

# IDIOPATHIC SMELL/TASTE DISORDERS



**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.

## Why is there no apparent reason for my smell loss/disorder?

Having no known cause is often very difficult to come to terms with for any medical condition. Chronic Fatigue Syndrome, Idiopathic Scoliosis and Idiopathic Pulmonary Fibrosis are other conditions for which a known cause cannot always be found. Idiopathic smell disorders account for about 1 in 5 of those who attend a specialist Smell & Taste Clinic. In some cases, despite examination with a special camera (endoscope), scans of the head (MRI/CT) and blood tests, no apparent cause is found. If your case has not been fully checked out in a specialist clinic, it is important to ask for a referral to one by your GP, in case you have a reversible cause for your loss of smell.

## What hypotheses are there?

In some people it is possible that a virus has damaged the smell receptors but without any other symptoms being present to make them aware that this could be the reason. As has been seen with COVID-19, it is possible to carry the virus and not display any symptoms. In other cases, there is a small possibility that smell/taste loss is the first sign of a disease of the nervous system such as Parkinson's disease. For those over the age of 65, it may simply be a decline in the sense of smell due to the ageing process known as presbyosmia.

## Will my sense of smell / taste come back?

If a specialist clinician has been consulted and any reversible causes of smell loss have been completely ruled out, then it is unlikely that the sense of smell will return. However, people may want to consider trying treatments that might be offered for post-viral olfactory dysfunction on the basis that they have suffered a viral cause for their smell loss.

## Are there treatments available and how do I get them?

There remains a need to conduct studies that look at treatments specifically in this group of patients, however there are some studies where a mixed group of smell loss patients have gained some apparent benefit, including those with idiopathic cases. We would recommend that you discuss this fully with the doctors in a specialist smell & taste clinic.

## Is there anything I can do at home to help myself?

You can try smell training. The Fifth Sense SmellAbility© toolkit is available at: [www.fifthsense.org.uk/smell-training](http://www.fifthsense.org.uk/smell-training)

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).

## What relevant research is happening in this area?

The Fifth Sense James Lind Alliance Smell and Taste Disorders Priority Setting Partnership is currently considering the main questions that people affected by smell and taste disorders want research to address. More details can be found at [www.fifthsense.org.uk/smell-taste-ppsp/](http://www.fifthsense.org.uk/smell-taste-ppsp/). For information about research projects and to access published research, please check our research resources on our website [www.fifthsense.org.uk/research](http://www.fifthsense.org.uk/research).

The Predict PD study is a research study to help understand who, within the general population, might be more likely to be diagnosed with Parkinson's. The more that is known about the early stages and indications of Parkinson's, the better it is to find treatments and a cure. To find out more visit [www.parkinsons.org.uk/research/predict-pd](http://www.parkinsons.org.uk/research/predict-pd)

## Are there any organisations/podcasts/support groups/charities etc that can offer support and keep me updated on the latest findings?

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). There are also several private Facebook groups and other social media sources that provide a place for those who wish to engage in conversations online with others. Inclusion of these sources does not reflect an endorsement and a list can be found on our **Learning Zone Information Sheet #10, 'Other Support and Help'**.

## How can my family and friends support me?

We know that it can be challenging for other people to understand the impact that a smell or taste disorder can have. Try talking to your partner, family and friends about how your condition affects you, so they can try to understand and support you. Ask someone to be a 'designated nose' - check the milk to see if it has gone off, tell you how you smell and help keep you safe from gas and smoke risks.

# HELPFUL HINTS

## TIPS FOR MANAGING YOUR RELATIONSHIP WITH FOOD

- Keep making and eating interesting foods - texture, temperatures, heat (chilli/mustard/pepper/spice) can all bring interest to a meal. Focus on the basic tastes (sweet (sugar), sour (lemon juice), acid (vinegar), salt (salt), umami (savoury)).
- Use mindfulness and your other senses to tune into the characteristics of each meal and drink.
- Focus on the sensations you can perceive, not those that are missing:
  - Roasted vegetable curry with poppadoms, cool yoghurt and mint mango chutney, lime pickle.
  - Lamb tagine with chickpeas, dates, toasted flaked almonds, pomegranate seeds, and cool yoghurt and mint.
- Nutrition: Moderate the use of salt/sugar as it's easy to overdo to compensate for lack of aroma. A balanced diet with plenty of fruit and vegetables is more important than ever and can support the healing process.
- Get a timer. If you can no longer rely on detecting when a food is cooked by smell, consider using a timer to prevent any culinary disasters.
- Follow trusted recipes carefully if you can no longer rely on flavour to correct estimations.

## TIPS FOR MANAGING YOUR HEALTH AND SAFETY

- Be vigilant regarding smoke and natural gas. You may want to install and regularly check smoke/heat detectors. You could invest in a natural gas detector or change appliances from gas to electric.
- Establish or maintain a regular personal hygiene routine including washing, deodorising and paying attention to oral hygiene. Ask a friend/family member to be your designated nose and give you honest feedback.
- Be mindful of the vapours produced by cleaning products in the home. When cleaning ensure you have ventilation to stop the fumes from building up and keep on top of cleaning and washing of clothes and bedding (human and pets).
- Be cautious around chemicals and pollution. When using cleaning products or chemicals, ensure you ventilate the room(s) you are using them in to avoid the build-up of fumes. Always ensure you store products in their original container but if you decant anything ensure you clearly label what is contained - this applies to alcohol, chemicals, cleaning chemicals, petrol etc).
- If you rely on your sense of smell to perform your job, you should discuss the matter with your manager or supervisor, who with your permission, can contact us for further advice if required.

## TIPS FOR MANAGING YOUR WELLBEING

- Use the SmellAbility© toolkit diary to track any changes and/or progress of your ability to smell and celebrate any improvements.
- Use your memory to imagine the flavour and aroma of foods as you eat them. This can be powerful and may improve your enjoyment and eating experiences.
- Engage in interests that don't depend on a sense of smell – e.g., exercise - get as fit as possible to help your body recover from Covid-19, learn a language, do an online course, learn to play an instrument, take up crafting etc.
- Reach out if you need help. There are lots of support services available (as detailed in the table on page 1).
- Indulge in some self-care. Take time out to relax, look after yourself, meditate, treat yourself to beauty treatments, spend some time outdoors appreciating nature.

## TIPS FOR MANAGING PAROSMIA

### SEE INFORMATION SHEET #7- COPING WITH PAROSMIA

- Sometimes, total smell loss can be replaced by a smell disorder called Parosmia - a distortion of the sense of smell which is often an unpleasant odour that replaces something pleasant. Whilst this can be very distressing it can be a good sign and an indication that the sense of smell is trying to recover. This is often temporary, although its longevity is widely variable, and it can affect certain aromas and not others.
- 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.
- 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 an alternative, if mint is an issue.
- Seek out non-scented toiletries and fragrances to avoid any scent becoming distorted.