

# COPING WITH PAROSMIA/ PHANTOSMIA



**Our Learning Zone suite of Information Sheets were created by a collaborative panel of experts: medical, scientific and people who live with smell and taste disorders. We would like to thank them all for giving and sharing their time, experience and knowledge.**

Fifth Sense is the charity for people affected by smell and taste disorders. Based in the UK, we are the first charity providing direct support, information and a signpost to potential diagnosis and treatment to people affected by these conditions. We play a leading role in educating

people about the importance of the senses of smell and taste to our lives. Through this we can promote awareness of the consequences of smell and taste disorders, demonstrate the need for greater availability of medical services and advocate for further research into treatment for these conditions.

Fifth Sense is a membership organisation. Membership is free and open to anyone affected by or with an interest in smell or taste-related disorders, including family members, carers and health or scientific professionals.

## Who should read this?

Anyone who is experiencing distortions of the things they smell. These are usually unpleasant – burning rubber, smoke, sewage and it may also be affecting the flavour of food and drink making them taste equally bad.

## What is parosmia?

Parosmia is the medical term for experiencing distortions of the sense of smell. Someone with parosmia may be able to detect odours, but the smell of certain things – or sometimes everything – is different, and often unpleasant.

These unpleasant smells are often described as being like chemicals, burning, faeces, rotting flesh, mould. For some people they appear in response to specific odours, and for others they can be triggered by virtually any smell.

Parosmia can range from mild to severe, and can be an incredibly debilitating and depressing experience. We've heard from people who have said that their experience of parosmia was far worse than their initial loss of smell.

## What is phantosmia?

Phantosmia, as the name suggests, is the term for olfactory hallucinations, or phantom smells, that appear in the absence of any odour. These can manifest as 'normal' smells – for example, being able to smell garlic when there is no garlic present – but they can also be unpleasant.

Parosmia and phantosmia are both classed as 'dysosmia', or qualitative disturbances of the sense of smell.

## What causes these conditions?

The mechanism by which parosmia and phantosmia occur is not fully understood, but they are thought to result from damage to the olfactory receptor neurones, the cells in our nasal cavity that detect odour molecules. It's quite possible that damage to other areas of the olfactory system, such as the olfactory bulbs, can also cause these conditions.

Parosmia most commonly occurs when the sense of smell has been lost following a virus such as the common cold (**see Learning Zone Information Sheet #1, 'Post Viral Olfactory Disorders'**), although it can also occur as a result of head injury, exposure to toxins, diseases of the nervous system and sinus problems.

Phantosmia can occur after smell loss due to a head injury (**see Learning Zone Information Sheet #2, 'Post Traumatic Olfactory Loss'**), but it can also be associated with viral infections, exposure to toxins, diseases of the nervous system and sinus problems.

## How can these conditions be treated?

Both parosmia and phantosmia tend to occur following a loss of the sense of smell, so any treatment for the cause of this may help. The good news is that symptoms of both conditions often decrease with time.

## How can I help myself?

You can ask your GP to refer you to an ENT specialist - there are a number of consultants who specialise in smell and taste disorders that can be viewed at: [www.fifthsense.org.uk/clinics](http://www.fifthsense.org.uk/clinics).

- Keep a diary log to establish changes, triggers and what are safe for you. There are lots of commonality reported anecdotally but these vary from person to person. Establishing what your triggers are and what you can tolerate is important. A couple of diary logs with some starter examples is provided on page 2.
- Work out your triggers and avoid them – sometimes certain foods/drinks can trigger a distortion such as coffee, dark chocolate, wine, egg, onion, roasted/fried foods, citrus. To combat this try different foods and aromas to find those that don't cause distortion and enjoy them (e.g. white chocolate, cheese, fruits, miso, salads, vegetables, pasta, sushi, gin). Some of these can soften the distortion of some foods/flavours/aromas.
- There are products on the market that don't use onions/garlic which can be a common trigger food. Some people have found that the FODMAP foods can be helpful in coping with parosmia. FODMAP stands for the different types of sugars that are found in foods – Fermentable Oligosaccharides, Disaccharides, Monosaccharides and Polyols - it is primarily used help people manage Irritable Bowel Syndrome and you can read more about this here [www.monashfodmap.com/about-fodmap-and-ibs/](http://www.monashfodmap.com/about-fodmap-and-ibs/)
- Mask foods affected with a strong flavour that doesn't cause a distortion (cinnamon, chilli oil, peppercorn sauce). Try using cinnamon or herbal toothpaste as a good alternative, if mint is an issue.
- Seek out non-scented toiletries and fragrances to avoid any scent becoming distorted.
- For some people, wearing a padded biotronic nose clip when eating can help eliminate/reduce the distortions.
- You can read about the experiences of people from across the world who are experiencing or have recovered from smell and taste disorders on our website [www.fifthsense.org.uk/stories](http://www.fifthsense.org.uk/stories)

