ANOSMIA FAQ

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2019
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This FAQ

What is anosmia? What are the causes of it and can it be cured? How does anosmia affect how food taste? These and other questions are answered briefly in this FAQ. You will find short basic facts and information about anosmia. It is a mix of data from scientific knowledge and experiences shared by anosmics around the world. If you want to learn more, there are a few suggestions for further reading at the end.

I have tried to include information relevant to both congenital and acquired anosmics. However, I am myself a congenital anosmic and can't really understand what it means to lose the sense of smell. I apologize for errors caused by my lack of understanding.

Lars Lundqvist
What Is Anosmia?

Anosmia comes from the Greek words \textit{an} meaning 'without' and \textit{osme} meaning 'smell'. Together they mean 'not having a sense of smell', not having a functioning olfactory system.

There are two types of anosmia – acquired and congenital.

\textit{Acquired anosmia} means that the person has had a functioning sense of smell since birth, but that something – a disease, an accident, a medicine or something else – suddenly caused a loss of the sense of smell. For most of those afflicted it is only temporary – a few days, some weeks, a few months, or at the worst a year or more – but they eventually get it back. But for some, the loss becomes permanent. They become anosmic for the remainder of their lives.

\textit{Congenital}, strictly speaking, means “present from birth” but congenital anosmia is usually defined as “not having any recollection of ever having experienced smells”.
What Are The Differences Between Congenital And Acquired Anosmia?

Having a sense and suddenly losing it is usually a very traumatic experience. It may lead to depression and even suicide. Losing the sense of smell means that one suddenly cannot smell flowers, one's partner or children, changes in the weather, or the shift of seasons. But it also means that food suddenly has little or no taste because most of what people with a sense of smell perceive as taste is actually smell.

Being born anosmic means there are no smells in the world one experiences, and never were. In a way, smells do not exist to a congenital anosmic. Because of this, congenital anosmics live in a different world than people who have a sense of smell, but because they have grown up in a smell-free world, congenital anosmics seldom think about how different their world is. Not sensing smells is normal to a congenital anosmic.
What Causes Anosmia?

Acquired anosmia is usually caused by some kind of disease or physical damage.

Many diseases can cause anosmia like common colds, sinusitis, polyps, diabetes, asthma, allergies, and so on. The direct cause of the anosmia is usually that the disease induces inflammation in the areas where the olfactory receptor cells are situated. If the inflammation is cured, the sense of smell usually starts functioning again, but sometimes the area with receptor cells is damaged and causes a permanent loss of the sense.

Physical damage can be caused by a hard blow to the head, which can damage the part of the brain that contains the smell center or sever the nerves going up through the bone tissue from the receptor cells to the olfactory bulb.

Congenital anosmia can be caused by a genetic error, causing one or several parts of the sense of smell never to develop – the olfactory nerve cells, the nerves that that go up through the bone structure or the olfactory bulb. Sometimes this is hereditary, and other times it appears spontaneously.

It can also be caused by something being damaged during birth, or soon after birth. In these cases, it is a kind
of acquired anosmia, strictly speaking, but the damage occurs so early in the child's life that she has no memory of being able to smell. Therefore, it will be experienced and described as congenital anosmia.

Anosmia can also be associated with less common diseases and can, to some extent, be part of the diagnosis or early warning system for such diseases. One example is Kallmann's syndrome, a genetic disturbance of sexual development.
Can Anosmia Be Cured?

Acquired anosmia can result from infection or inflammation, causing swelling inside the nose so that the air can no longer reach the mucous membranes in the nose, holding the smell receptors. Anti-inflammatory medicines can sometimes make the swelling disappear. The person then usually regains her sense of smell. If the smell receptors were damaged by the inflammation, the end result could be total or partial loss of the sense of smell: anosmia or hyposmia.

If the anosmia is a result of brain damage, caused by a blow to the head from a hit or a fall, there is usually nothing anyone can do. In those cases the anosmia is permanent. If the head trauma only severed the nerves going through the bone structure from the olfactory receptor cells up to the olfactory bulb, they can sometimes re-connect. Smell-training with a few distinct smells has, in some cases, helped this process.

For congenital anosmia, the situation is quite different. In many cases the cause is unknown, and without a cause, it is impossible to know what to treat. When there is an identified cause for the anosmia, the most common appears to be a missing or not fully developed olfactory
bulb. This often has a genetic cause, and it cannot be treated, at least not with the current level of medical knowledge.
Should I Try To Find The Cause For My Congenital Anosmia?

A reason not to see a doctor is that congenitally anosmia cannot be "cured". At best, a visit to an ENT clinic will give an explanation to the anosmia, but at the worst, it will make things even more confusing. The general level of knowledge about congenital anosmia is usually so low, also among practicing medical doctors, that the probability that one will get relevant answers and advice is very low.

However, congenital anosmia is in rare cases a symptom of a more severe affliction. One example is Kallmann's syndrome, which is a congenital lack of certain hormones, preventing normal development during puberty. If it is spotted in time, the child can be treated with hormones and get a normal sexual development. In this case, the anosmia serves as a warning for something else, so for that reason, it might be a good idea to have a doctor rule out Kallmann's syndrome as a cause for the anosmia.
How Common Is Anosmia?

Researchers estimate that about 20% of the population acquire temporary problems with their sense of smell sometime during their lives. About 5% have anosmia. For a few of those, less than one percent, it becomes permanent.

For congenital anosmia, the numbers are unreliable because most congenital anosmics never visit a doctor or hospital to get it checked. Some researchers have tried to guess the prevalence of congenital anosmia, but the guesses vary between one in a thousand births to one in a million births, with recent estimates talking about one in 10 000 births.
Are There Technical Aids?

Several companies are trying to develop sensors that are meant to work as an electronic nose. You point the gadget at something, it "sniffs" with a little built-in fan, and then presents what it senses on a scale. In its simplest form, it could be set to recognize, for example, smells that tell if food is okay to eat or not, or to decide how much smell a dirty shirt is emitting. There are currently no such gadgets available for ordinary day-to-day use. Sensors warning for gas leaks are already available though.
What Is "Noseblind"?

Noseblind is sometimes used as a synonym for anosmia, but it is also used for other kinds of problems with the sense of smell, including reduced ability to smell, being unable to sense specific smells, and so on. It is also used to describe "the gradual acclimatization to the smells of one's home, car, or belongings, in which the affected does not notice them", referring to situations where a smeller gets so used to a particular smell that she no longer notices it. The unprecise meaning of the expression makes it rather improper to use to describe anosmia.
How Does My Sense Of Taste Function?

Almost the entire tongue is covered by papillae. Some of them contain the taste buds, the structures that register taste. Each taste bud consists of 50-100 taste cells, positioned roughly like the sections in an orange. These taste cells register the different tastes of what we eat. There are taste cells for all basic tastes in all taste buds, and therefore, all taste buds can register all tastes.

Earlier it was believed that there were four basic tastes, but some years ago 'umami' was added. It can be described as "meat taste". Researchers are also discussing if "fat" and "carbonation" should be classified as basic tastes because receptors for these tastes have been identified. So in total, there are five, six or seven basic tastes, or perhaps even more. Researchers continue to identify more receptors as research progresses, and the concept "basic tastes" may have to be redefined in the future.

In addition to the taste buds, there are other receptors in the mouth, connected to the trigeminal nerve. Their function is to register pain, heat, cold, and tingling, but also the texture and shape of what we eat.

Mint is registered by the trigeminal nerve as cold. Mustard, pepper and onion activate receptors for heat and
pain. Some vegetables, like rhubarb, unripe fruit and some brands of tea contain tannins which are also registered by the trigeminal nerve.
Why Can I Smell Some Things?

Sometimes anosmics say that they suddenly smelled something. For an acquired anosmic, this could actually be true and indicate that the sense of smell is beginning to come back. However, a more likely explanation, which is the only likely one for congenital anosmics, is that it is the trigeminal nerve that is reacting to something.

The trigeminal nerve has receptors on the tongue and in the mucous membranes in the mouth for touch, heat, cold, pain, etc. and it is these receptors that react to pepper, peppermint, vinegar, and other similar substances. But the trigeminal nerve has receptors also in other mucous membranes, like the eyes and inside the nose. Those receptors can react to the fumes from things like gasoline, ammonia, bleach, vinegar, alcohol, and several other substances. But unlike the sense of smell, the trigeminal nerve can't identify which substance it is reacting to. It can only warn that there are strong, potentially dangerous fumes.

However, when such fumes occur in combination with moist air, some anosmics have been able to identify the fumes with the sense of taste if they breathe through the
mouth.
Why Can I Not Identify Food?

Almost everyone with a functioning sense of smell can identify thousands of individual smells, and each smell has a name. Taste does not work like that.

The input from the different receptors in the taste buds are usually blended into one single taste. As a result, anosmics can seldom identify individual ingredients in a dish. However, when eating things with very different textures, the brain can often connect taste and texture so different ingredients can then have different taste.

One can compare the sense of taste with colors. If different colors are mixed, the end result is one single color, and afterward it is impossible to say which colors were mixed to attain that specific color. Humans can distinguish numerous shades of colors, but we do not have common names for every single shade. We only have names for a few "basic colors". If we are presented with two slightly different shades, we can see that there is a difference, but if we only see one of them, we cannot be sure which one it is. But we can definitely say which basic color(s) it leans towards.

It is the same thing with taste. Presented with two slightly different tastes an anosmic can often tell there is a
difference between them. If presented with only one of them, it is often impossible to say for sure which one it is.
Does Anosmia Affect Food Preferences?

Food preferences differ between individuals, and this is just as true for anosmics as it is for people who have a sense of smell. However, the *flavor* of food is the combined result of smell, taste and trigeminal nerve input, and most of it is based on smell. As a result, anosmia definitely affects different persons food preferences, and there are some general differences between congenital and acquired anosmics.

For congenital anosmics, it is natural that only the taste and trigeminal components of the flavor is present. Some food tastes differently to a congenital anosmic than to a person with a sense of smell, but being born this way it has always been like this, so it is normal to a congenital anosmic.

For acquired anosmics, the situation is different. Without the smell component, the food loses most of its flavor, and many acquired anosmics complain that the food no longer has any flavor at all.

Herbs are an example where the experiences of anosmics and persons with a sense of smell are very different. For herbs, the function as a spice is almost entirely based on smell. Most herbs have very little taste that stimulates the
taste buds.

For many flavored foods available in stores, it is not a taste that has been added, but a smell. If you read the description carefully, it says that an aromatic has been added, and those aromatics are usually volatile substances that only emit smells, not taste. As a result, the flavored food tastes just like an unflavored version to an anosmic.

Candy is a typical example of smell enhanced flavored foodstuff. There is usually no difference in taste between the differently colored pieces of candy, although they may even be made to mimic different fruits. The explanation is again that the flavors are created by volatile aromatics, only changing the smell and not the taste of the candy.

If the food is very spicy or very hot, the signals from the sense of taste may drown in the strong signals from the trigeminal nerve whereas the input from the sense of smell is not affected at all. As a result, a person who can smell can register both the trigeminal input and the smell, whereas an anosmic only registers the trigeminal input. Because of this congenital anosmics often prefer tepid and mildly spiced food, whereas acquired anosmics may instead prefer food that really stimulates the trigeminal nerve as a compensation for the loss of the smell input.

Without the sense of smell to complement the taste, the texture of the food becomes more important. Crunchy things are usually appreciated whereas sweet gooey stuff often is less liked.
Anosmia does affect how food is experienced, but little has been done so far to help anosmics to handle this. However, the UK-based non-profit organization Fifth Sense has recently begun to take an interest in this and has collected some advice on its web site (http://www.fifthsense.org.uk).
Are Smells And Memory Connected?

Smells can trigger forgotten memories, also referred to as involuntary memories. It can be memories of one's childhood or a particular environment from the past. But it can also be specific experiences, both happy and unhappy ones. Anosmics do not have this ability, but some say that music sometimes triggers memories in a similar way.

Some diseases that affect a person's memory, like Alzheimer's disease, can also reduce a person's sense of smell. It has even been suggested that an unexplained gradual loss of the sense of smell sometimes may be an early symptom of an approaching neurodegenerative illness like Alzheimer's disease. But it is the disease that affects both processes and not a direct relation between memory and sense of smell.

There is no research suggesting that congenital anosmia or anosmia acquired through head trauma or inflammation in the mucous membranes in the nose would have any adverse effects on the memory function of an anosmic. The ability to memorize and remember things is not impaired by anosmia.
What Are The Biggest Dangers In Day-to-day Life For An Anosmic?

There are mainly three areas where anosmia may cause real danger: food, fire and gas.

All food sooner or later becomes unhealthy to eat. Food based on meat or fish that has gone off may cause acute food poisoning. A person that can smell would notice the strange smell coming from the food and throw it away. An anosmic has to rely on sight and taste, and food can be quite unhealthy before looking strange or tasting wrong or even slightly different from its ordinary taste.

Fire is a major concern for many anosmics. Having several smoke detectors help, but the inability to locate the source for setting off a smoke detector can be scary.

Gas stoves are a constant risk for anosmics. The gas (propane or butane) is explosive when mixed with air in sufficient quantity. Mercaptan, a component smelling like rotten egg, is sometimes added to the gas, to warn for leaks. But that does not help anosmics. There are gas detectors for sale, but another solution is to replace gas appliances with electric appliances instead.
Is Anosmia A Disability?

Lacking one of the five senses, not being able to smell, is of course by definition a physical disability. But maybe a more relevant question is if it is a hindrance in day-to-day life? Many congenital anosmics say that they do not suffer from their anosmia, that it does not affect their everyday life, and that they are not restricted by it. Other anosmics are deeply concerned about problems connected to their anosmia: not knowing if others think you smell of sweat or dirt, not knowing if food is safe to eat, not knowing if something in your home is making it stink, not sensing the smell of smoke from a smoldering fire.

Some congenital anosmics hardly think at all about smells and how much smells are an integrated part of the life of others, whereas others think about it a lot. The degree to which anosmia is perceived as a hindrance thus differs considerably between individuals.
Where Can I Find More Information About Anosmia?

This FAQ is only a short introduction to anosmia. It is primarily based on the book I have written about my anosmic life:

“*A World Without Smells*” by Lars Lundqvist

The book gives a more in-depth analysis of the things
covered by this FAQ, but also include other topics like what it was like to grow up with anosmia, how anosmia affects day-to-day life, being an anosmic parent, how to cope with dirt and staying clean by living by rules, and how anosmia affects how one perceives space and time.

It is available as both ebook and paperback at Amazon, Smashwords, Kobo, Barnes & Nobles, Apple's Books, Scribd, and most other internet bookstores.

There are several good sources of information on the internet:

FifthSense [http://www.fifthsense.org.uk](http://www.fifthsense.org.uk) is a non-profit organization based in the UK, established in 2012. Its vision is "for the senses of smell and taste to be recognised as being essential to our lives, health and general wellbeing", and it aims at both educating society and providing support and advice for people with smell and taste disorders. On their website, you will find all sorts of information about a variety of problems with the sense of smell, including anosmia, and also information about ongoing research. Although they reside in the UK, they accept members from around the world.

On Facebook, there are two rather large and very active groups:

"Congenital anosmia" - as the name says, people born with anosmia dominate this group, but there are also spouses of anosmics and parents of anosmic children in the
group.

“Anosmics of the world, unite!” - people with acquired anosmia dominate this group, but there are also congenital anosmics and relatives to anosmics in the group.

Both groups are goldmines of information for anyone interested in anosmia. The atmosphere is generally welcoming and supportive.

There are also blogs, youtube channels and other books. You can find links to these other sources at for example Fifth Sense’s, Sharika’s, and my websites:

http://www.fifthsense.org.uk/further-reading/
https://myanosmaticlife.wordpress.com/links/
https://congenitalanosmia.wordpress.com/links/
Contact

I hope this short FAQ has provided you with some useful information. If you found it through an internet bookstore, leaving a review makes it easier for others to find it.

If you have comments or questions, feel free to contact me at

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