

The Impact of Olfactory Disorders

Fifth Sense Survey

Following the first Fifth Sense conference in 2013 a survey of members was undertaken to provide evidence of the impact that the loss of the sense of smell has on the sufferer. Many questionnaires were returned and an analysis of the first 496 was completed earlier this year. The results of this analysis were recently published in a science journal by Carl Philpott and Duncan Boak (Chem. Senses 39: 711–718, 2014). A summary of the findings is given below, and a list of the questions in the survey can be found at the end. This publication provides an important reference for the justification of research into olfactory disorders and we wish to thank members for their help in this work.

The survey was completed anonymously and comprised four parts which included questions which were answered either by choosing from scales (e.g. 1 to 10 or levels of agreement/disagreement with a statement, or yes/no) or by providing statements of the respondents experience. The former were analysed statistically while the latter were grouped by topic raised by respondents. The age range of respondents was 8–95 with an average of 55 (parents responded on behalf of the 8-year olds). The respondents comprised 178 men and 318 women.

In the first section of the survey where members were asked to rank 24 statements/questions, the key subjects that elicited the response of “agreed” or “agreed partly” in more than 50% of answers included (Figure 1):

- Reduced appreciation of food and drink (92%)
- Exposure to certain dangers (e.g., gas, rotten food) (85%)
- Emotional difficulties including anger, frustration, stress, and isolation (56–76%)
- “I go to restaurants less often than I used to” (55%)
- “My relationship with my partner/family/friends is affected by my difficulties with smelling” (54%)

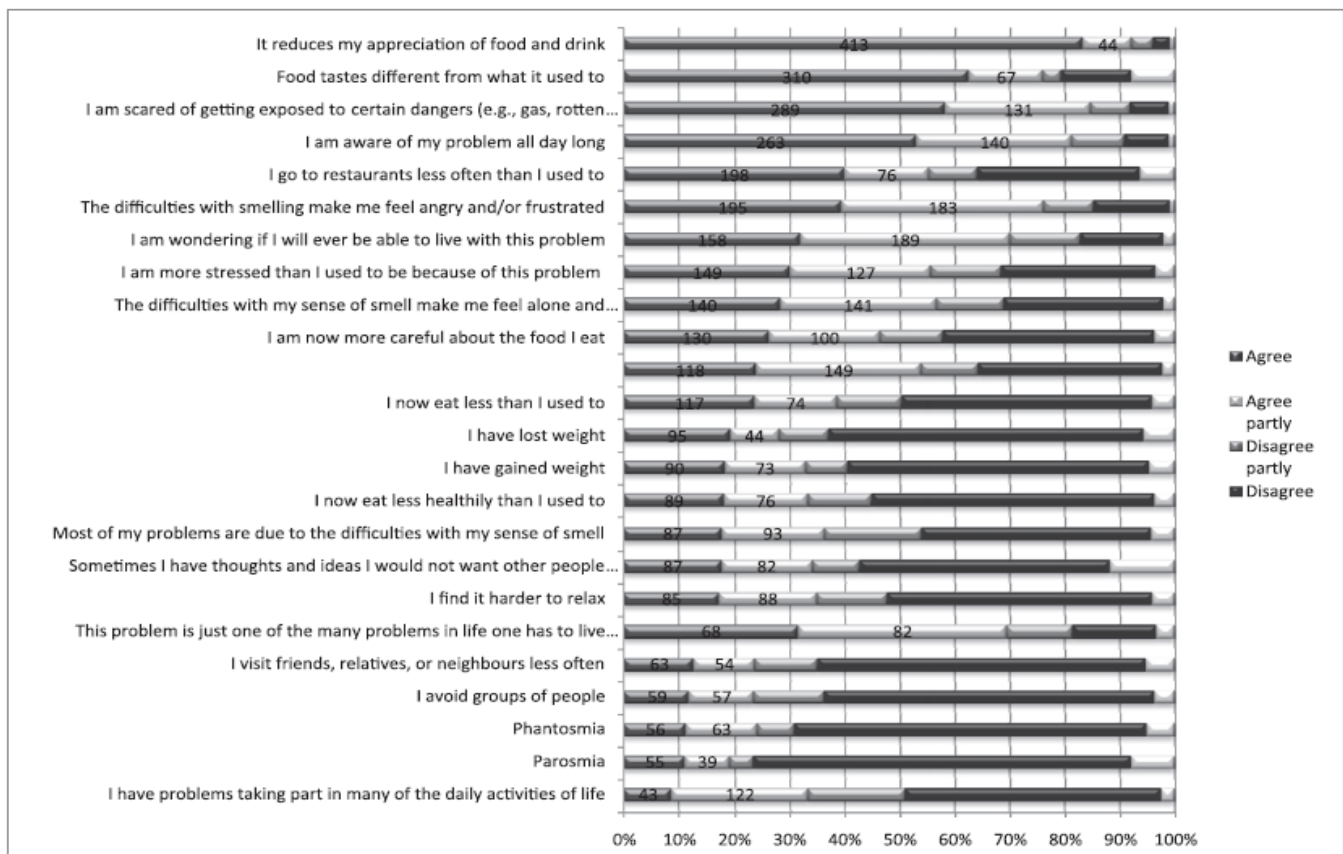


Figure 1 Quality of life questions—percentage of respondents agreeing or disagreeing (no response indicates that the member thought the question was invalid or did not understand it).

In the second part of the survey where members were asked to provide a yes or no answer, the rate of depression was 43%, compared with a rate of depression in the general adult population of 8–12%. Those suffering either depression and/or anxiety comprised 52% of respondents and 25% had received prescriptions of medications or NHS counselling services in relation to anxiety and depression resulting from their olfactory disorder. Furthermore, there are significantly higher rates of depression and anxiety in female respondents (47%) compared with male (34%). Over the counter medications had been used by 14% and 20 % of members had tried various alternative medicine therapies including acupuncture, hypnotherapy, cranial osteopathy, and reflexology.

In the third part of the survey, members appeared to have noticed the greatest impact upon social and domestic life (Table 1), but with women again significantly more affected than men, even taking into consideration the higher number of female respondents. When these impact ratings were correlated against increasing age, significant trends can be seen with all four factors such that younger sufferers are more likely to be adversely affected by these issues.

Looking in more detail at the specific impact of parosmia (distorted smells) and phantosmia (imagined smells), compared with those who do not experience these symptoms, sufferers of parosmia and phantosmia reported significant issues with flavour perception, eating unhealthily, eating less, despair, being less sociable, and stress. Phantosmia sufferers reported significantly higher rates of depression related to their smell disorder than those without (53% vs. 40%); parosmia sufferers did not show any significantly different rates of depression but did have a higher rate of anxiety. Other notable findings are that younger aged sufferers (<50 years) show significantly higher rates of weight gain, isolation, depression, and being scared of dangers; older sufferers showed higher rates of resignation to their sensory loss.

The fourth section asked for personal experiences of professional, social, domestic, and sexual issues, and responses were made by 185, 243, 288, and 130 members respectively for those topics. A number of key themes were identified as detailed with frequencies in Table 2. Professions most affected by smell disorders included those working in the food industry, the medical profession, childcare, and the housing and engineering industries. Many comments related to respondents' concerns about personal hygiene at work and about difficulties with eating with colleagues. The latter also ran through into social circumstances, whereby many respondents described annoyance at the lack of understanding by family and friends in social gatherings and hence avoidance of these situations. Other social and domestic issues encountered included birthdays, food preparation (for example, spoilt and burnt food) dinner parties, gas leaks, reliance on partners for their sense of smell, room/pet odours, body secretions smelling foul (parosmia sufferers), concern about personal hygiene, and child care issues (for example, nappies). Among the free text entries into the survey there are a number of examples of key messages of impact to these sufferers which are listed in Appendix 1.

Table2 Free text themes in response to professional, social, domestic, and sexual issues (number in brackets = respondents entering comments)

Professional	Social	Domestic	Sexual
Housing/engineering (5)	Birthdays/family events (10)	Lack of enjoyment of (preparation of) food (107)	Missing smelling partner (6)
Food industry (22)	Dinner parties/eating out (160)	Gas leaks, burnt/spoilt food, etc (133)	Loss of libido/desire (23)
Hazardous chemicals (27)	Embarrassment (16)	Reliance on partners for their sense of smell (45)	Concern about smelling appealing to the opposite sex (14)

Medical and allied professions (13)	Annoyance at lack of understanding by others (17)	Room/pet odors (63)	Loss of intimacy (53)
Childcare/teaching (9)	Concern about personal hygiene (30)	Children, e.g., nappies (8)	Cessation of dating/relationship (3)
“Do I smell at work?” (19)	Loss of nice environmental odours (27)	Personal hygiene/household smells (63)	Concern about not being able to detect sexually transmitted diseases (1)
Avoidance of eating with colleagues (9)	Relationship difficulties (9)	Hobbies (4)	Anxiety (2)

Finally, Table 3 compares the results of this survey with similar surveys in other countries. It can be seen that generally the Fifth Sense figures show a more severe impact from olfactory disorders. The most likely explanation of this is that those affected most by olfactory disorders will be Fifth Sense members and that the 496 respondents are the most proactive about their plight. Nonetheless, the extent of the impact of smell loss is plain to see.

Table 3 Evidence of impact of olfactory disorders on quality of life from the literature and comparative Fifth Sense survey findings

Quality of life area	Percentage of sufferers affected	Percentage of Fifth Sense respondents affected
Reduced enjoyment of food or reduction in appetite	27–69	95
Problems with cooking (spoilt or burnt food)	37–73	46-86
Eating more/weight gain	3–20	36
Eating less/weight loss	20–36	33-40
Social interaction issues	19–36	59
Problems detecting hazards such as smoke	20–42	86
Depression	25–33	49
Professional issues	8–33	41

The findings of this survey have clearly demonstrated that British sufferers of olfactory disorders suffer significant physical, social, psychological, and emotional impacts. Fifth Sense, as a patient support organization, has clearly illuminated the largely unspoken voice of these sufferers through this survey, demonstrating the need for these conditions to be taken seriously by medical practitioners in the NHS as well as the need for more research into treatment and coping strategies for these patients.

Appendix 1: Examples of Key Impacts Experienced by Respondents

Emotional

The key issue for me is one of frustration, and the future regarding my anosmia feels dismal. It's difficult to quantify and I can see how some people might easily become depressed by it. It removes colour from a life.

I am devastated that I have not regained my sense of smell and upset that we're expecting our first child and I won't be able to smell them.

Life is totally unenjoyable. Is full of odours and tastes that make us aware of dangers and delight. This has been removed from me and my life. Something needs to be done to help us.

Input from the medical profession

One of the most depressing issues is the lack of concern by the medical profession. Getting help from GP and then being told by specialist that there was "nothing that could be done" and sent away to live the rest of your life missing one of your vital senses. If I had lost my hearing, sight, a limb or had been disfigured more help would have been given. More training should be given on this issue for GPs and especially ENT students, with more smell and taste clinics provided. I saw a consultant at my local clinic who said he'd never heard of the symptoms I have experienced over the last 20 years.

Even a specialist from a large teaching hospital could give me no hope of any form of self or professional help I was just told it was something I had to live with

When I was told my anosmia was permanent, the doctor who told me became very embarrassed and possibly threatened by my reaction and actually told me that I should consider myself lucky it wasn't my sight. It's over 9 years later and I am still very angry at the medical response.

Professional

It can be dangerous in the construction industry as unable to smell leaking gas etc

I am a chef and it has undermined my confidence in my ability to create new recipes

Working with children I am fearful that I cannot smell things of danger

I'm a psychiatric nurse ...so I can't tell if somebody has been drinking or if they have tell-tale smells of certain conditions.

Isolation and danger

As a lone elderly man with few interactions other than with his family... Above all smell is the sense which makes reality different from a highly sophisticated TV facsimile. Its absence thereby gives a feeling of isolation as well as depriving one of a myriad of pleasures, and, as I have personally experienced following

a gas escape, can put one - and others - in very dangerous situations.

My house is rigged full of fire alarms and carbon monoxide alarms as I'm scared of not smelling fire.

I lost my sense of smell 34 years ago. I have still not come to terms with it. I remember what pleasure and learning I got through smelling things. I used to be an avid cook and perfumes were a serious interest. Because it is an invisible disability, most people do not know I have it and do not understand.

Personal interaction and sex life

So much of sexual closeness is wrapped up in smell. It's how you know who you are with when the lights are off. It has reduced my interest / desire.

Well many of us deal with it because there is no choice...and make the best of it...but it's like seeing the world in monochrome and I worry I will never be able to share again properly in my social and sexual life. I feel like I'm just an observer.

Postoperative bliss

My sense of smell returned 5 days post-op and my life has since improved immeasurably. Every aspect of my life is happier having regained this very important sense.

Appendix 2: Fifth Sense Members Survey Questions

How old are you?

What is your gender?

How do you feel about the following statements relating to your smell disorder?

1. I often perceive a bad smell, regardless of whether a potential odour source is present
2. My biggest problem is not that odours are less intense (or absent), but that things smell different from the way they used to
3. I am aware of my problem all day long
4. It reduces my appreciation of food and drink
5. Food tastes different from what it used to
6. I now eat less than I used to
7. I now eat less healthily than I used to
8. I am now more careful about the food I eat
9. I have gained weight
10. I have lost weight
11. I go to restaurants less often than I used to
12. I am wondering if I will ever be able to live with this problem
13. I am more stressed than I used to be because of this problem
14. Sometimes I have thoughts and ideas I would not want other people to know of
15. Most of my problems are due to the difficulties with my sense of smell
16. I visit friends, relatives, or neighbours less often
17. I find it harder to relax
18. The difficulties with my sense of smell make me feel alone and isolated
19. I avoid groups of people
20. This problem is just one of the many problems in life one has to live with
21. I am scared of getting exposed to certain dangers (e.g., gas, rotten food)
22. I have problems taking part in many of the daily activities of life
23. The difficulties with smelling make me feel angry and/or frustrated
24. My relationship with my partner/family/friends is affected by my difficulties with smelling

Have you suffered from the following in relation to your smell disorder:

- Depression – Yes/No

- Anxiety – Yes/No

If you have suffered depression or anxiety as a result of your smell disorder, have you...

- Taken any medication prescribed by your GP (e.g., antidepressants, sedatives, anxiolytics)?
- Taken an over-the-counter medicine?
- Taken an alternative medicine remedy?
- Received counseling?
- Other (please specify below)

Has your smell disorder had an impact on your professional life? (0–10 scale)

- Please provide details of any specific issues here

Has your smell disorder had an impact on your social life? (0–10 scale)

- Please provide details of any specific issues here

Has your smell disorder had an impact on your domestic life? (0–10 scale)

- Please provide details of any specific issues here

Has your smell disorder had an impact on your sex life? (0–10 scale)

- Please provide details of any specific issues here

Do you think there are any key issues that have not been covered by the above questions? If so, please provide further details here.