

**Dee's story May 2024**

**Service name:** Outpatient Dietetics

**Main purpose of service:** All patients are assessed, treated and advised during clinic or telephone consultation appointments. The service receives referrals for people who are registered with a Huddersfield GP and who need the expertise of a dietitian. Patients are referred to the service for dietary advice related to a wide variety of conditions including Diabetes, Irritable Bowel Syndrome, Diverticular Disease, Coeliac Disease and Nutrition Support.



**About the person:**

Dee is a retired NHS administrator and lives with multiple health needs, including diverticular disease, lupus and fibromyalgia. She also has orofacial granulomatosis (OFG), which means Dee suffers chronic mouth ulcers. She was referred to the service because she needed help to follow complex dietary advice for both diverticular disease and OFG and was supported by dietitian Sarah.

For information on diverticular disease, <https://www.nhs.uk/conditions/diverticular-disease-and-diverticulitis/> For information on lupus, <https://www.nhs.uk/conditions/lupus/> For information on fibromyalgia, <https://www.nhs.uk/conditions/fibromyalgia/> For more information on orofacial granulomatosis, <https://www.kcl.ac.uk/slcps/our-departments/ofg>

Dee takes up her story, **“I had seen a specialist, as my mouth ulcers were getting worse, who told me to follow the OFG diet. I call it my OMG diet! I had to try to cut out all cinnamon and benzoates and their derivatives (of which there are many) and follow a low/high fibre diet dependent on a flare up of my diverticular disease.”** At the same time, Dee was trying to eat foods that did not aggravate her diverticular symptoms. She also noticed that during a 3 day fast whilst experiencing a diverticular flare, some of her rhinitis (nasal) symptoms had improved. Dee was keen to better understand what she could eat and what she should avoid. **“Sarah sent me a leaflet about Diverticular Disease – that was the easy bit! Sarah had never supported anyone on the OFG diet before as it’s quite a rare condition. She was really interested and wanted to do some research.”**

**Restrictive:** Dee describes her experience of mouth ulcers, **“When my ulcers are bad, my tongue, the back of my throat, bottom lip, cheeks are all so painful. Even drinking tea is painful. It’s so debilitating and restrictive. Food is no longer enjoyable.”** Dee explains that she has lost her senses of taste and smell due to her other health conditions. **“I’m not interested in food at all. I eat to keep me alive. I’m very limited. I’m lucky that we’ve always had a garden, so I can eat home grown veg. I’ve never eaten junk food.”**

**Dietetic support:** Dee continues her story, **“Sarah found out that derivatives of cinnamon can be in face creams, toothpastes, lotions, and many other things! I now try to avoid some ‘e’ numbers and benzoates, which are used as preservatives – it takes me ages to go shopping! Now I only use 100% organic face creams, toothpaste and shampoo. Processed food is a no no! I’ve now cut out garlic, onions and pineapple. I can eat fresh tomatoes, but cooking tomatoes releases benzoates which make my ulcers worse. I can tolerate three different cereals, so I now rotate them, a day each.”** She continues, **“I’ve learnt such a lot. Sarah really wanted to help me. She was compassionate and professional. I felt so overwhelmed with it all. I burst into tears and cried for half an hour on the phone. She was supportive and never patronising. She’s an educator. She’s opened my eyes to the bad things in food. To get to 70 and then to get such an education about the food going into my mouth! She has made me ‘ingredient aware’ with cosmetics and other things too. She’s completely changed my life! Full marks for Sarah!”** Dee adds, **“And my rhinitis is the best it has been since I was 18, I’ve even been able to stop all my nasal sprays.”**

Dee spoke to Jo Vaughan in Locala’s Engagement Team and gives full consent to widely sharing her story.