

POST TRAUMATIC OLFACTORY LOSS (PTOL)



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.

How do people lose their sense of smell following a head/brain injury?

As air enters the nose, it transmits odour particles to the roof of the nose, in turn stimulating nerves lining the olfactory cleft. These nerves bring information to a part of the brain called the olfactory bulb - the part of the brain that enables us to recognise smell patterns. Loss of smell may result from head injuries where damage can be caused at different points along the pathway from the olfactory nerves that carries smell sensation from the nose to the brain to parts of the brain that process smell.

In addition, trauma to the face and nose can cause the nasal bones or nasal septum (the inner partition of the nose) to become pushed to one side which may in turn block odours from reaching the olfactory cleft. Trauma to the nose may also cause swelling and infection to the lining of the nose and sinuses (secondary rhinosinusitis) again affecting the transit of odours through the nose.

Head injuries can also directly stretch or sever the olfactory nerves as well as cause bruising and trauma to the olfactory bulb and medial orbitofrontal cortex (another part of the brain involved in processing and recognising smells).

Will my sense of smell / taste come back?

The likelihood that your sense of smell will return to normal following head injury is very variable and is difficult to predict but more severe head injuries are linked to a lower chance of recovery. This usually depends on which parts of the smell pathway have been affected and the extent of injury involved. Some patients may notice that their sense of smell spontaneously resolves; however, this becomes less likely the longer it has been since your head injury.

Are there treatments available and how do I get them?

The effectiveness of treatments for PTOL is not well established. Identifying new treatments remains an area of ongoing research; however treatments that have demonstrated the most evidence for improving olfaction in PTOL patients include smell training and early steroids.

Some studies have demonstrated improvements in olfaction in PTOL patients following oral steroid use. The exact mechanism of action is not fully understood but may be related to a reduction in swelling around the olfactory nerves/centre within the brain or directly through olfactory nerve regeneration. The use of steroids has been found to be most effective when used within 12 months from the onset of PTOL and in the most recent trial, in combination with zinc supplements.

Some conditions, such as diabetes, can be affected by using steroids if your blood sugar levels becoming harder to control. Therefore, the use of steroids may not be appropriate in all patients. Oral steroids (e.g. Prednisolone) can be associated with side effects such as heartburn or disturbances in mood and sleep, which your doctor can discuss in further detail. A course of medication used to reduce stomach acid production may also be prescribed alongside any steroid tablets.

The use of topical steroids in the form of a nasal spray has also been investigated with some studies showing a benefit in PTOL either alone or in conjunction with oral steroids. Steroids in this form are absorbed locally within the lining of the nose and are not associated with some of the more systemic side effects seen with oral steroid use.

Is there anything I can do to help myself?

You can try smell training. The work of Thomas Hummel et al and further research into smell training following a virus or brain injury has found some evidence to support recovery by using rehabilitative smell training. The Fifth Sense SmellAbility© toolkit is available at:

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 these can be viewed at: www.fifthsense.org.uk/clinics

What relevant research into future treatments 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/. For information about research projects and to access published research, please check our research resources on our website www.fifthsense.org.uk/research

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. 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.

References:

1. Philpott C, Erskine S, Clark A, Leeper A, Salam M, Sharma R et al. A randomised controlled trial of sodium citrate spray for non-conductive olfactory disorders. *Clin Otolaryngol.* 2017;6:1295-1302
2. Aiba T, Sugiura M, Mori J, Matsumoto K, Tomiyama K, Okuda F et al. Effect of zinc sulfate on sensorineural olfactory loss. *Acta Otolaryngol Suppl.* 1998;538:202-4
3. Jiang RS, Twu CW, Liang KL. Medical Treatment of Traumatic Anosmia. *Otolaryngol Head Neck Surg.* 2015;152:954-8
4. Henkin R, Velicu I, Schmidt L. An open-label controlled trial of theophylline for treatment of patients with hyposmia. *Am J Med Sci.* 2009;337:396-406.