touch is a source of information about the environment especially for people with impaired vision. It is important, if someone has dementia as well, that what they touch makes sense to them. A tap should feel like a traditional tap or someone will not know what it is or how it works, a chair should feel like a chair and so on.

Normal, everyday things should feel pleasant and comforting, e.g. a wooden handrail feels more comfortable than a metal one and a wooden bench more comfortable than a metal seat. For people with dementia at the end of life, touch is a crucial sense. It is important that there are pleasant things to touch such as soft fabrics and the gentle touch of another human being may be of particular importance.



Could you work out how to use this tap by touch alone?

Self-management and care partner tips

- Be aware if any kind of touch is unpleasant for you or altered in some way—increased or decreased.
- Make sure you write it down so that if you go to stay with someone or go into hospital, they know what to avoid.
- Adapt your home and routine to avoid problematic sources of touch. If decreased sensation is noted, be careful while touching hot surfaces or applying heat packs.

For care partners

- Be aware of the problems some kinds of touch can bring.
- Accept that this is a sensory problem that you cannot change.
- Adapt your home and routine to avoid it.
- Avoid situations where this kind of touch might arise.
- Remember that appropriate touch is essential and offer every opportunity such as hand-holding or massage. You may want to consider whether a comforting item might be helpful when you are not present.
- Touch is especially important at the end of life when other senses are not working well.



04 Position sense and balance

Position sense (known clinically as proprioception) and balance are not generally thought of as senses—but they should be. They help us perceive and interact with our environment alongside the traditional five senses

Position sense

Position sense can be thought of as a variety of muscular senses working together to help us perceive where parts of our body are and where our whole person is relative to others. Position sense is an awareness of where our arms and legs are, and what they are doing, without using our eyes.

This is possible through messages from nerve cells in the skin (somatic receptors), muscles, tendons and joints—sent to the brain by way of sensory nerve terminals (called spindles). If your feet and legs are under a table you cannot see them but you know where they are. You continue to know where they are even when you move them. Proprioception plays a crucial role in human movement control, which is fundamental for daily activities. Usually this information goes to our brain without us being aware of it.

Vestibular system

The vestibular system contributes to balance and spatial orientation. It enables us to coordinate our movement and balance. This happens within the inner ear (called the labyrinth). Signals are then sent to the neural structures that control our eye movements and to our muscles so that we remain upright.

The combination of position sense (proprioception) and the function of the vestibular system are referred to as kinesthesia—a subconscious but essential awareness that allows us to safely navigate the world.



Position sense and balance are vital in helping us enjoy movement and activity.

Impact of ageing

Ageing affects both proprioception and the vestibular system. As our joints stiffen or are replaced, our proprioception works less well. We compensate by using our eyes more to know where our limbs are, e.g. looking at our feet when walking. As we age our ears become less efficient and this includes the vestibular system. Balance is increasingly an issue.

Impact of dementia

Although all the senses have a role in balance, to understand the impact of dementia we also have to include both proprioception and the vestibular system. Position sense also helps us navigate through spaces and around objects. When this is affected, so is the ability to navigate our bodies within physical and social spaces. People with dementia may find that they are wobbling about, banging into furniture or even falling without having any idea why. It may be because of balance problems.



Walking around a busy café may assist when a person's balance and position sense is a challenge.

Mr Proctor could not walk through his local café with his family without banging into the seats of other customers. This irritated some people and embarrassed the family. If they had been aware of his difficulties with 'position sense' they could have chosen better options such as to walk with him around the edge of the café or choose one that was less crowded.

Design implications

Enabling design for people with dementia with impaired position sense and balance can include many features, some of them vital:

- As many older people may look down at their feet while walking, it's important to put crucial signs at a lower height.
- A cluttered space with furniture close together is problematic since navigation through space is impaired and people will bang into furniture.

- Good lighting is essential for people who are anxious about their position and their balance.
- An even, plain floor which does not have patterns will be helpful.



Signs at lower heights may assist people unsure of their balance, who may be watching their feet as they walk.

Self-management and care partner tips

- Be aware that you may experience problems with ‘position sense’.
- Check out possible causes with your GP.
- Ask for a referral to a physiotherapy review for assessment of balance, aids and falls prevention measures. If you are in the UK you may find a specialist physiotherapist, called a neurological physiotherapist.
- Consider using a stick or walking aid.
- Ensure good lighting levels in your home.

For care partners

- Be aware that the person with dementia may have balance problems.
- Consider how to keep the person safe if they sway about or were to fall.
- Understand why the person with dementia may tap hands or feet constantly—it can be very annoying but it is an instinctive reaction if you are not sure where your limbs are.
- Be aware that the person with dementia may be looking down at their feet a lot. This could be because they are anxious about where their feet are or trying to maintain balance.
- Undertaking a thorough assessment of environments drawing on the latest evidence. We suggest the Dementia Centre Design Audit Tool available at dementiacentre.com



05 Taste and smell

Taste and smell are senses we rely on for a range of daily activities such as mealtimes, and for safety as well. When these senses change due to ageing or dementia, being aware of what is happening and having strategies to manage can reduce distress and even danger.

Taste and smell are interlinked and, at their most fundamental, are the way the body detects chemicals. Tasting chemicals (tasty chemicals in food are known as ‘tastants’) that we are attracted to facilitates the enjoyment of foods while smelling pleasant odours (known as odorants) guides us to seek out favourite foods again.

The sensing of chemicals also has the important function of informing of us of hazards and unpleasant objects to avoid, such as spoiled food, gases and smoke.

Taste and smell work closely together in activities such as enjoying food and keeping safe. As well, taste and smell in the context of a delicious meal or pleasant aroma can improve social interaction and enjoyment of life.

Taste and the tongue

The tongue is covered with thousands of small bumps called papillae, which are visible to the naked eye. Within each papilla are hundreds of taste buds. They are located on the back and front of the tongue as well as the roof, sides and back of the mouth and in the throat. Taste is the sensation when these taste buds are stimulated by something in the mouth.

Smell and the nose

When an odorant stimulates the olfactory receptors in the nose, electrical impulses are passed to the brain. Interestingly, the olfactory lobe in the brain is very near the memory system.



Taste and smell signals are processed through different areas of the brain but ultimately converge to help detect flavours of food.

The impact of ageing

Sensitivity to taste decreases as you age although diminished smell may have more of an impact than diminishing taste buds¹⁸. The taste buds do become less effective and problems with oral health and certain medications can also affect the efficiency of taste buds.

Sense of smell can also diminish especially after the age 70. This may be related to loss of nerve endings and less mucous production in the nose. Mucus helps odours to stay in the nose long enough to be detected by nerve endings. It also helps clear odours from nerve endings. However, certain diseases or smoking and exposure to harmful particles in the air can speed up the loss of taste and smell.

One resulting problem is a loss of appetite, which may be made worse because, as we age, less saliva is produced and so the mouth is drier. When the mouth is dry it is harder to swallow, and eating is not as enjoyable. Some medications can make this worse.

The impact of dementia

Smell and taste impressions have an important role in our lives: scents and flavours stimulate various associations and can lead to the recall of either a pleasant feeling or one of disgust, revulsion or even desire. The centre for emotions and memory in our brain responds to olfactory information.

Many people with Alzheimer's disease have a much-diminished sense of smell, it can even be a diagnostic clue.

Grace guessed that her husband had dementia before he began to have any other changes, because he lost his sense of smell a couple of years earlier. She worked in the field of dementia care and had read about this possible association. It caused her a great deal of worry although she said nothing about it to anyone.

Because the olfactory lobe is situated near the memory part of the brain, smell can be quickly and intensely evocative of times past. This can often be pleasant such as the smell of lavender bringing to mind a much-loved grandmother. It might be something very distressing such as the smell of fire and an experience of war.

Being aware of associations and avoiding smells which cause distress is important. On the other hand, reminiscence sessions using little bottles of strong smelling cleaning materials such as Brasso or polish, or herbs such as sage or lavender can be a real treat and lead to enjoyable discussions about memories.

Other experiences include taking a dislike to previously enjoyed foods because they no longer taste or smell nice to the person concerned. Other people also describe usually enjoyable smells such as fresh linen smelling unpleasant or rotten.

Phantom smells

Some people with dementia experience olfactory hallucinations or phantom smells¹⁹ which are often reported as being foul smells. Where someone is alarmed by a phantom smell such as smoke, they may become unsettled thinking there is a danger.

Robert cannot tolerate the smell of hair spray or perfumes which are so unpleasant to him that they have to be avoided. He says he gets a kind of migraine. His family have found it hard to completely avoid perfumes of any sort and going to department stores has become difficult because the perfume section is nearly always near the entrance.



Smooth pureed meals can look appetising and taste great!

Swallowing difficulties

Some people with dementia can develop swallowing problems. When this happens a speech and language therapist (or speech therapist, speech pathologist) may be able to help. Speech and language therapists provide treatment, support and care for people who have difficulties with communication, eating, drinking or swallowing. Food can also get stuck in the airways causing a risk of choking.

A dietician can help where changes in taste have resulted in changes in food preferences or food avoidance.

HammondCare has produced three cookbooks that address the needs of people with dementia and also those at the end of life. They cover nutrition and swallowing difficulties, as well as providing innovative recipes²⁰.

Design implications

Once again, consistency of stimuli is needed. A dining room, for example, will be more quickly recognised as a place to eat if there are smells of food, and more slowly recognised if it smells of disinfectant.

A care home for people who are blind or partially sighted, uses smell to assist way finding. The toilets smell of disinfectant, the lounge of polish, the dining room of food.

Stimulating appetite is important as so many people with dementia can lose interest in food. An attractive cooking smell such as toast can be a huge help. In HammondCare's cottages for dementia care each has their own fully-functioning kitchen—opening on to the dining room—where the all meals are prepared and cooked.



The domestic style kitchen in a HammondCare cottage for dementia care.

Tips for self-management and care partners

If you are worried about changes to taste and smells or smelling things which seem unlikely:

- Ask your pharmacist to check your medication to see if a loss of taste and smell could be a side effect.
- Consider keeping a diary of what affects you and when it happens. There may be a trigger such as being tired or stressed.
- Consider strategies for coping, e.g. if you worry that you smell smoke and there may (or may not) be a fire, ensure you have a working smoke detector so you don't have to rely solely on your senses.
- You may have to accept that you experience smells which are not there. If there are things which trigger your phantom smells, you may be able to work out ways to avoid them.

For care partners

If the person with dementia experiences a diminished sense of taste or smell you could plan to:

- Talk to a health care professional.
- Make sure food has more taste by using more seasoning and spices. A food diary may help identify which kind of food is not being eaten.
- Contact fire safety at your local fire service and ask their advice. They may assist in the installation of smoke alarms and discuss alerts to other providers such as utilities.
- Give more attention to good quality oral health and hygiene.
- As mentioned previously, use HammondCare's cookbooks for more hints and tips²¹.

o6 Where do we go from here?

We have come a long way in our understanding of the sensory changes associated with both dementia and ageing.

Dementia knowledge—once considered the domain of doctors and nurses—is now also being understood from the perspective of sensory challenges, as told by the people living with the condition. Our wish for this book is that it offers hope to everyone who is facing these new sensory challenges.

The experience of dementia and the quality of the places and spaces in which we live are intertwined. Dementia can mean a heightened sensitivity to the built and social environment. The more that we understand ourselves and the ways in which we can modify our environments, or take positive actions, the better prepared we can be for what might come.

It is important for all of us concerned about dementia to understand the biological changes of ageing and the perceptual problems of dementia and how these challenges together can affect the person with dementia.

Sources of support and signposting are essential. Professionals who work in this area are just some of the points of navigation in this process. The list includes:

- people living with dementia
- care partners and support networks
- professionals in sensory, health and social care
- professionals in dementia fields
- home care partners
- care homes
- planners and designers

- project commissioners and managers
- trainers and educators
- researchers.

Continued improvement in support starts with: ‘Think dementia, think sensory, think solutions’.

Speak out

We hope *Talking sense: Living with sensory changes and dementia* is a stepping-stone in this important area of work and that it will inspire others. It is vital that this topic is included in education on dementia. Research on dementia must also begin to address this important area of work.

Most of all we want to ensure that no-one faces these issues on their own or feels that they are isolated because of these difficulties. We encourage you to speak out and seek the help and assistance you need. After all that is where this journey started...

To continue the conversation about living with sensory challenges and dementia, and to provide updates for future editions of this book, please visit hammond.com.au and add your comments, ideas and questions.

Appendix—contrast in tone

When we talk about contrasting colours, what we are actually talking about is contrast in the tone aspect of colour. Contrast in tone is measured in LRV, which is an acronym for Light Reflectance Value. This describes how much a surface or colour reflects light.

The scale goes from zero to 100. Black is zero because it does not reflect light. Pure white is 100 because it reflects all light. It does not matter what the 'hue' (e.g. red, blue, green) is.

The important thing to remember is that for the ageing eye to see something, it needs to contrast with the background by 30 LRV or more, e.g. a handrail needs to contrast with the wall by 30 LRV or more.

If you want to have a surface with no visible contrast, the difference in LRV needs to be five or less. This is often significant for furnishings such as floors which need to be a consistent tone so people with perceptual problems do not see a step.

The RNIB website (see 'Support and advice') has a lot to say about contrast since it applies to every aspect of seeing such as reading text, seeing signs and so on.

You will find that most paint firms give you the LRV with information about the paint.

One way of assessing LRV is to use the camera on your smart phone and put it on 'greyscale'. It is then clear whether there is a reasonable degree of contrast.

Authors and acknowledgements

Agnes Houston

Agnes Houston MBE is a dementia activist who has always put others first. She was diagnosed with younger onset Alzheimer's disease in 2006 at the age of 57. She has campaigned for best practice and improving the lives of people with dementia (especially those experiencing sensory issues) in Scotland and received a lifetime achievement award from Alzheimer Scotland in 2013. Agnes is former Chair of the Scottish Dementia Working Group and former Vice Chair of the European Dementia Working Group and a board member of Dementia Alliance International. In 2015 Agnes was awarded an MBE and in 2016 was awarded a Churchill Fellow. In 2016 she was the editor of *Dementia and sensory challenges: Dementia can be more than memory* and in 2018 was co-author of *My home, my life: Practical ideas for people with dementia and carers*.

Agnes is a Knowledge Exchange Associate with HammondCare and a Knowledge Exchange Fellow with the Edinburgh Centre for Research on the Experience of Dementia (ECRED).

Julie Christie

Julie has worked as a nurse, social worker and social work manager, and has a PhD focused on resilience. She has worked across a range of settings including integrated health and social care, residential care homes and hospitals. Julie has extensive knowledge of co-production, assessment, risk enablement, self-directed support and issues of support and protection. Julie is an Adjunct Lecturer at the University of New South Wales and a Visiting Research Fellow at the University of Edinburgh. As co-founder of the dementia PhD twitter community #demphd, she has created a social media space for people with dementia and researchers.

Acknowledgements from Agnes:

Thanks to my husband Alan and my daughter Donna for supporting me on this road.

Thanks to HammondCare and Associate Professor Colm Cunningham for making my dream of this book a reality, to Professor Mary Marshall for practical assistance in translating my collection of writing into this book, and to my writing partner Dr Julie Christie.

Thanks also to my colleagues Dr Raj Anand, Joanna Fozard and Annie and Ricky Pollock for their help and support.

Finally, I want to thank my many friends and peers who are living with dementia, for taking the time to share their own experiences.

Support and advice

United Kingdom

Alzheimer's Society: alzheimers.org.uk or +44 (0) 300 222 1122

Alzheimer Scotland: alzscot.org or +44 (0) 808 808 3000

British Tinnitus Association: tinnitus.org.uk or
+44 (0) 800 018 0527

Carers UK: carersuk.org or +44 (0) 20 7378 4999

Dementia Centre: dementiacentre.com or +44 (0) 7787 168168

Dementia UK (Admiral Nurses): dementiauk.org
or +44 (0) 800 888 6678

Huntington's Disease Association: hda.org.uk
or +44 (0) 151 331 5444

Lewy Body Dementia Association UK: lewybody.org
or +44 (0) 131 473 2385

Life Changes Trust: lifechangestrust.org.uk
or +44 (0) 141 212 9600

NHS: nhs.uk/conditions/dementia

RNIB: rnib.org.uk or +44 (0) 303 123 9999

Royal Blind/Scottish War Blind: royalblind.org
or +44 (0) 131 229 1456

Winston Churchill Memorial Trust: wcmt.org.uk
or +44 (0) 20 7799 1660

Australia

Better Hearing Australia: betterhearingaustralia.org.au
or 61 7 3844 5065

Blind Military Veterans Australia: bmva.com.au
or +61 0417 880 700

Carers Australia: carersaustralia.com.au or AU 1800 242 636

Dementia Australia: dementia.org.au or AU 1800 100 500

Dementia Centre: dementiacentre.com or 61 02 8437 7355

Dementia Support Australia: dementia.com.au or
AU 1800 699 799

Department of Health: agedcare.health.gov.au

Royal Society of the Blind: rsb.org.au or AU 1300 944 306

United States

Alzheimer's Association: alz.org or US 1800 272 3900

American Foundation for the Blind: www.afb.org

Blinded Veterans Association: bva.org/BVA or
US 800 669 7079

Dementia Society of America: dementiasociety.org
or US 1800 336 3684

Dementia Care Central: dementiacarecentral.com

Hearing Loss Association of America: hearingloss.org
or US 301 675 2248

Vision Aware: visionaware.org

International

Dementia Alliance International: dementiaallianceinternational.org

Alzheimer's Disease International: alz.co.uk or info@alc.co.uk

World Health Organisation: who.int/mental_health/neurology/dementia

‘Most of all we want to ensure that no-one faces these [sensory change] issues on their own or feels that they are isolated because of these difficulties.’



Further reading and references

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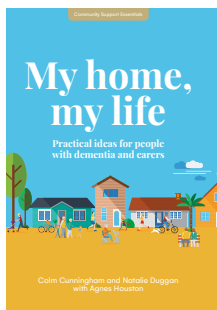
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²⁰ The three cookbooks are *Don't give me eggs that bounce: 118 cracking recipes for people with Alzheimer's* (HammondCare Media 2014), *It's all about the food not the fork: 107 easy to eat meals in a mouthful* (HammondCare Media 2016), *Lobster for Josino: Fabulous food for our final days* (HammondCare Media 2018).

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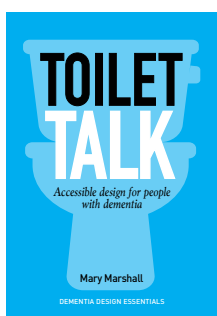
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More from HammondCare and the Dementia Centre



My home, my life: Practical ideas for people with dementia and carers

My home, my life: Practical ideas for people with dementia and carers brings together the voice of people with dementia and carers with the best learning from research and care experience to provide insightful tips, strategies and real-life stories to support greater independence. Whether it is through a better understanding of the impact of dementia and ageing, tips on good design at home, strategies for going out or approaches to communication and care, *My home, my life* will enable people with dementia, carers and their support networks to meet challenges with courage and creativity.



Toilet talk: Accessible design for people with dementia

Toilet talk: Accessible design for people with dementia addresses this important question: Why are public toilets so hard to find and often challenging to use? It's a topic few people want to talk about but one that is vital to the dignity of many older people and people living with dementia. In this brief but informative book, Professor Mary Marshall pushes past the 'anxious laughter' which often greets this topic, and speaks frankly about what good, accessible toilet and bathroom design looks like, and why it is desperately needed.

‘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 Houston 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.

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