

Tuesday 18/03/2014

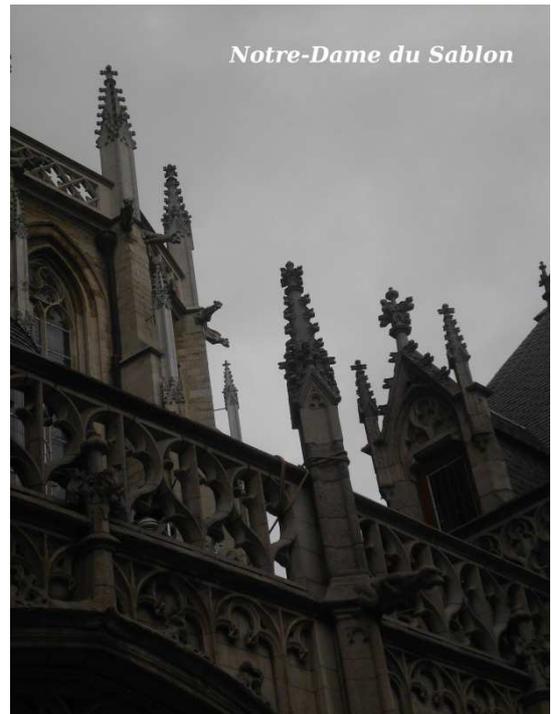
5:30 am: The alarm goes off. A sip of tea and one last look inside my backpack. Yes, the passport is in there as is the money. The spires of the church are dipped in gold when I wheel my suitcase down the hill. The emptiness of the streets calms my nerves a bit and I listen to Bach's Art of Fugue as I walk to the train station. The train pulls into Kings X station just after 9am and so I have 30 minutes before meeting the other members of my group. I giggle a bit as I walk into 'Le Pain Quotidien' - how appropriate to have the first coffee of the morning in a coffee shop chain founded in Brussels! I get a bit confused as there seem to be two separate doors leading into the coffee shop and only later understand that one is for take-away only. I order, but then feel unsure whether I need to wait for my coffee or collect it at the other side of the counter. I leave. Go back in. Then I see a paper cup on the counter and take it. Fortunately a table outside has just cleared and so I sit down and start reading my book (in French of course to get me in the right frame of mind!). There is some building work going on so I find it hard to concentrate and I also feel like I should be looking out for the others. I wouldn't want anyone to touch me or start talking to me when I am engrossed in my book. 9:43am. I get a bit panicky. Shouldn't the others be here by now? I finally spot S. sitting down on the table next to me. Relief.

Someone starts drilling again. I don't want to be rude and put on my headphones. S. reassures me that it's ok, so I do.

E. and her mother come back and we decide to buy some salads for lunch. Then we slowly make our way to the security checks where S. speaks to one of the people in charge to make them aware of our particular needs in case we need to be searched. Thanks to this everything goes smoothly and we board the train (which as K. warns us is a lot less shiny and modern than one would expect!). First stop: the metropolis of 'Ebbsfleet International'. No one has heard of it before. This comes as no surprise as wikipedia told me later on that the name is an artificial creation and work on the town only began in 2007. However there is a historical reason as the original Ebbsfleet (*Ypwines fleot*) in Kent is believed to be the landing place for the 'Europeans' Hengest and Horsa in 449 AD, so it seems appropriate to have an interlude here on our way from the UK to the continent. Sadly the interlude lasts longer than we would have liked as we are stuck admiring the Ebbsfleet International architecture for nearly an hour due to a shut-down of the Eurostar tunnel. Finally we are allowed to enter the tunnel. "Welcome on board the Eurostar going to Brussels via Lille. We apologise for the delay..." I struggle with the noise levels; there is something about train announcements, the mixture of ring tone, static signal noise and overly loud speech that makes my brain rattle like a plucked string. The pressure starts building up behind the skull and I feel like humming. And when I think it's over they start to announce it all again in French. And Flemish.

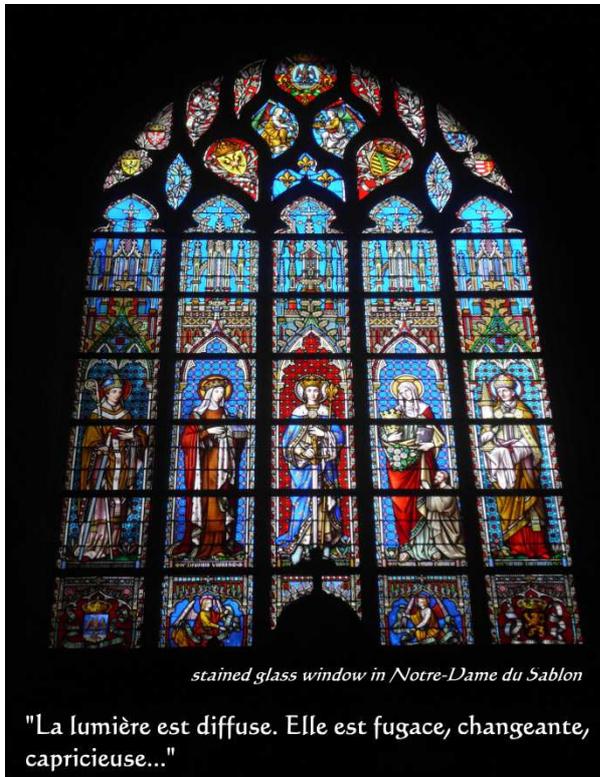
S. gets out the laptop so we can practice our talk for the meeting with the MEPs. And so we do, although it's still mostly reading from our little sheets of paper. This proves to be a good distracting and shortly thereafter we pull into the station and make our way to the hotel. We check in and ask for directions into the town centre and I manage to speak my first French of the day. Unfortunately the delay means that my original plan of going to a museum falls through, but we manage to explore in dusk before returning to the hotel to join S. and K. for the evening. I try to not let it bother me too much. There is always a trade-off between the sense of security I get from making plans and the subsequent meltdowns caused by unexpected changes. Need to reason my way through. Reason. Reason. I enter the late Gothic church of Notre Dame du Sablon. Churches always calm me down. Tranquility. The symmetry of the arcade and a sense of awe. The brightly coloured stained glass windows which make the light dance on the floor in a whirlwind of colours. I think of the -

appropriately - Belgian author and glass artist Bernard Tirtiaux and his book "Le passeur de lumiere" ("*La lumière est diffuse* ", dit Rosal de Sainte-Croix au jeune Nivard de Chassepierre. " Elle est fugace, changeante, capricieuse. Elle a toutes les ruses. Jamais tu ne seras satisfait de ton ouvrage, si beau soit-il. Jamais tu n'auras assez de couleurs dans tes casiers pour donner vie à un vitrail comme tu le souhaites, jamais tu n'auras la certitude de colorer juste comme on chante juste. Qu'importe! Tes pas partent du feu et tu dois atteindre le feu, devenir un maître en ton art."); "*The light is diffuse*", said Rosal of the Holy-Cross to the young Nivard de Chassepierre. "It is fugacious, ever-changing and capricious. It knows all the tricks. You will never be satisfied with your work, however beautiful it is. You will never have enough colours on your palette to give life to a stained glass window as you imagine it; you will never have the certainty of colouring it 'right' as one can sing 'right'. Who cares! You need to step away from the fire in order to recapture it and become a Master in your art.", my translation).



Notre-Dame du Sablon

I sometimes feel the same way about my efforts to overcome my disability. Autism is a multi-coloured condition and it affects so many facets of my being. My difficulties are often diffuse and elusive. They are often inconspicuous to others. One day I am doing fine in a Tesco superstore and



stained glass window in Notre-Dame du Sablon

"La lumière est diffuse. Elle est fugace, changeante, capricieuse..."

the next I cannot even handle the quiet hum of my computer laptop. Yesterday's successfully managed tasks can become insurmountable obstacles today. It's erratic to the point where I don't know how to explain it to others when even I can't see a pattern or tell in advance whether it is going to be a good day or a bad day. On other days I question whether my difficulties really merit a diagnosis or label at all. I am doing so well and surely being a bit quirky and socially withdrawn is nothing pathological. And then I am reminded once again why it isn't all as simple as that. I try my best to improve things, both for myself and others around me, but the ever-changing and yet so pervasive character of autism makes it difficult to master the art of doing things the 'right' way. Is there even a right way of dealing with it? Some would see my 'normality' as an achievement. Not looking and behaving autistic anymore is surely what you call

"optimal outcome", right? Not looking and behaving autistic is not the same thing as not being autistic though. It is not the same thing as not being disabled. It means that my disabilities are

invisible. And all too often this is far from optimal. An invisible disability means that you struggle to get the right support, you struggle to explain to others what your needs are, others struggle to accept your difference. And then there is the added stress of keeping up the façade of normality and associated anxiety. At the same time I am grateful for being able to “fit in” so well. I managed to finish school, go to university and I even have a part-time job. I do not need to introduce myself with “Hi, my name is and I have autism” and can avoid the pigeonholing and stigma associated with the diagnosis. On the one hand it gives me the freedom of doing things like everyone else and on the other hand takes away my freedom of just being myself.

No, I will never have the certainty of colouring it ‘right’. There is no right or wrong. You can only try to master your life and the balance between fitting in and being oneself as best you can in any given situation. If I had a child with autism myself I wouldn’t even know whether I would want them to receive some form of therapy. Maybe there’s something to be said for being a bit “off”, but happy? But how do you know what the future holds and whether being a bit different will later on cause considerable difficulties?

If only there was a guideline on how to improve things for yourself and others around you. My thoughts are spinning in my head, it is all such a mess...

Once I feel more relaxed I step out into the street again and pass the various museums on the ‘Mount of the Arts’ after which I get a first glance of the old centre of Brussels:



Modern architecture blends in with Flemish gabled roofs and Renaissance buildings. A busker playing the flute captures my attention as I walk past. It somehow is an excellent reflection of the serene and yet creative atmosphere, but unfortunately I don’t have any coins to give to him.

More people pass me with instrument cases and I later see on a map that the music conservatory is close-by. It is strange how even though I never take notice of individual people in the street (all I see is crowds), they become distinct entities as soon as they carry a musical instrument. As if some sort of “special interest radar” picks up an important signal. This also applies to animals. I will often take notice of a dog before I see its owner for example.



In the middle of a busy square is the Marie-Madeleine chapel, resonating calmness among the hustle-bustle of Brussel's first popular tourist destination. Inside a prayer meeting is under way and a man asks me in French whether I am also part of the pilgrimage group who came to see the head friar. It is strange to have such a secluded, almost monastic little chapel so close to the city centre, but I take in the special atmosphere.

I quickly cross the main shopping mile and the Groot Markt (I can see why it's a UNESCO World Heritage Site, but apparently so can 3000 other tourists...) and try to make my way to Manneken Pis in order to tick off all the major tourists attractions on the first afternoon.

Brussel's favourite landmark is surprisingly difficult to locate without a map. Just when I want to give up to walk back to the hotel, I stumble across a comic book shop in a little side alley. This is clearly a mistake. I spent

the next 2 hours perusing stacks of second-hand "bandes dessinées" from classics to novelty genres in search of a particular comic book I had previously spotted in Dunkerque half a year earlier. Sadly I can't find it and when I finally manage to ask the shop assistant in my best (and not very good French) whether he has it in stock, he says that he doesn't keep any records of the books he sells and therefore can't tell me if I might be able to find it among the thousands of copies. The clockhand ticks off seconds. Minutes. I get nervous – I now *really* want to find this comic book. I always buy a comic book when I am in a French-speaking country. It's tradition. I go back to the first stack, look



through it more carefully and feel like the shopkeeper is eyeing me more closely now. Not many customers look at bookshelves for 2 hours I figure. I am running out of time, so I take a BD with inspiring artwork. But it's not the one I was after and this preys on my mind as I run back to the hotel. Why do these trivialities bother me so much? Why can't I just switch off and focus on other things? Why can't I reason my way through these things like I normally do? Why is my distress so often out of proportion to the

actual situation when I **know** that nothing serious has happened?

When I get to the hotel I am a couple of minutes late – which I hate – but fortunately everybody is still getting ready as well.

A taxi drives us to a hotel near the European Parliament where we meet the other participants, country leaders and support staff for dinner. Soon after we get there, the Portuguese group joins us.

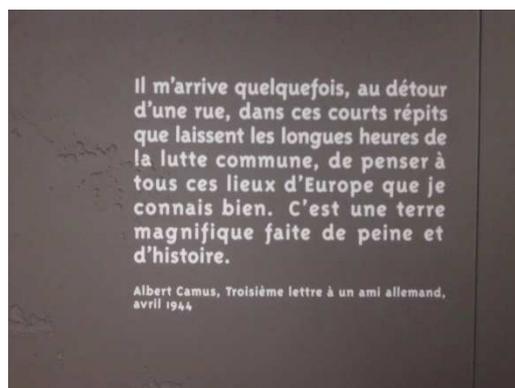
The two participants from Portugal are still in their teenage years and can't believe that I have already left school and am attending university. Despite the fact that I struggle to follow the conversation (I am terrible when it comes to contemporary music or movies!) and language as an additional barrier, we manage to communicate and I am touched by their positive outlook on life, their deep desire to make friends and connect with others. G. at some point takes my hand and declares that we are now 'best friends forever'. In some ways I see my earlier carefree self in them. There is something liberating about their light-heartedness and enthusiasm.

The loud conversations with several people at a time combined with the constant background chatter is starting to get to me after a while and I leave the room to get some fresh air and calm down. Unfortunately the street turns out to be equally noisy and instead of fresh air a cloud of cold smoke greets me when I step through the hotel doors. I go back inside in the hope that the lavatories are free, but the hotel decided to entertain their guests by playing the radio. I'm getting a bit worried. I don't want to slide into a complete sensory overload, but I also can't think straight enough anymore to come up with an alternative solution. Back at the table S. and K. look after me and shield me from conversations a bit which helps and luckily I am soon able to join in again. It is exciting and fascinating to talk to so many different people who are all in some way touched by autism. I am overwhelmed by the diversity of thoughts, expressions and attitudes. Back in my bed it takes me a long time to get to sleep.



The next morning starts with a meeting at the European Disability Forum (their wallpaper bears the motto of the Autistic Self Advocacy Network – “nothing about us without us” - a funny coincidence?) and the European Womens Lobby. Having never been much of a feminist I can only relate to few issues raised by the latter, but the meeting progresses very positively and I am touched by other people's concern over the current situation. Even though I know that it is unlikely that there will be a concrete outcome from this meeting it is good to know that things are moving forward.

We then walk over to the European Parliament where we have some time to explore its very own award-winning museum – the Parliamentarium. Aside from the fact that the museum was (unsurprisingly) populated by a number of (rather noisy) students trying to make the best out of a parliamentary buildings, it was quite enjoyable. My knowledge of politics in so most of the general is meagre enough, but the architecture and use of media was very inspiring. Quotes about Europe in its various historical stages



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invited the readers to think about Europe both as a political as well as cultural concept. And it refocused my thoughts on the purpose of our visit: To improve lives of women and girls with autism in every part of Europe. The issues raised during our workshops (naturally) centered around UK policies and problems as this is what we were familiar with. The difficulties with seeing a more global picture already emerged during our preparations of the presentation, but the exhibition makes me re-examine my thoughts and ideas about Europe as well as my own identity as a European and a “European” ambassador for disability rights.

I become so engrossed that I lose track of time and K. needs to come and find me to remind me about lunch.



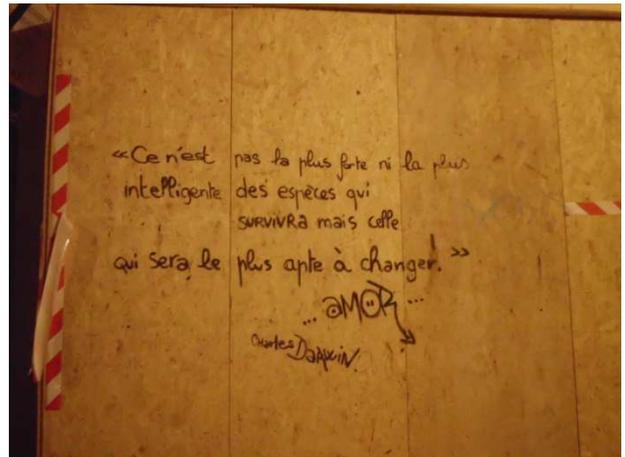
Then the time had finally come. The purpose of our trip. The meeting in the European Parliament. I rarely get nervous before talks and I didn't really have any stage fright, but I was certainly a bit edgy as I had no clear idea of the format of the talk. What would the room be like? How many people would be there? Would I have to stand or sit during the presentation? How would our talk slot in with the one by the Spanish and Portuguese women? To my relief everything went fine and since my bit of the presentation only comes 10 minutes into the

talk, I get a chance to observe the others and adjust to the room and the new people. Unfortunately only few of the registered MEPs actually show up to the meeting and most have to leave before the end of the presentation or come in half-way through. This is particularly distracting for the speakers and I get confused because I'm not sure whether I need to recap some of what has been said so far when a new MEP arrives. I decide not to “improvise” and only summarise things in one or two sentences so as not to lose the thread of my talk. Then again nobody had said that this would be an autism-friendly environment.

Towards the end of our discussion, one member expresses her disappointment over the poor attendance which prompts other members to comment on more personal issues and viewpoints. Emotions surface. I find this “unscripted” discussion extremely valuable and powerful and I wonder whether it might have an even bigger impact than our neat and tidy powerpoint presentation. It became clear that our meeting was more about raising awareness than about coming up with concrete solutions and strategies. Talking about personal perspectives and experiences certainly grabs people's attention and I am sure that most committee meetings in parliament do not end in tears as ours did. I would do anything to read the MEPs minds at this point. Some had prepared little speeches on inclusion, diversity, acceptance and tolerance that they read off pieces of paper. Is it just empty phrases or do they genuinely care? And what has our presentation changed in their opinion about autism and current gender issues?

A theme that resurfaces again and again is the issue of mis- and underdiagnosis of autism in women which none of the representatives seem to be aware of. If you live, breathe and work with autism on a day-to-day basis it is easy to take some obvious pieces of knowledge for granted without realising that the general public is unaware of so many things.

After the parliament people head off in different directions. There is no official goodbye which makes the whole situation a bit awkward. At the same time I can feel my thoughts evaporating and my body quiver. I need some time to process the experience and information and would therefore like to leave. Finally I do and head off in the direction of the city centre, but when I get to the music museum it is still closed. I look for quiet, empty sidestreets to avoid tourist crowds and come across many interesting bits of architecture and street art on the way. There is something special about exploring an unfamiliar city on your own. The experience of the newness of things, exploring new territory... making it familiar, making it "my own". The sense of freedom one gets from managing these things without any help; being independent.



My first destination is the comic book museum. I have loved comic books ever since I was little and I still maintain that it is an underrated genre of literature. The museum has everything – from Anglo-Saxon "picture stories" to classics such as Tintin and contemporary surrealist comics. And now that I am sensitive to it it's surprising how many comics use typically autistic traits for comic relief:





There is a special exhibition on a graphic novel by Baru ("Canicule") which is a study of human greed and cruelty. Given this rather philosophical bent of the current temporary exhibition I take my chances and look for "my" book in the museum shop. And I finally find it! An amazing illustration of Camus' "L'Etranger", the story of a man who is condemned for not conforming to society's expectations. The protagonist Meursault has been speculated to be a textbook example of Asperger's syndrome – here is

someone who has trouble expressing feelings, someone incapable of lying, someone who gets overwhelmed by sensory experiences. And although I disagree with the "autism analysis" of Meursault's character it nevertheless seems apt to buy this book I've been looking for during this trip.

As usual I feel refreshed and energetic after a trip to a museum and so I head back to the main square to take in a bit more of the scenery. After relaxing for a bit in a small Arabic coffee shop I decide to go to the cinema and watch a French movie. As it's already late I don't have much choice and so rush to the closest cinema complex to buy a ticket for the last film of the night. It turns out to be "*Les garçons et Guillaume, a table!*" a comical autobiography by Guillaume Gallienne which starts like a million other LGBT comedy films. Owing to the fact that the main



character (who not only played himself as a child and schoolboy, but also portrayed his own mother in drag) is an actor from the comedie francaise with very clear diction I actually understand every single word that is spoken and thus I am soon drawn into a hilarious story of an effeminate young boy who is categorised by his close family and friends as a homosexual (even though this word is never uttered in their social circles). However there is a twist: After years of trying to fit in, insecurity, therapy and unhappy relationships, Guillaume realises that the real problem is not his sexuality, but the way society defines and categorises you before you even get a



chance to discover things for yourself. This resonates with me. How do you maintain your sense of self if everyone has a strong opinion about how you should and shouldn't be? This is an issue every minority group faces. Growing up with autism can mean being constantly misunderstood and told off for not fitting in. It can also mean that people pigeonhole you at an early stage and never expect you to achieve anything that doesn't fit their stereotype. Both approaches are problematic in their own right.

Why can't we take the world and its people as it is. As something uncategorisable, new, enigmatic and surprising? I guess it is frightening at times to know so little and categories offer security and a sense of stability.

My short trip to the Magritte museum the next morning sums up my emotions nicely:

"Le surréalisme c'est la connaissance immédiate du réel."

"L'idée de progrès est liée à la croyance que nous nous rapprochons du bien absolu ce qui permet à beaucoup de mal actuel de se manifester."

Let's hope that we make progress.