

CONGENITAL ANOSMIA



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?

People who were born with no ability to smell or have no recollection of ever being able to smell and have no smell memories

What is congenital anosmia?

Not being able to ever recall having a sense of smell can be congenital (you were born with it) but could also be a result of a viral infection, severe allergies or brain injury that happened when you were very young. If you can, ask family members if they recall you having any of these before your ability to remember. If nobody can establish any reason, then you may have a congenital condition that means you either have no olfactory bulb or your olfactory system is not developed. Both these things happen as you are developing and before you were born. Some people born without the ability to smell have a condition called Kallmann Syndrome. It is a rare genetic hormonal disorder which is estimated to affect between 1 in 10,000 and 1 in 50,000 people and is thought to be between two and three times more common in men than women. People with Kallmann syndrome have a hormonal deficiency which prevents the individual from starting or fully completing puberty and is also accompanied by a lack of sense of smell.

Is it genetic?

Most cases of congenital anosmia are isolated and there is insufficient evidence to suggest it is inherited. However, Kallmann Syndrome is a genetically inherited condition (see above).

Congenital anosmia is diagnosed by an MRI scan to look carefully at the detail of the olfactory bulbs; you may also have a nasal endoscopy to check for any blockages, this is camera that goes up into the nose. Kallmann Syndrome also requires blood tests to confirm the hormonal deficiency. Occasionally the scan may reveal that there is a blockage at the top of the nose which is causing the problem.

Is congenital anosmia permanent?

If the olfactory bulbs have not formed, this is currently an irreversible problem. It might become possible in the future to replace them as advances in medical technology develop.

Are there treatments available and how do I get them?

There are currently no treatments for congenital anosmia.

Why can I taste if I can't smell – I thought they were connected?

Your sense of taste (salt/sweet/sour/bitter/umami) is linked to the tastebuds which are found on the tongue and other areas in the mouth and throat. These will not be affected by the missing olfactory bulbs as being able to detect pure taste involves 3 separate nerve pathways. If you cannot smell, you are unable to achieve retronasal olfaction when breathing through the nose whilst eating that provides the tongue with the ability to detect the flavour of food. So, you may very well be able to detect the taste of food and drink but not the full flavour.

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 <https://www.fifthsense.org.uk/smell-taste-pp/>. For information about research projects and to access published research, please check our research resources on our website <https://fifthsense.org.uk/research>.

Is there anything I can do at home to 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.

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 <https://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 **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 to avoid estimations - especially if you are cooking socially!

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

- Engage in interests that don't depend on a sense of smell – e.g. exercise - get as fit as possible to help maintain your general well-being, 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 (see 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.
- Ask trusted friends and family members to be your designated nose to keep you safe – this might be in detecting dangers from smoke or in drinking alcohol.
- 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.
- Nearly everything has a scent – some are greater than others, some are more pleasant, some are less pleasant. Never be afraid to talk about smell, ask questions and start up those conversations to improve awareness – your story will be just as interesting to someone who can smell as your questions about what smells are like.