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## Original Article

# Parosmia and altered taste in patients recovering from Covid 19

Christine E. Kelly <sup>1</sup>

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### SUMMARY

Parosmia is a well-documented consequence of smell loss associated with Covid 19. Those who experience this qualitative olfactory disorder during recovery find that the odour of common foods and household items is distorted, and the experience can range from merely altered to profoundly disgusting. This can lead to a greatly altered relationship with food, including the physical symptoms of loss of appetite, nausea, vomiting, as well as wider reaching issues such as withdrawal from social situations, emotional distancing from others in their close social circles, and anhedonia. There is at present no known cure or intervention to mitigate the condition. The AbScent Parosmia and Phantosmia support group on Facebook became an important resource for patients with this condition during the early part of the pandemic, and the crowd-sourcing of experiences, tips and peer-to-peer advice became a valuable source of information for the community as well as researchers trying to understand the condition. Using protocols described in earlier literature on the use of social media for qualitative research, this paper provides information on the management of parosmia based on the experiences of over 30k patients in the AbScent Parosmia and Phantosmia group on Facebook and 6k member of the AbScent Network.

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E-mail address: [Chris@abscent.org](mailto:Chris@abscent.org).

<sup>1</sup> Founder, AbScent, a Charity registered in England and Wales No. 1183468.

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## Introduction

### *Background*

The arrival of the SARS-cov-2 epidemic brought with it smell dysfunction as one of the most commonly reported symptoms and one with major impacts on eating and quality of life [1,2]. The number of people affected has varied depending on the variant, geographic location and at different times throughout the pandemic but on figures from February 2022 between 18-30 million people were living with post COVID smell dysfunction [20]. Early on in the pandemic, smell and taste changes were recognised as a key diagnostic symptom in over 60% of cases of infection [3,19]. The sudden high prevalence of olfactory impairments brought thousands to patient support groups to share symptoms and stories of effects that were not as ‘mild’ as initially presented in the media and that were frequently dismissed or unrecognised by health care professionals [4]. AbScent, a UK based charity, ran support groups through Facebook, later adding a private social network to expand the charity’s offering and reduce unwanted “noise” in the feed. Given parosmia was a little known condition prior to the pandemic, online forums quickly became a useful resource for researchers. The analysis of qualitative data provided a basis for articles on the illness experience of Covid-19 related smell loss in general and, as it developed as a ‘late complication’ of smell dysfunction, parosmia in particular [1,5] Parker, J. K., *et al.* [6]. The observation of patient comments and themes provided a detailed picture of how parosmia alters relationships with food and how this affects well-being.

This paper distills the illness experience of parosmia based on the AbScent patient forums as well as recent literature, and makes suggestions for patient support. This is considered necessary because it is known that long term parosmia severely impacts on health related quality of life [7] and there remains a paucity of peer-reviewed evidence for interventions that provide help and relief [8]. The paper contributes to a body of research on the qualitative exploration of illness experience from the patient perspective [4]. In this paper, we present suggestions for managing the food related challenges as well as comments concerning the psychosocial effects of living with this condition, both of which could be helpful in providing support to individuals experiencing parosmia.

### *Quantitative and qualitative smell disorders*

Two categories of smell disorders are recognised at this time: quantitative and qualitative. The focus of this paper is on the qualitative disorder parosmia, however an understanding of quantitative disorders is helpful in an overview of smell disorders generally.

#### *The quantitative impairments to smell*

Anosmia is defined as the absence of smell. Hyposmia is the diminution of smell to a greater or lesser extent [9]. This might be the ability to perceive only the briefest experiences of odour, or may be quite functional without being in the “normal” range. Thus “quantitative” smell disorders are on a sliding scale from no sense of smell at all to “normal”. Quantitative disorders are the most frequently researched because they can be objectively assessed in ways that are validated. Quantitative disorders may well affect the perception of flavour because the sense of smell contributes significantly to the experience of food [10].

#### *Qualitative impairments to smell*

Some conditions can cause qualitative changes to smell, including the SARS-Cov-2 virus. This is considered part of the recovery process [11]. Two qualitative olfactory disorders are widely recognised: parosmia and phantosmia [9]. Parosmia is the distortion of smells, where common odours, many of which are associated with favoured foods in diets around the world, can become unbearable and provoke feelings of disgust [6,12]. Typical triggers for parosmia include coffee, onions, garlic, fried/roasted/browned meats, eggs, toothpaste, bell peppers, and cucumbers. Sometimes the reaction is so strong that the individual gags or vomits. In extreme cases, it is not possible to eat and the patient needs hospitalisation and tube feeding in order to maintain adequate nutrition [13]. It is important to

note that with parosmia, the disgust perceptions are continual and recovery happens over long time scales. The distortions described here are considered a sign of regeneration of nerves and recovery [11].

Phantosmia, the second of the qualitative olfactory disorders, is the experience of smell in the absence of a triggering odorant [9]. Because phantosmia is not the result of a stimulus in the atmosphere but instead originates in the brain, it will not be described further here.

## Materials and methods

### *Methodology for collecting qualitative data from social media*

The AbScent social media platforms are private, closed groups and cannot be accessed by the public. They consist of groups on Facebook, and that of the AbScent Network. The groups are screened and highly moderated to maintain content quality. Anyone wishing to join the community must answer a question to state that they have a smell disorder, and also agree to admin rules (Appendix A) which clarify the privileged nature of the discussions and other topics such as the policy on spam, foul language, etc. AbScent uses the community for the purposes of understanding the development of the condition, and therefore when posts with questions are introduced into the feeds to fulfil research objectives, this is clearly stated. Comments, where collected for qualitative research purposes, are anonymised.

Social media has proven a fruitful method for obtaining qualitative data on patient experience [14–16]. For the work described here, a post was made on July 1, 2022 by admins in the AbScent Parosmia and Phantosmia group and AbScent Network, asking about the greatest challenges of living with parosmia. Over 600 responses were posted in the following month and these provide the material for the following analysis. Key themes were identified and are presented along with representative quotes. These results add to qualitative research based on comments from the AbScent Facebook groups that have previously been published [1,6,12].

## Results

The thematic headings below reflect recent observations made by members of the AbScent social media forums on the problematic nature of parosmia. Of key importance to participant reflections were how parosmia affected food and eating.

### *How parosmia manifests as an altered relationship with food*

Food is central to the recognition and experience of parosmia. The first signs of parosmia are usually felt in the experience that food is “off”. Because the experience is so unexpected, it is common that the condition is initially associated with spoiled food or other environmental factors as we have noted elsewhere [6]. While improvement over longer time scales is expected, in the short term the condition might remain stable or get worse, sometimes fluctuating on a daily or weekly basis (see also [17]). When the transformation of odours becomes both striking and constant—as well as awaited—extreme anxiety can set in. Simple morning rituals, like coffee, eggs, and toast, may become excruciating. It is not uncommon for those with parosmia to be unable to remain in the same room where coffee is being brewed or offensive foods are being cooked.

### *A social and psychological burden*

Parosmia can be isolating, destabilising and difficult to manage as food is central to the social and psychological burden of parosmia. Food underpins a host of social interactions, and unexpected changes in hedonic value can be disorienting, destabilising and give rise to anxiety. There can be fear of encountering foods that may trigger vomiting or retching. Hunger pangs and cravings, which often arise when triggered by food aromas, are absent. Food is continually thrown away which leads to feelings of distress over waste.

- *The horrible thing about parosmia is that it isolates you. It makes you feel like you're not human anymore. You constantly are hungry, and constantly feel defeated because everything is so gross tasting. Not only the taste, but the smells that come from [food] make simply breathing in intolerable. Parosmia steals your joy*
- *Mine started with onion smelling bad, then it was garlic, eggs, meats, coffee. They all smell horrific and I can't eat them anymore, they taste like they smell. It is becoming a real challenge*
- *I sometimes eat really slowly/picky, analysing the food and maybe even turning my nose up a bit - so it comes across as rude, when its actually just the awful taste/smell you're trying to deal with*
- *Very isolating as unable to go out socially or eat with/be near work colleagues at break time because don't know what & when 'smells' will arrive or be triggered & prompt vomiting*

To add to the social and psychological burden, one of the most frequently cited concerns of people with parosmia is their inability to adequately communicate the devastation they feel about their condition. When family members and friends are not sympathetic to the changed experience of smell felt by those with parosmia, relationships can become estranged. This inability to directly communicate their experience is profoundly distressing and leads to further anxiety.

- *When I explain to people they find it funny. I suppose we laugh when we don't understand something. It's frustrating and isolating and makes me feel sad*
- *It's debilitating, isolating and sad. It's a handicap*
- *many relationships are strained as some people don't believe parosmia is real and tell me I should just try more foods or that it's all 'in my head'*

#### *Altered behaviour and the meal-time trajectory: from shopping to washing up*

Such a disrupted experience of food alters all aspects of the social experience of eating and behavioural activities. From the tasks of shopping and unpacking groceries in the kitchen, to handling food during preparation, then the application of a heat source to process, to sitting down at the table and sometimes feeding small children, followed by clearing up, storing leftovers, etc—every stage of this process can be another distressing assault. Respondents describe feelings of disgust and urgency about it that are relentless, as if a panic button was being continually pressed. Where family members or friends lack understanding of the experience of parosmia, the problem can become exacerbated, leading to feelings of isolation, anger, and sadness.

- *Shopping is a chore as I have to read the labels on everything so I give up*
- *[I] eat in my bedroom because eating with my family is gross*
- *Eating my favourite food after a bad day or comfort food when I'm feeling down made all the difference. I don't have that anymore*

#### *Altered relationship to self: disrupted self-smelling*

While parosmia causes distortions of common foods and household odours, the condition also affects perception of body odour. Many describe that their own body odour is foul, and no amount of washing will alleviate this experience. Conversely, the perception of faecal smells is altered in another way, being experienced as the smell of food. This switch in hedonic values, rendering food smelling like sewage, and faecal smells being described as smelling like food, profoundly alters the experience of the parosmia patient in a troubling way.

- *My own body smells like rotting onions and my husband and dog don't smell right. When I kiss them I no longer inhale their familiar smells because they smell wrong*

- *I don't know if my faeces smell awesome or my food smells awful. It's the same. Luckily my faeces smell like seasoned lamb*
- *No clue if I personally smell and the body smell that I do smell sometimes is repulsive to me, and it concerns me what others are smelling of me*
- *When it was at its worst, my own body odour was something I needed to escape from but never could. Showering didn't help*

#### *Altered social and work relationships*

Olfactory distortions can also have a profound effect on the relationships between people, both at home and in the workplace. Intimate relationships within families can be affected as individuals may feel disturbed by their own odours and feel disconnected from others because of the loss of odours that help define these relationships. Food is frequently key to both social and work relationships and parosmia affects this [1]. The following quotations provide examples that demonstrate the breadth of the impact.

- *Losing the smell of my home, my baby, my body, having it affect every single aspect of my day from the moment I wake up and having to brush my teeth, to my showers, the way it took away some of my greatest joys in life,... smelling my husband after a shower, kissing my husband and being close to him, the smell of a campfire, the smell of fresh air, not being able to escape the bad smells, not having one familiar scent ... so much.*
- *I don't recognise myself as a person, this has completely changed who I am physically & psychologically & socially*
- *[I have] anxiety to socialise when food is involved*
- *Going out for meals or socialising is challenging and I try to stick to only going to places where I know the menu and with people who are sympathetic*
- *I couldn't follow behind my coworker in the stairwell because her perfume was literally going to make me sick. I left and took the elevator*
- *[I'm] Missing out on days out and social interactions.*

#### *Support comes from the care/family circle*

Patient groups can serve as a place to pool resources and share “what works”. Where a condition is as long lasting as parosmia, support should ideally come from the same intimate relationships that are disrupted. As one participant suggested, it was unimaginable how one would cope without the support of close family. Those with parosmia can learn these crowd-sourced skills, and share these with the people who are in their closest circles.

- *I rely on my husband a lot ... and I don't know how single people get through it*
- *I worry how it affects my family's life, because I have a strong aversion to cooking now - my kids are hungry a lot because I forget to start making food when I need to*

#### *Trigger foods/safe foods*

A common concern amongst respondents was that even tiny amounts of additives, for instance processed foods which contain extract of onion or garlic, can pose a problem. Parosmia can be seen as a hyperawareness to certain odour molecules, so extreme care is needed to avoid having trigger foods prepared in the house. It is not enough for other family members to cook trigger foods & expect the

odour to dissipate through open windows. Like nut allergies, even the smallest amounts can be problematic:

- *Hubby can eat 8 hours before and I can still smell it when I get home (with all doors/windows/air fresheners used to the max)*
- *Onion powder seems to be on everything! It's a nightmare !*
- *When people talk closely to me the mouth stench from them is almost too much and if they have just consumed anything with onions or garlic beyond repulsive and the stink just hangs in the air like I'm standing in a garbage dump*

Further complicating the experience of trigger foods, what is manageable one day may be intolerable in the short term. This creates frustration and anxiety. In our patient forums, members also discussed how a food item manufactured by one company may be disgusting, but another similar product made by another can be well tolerated. Thus trigger/safe foods were continuously under review.

- *I no longer enjoy food at all. One day I can somewhat tolerate an entree, but next time it may have the dreaded nasty taste. List seems to grow. What's good today is not necessarily good tomorrow.*
- *[I] don't know what & when 'smells' will arrive or be triggered & prompt vomiting*
- *Constant changes of smell/tastes, never knowing if it's going to be ok this time*

#### *Anxiety over experimentation*

Experimentation, which runs the risk of provoking feelings of disgust and nausea, may lead to more manageable options, but it is a trade-off. In the most severe phases of the illness, respondents reported being unable to cope with even the slightest experimentation for fear of vomiting.

- *Being scared of trying food in case I am sick*
- *Too wary of trying new things as most of the time it's bad*

#### *Discussion*

It is well established that patient advocacy and support groups have an important role to play in providing an outlet for sharing the illness experience [4]. Asked about the greatest challenges of living with parosmia, participants' responses frequently concerned the problem of managing relationships with food – both in recognising and re-experiencing parosmia on an unrelenting basis, but also in the ways in which food mediated social relationships.

The analysis also revealed a less well documented aspect of research on online support which concerns how the affected person can share their burden with their close contacts and how patient groups serve as a place to share experiences. Such 'crowdsourced' information and solutions have been widely discussed and developed on the AbScent Network. Based on the discussion above, our research (eg [1,18]) together with the collective wisdom that has arisen within these online support groups has allowed identification of some of the key 'hints and tips'. The following section is a list of 'crowd-sourced' suggestions that speak specifically to the central problem of food. These are summarised below in [Table 1](#).

#### *Learning to work within the limitations of safe foods*

Once it is clear what foods are safe – and this can be as limited as three bland food items such as plain pasta, rice, and plain yoghurt – it is important to find ways of making these foods as palatable as possible. Experimentation is again required. Finding a support partner who will sit with them and

provide reassurance during any experimentation, having a “palate cleanser” to hand, or a beverage to wash the offensive food from the mouth can be helpful.

Some spices may provoke disgust also, but in general this seems to be less of a problem. Cinnamon, clove, fennel seed, allspice, black pepper and blended pepper mixes, ginger: these are some common spices that those with parosmia have found helpful. Investigations into the types of foods people find disagreeable has shown that no food item can be considered an absolute trigger or absolutely safe [6]. Each patient is individual and will have their own opinion of what works and doesn't work. Again, it is important to point out that this will be changing frequently, and it requires an open mind to review a trigger food to see if there are any changes. This is where steady and empathetic support from those in the care circle can be of vital importance.

### *Staying updated*

It is helpful to keep a list on the fridge or in another easily accessible kitchen location so that anyone living in the same household can be aware of current triggers. A list of safe foods should be kept updated. Trigger/safe foods should be monitored regularly.

### *Cooking methods and the maillard reaction*

The Maillard reaction that is achieved by cooking at high temperatures is known to release volatiles that are known parosmia triggers [18]. Sautéing, roasting at high temperatures, deep fat frying, and baking to the point of browning (as with bread) can all be problematic. This can rule out almost all meat preparation techniques with the exception of poaching and sous-vide. Caution should be exercised when using a slow-cooker, as this can disperse cooking odours steadily over long periods.

### *Temperature*

Hot foods by definition give off more volatile molecules and therefore have a higher olfactory profile than room temperature or cold foods. For this reason, cooled foods are reported to be a good strategy for the parosmic patient. Where a roast chicken is often highly objectionable, a cold poached chicken breast can be manageable.

### *The joy of gustation*

Gustation is defined as the perception produced or stimulated when a substance in the mouth reacts chemically with taste receptor cells located on taste buds in the oral cavity, mostly on the tongue. There is considerable confusion in the AbScent patient groups between gustation (“taste”) and flavour (also known as “taste”). As an understanding of these concepts is helpful for some patients, AbScent has

**Table 1**  
Management Tips for Parosmia

Safe/trigger foods	A tally of safe and trigger foods should be kept in an accessible place in view of cohabitants. This will prevent the affected person from coming into contact with trigger foods unnecessarily. The list will change frequently, therefore experimentation is helpful.
Bland “safe” foods	These foods can be made more palatable by experimenting with spices, chili, nuts, seeds etc.
Cooking methods	If deep-fried, sautéed, roasted foods are objectionable, low temperature cooking is advised.
Hot foods vs cold foods	Foods served at a higher temperature will give off more volatiles. Room temperature or cold food is better tolerated. This also goes for meat, such as cold chicken in a sandwich.
Gustation or “true taste”	Experimentation with the “true tastes” of salty, sweet, sour, bitter, and umami can make a bland plate of food more interesting. Salty and sweet, or salty and sour for instance.
Spice, texture, and temperature variation	The addition of spice to add heat, and texture combinations such as crunchy and creamy, can be helpful in making a meal palatable. Variation in temperature on a plate creates similar interest.
Food presentation	Care taken to present an attractive plate with a range of colourful vegetables and fruits can help with appetite. Bland food with little colour served on a white plate can be dispiriting.
Nose clip	For extreme cases, nose clips can offer welcome relief.

adopted the following terminology: “true-taste” is the phrase used to describe tongue perceptions: salty, sour, sweet, bitter, and umami. “Flavour-taste” is the combination of retronasal olfaction and gustation. “True-tastes”, used in combination (for instance sweet and sour, sweet and salty) can provide non-olfactory interest in food. For example, a savoury dish with a fruit garnish will provide colour and tang where fruit is tolerated. Salty mixed with sweet, or tartness, can make bland foods more interesting.

### *The importance of spice, texture, and temperature*

The kinds of foods associated with the trigeminal reaction, such as chilli, ginger, horseradish, peppermint, black pepper, Szechuan pepper and cinnamon are reported to add further depth and interest to the meals eaten by patients with olfactory changes. The texture of food has been found to be important in liking/dislike, and foods that are crunchy, chewy, soft, etc sometimes create an appealing variation to the meal. Serving hot and cold foods together on the same plate can also be appealing.

### *We eat with our eyes*

Within the confines of the parosmic patient's safe foods, there should be attention to the look of the food, presentation, and colour. All of this goes toward making any dish look more appetising. This also extends to the use of crockery. Where bland foods such as boiled pasta and rice are the only things tolerated, white crockery should be avoided as this only underlines the blandness of the food. Finely chopped parsley—in tiny amounts, sprinklings of pepper, sumac, nigella seed, chopped nuts, finely chopped red chilli or tomato, fresh pomegranate seeds, where tolerated, all provide an attractive backdrop. So often patients with parosmia end up eating alone for fear of being triggered by the food of others, and photos appearing in patient forums often show food eaten off paper plates with plastic cutlery, “picnic” style, in solitary circumstances. This can be a dispiriting experience of food.

### *The nose clip*

The nose clip, such as is used for swimmers, can be a most helpful intervention when parosmia is extreme. Occluding the nostrils has drawbacks however. Food must be chewed with the mouth open, and some find the experience limits breath to an unpleasant extent. As a last resort, however, it can be beneficial.

## **Conclusion**

As illustrated by the patient comments above, living with parosmia can provide challenges and lead to considerable changes in quality of life. Parosmia also poses difficulties for researchers of the condition because it is at this time impossible to assess objectively. In an effort to respond to the pressing need for strategies that support the many patients affected by post-Covid parosmia, a number of qualitative thematic reviews have been conducted in the AbScent Parosmia and Phantosmia support group on Facebook. This and other research shows that online support groups are highly valued in providing opportunities for sharing the lived experience of illness. Here, we emphasised how they also serve as a reservoir for crowd-sourced hints and tips to mediate the challenges of living with parosmia. Our research also suggests that intimate relationships may be challenging with parosmia, but that these relationships are also a support to those living with this condition. Further pooling and development of coping strategies may thus be useful to support those with parosmia not only with challenges of eating, but also in enlisting the help of near care circles.

## **Conflict of interest**

I declare that I have no conflict of interest to disclose.



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## Appendix A

Rules of the Covid 19 Facebook Group:

1. Please spend some time reading the feed before you begin posting.
2. We discuss parosmia (aka “the smell”) and phantosmia (phantom smells) over at Facebook. com/groups/AbScentparosmia. Please join that group for discussion on these topics
3. We represent evidence-based science. We take the advice of our scientific advisory board on all matters to do with treatments.
4. Do not post, link or promote to members, either for your own or other business. Irrelevant or copyright protected content is not permitted.
5. Please be respectful to others and do not use foul language.
6. We are a group to discuss smell and taste loss. Other groups are available to share and discuss other long Covid-19 symptoms.
7. Please share your experiences but do not give medical advice. Remember that individual circumstances are different and unqualified advice can be dangerous.
8. Posting polls is not permitted as we use them for our own research purposes.
9. Content and member comments made in this group represent privileged information. Unauthorised use of the content for outside purposes is not permitted. For further details please contact AbScent.org

Rules of the Parosmia/Phantosmia Facebook Group.

1. Please spend some time reading the feed before you begin posting. Check out the Featured section.
2. Please stay on topic!
3. We take the advice of our scientific advisory board on all matters to do with treatments. We need scientific evidence in order to promote any potential treatments.
4. Do not post or link to advertising, promotion or irrelevant or copyright protected content.
5. Please be respectful to others and do not use foul language.
6. Please share your experiences but do not give medical advice. Remember that individual circumstances are different and unqualified advice can be dangerous.
7. Do not link to outside surveys.
8. The content and member comments made in this group represent privileged information.
9. Unauthorised use of content by third parties, for whatever purpose, is not permitted. For further details please contact AbScent.org.

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