

Dementia & Sensory Challenges

Dementia can be more than memory

hallucinations

seeing

smell

taste

hearing

touch

Inspired by and created with the
words of people with dementia

“I read this book after I had my dementia diagnosis, and everything then made sense. There’s no need to be afraid of dementia, life goes on” *Glenda Roberts.*

Dementia can be more than memory...



This project was instigated by Agnes, a person with dementia, to raise awareness and give hope to other people with dementia as well as carers on how to live a positive life with sensory challenges.

“I was diagnosed with dementia of the Alzheimer type nine years before printing this booklet, when I was 57 years old.

I expected the memory issues but when I started to have sensory challenges, I did not know what was going on.

While campaigning I have had the privilege to speak to others with Dementia and discovered I was not alone.

Others had these issues but very little had been written about them, so in desperation I decided to write a booklet in the hope of enlightening others to the sensory challenges some people with dementia may face.

I hope this booklet will give the reader ideas on how to make the lives of people with dementia more pleasant, allowing them to be more socially included and no longer feeling alone.

This booklet is not intended to have all the answers but a snapshot of our lived experiences with a video explaining in our own words how it feels and how you can help us.

Agnes Houston MBE

<https://bit.ly/Sensesvideo>

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Key Findings

Although changes to the senses occur during the ageing process, the ages of those quoted in this booklet range from early fifties to late seventies, yet their experiences were similar regardless of age, stage or type of dementia.

Cognitive problems can be exacerbated by sensory issues.

More information around dementia and sensory challenges needs to be available:

'I wish someone had told me in the beginning what it (sensory symptoms) was...' *Helen*

'There are many types of dementia: I have PCA (Posterior Cortical Atrophy) a variant of Alzheimer's that affects my vision. Nothing out there for me...' *Ann*

'We are ordinary people living ordinary lives, who happen to have a long term condition called dementia. Please help us continue to live in our homes and our communities, which is something we can do very well if society understood how to support us with our sensory challenges...' *Agnes*

'There have been a lot of people videoed for this booklet - we can't all be wrong? So look at it and take something out of it...' *Ross*

Donna, carer:

I was privileged to meet, film and transcribe these wonderful people's lived experiences around sensory challenges. What I noticed was a common thread running through all the stories. I call these the four A's:

- Awareness
- Acceptance
- Adaption
- Avoidance

Seeing

Information travels from eyes to the brain where it is interpreted alongside information from other senses, thoughts and memories. So if you have 20/20 vision and still experience problems seeing, this might be because you have visuo-perception or spatial awareness.

I call it *Brain Blindness* which means your eyes see, but your brain doesn't interpret the information immediately.

Our thoughts

'I did not think that getting a diagnosis affecting cognition would affect senses so when I started to have sensory challenges I did not think it had anything to do with dementia...' *Peter*

'I lack spatial awareness as well and I was given a stick in the hospital to correct me...' *Carol*

'In shops they always have a big black mat and that looks like a hole, so it is perception and a leap of faith to actually step on to it...' *Tommy*

'I started tripping over a lot... I wasn't seeing the steps... I saw the optician and my eye sight's fine.' *Chris*

'Coming out of a shop, I find myself jumping (when I see a reflection of people in the silver doorframe) as if there is somebody there and I am trying to avoid them ... that's kind of frightening ...' *Alan*

'Difficulty processing what I see... stairs, light, black on black, glass doors...' *Ann*

'Shopping is a nightmare now as I experience double vision and ghosting. Add sensory overload and it's all too much...' *Agnes*

‘Watching TV - some nights it’s single vision, other times double vision: I just switch it off...’ Ross

‘Can’t see to read, so I use talking books...’ Carol

‘I went to use my computer and I could not see the letters on the keys ... they kept jumping...’ David

Stuff that helps

- Give yourself more time to process information before acting on it
- Wear correct glasses and make sure they are clean
- Ensure there is bright, even lighting (to reduce shadows)
- Make sure colours contrast
- Have plain backgrounds, especially with carpets
- Use talking books
- Prisms can assist with double vision - ask your optometrist
- As can coloured overlays for reading
- A folding white stick to help me with vision and perception and also alert others that I have a visual problem
- White pointer stick to inform others of a visual problem
- If you experience double vision/ghosting go to your optician who may refer you to an orthoptist who is a specialist in this area (remember to tell them you have dementia and what type it is)
- If optician confirms your lens prescription is adequate, but you still can’t see, consider further investigation

Who can help?

- RNIB Wales
- An Optician
- An Optometrist
- An Orthoptist
- An Ophthalmologist
- Occupational Therapist

Hearing

This booklet does not deal with hearing loss, but rather what was important to people who were interviewed.

Hypersensitivity to noise and certain tones, sensitivity to noisy environments and information overload leading to social isolation were common themes...

Our Thoughts

'It (the noise) hurts me sometimes...' *Rozel*

'It (the noise) builds up in a crescendo and I get agitated and upset... when the music starts I go home ...' *James*

'Difficulty with loud noise... this has a huge impact in my life... social and family...' *Helen*

'Any loud noise and I hit the ceiling...' *Joy*

'Can't stand music in shops... find myself getting very angry ... it was torture...' *Peter*

'It (noise) just seems to ring in my head...' *Rita*

'So every other word gets lost ... words go missing... then they (the person talking) start to shout...' *Tommy*

'In noisy environments I just can't think... my brain shuts down...' *Agnes*

'In the morning I cannot stand having the television on... when he (husband) has it on I tend to go into the bedroom...' *Elaine*

'Noise in acute hospital wards can be a particular problem for people with dementia, increasing levels of anxiety, anger and distress and potentially affecting someone's appetite, sleep pattern and awareness of pain.' *Shifting the Paradigm NHS Lanarkshire*

Stuff that helps

- Let people know your challenges and how they can help if they do not know the problem
- Give us time to hear what you are saying
- Allow time for our brains to process and think of the answer
- Use reflective listening by repeating what we have said back to us
- After a busy morning we may need a quiet time to recover
- Reduce sudden unexpected noises and sensory overload which may lead to confusion
- Pick a quiet time when going out for a meal
- Use ear plugs (to reduce noise)
- Sit at the end of a table (reduces noise)
- Lean with your back against the wall (reduces noise)
- Leave for a short time and go for a walk to clear your head

Who can help?

- A Hearing Therapist, accessed through your NHS audiology department.
- Speech and Language therapist
- Psychologist

Crossing the Road

As children we are taught to LOOK LEFT, RIGHT and then LEFT AGAIN. But to do this you need to use multiple senses: eyes to see; ears to hear; memory to judge the speed of cars before making a decision to go or not. Add in the environment, noise levels, and weather conditions and suddenly crossing the road becomes hazardous to say the least!

Now, imagine if you have dementia too!

Touch/Taste/Smell

During our interviews, people with dementia found they had noticed changes around touch, taste and smell:

- couldn't differentiate between hot and cold
- taste had changed affecting appetite and eating habits
- smells could be intense and overpowering
- in some cases the sense of smell had decreased

Our thoughts

Touch

'I feel the cold more...' *Liz*

'I poured boiling water over my hands instead of into a cup and didn't feel it...' *Ross*

'I've become more touchy-feely now... I hug people which I didn't do...' *Wendy*

Taste

'I lost my taste and smell nine years ago... maybe half year later I was diagnosed with Alzheimer's... I can't smell what I am cooking... I use my imagination...' *Nina*

'My taste has changed... never liked coffee now I am mad about it...' *Liz*

'I used to take sugar but now I don't like it... also don't like salt... I used to enjoy a pint but not now...' *Peter*

'Everything is quite bland now so you don't want to eat...' *Archie*

Smell

'I'm hungry but sometimes food just doesn't smell/taste right so eat chocolate instead... I go around sniffing myself as I think I smell bad... I use a lot of perfume...'

Agnes

'My sense of smell is less so can't tell if food is bad...'

Alan

'I often ask my wife to show me the packet (because I don't believe it's what I asked for)... It's (the smell) just not right...'

Ross

Stuff that helps

- Fit special taps to judge temperature
- Speak to a Dietitian about managing changes to taste
- Understand why this is happening and begin to accept the changes
- Share what's happening to you

Hallucinations

Our Thoughts

Visual hallucination:

involves perceiving/seeing something that is not in the real world

'Rather than hallucinations, I have very vivid dreams but I also suffer from lack of knowing when dreams stop and where reality starts...'

Chris

'I was looking at photos on the wall ... I was frightened because the people in the photos were waving at me...'

Eddie

'I paint my hallucinations...'

Edward

Continues over the page...

Hallucinations continued...

'My hallucinations just jump at me... She (my Psychiatrist) taught me to count tiles or flowers on the wallpaper... distraction therapy...' Carol

'Using meditation seems to help me ...' Helga

Olfactory hallucination:

involves experiences/smells that are not there

'Mine are definitely chemical smells...' Carol

'I smell a smell nobody can smell, it's a foul smell...' Liz

'Burning... since I had dementia (she laughs)... One time I actually phoned the fire department...' Elaine

'A drain-type smell or a mouldy-mop smell...' Joy

'I smell cat's pee and don't have a cat...' Agnes

'I smell curry and it's not there...' Edward

Auditory hallucination:

involves voices/sounds that are not real

'I think I heard a noise in the house and I am up looking for it and there is nothing there...' Alan

'What made me go to the doctor was my driving was a problem... I was hallucinating... I was convinced people were following me... and went to find them...' David

Stuff that helps

- Try to explain to the person with dementia what's happening
- Offer reassurance
- Trying to convince someone that they are mistaken can distress both partners
- Try distraction techniques
- Check environment conditions/eliminate shadows
- Careful attention to eye health/care
- Check medications for side effect
- Check for infection/delirium

More information available by SCW here https://bit.ly/SCW_Dementia

This leaflet is the result of many hours spent talking to people with dementia from Scotland, Wales, Ireland, England, Germany and the Czech Republic about their sensory experiences and we would like to thank each and every one...

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Agnes published “Talking Sense” as an ebook and audiobook in 2023. Access your free copy here <https://bit.ly/SensesBook>

We would love to hear from you!

Please get in touch if you would like to:

- Tell us how the booklet has helped you.
- Make suggestions for amendments.
- Order copies of this booklet.

Please visit <https://bit.ly/DementiaSenses> or follow the QR code to fill in a short questionnaire.

Or, you can contact Catrin Hedd Jones

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