Community Support Essentials

Talking

LIVING WITH SENSORY CHANGES AND DEMENTIA

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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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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

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.

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.