

Sensory Changes and Dementia

Sense of Taste and Smell

A collection
of personal
experiences,
hints and tips

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About Agnes Houston



I was diagnosed with dementia, of the Alzheimer's type, around twelve years ago. I found that I was experiencing lots of sensory changes. I couldn't find any information about these changes and found it difficult to get the support I needed.

Since then I have created a booklet 'Dementia and Sensory Challenges', this was to raise awareness that dementia can be more than memory. These booklets and accompanying video clips can be found on the Life Changes Trust website www.lifechangestrust.org.uk/publications

This follow-up booklet will focus on the changes to the sense of taste and smell.

About this booklet

When you are living with dementia, sometimes your sense of taste and/or smell can change. This booklet has been created alongside people who live with dementia. It has been designed for:

- People living with dementia, who are experiencing changes to their sense of taste and smell.
- Friends and family of people living with dementia who may be able to offer support with these changes.

- Social clubs and community groups who may be able to adapt their activities to make it easier for people who experience these changes.

This booklet will:

- Share their experiences of the changes to their sense of taste and smell.
- Explain the impact of these changes on their lives.
- Offer hints and tips of how to live well with these sensory changes.

We hope that this booklet will encourage others to speak to their Doctors, families or friends if they are also experiencing these sensory changes. Our sense of taste and smell are closely linked. Changes to one can have a big impact on the other.

Acknowledgements

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Agnes Houston MBE



Introduction

Olfactory illusions and hallucinations cause people to smell things that are not there, or can make things smell different to how they usually would. These can be anything, but are often unpleasant smells such as burning, food that has gone off or cat's urine. The medical term for these phantom smells is 'phantosmia'.

Changes to your sense of taste can often make food and drinks taste stronger, weaker, or sometimes completely different. This can mean that you no longer enjoy your favourite food and drinks. Cooking can become difficult when things don't taste or smell the same as they used to.

When did you first notice the changes?

“Certain smells would give me very specific headaches. I had no history of migraines.”

“For me it was twelve years ago. One year before my diagnosis of Alzheimer's Disease.”

“Once my husband came home while I was cooking, he immediately opened the windows. He said the smell of garlic and onion was everywhere – I didn't agree...only later when I was choosing which perfume to use, I realised that I couldn't smell anything. So, I understood at that point that I had lost my sense of smell.”

These changes don't happen in isolation to one another. Some people can experience multiple sensory changes which can be extremely confusing and distressing.

What changes do you experience?

“The changes got worse before my diagnosis: my sense of smell and hearing. It was more heightened.”

“I'm hyper-sensitive to most smells. My tastes have changed and are continuing to change.”

“Some smells are a lot stronger, especially chemicals such as bleach, or perfumes.”

“Food can smell ‘off’, so I throw away a lot of food that is perfectly good.”

“I've noticed more of a change with savoury foods – they taste bland now.”

These symptoms can also change, so you may react to different triggers at different times of the day. They might intensify at the end of a day or when you become tired. This can mean that your physical and emotional responses can also vary. People are often left feeling drained and disorientated because of these sensory challenges as they impact on all aspects of life.

How do these changes impact your life?

“I find it most difficult during cooking, I don’t know how it tastes or smells. You can imagine that together with forgetfulness cooking can often be problematic.”

“I’m more isolated. I need more help to negotiate the environment.”

“Travelling on public transport, such as the bus, is very difficult now.”

“There are certain places that I just avoid now, such as the hairdressers as it has a nail bar – the smell is just too strong.”

Many people we spoke with told us that they found it difficult to find information about their sensory changes.

“There was no understanding of the sensory side of dementia.”

“I have no support for that from Doctors, but I cannot imagine how they would support me.”

“It was neurological doctors and professionals that knew about it, but not my GP or nurses.”

Living well with sensory changes

We hope that by raising awareness of these sensory changes more people will be able to receive the advice and support that works for them.

We asked people if they had any messages for others who experience similar challenges:

“Speak out about this. Teach others.”

“Get information and tell others. Ask for help.”

“I was sad and felt quite down – until I realised that I can still be ME, with help and strategies.”

Many people said that it can be difficult to socialise when you experience these changes, but they have found ways to adapt and still enjoy themselves.

“I stopped going out with my friends as I didn’t enjoy going for coffee anymore. My advice to others...be pro-active and stay connected to others.”

“Alcohol has a stronger effect on me now, so I don’t have my Gin and Tonic’s...I’ll just have the tonic as it tastes the same.”

“My friends accept it, they try to explain the tastes to me. I’ve started to imagine the taste of the food I know. It’s the same with smell, as far as I am able to remember it.”

Sense of Taste: Hints and Tips

The flavour of food is created by your sense of taste and sense of smell. When you experience changes to either of these it can make it difficult to know what you do and don't like.

“I don't know if I'll like a certain food until I actually taste it. My daughter and I will order two different meals so if I don't like what I order we'll swap. It makes eating out easier for me.”

- If tea or coffee becomes overpowering, try fruit or herbal teas.
- Honey, sweet sauces and chutneys can help to make food taste a little sweeter. They work well in savoury foods too, such as soups and stews.
- Herbs, spices, sauces and other condiments can be added to your normal meals to boost the flavour.
- Lemon juice can be used to season your food. The acid boosts and balances other flavours.

Sense of Smell: Hints and Tips

“My fire alarm is channelled directly to the fire service to bypass my own sense of smell, this helps as I have ‘burning’ as a phantom smell. I would encourage others to contact the Fire Service, and ask them for support to make you and your home safe.”

- Install a gas detector in your home.
- Clearly label the expiry date on your food and any leftovers.
- If a smell follows you from one space to another and it seems out of place, it might be a ‘phantom smell’.

Who can help?

Keep a diary of the changes you are experiencing, such as phantom smells and changes to your sense of taste. Share this with your Doctor, friends and family.

Speech and language therapists may be able to help if you are struggling to eat and/or have issues with the textures of food.

Nutritionists can offer you support to keep your diet healthy and balanced. This is particularly helpful if you no longer enjoy your usual meals and have found your appetite reducing.

Eating well

Lots of people have told us that they find it difficult to eat well with these changes. Some people lose their appetite and no longer enjoy eating or drinking.

“Grazing on a platter is much better for me. It stops me being overwhelmed by a big portion of food”

“Don’t be afraid to try new things – experiment with tastes and have fun!”

Grazing platters work well for people who are not sure what they enjoy anymore. Trying small amounts of different foods allows you to test out new flavours and textures. Try out:

- Fruits – dried and fresh
- Breads, crackers and oatcakes
- Vegetable sticks
- Dips and spreads
- Different temperatures – hot and cold
- Different textures – smooth and crunchy
- Different tastes – spicy, sweet, salty, sour and bitter

Foods that are high in natural fats work can well for people with smaller appetites:

- Nuts and Olives
- Cheese
- Avocado
- Humous
- Peanut Butter and chocolate spread
- Soups with beans or lentils
- Milky drinks like milkshakes or hot chocolate

Serving food on crockery that provides high contrast can also help, so try to avoid serving white food on a white plate. Blue crockery works well for most foods.

Peter Morgan Jones is the Executive Chef for HammondCare. He has created two cookbooks that offer great recipes, tips and advice: **‘Don’t give me eggs that bounce; 118 cracking recipes for people with Alzheimer’s’** and **‘It’s all about the food not the fork; 107 easy to eat meals in a mouthful’**.

“These books are really helpful. They show that he really understands these changes, and that’s unusual. He understands our challenges and that we want to eat food that we recognise and connect with, through all stages of our dementia journey.”

Agnes Houston

“I love food – I eat
nothing else!”

Group participant

Contact for more information

Kate Robertson

Community Development Advisor

M. 07841015945

kate@otbds.org

Outside the Box

T. 0141 419 0451

3.10 The Whisky Bond, 2 Dawson Road, Glasgow, G4 9SS

www.otbds.org

Scottish Charity: SC035317 Company Number: 265077