

# Off road, 32 times a day

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This portrait of Leonieke was created by Leonieke, Delphine Callewaert and Delfien Versaevel, under the authority and guidance of SIHO.

## **A regular day in my life.**

6 A.M., my alarm. I roll over and with my eyes still closed I reach for the light switch. The light and I awake slowly. A glance at my phone let me realize that action should be taken. I grab my white box. Four strips. Stick to the recipe. I take one of each strip. In my mouth, large zip of water, swallow and we're ready to take off.

This is my daily ritual. I need it to start my day properly and that goes rather automatically.

Awake, fed and washed I continue my morning bright and early. I take my coat and bag and walk to the train station.

On my way I listen to music and I enjoy the little things in life:

I laugh about children who are getting their ass kicked by their parents because they need to hurry up on their way to school, an elderly person walking his dog, flowers growing or fresh snow.

In the train I listen, amused, to the people whom are discussing various topics. The discussions between friends, lovers, family members and colleagues are about politics, recipes, raising children, sex, love and what to wear tonight. I heard them all on my way to work.

It are those small things that can break or make my day, even though they may not make any sense to you.

When, after about 40 minutes, the train stops, it is time for me to hop off and take a last walk. A last walk through an awakening city, lovely... It is the last moment before my daily task starts.

My job is great and I have a lot of personal contact in my job. As a job coach I see a lot of different people, all with their own stories.

Most of the people that I see live in various and complicated situations. Sometimes they even lead me beyond the tasks of my job description and by this they give me the chance to cooperate with different parties from outside the company where I work.

Although I have a real paid job that takes a lot of my time - often more than it should - it sometimes seems that my day is only getting started when I hop off the train in Hasselt, where I live. This feeling grows when I open the door of my apartment and when I notice that there haven't been any visiting leprechauns to do the dishes, the laundry or to mop the floor. Also when I open the fridge it seems it is still as empty as when I left.

Since I don't have any partner or roommate I have to do all those chores by myself in the evenings or especially during the weekend. Why? I will explain!

Monday: debate on social security.

Tuesday: a master class about sustainable economy.

Wednesday: a local brainstorm session about the situation of cyclists.

Thursday: a debate called: 'School is looking for a future'. And

Friday? Yeah, Friday so far so good, nothing planned. Saturday:

something creative and mysterious I signed up for, called #YTLF<sup>1</sup>.

During the weekend I might have a monthly meeting for the young, social democrats.

I can hear you think: 'You probably don't have so many debates, master classes and brainstorm sessions every week'.

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<sup>1</sup> The # symbol, called a hashtag, is used to mark keyword or topic in a Tweet. ("About hashtags.org", n.d.)

That's true, but they will be replaced by meetings or working groups of the local youth council, or meetings about epilepsy...

As you can see it happens more and more that I don't have any evening left for myself during the week. And even when I'm at home, there are always letters of companies, who claim that you owe them money. Really stupid system, but it seemed that they are right, so I pay them.

In between all of that, I try having a social life.

When I manage to end my day around 10 pm I brush my teeth, grab my white box, take 3 pills, a great zip of water, crawl into my bed and start sleeping.

Although I'm always busy doing things and, I try to be cheerful and look quite normal - at least that's my impression, I can tell I'm a little different. Just a little.

Why?

Because I've got epilepsy.

Once again  
Just another  
Second  
Lost  
Once again  
It takes  
A few  
Before I find myself  
Knowing  
Where  
With who  
And even  
More important  
What about.

## Just a little absent

It was the summer of '96 when my mother and I were walking on a fair. At a certain moment she stopped at a stand of the Dutch Union of Epilepsy and read some of their brochures. Suddenly she said, pretty convinced - at least that's her story: 'my daughter has epilepsy'.

After reading the information and realizing that there was something wrong, the next step had to be taken. We made an appointment with our doctor who referred us to the neurologist of the hospital. The neurologist decided to do a standard Electroencephalogram (EEG). Before the investigation we were warned that in 60% of the cases nothing visible is shown on the EEG that lasted for about 20 minutes. After the investigation, the EEG-assistant came to my mother and asked her when we had to come back for our next appointment. My mother said that our next visit would be in about two weeks. The assistant answered that this could not wait that long. She said: 'your daughter has to start medication immediately'.

Why is my mom so present in my story? Is my mom bossy? Am I mentally ok? No and Yes! But at that moment I was only ten years old and I don't remember anything of that period. I also hardly remember things of the period before, the period without epilepsy.

People often ask me how it was to live without epilepsy. I can't answer that question, simply because I can't remember the difference between before and after I was diagnosed. Maybe it came up at that moment, maybe I had it long before.

Ten years... I was only ten years when a man in a white coat told me what I was allowed to do and what not. No bath, no swimming, only ride a bike when putting on a helmet.... Ten years, was I, when I heard for the first time that I would probably never get my driver's license and that I had to give up my dream job: joining the navy. And then it all started: the quest for the right medication. The moment when the first doses of toxics went into my body. The poison my body seemed to depend on. Even that's not a moment I can remember.

### **Just a pill or 2, 3 maybe even 4.**

We started on Depakine. Why 'we'? Searching for the right medication is not something that I did on my own. I gained a lot of weight when I took Depakine. Not just 1 or 5 kilo's but about 20 kg. And nobody seemed to care enough to ring the alarm. Only my mom and grandma showed their concern by telling me I shouldn't eat that much. But I couldn't help it... I was so hungry all the time. Really all the time!

It took years before somebody suggested my weight gain came as a side effect of the medication I was taking. Now, we are sixteen years and five different sorts of medication in different doses and mixes later. During those years I had to cope with the following side effects: gaining weight, nausea, losing hair, pain in my limbs, being sleepy, memory problems, mood swings, being agitated... I had all of them and without any doubt a lot more because the problem with side effects is that you don't always recognize them as side effects.

Now, after years of searching and trying different things, it seems we found the right cocktail and the best moment for taking the

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medication. Because - it might sound simple - taking daily medication is more than just opening and shutting your mouth. It's a mental process, and a struggle sometimes. It's realizing that you're taking drugs, toxicating your body to feel better. Realising that actually the pills don't make you feel better, that they don't do the stuff you want and do things you don't want them to do. Some idiot decided to call these last things side effects. In my opinion we should call those just the effects. I rebelled sometimes according to using my medication. I accidentally - on purpose? - forgot my meds too often. But hey! Nobody can convince me that a person that has to take daily medication never had the desire to flush the meds in the toilet or throw them in the bin.

It's keeping me busy and alert to look and search for the perfect cocktail. It's about finding a balance between little side effects and less pills on one hand and having as much result as possible on the other. Together with my parents, family and friends I spent years of searching and like I said, it seems that since 2009 I found quite a suitable mix. Result: a severe reduction of my tonic-clonic seizures. Since the summer of 2009 I can count them on two hands and even the absences seem to be less severe.

## **Let's start living**

Let me be clear: I've never been the type of person who stays inside just because life has some risks. I never took or take more safety measures than the girl next door would take.

Was my life still the same after I realized I had epilepsy? Of course not. I started to tell people about my condition. Telling them what to do in case of... But it's more than that. You have to find a new way of living, a way of living up to your boundaries.

For example you want to know what kind of things trigger your seizures. It's not like I only have one trigger but I seem to be very sensitive to emotional stress.

You look for your best biorhythm.

But I also asked questions like: What about alcohol, sex and drugs?

When I was about 16 years old I asked my neurologist: 'Doctor do you think it's safe to smoke pot?' The doctor said: 'you should just try it, otherwise you will never know'. But he added: 'When you are going to try it, do it in the company of someone whom you really trust and who knows what to do in case of a seizure. Also use the good stuff...'

I will always remember this consult as a special moment because in this moment there were two important things to remember: No two sorts of epilepsy are the same and no two persons with epilepsy have the same triggers or boundaries. Therefore a doctor can never tell me how to live. I just have to find out myself. I think that's one of the reasons it took me about 7 years to get my bachelor degree.

## **College tour**

Seven years for a degree that normally takes 3?

Yeah.

How come?

Well I'll tell you.

In Rotterdam I started a bachelor in occupational therapy and during the first year I thought all went nice and well. I liked the aspect of working with people, but we also had a lot of Latin. I really hated that. So I decided to drop out at the end of the first

year and start up another bachelor. One which was closer to following my dream. Bachelor in Applied Psychology it was.

Why didn't I do that before?

Because before I didn't know that there was a professional bachelor in psychology. I was always assuming you could only study psychology at university. Something I would not be able to do because of my epilepsy. Too many absences a day. Too many reboots a day.

But like I said, when I heard that there was a professional bachelor of Applied Psychology in Antwerp I decided to restart my dream. I packed my stuff and moved to Belgium. A big step.

I didn't know a single person in the city, I didn't know any other student in Belgium and I didn't know the system. I had a really hard time getting used to that system as well. Not only the educational system, but also things like the government, law, understanding social security... I tried to find a way of living as an illegal immigrant because the city of Antwerp didn't think it was necessary to make me a citizen of Belgium.

Besides all the practical stuff I also had a lot of difficulties getting used to the Belgian mentality. I didn't expect it but the Flemish are so different from the Dutch people where I grew up. Especially people in Antwerp. They are colder, more distant, live more in their own world and it's harder to get to know them. I spent a lot of nights crying in my room but I never thought of moving back home because I wanted this and I was about to show everybody I could do this. But I couldn't.

School was though: a lot of theory, a lot of books, a lot of emotional confrontation, which accumulated to a lot of stress.

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Certainly in combination with all the not-school-related problems I have already described above. All this resulted in a lot of seizures. Really a lot! So after two years of fighting the seizures and doing everything I could to make my dream come true, I gave up. I was tired of trying and failing. So I studied 4 years and I achieved, hum, what can I say, oh yeah... nothing.

It was the end of summer when I decided to quit. The following year of my study was about to start and the only thing I knew for sure was that I didn't want to continue. But what did I want to do?

All kinds of studies passed my laptop screen: teaching, social work,... I also considered following alternative ways of education. Suddenly one morning I woke up and all seemed clear: I had to study social work. I didn't know why and frankly now that I am graduated I still don't know, but in some way I had to. Probably it was some inner voice telling me to do this.

I checked out the different schools, in Antwerp, where the courses of Social Work could be taken. Even though I didn't really like Antwerp I didn't want to move back to the Netherlands and start all over. Besides, the academic year already started there.

In a short period of time I picked out my school because of two reasons. The first one was the presence of a quite unique specialization 'art- and culture mediation' and the second was the possibility to do a study trip to Denmark in the last year. As it happened, I registered at the school website and after taking a few detours I was in. I was one of the hundreds students studying Social Work at the 'Karel de Grote College'. And everything went well. My first two years were quite easy going. When I started, I still had seizures but they reduced seriously. Probably because I felt better. The way of educating was totally different than before, more

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Dutch, and I finally felt better emotionally. I started to feel more at home in Antwerp.

Besides a temporary trigger during my first year of Social Work, my brain couldn't handle the colour red in PowerPoint® - everything seemed to work out fine. I made an agreement with the social service that said that, when needed, I could spread my exams to reduce the stress. I also had a 'special' place in the room during the exams in case of a seizure during an exam. Like this I wouldn't bother the others as much if I would have a seizure. Also, all the teachers were informed about what to do in case I had a seizure.

To my classmates, I only told the ones I saw very often. The ones with whom I spent most of my time with and had specialized classes with.

During my second year everything stabilized, except during the period of my internship. Those 9 weeks and a half were like hell. Again: lots of seizures. Probably because of the new rhythm. I wasn't used to work from 9 to 5 and to do all my other stuff after that like shopping and so on.

My last year was coming, I was on my way to become a bachelor in Social Work with a specialization in Social Cultural Work - not the mediation I was aiming for at first. When I heard that the study trip to Denmark was cancelled and changed by a two day exchange to Utrecht, I was very disappointed. How lame is that? The Netherlands were not a foreign country to me.

Luckily, a solution was right around the corner: Erasmus. I wanted a five month experience in Copenhagen, the capital of Denmark.

## **København, her kommer jeg!**

29<sup>th</sup> of August 2009, it was finally happening. After already studying abroad for 4 years, as a Dutchie in Belgium, I could finally spread my wings. I packed my suitcase, unpacked it again 'cause it was way too heavy, and left everything for 5 months.

Was I scared?

No!

Excited?

Of course.

Sure I was wondering how I would cope, again, with all the changes. The language, the social life, the school, the surroundings... and how my epilepsy would interact with all of that. But everything went great! It was the start of a long period without seizures. Probably, because somehow I found out how to cope with some heavy and difficult stuff.

During my Erasmus experience I lost my granddad to cancer on the same evening I broke up with my boyfriend. Because of the fact that my granddad's death and my break-up happened on the same evening, looking for a new place to live in Belgium wasn't my number one priority. Therefore I only started looking for a new place to live, one month before flying back to Belgium. And there it was: the problem a lot of students have when trying to find a room in January that is safe and has an acceptable rent. That's like: impossible. Because of that a very good friend of mine at that time, suggested to have a look in Hasselt. A student city, which is not recognised as one yet.

And there it was: my new home. I had lived in Antwerp for several years and I never had the feeling of being home. Antwerp doesn't have anything cosy to me. It's too big, too anonymous and all. I still remember calling my mom when I was only in Denmark for two weeks or so and telling her that Copenhagen already felt more like home than Antwerp ever did. So at the end of January I left Copenhagen, the city which has been my home for 5 months, to start a new life, to build my own home and my own habits.

## **#Worlddomination<sup>2</sup>**

People often ask me if it was a big step for me to go on Erasmus because of my epilepsy. I don't think so, because I had already lived abroad on my own for some years. I kind of knew what to expect.

However Denmark was really another country, another language, another system and somehow the country I'm in love with since I went there on an International Youth Camp in 2007. I think I had to go on Erasmus, just to prove I could.

Living in Belgium was quite close to home. My second year of college was a very busy one. I had a total of 63 ECTS, I was quite active in the student participation and besides that I was active as a volunteer in a working group for the North-South problems at my department. There were weeks that I wasn't home for one evening. This was something my boyfriend didn't really like, although we weren't living together. Or maybe just because we weren't living together. Anyhow, even despite it was a busy and tough year, my

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<sup>2</sup>The hashtag World domination is used to send out new and inspiring messages or ideas to the world.

brains were nice to me – I didn't have seizures - and it gave me confidence.

I started to have the feeling that I could do anything I wanted as long as I was motivated. And I think going to Denmark was the icing on the cake. The idea of: If I do this and everything works out great, I can do everything! And I did, I had a really great time, made some really great friends and experienced new stuff. I also started going out for the first time. Carefully and not for too long but I did. I started exploring my boundaries and for the first time I can remember I went abroad without my parents and without ending up in the hospital. That also happened before but then I took better care of myself, for example by getting more sleep.

## **Graduation**

After returning to Belgium I settled in Hasselt. After a while I started my internship and a new relationship. I was really convinced about graduating after seven years of studying. But then I fell on my back because of an icy road and I got a whiplash. Result: I had to stop my internship and start over in September. That sucked, really bad. Mostly because, since I started Social Work, I always said there was just one reason that could stop me from graduating in the scheduled time: my epilepsy. And since that was going so great I didn't expect to graduate with six months of delay. But hey, that's how it happened. And like my grandfather used to say: 'there is a reason for everything'. And I agree. Because I fell on my back I needed to search another internship place to start over in September. Afterwards, I realised that I learned a lot more than I would have had in the previous company, not only about work, but also about myself.

What about my epilepsy at that time? During the spring, before I had to start my internship, I had a seizure without any reason. I still don't have a clue. It felt like somebody stabbed me in the back. I didn't have a seizure for over a year, I was thinking about getting my driver license and then it happens again... It keeps you realistic and made me a little shaky about myself. Cause although I was pretty sure about my capability, apparently I still had a body I couldn't rely on. And actually I shouldn't talk in the past, because to be frank it's still the same. I didn't have a tonic-clonic seizure for over a year now, again. And it makes me feel good. Like I rule epilepsy, instead of the other way around. But at the same time I know it can change in a flash.

## **Happily ever after**

February 2011. I presented my bachelor paper with success and I was ready to make the job market unsafe. At least I thought I was. I started to look for vacancies, started to apply, but I ran into some barriers. Nobody could have predicted the problems I ran into.

Since I lived in Hasselt I had to widen the area where I was searching because there isn't a lot of work for social workers in Hasselt. A problem which appeared was my driver's license or actually not having one. A lot of the vacancies I spotted were not realistic for me just because a driver's license was required. Another barrier which often kept me from applying were a lot of evening- and/or weekend hours. It's not because I like to go out till 5 in the morning that I can work the evening hours. It's a big difference. First of all working and having fun are two totally different things. For the second one you don't need so much focus. And if you do something you choose for yourself you can easily change your mind and just skip it. But you can't skip a meeting 5

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minutes before just because 'you're too tired and you need to rest because otherwise your brain is going to crash'. Somehow people don't really accept and understand that. After 9 months of searching I found a job as job coach where I help other people improving their skills. Right now it's just part time but I really would like to do a full time job, so I'm still looking.