**We have created some questions to get your conversations started. Please add in your own questions, ideas and thoughts. If you would like some support to take notes and record your ideas please contact:** [kate@otbds.org](mailto:kate@otbds.org)

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| **What are you experiencing?  Questions / Issues / Changes** | **What can be done to make this easier?  Solutions / Ideas / Advice** |
| **How did you first notice that your sense of taste and /or smell was changing?** | I started to ‘go-off’ my favourite foods. My favourite drink was coffee but I started to not like it. Now, I cannot even tolerate it, I must spit it out. |
| **What are the changes that you experience?** | I smell ‘awful’ smells – horrible, disgusting things such as the smell of burning, cats pee and food that has gone off. I now know these smells are not real to others but they are real to me. I call them ‘phantom’ smells. |
| **How does this affect you in day-to-day life?** | I am reluctant to try new foods as I often spit them out because they taste so bad. I’m not sure what food I like anymore. If someone asks if I like coffee cake, for example, I would need to taste it and see. This isn’t to do with my memory – I remember coffee cake, but my own tastes have altered. |
| **Did you get helpful advice or support from other people?**  **Your family and friends?**  **Doctors and other professionals?** | No. Lots of people offered support but they couldn’t provide what I needed. I felt that people didn’t understand what I meant when I talked about my sense of taste and smell changing. |
| **What about the social aspects, such as having meals with people or seeing friends?** | I stopped having meals out and going to social events with food until I understood what was happening.  I often send food back thinking that it is ‘off’ – but it’s perfectly fine. I feel that I sometimes cause ‘drama’ when we’re out. |
| **How do you feel about all this?** | I felt disappointed that there was no help for me but now I feel more hopeful that I’ve found some tips and solutions. |
| **What are your tips or messages for anyone else in this situation?** | Tell your friends and family, share what your experiencing so they can begin to understand.  Don’t be afraid, you’re not going ‘mad’. Your brain is misinterpreting due to your dementia.  Enjoying eating and drinking is still possible – just different. |
| **Do you have any tips or messages for people such as families and professionals?** | When me and my daughter eat out we order different meals. If I don’t like mine we swap. It just makes it easier and causes less ‘fuss’.  I’ll often eat before going to a social function so I won’t have to eat the food if I don’t like it – I can just enjoy the event and ‘graze’ instead. |
| Add your own here: |  |
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