# Loss of smell after COVID-19: a view from the patient forums

## **BY CHRISSI KELLY**

Patient advocate, Chrissi Kelly, founder of AbScent, talks about how the pandemic has changed the way we think about smell loss.

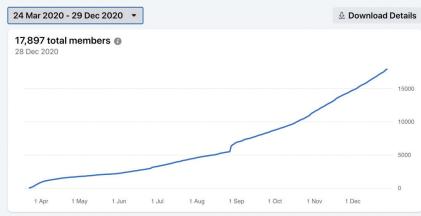
he high prevalence of chemosensory impairment as a result of the SARS-CoV-2 virus has shone a muchneeded spotlight on the problem of patients experiencing post-infectious smell and taste changes. For many years a niche field that received little attention, both in the public arena and in research, olfactory dysfunction in coronavirus patients is now known to range from 64.4% to 85.9% in milder forms of the disease. This brought the matter directly to the attention of the media as patients have struggled to adjust to life without smell. As a patient with postinfectious olfactory dysfunction in 2012, and another loss of smell from COVID-19 in April 2020, I have welcomed a sea change in the way patients are seen and heard. I have been working with patients since 2015 in a closed Facebook group, and founded the charity AbScent in May 2019. In my role as patient advocate, the emphasis has been on raising awareness of olfactory loss. Awareness is with us now. The next challenge is proper support of the growing ranks of those whose sense of smell has been affected by COVID-19. Patient advocacy in this area has adapted and is providing a new kind of interaction between patients, researchers, and clinicians.

The first indication that smell loss might be a part of the coming pandemic came

"We require researchers who access our community to feed back their results, in ways that are accessible to the layperson, so that patients feel they are heard and valued"

to me on Twitter in February 2020 from Iran, followed a week later by a front-line ENT surgeon in Italy who had suddenly lost his sense of smell, without other symptoms, and was seeking advice on smell training. By March, the Global Consortium for Chemosensory Research (GCCR) was formed, where I served on the forming committee as patient advocate. At the same time that the GCCR's research was gearing up to learn more about the prevalence of COVID-19 chemosensory changes, the ranks of the original AbScent Facebook group were swelling.

On March 24, 2020, the day of lockdown, numbers in that Facebook forum had increased to the point where all discussion



Growth of the COVID-19 Facebook group, March-December 2020.

parosmia is an example of original research that commenced in the pre-pandemic

Facebook group [5]. The people who join our COVID-19 groups are anxious, anguished, and discouraged by lack of interest from their GPs. Their expectation is that because smell loss has originated in the nose, the support needs to come from the ENT community. Sadly, there are few medical interventions that can be offered, although interest in new therapeutics has equally increased during the last year. In our own research, and in

was dominated by COVID-19, and this

was problematic for the many members

who had joined the discussion to discuss

smell loss via other non-viral pathways.

The dramatic rise in membership caught

the attention of Professor Claire Hopkins,

Society (BRS), and Consultant, Mr Simon

Gane, AbScent trustee, culminating in a

letter to Rhinology on the subject [1]. As

the numbers continued to grow it became

necessary to add a further Facebook group

to discuss parosmia and phantosmia. Today

our online community, across all platforms,

The research potential of the patient

groups was soon obvious. With expanding

numbers of members who represented a

the group that would benefit members

and researchers alike. We reinforce the

participating in research but, equally,

we require researchers who access our

community to feed back their results, in

reservoir of real-time experience, AbScent

quickly established ways of interacting with

message about the importance of members

ways that are accessible to the layperson, so

that patients feel they are heard and valued.

Too often, patients are seen by researchers

as merely data points. AbScent's model

of patient advocacy is a virtuous circle

where patients can share their stories, providing both qualitative and quantitative data, generate new research themes [2-4]

and learn about the latest research. Our research with the University of Reading on

numbers over 65,000.

President of the British Rhinological

ENT FEATURE

Word cloud result of a survey asking what patients would like when consulting their doctors about smell loss.

information reassurance understanding

timeline

solution honesty validation support stem-cells recognition CUICE DODE facts compassion solutions restoration investment resources optimism care credence interest empathy science treatment answers

esearc

"Within the safe space of our closed networks, peer support provides what medical interventions cannot at this time: validation and empathy"

......

listening to the responses to detailed questions delivered by admins in the Facebook groups, we have concluded that support for patients experiencing the distress of olfactory loss needs to come from three other important areas: mental health, dietetics, and peer support.

The relationship between olfactory disorders and depression is well known. There is loss of simple pleasures like the enjoyment of food, social interaction, intimacy, and the enjoyment of natural surroundings; anxiety over safety issues such as fire, or the inability to sense potentially life-threatening allergens in food can become severe. Where parosmia is so overwhelming that eating becomes a challenge, we are offering support to those who are experiencing weight changes with our partners at AlteredEating.org. Within the safe space of our closed networks, peer support provides what medical interventions cannot at this time: validation and empathy.

In all areas, AbScent has been working to provide support in the form of online

forums, webinars with leading experts, blogs, and other written materials. Our YouTube channel has had over 201,000 views since 2019, and also includes the NoseWell videos, created with the BRS to assist COVID-19 patients. Smell training, recommended in the BRS/ENT UK Management of New Onset Anosmia in the COVID Pandemic, is offered by AbScent through several different channels. AbScent is entirely self-funded through the sale of smell training kits. Patients who wish to support us this way do so knowing that all proceeds go into running the charity and helping people like themselves.

#### References

- Gane SB, Kelly C, Hopkins C. Isolated sudden onset anosmia in COVID-19 infection. A novel syndrome? *Rhinology* 2020;**58(3)**:299-301.
- Cook E, Kelly CE, Burges Watson DL, Hopkins C. Parosmia is prevalent and persistent amongst those with COVID-19 olfactory dysfunction. *Rhinology* 2021;59(2):222-4.
- Parker JK, Kelly CE, Smith B, et al. An analysis of patients' perspectives on qualitative olfactory dysfunction using social media. *medRxiv* 2020;12(30):20249029.



Smell training.

 Watson DLB, Campbell M, Hopkins C, et al. Altered Smell and Taste: anosmia, parosmia and the impact of long Covid-19. medRxiv 2020;11(26):20239152.

 Parker JK, Kelly CE, Gane SB. Molecular Mechanism of Parosmia. medRxiv 2021;02(05):21251085.

AUTHOR



### Chrissi Kelly, BA, MSc,

Patient Advocate, AbScent, Twitter: AbScentUK Instagram: AbScentUK

AbScent is a charity registered in England and Wales, No 1183468.

## ......

"We have concluded that support for patients experiencing the distress of olfactory loss needs to come from three other important areas: mental health, dietetics, and peer-support"

......