

Going to university with MCS

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In 2010, after I assisted with organising the AESSRA Seminar, I decided to go to university. I felt compelled to develop my writing skills. I had left school at fourteen and had gone back to TAFE in 2005 to learn how to use a computer because I was starting my own business. Study and access to classes was fraught with difficulty and misunderstanding—or no understanding at all—and I didn't get to finish the last subjects of my third year in Business Certificate III.

I couldn't access the classes due to becoming incredibly ill from constant daily exposure to spray deodorants, hair spray and spray on fragrance. I'm the type of student who needs to be in class. I find it difficult to learn a huge subject via a textbook arriving in the mail while everyone else is in class—a text book that needs airing out before even diving in! I won't mention the name of that institution because I had put a complaint in with the Victorian Equal Opportunity and Human Rights Commission and won reasonable accommodations, which were online and phone tutor study because I had moved out of the area by the time it was sorted out. The process was simple: fill out a written complaint, supply dates and incidents of discrimination. Still, it's a stressful process and one better avoided!

So when I enrolled at Victoria University (VU) to study the Diploma of Professional Writing and Editing, I knew I had to be more assertive and make access to learning different or not go at all. Luckily, at this Australian university, the Disability Services staff had experience with students with chemical sensitivity. This made mapping out my own path, based on my own learning and access needs easy. I just had to tell them about any issue and they'd try a new strategy to fix it.

We tried a few strategies.

During the first year, and the following ones, staff put a note in the Student Handbook so that all first year students would know about it. Of course it took more than this to get everyone on board.

It actually takes many departments to facilitate an good outcome with the 'Access Plan' (sometimes called a 'Disability Plan'), which is the document that goes out to all teachers and if relevant the coordinator of the library, facilities (cleaning staff), the technical staff (for setting up Skype or Dropbox for all teachers and students (a very helpful tool!). Something I didn't complain about: access to the bookshop--very fragranced retail products. In a bookshop! Or the gardeners and sprays and equipment, I just took a detour if I even saw one. I'd try to take another student so I could get

ample warning of groups wearing heaps of deodorant, smokers and yard maintenance so as to avoid them.

However, I did insist on attending classes; besides, most of the course was classroom based and it wouldn't have been possible to do it online. It took 5 years to finish my Diploma, studying part-time, then, as I got sicker—from living in a water damaged building—only two subjects, then as my illness got worse, dwindling down to only one subject for a whole semester: I had to study from home for the rest of 2012. My Myths and Symbols teacher was awesome at providing extra reading material, interesting books and was available by appointment to meet in their office to go over my work. By the time I went back in 2013, my Access Plan was taking great shape, always changing based on all the different ideas that VU and I came up with.

My Access Plan and strategies during the final two years

We changed my Access Plan based on we had found worked well and didn't work well, and on my then declining health.

Duration of Disabilities/Medical Conditions

Duration: Long-term

Impact in Education: Many everyday chemicals cause multiple symptoms that affect ability to fully engage with the learning environment.

Chemicals cause fatigue, severe headaches, chest tightness, swelling, rashes, upper respiratory system, dry eyes, and inflammation of the sinus. Symptoms can last, causing deterioration in health.

Chemicals that impact are: aerosol deodorants; aerosol hairsprays; perfumes; aftershaves;

Room 10.222: A Fragrance-Free Environment

Please note that because we have students who are suffering severe chemical sensitivities and others who have asthma, Room 10.222 has been designated a fragrance-free classroom. To help all of our students enjoy a healthy environment, we ask that you please refrain from using perfume, spray-on deodorants or scents, or clothes that you've worn while wearing perfume into this classroom. We also ask that you refrain from bringing newspapers with you into this classroom as the ink fumes can also trigger symptoms.

This was in the Student Handbook.

chemical based cleaning products; vehicle exhaust; solvents; petrochemicals in inks (e.g. fresh newspaper print; and fresh photocopying).

Other students and staff are to be advised as early as possible in the year, concerning the necessity of fragrance free class rooms, so that arrangements can be made that cause the least distress to the student, and least disruption to teachers and other students while maintaining the classroom while maintain a fragrance free an environment as possible.

Student would prefer to work as mask free as possible in class.

In previous years, during mild to high fragrance exposure, I'd just wear the mask. This caused a further impediment because of the headaches caused from lack of oxygen, and losing my sense of smell, therefore not knowing when it was time to leave. As an example: I'd stay for a whole class, get a headache from the mask, then leave, take it off and get hit by all the fragrance that had adhered to my clothes, which is why I insisted it go into the plan.

It turned out that it was, under the Disability Act, Direct Discrimination to be forced to wear a mask that further impacted my health and also my ability to interact with people (facial expressions, speaking, being heard, running out of breath if talking etc.). Second-hand fragrance exposure is 'Indirect discrimination'. I found this out by enquiring with Disability Discrimination Legal Service in my state. The staff members there give great advice on disability and the law.

It's always best to speak to people in charge before putting in a complaint to either VEOHRC/AHRC or VCAT. The VEOHRC is for claiming damages, whereas the VCAT is for asking for reasonable adjustments. This is done with the assistance of your state disability discrimination service. A written complaint should always be a last resort.

Negotiation, communication and keeping a record of classes missed are key.

The rest of the Access Plan I have summarised below, as it's a few pages long.

- The Disability Liaison Unit (DLU) provided a BlueAir purifier for class. In one class there were two so that they could be run quietly while still doing their job. They also wrote a note on the purifiers saying the due date for change of HEPA filters.
- Another was placed in the Student Adaptive Technology Room in the library, which was made into a perfume free space. This was a glass corner room where I could go if the classroom was too high in VOCs. I could also go there to catch up on my work before the drive home, or to collaborate with other students who were fragrance free.
- Security staff turned on the filters and made sure the class door was closed on attendance days.
- The Disability Liaison Officer (DLO) provided appropriate support in advising students and staff in how to assist in maintaining a fragrance free environment.





Miche with the door with signs including AESSRA's 'Thank you for not wearing fragrance' sign on the cover of *Sensitivity Matters* December 2013.

- Two signs were placed on the door to remind students to keep it closed at all times—the outside hallways were full of fragrance chemicals. (One sign didn't work. It took two signs. We also used AESSRA's 'Thank you for not wearing fragrance' sign.)
- The DLO liaised with facilities ensuring that cleaning products were kept to a minimum. During the last year, they changed to fragrance free products so that the chance of other students or staff having a reaction to fragrance was negated as well. It's this step that shows VU to be progressive in this area.
- Hand soaps in the toilets near my classes and in the library were changed to a fragrance free soap. Facilities gave me a sample beforehand; I felt like a guinea pig knowing that I had to judge it based on what other people might react to as well, such as masking fragrance. This soap has very few ingredients. It's made by Silvan who also supplies the fragranced soap; luckily for me, they just happened to have a fragrance free range as well.
- Students were asked to come to

class without perfumes/fragrances/aerosols. (Often, due to people's right to wear what they want, initially, staff can only ask students to do this if someone has been made ill and puts in a verbal complaint. It's important to speak up, or leave and go to the DLO to tell them if the classroom is inaccessible every time; this sets clear boundaries. No one benefits if you suffer through it but appear to be doing fine!)

- If students "are wearing a fragrance/aerosol/perfume, please let student know as soon as possible so she can remove herself from the environment".
- This one is not in the Access Plan because it was organised after the plan: Each class had a tick sheet so the students could anonymously tick a box saying if they were wearing any chemical-irritant based products. This allowed me to judge the air based on an intellectual decision rather than taking my mask off and feeling the effect. It also had the dual effect of reminding the students each day.
- Printing (usually done in class) was sent to another room
- (The big one!) If possible, "classes should commence mid-morning to avoid morning traffic exposure." (I had to work this out with each teacher because some teachers won't tolerate lateness without prior arrangements.)
- A note taker was made available, however, it worked out better for the university to pay a student via book vouchers to take notes if I was away because they were familiar with the course material and the notes were in context to the subject.

Exams

- Exam paper to be provided on USB/CD
- If ill on exam day, student to complete Special Examination Request

- No more than one exam per day
- Requires use of laptop
- Be eligible for a separate room on their own
- iPad can be used instead of laptop
- Teachers were to be advised of the requirement not to wear fragrances/aerosols during exams.
- Air conditioning left off for the exam as this helps the air purifier work at optimal level and "reduces the impact of chemicals that are potentially present within the environment."
- Air purifier placed in examination room one hour prior and the door closed to maintain air quality.
- For chemical exposure: "If student becomes affected by chemicals or fragrances she may have to leave the area immediately. Alternate exam arrangements should be made in that case."

As you can see, this is an individualised plan.

Other things that helped

- AESSRA brochures handed out to class by another student or teacher on the first day. One way to do it is to ask permission to hand a stack to the first student who then passes them on. This is best done on the first day.
- Brochures left on the table where work was left and collected
- Two signs on the door. For some reason, we worked out that two signs worked: one was from VU, the other was the AESSRA poster
- A letter to the students: On a VU letterhead, the course Coordinator wrote a small paragraph introducing me and asking students to empathise with my situation. I then wrote a letter explaining my condition, what impacted on my health and what I needed.
- An alternative list of products—this is so important because you can't ask people not to do something without giving them

an alternative. Some people need antiperspirant; and not all people want to go natural, So, even though I included AESSRA's list for chemically sensitive people, I made a Listly List: <http://list.ly/list/2NG-fragrance-free-products-available-in-australia> internet list and a handout list of products I was okay with others wearing, even if not okay wearing myself. Essential oils were something I compromised about; compared to solvents or fabric softeners, they were barely an issue, what, with the air filter and a fragrance free class.

Things to be aware of

Not everyone will understand your condition and under disability law, it can be held confidential if you wish.

Apart from the first two years where I was well, for each new class, and often, a new batch of students, I missed on average 2-3 weeks of classes due to students forgetting to not wear fragrances to class. It's also up to the teacher or coordinator to follow up on reminders at the end of each class. Don't be afraid to prompt them! Most teachers are good at explaining this, as it's the same as asking for wheelchair access.

What I had to do to go to university

Besides working out an Access Plan, I had my own plan to follow at home.

- Air my car for an hour or more before I get in it
- Run an air purifier in it
- Make sure I have a clean mask for the trip (1.40 mins)
- Make sure I have one for class--hoping I don't need to use it
- Wear the mask into the building
- Check the checklist to see if it's safe for me to take it off
- Sit next to the air purifier

For emergencies

I would take a spare mask, tri-salts

Technological Assistance

Digital recorder "Student may audiotape lectures and tutorials" (Note: these were for personal use and to be destroyed when no longer needed.) VUDS organised a user-friendly digital recorder for classes, from the library. There was also a back up digital recorder.

iPad VU lent me an iPad from the library to minimise the amount of handling of paper/print; and to enable use of the camera to photograph documents and the use of Dropbox. This made it easy to keep my work in the one spot, was good for reading the class reader as well as taking photos of schoolwork or relevant documents I needed then and there, rather than waiting until after class for the teacher to send it to me. It's like having a scanning device. It can also hold ebooks. (You can turn off Wi-Fi and 3G.)

Dropbox: A file hosting service that is good for teachers to share PDFs, class readers, class notes, Powerpoint presentations (if you miss class due to illness), assignments; while also being great for students to drop classwork and assignments in. I found Dropbox eliminated the need to be poring over my studies while breathing in petrochemical-based inks.

www.dropbox.com/

Adobe Acrobat Reader: Good for reading work, highlighting it and making notes. A simple application to use, and free too!

<https://acrobat.adobe.com/au/en/acrobat/pdf-reader.html>

Skype: One teacher set up Skype so I could watch and take part in her classes from home. Free. www.skype.com/en/

and vitamin C, lots of water, and my MedicAlert card, which I laminated and had hanging off the back of my backpack. Also handy were, lunch and a snack, a spare set of clean clothes for the drive home.

I found that over a five year period, Victoria University staff were diversely talented at making sure each year's access plan improved, especially after I got sicker in 2012.

Even throughout my sickest periods, it's always been good to be able to have my mind on my writing and schoolwork. There's always that place in your mind where you can go to think about concepts, learning and projects when life with a chronic illness gets too much. It can also be slow going due to days wasted with fatigue and physical symptoms but so essentially worth it in the end. I'm terribly grateful to all the staff at Victoria University for helping me in such an outstanding way. And I'm the proud owner of a Diploma in Professional Writing.

It's now 2017, and I have an advanced placement in an Arts Degree. For now, I'm doing Communications within

Organisations online from home. I don't like studying from home but that's just how it is for this year. I plan to go back to the campus in 2018. Wish me luck. I'll let you know how I go. J

If you would like a copy of my Access Plan to show your educational institution, you are welcome to contact me via AESSRA or my contact page on my blog, The Labyrinth and finding our way out: <http://the-labyrinth.com>

Other helpful links

Dr Anne Stienmann, Fragrance Free Policies:

http://www.drsteinemann.com/fragrance_free_policies.html

CASLE (Canadians for a Safe Learning Environment): <https://casle.ca/school-scent-free-programs/>

Guidelines for Accommodating Staff and Students with Environmental Sensitivities" <https://casle.ca/wp-content/uploads/2015/03/articles-Environmental-Sensitivities-a-guide-for-schools.pdf>