
NAKED IN FRONT OF THE EYEDOCTOR: LIFE THROUGH THE EYES OF A GLAUCOMA PATIENT

"You have no idea how it feels to be there, totally naked surrounded by doctors and nurses." That is what my friend A., said a while ago when she confided in me about the fertility treatment that she needed to undergo. Indeed, apart from my annual visit to a gynaecologist, I have no clues to what undergoing such a treatment might be like. What I do know very well is how it feels to have to reveal one's most intimate parts for medical examination.

For me, these parts are my eyes as they have caused me feelings of anger, sadness, distress, and shame for years because I (and they) suffer from congenital glaucoma. These feelings tend to well up to the surface whenever my eyes are under medical examination. Luckily, I now only have to see my eye specialist every three to four months and, more importantly, whenever I have a (medical) question or concern, and on these occasions she takes the time to listen and respond. So it is certainly not on her account that I agreed to "reveal" my intimate parts here, by writing about my life and experiences as a glaucoma patient. Nor do I do this because of a sudden need for exhibitionism. (1) My motive is more humble: I experience quite frequently that people have no idea what it actually means to have impaired eyesight due to glaucoma, and I simply want to make this more clear to them. By people, I do not mean only the man or woman that I cross in the street but also doctors, nurses and other health care professionals, even those dealing with glaucoma and other eye diseases. Let me give you some examples to illustrate this to you.

I was diagnosed with glaucoma when I was almost four years old. In fact, that was already years too late because I was born with it. Shortly after my birth, my parents saw that there was something wrong with my eyes. At certain moments, my pupils would start to dilate and became very large. My parents mentioned this to my paediatrician but he did not pay much at-

tention to it. According to my mother, he just said, "don't worry about this, some kids have big ears, others have a big nose and your daughter tends to get big pupils once in a while. Nothing to worry about". But my parents kept on worrying and also took me to their house doctor and even to several eye doctors at the regional hospital. None of these doctors recognized the symptoms of glaucoma, so it took years before the right diagnosis was finally made. These years could have been spent treating glaucoma so that its impact on my eyesight today would not be have so serious

Maybe you think now, "sorry to hear this but all this happened when you were little many years ago and now this would not happen anymore because glaucoma is well-known amongst health care providers". If you think that, think again because in my experience, a lot of primary care providers have no idea what glaucoma is about. Let me give you two examples. Once in a while, I get a migraine attack. Because my head - eyes included - then get under huge pressure, it is urgent for it to stop as soon as possible. The last time this happened, I phoned my house doctor to come around but he was on leave and since he works in a group practice, a colleague of his agreed to come. When he arrived, it became clear very quickly that he did not know much about glaucoma, so I had to explain to him twice that I was in my thirties but suffered from glaucoma, so that he could take that into account when prescribing (me) medicines. At least that doctor was honest enough to tell me that he had never heard about glaucoma amongst young people and he defined a young person as someone younger than 60 or 70. So yes, probably no harm was done because he took my eye illness into account when prescribing my medicine. But I have to say that I was amazed that he, being a middle-aged doctor with a fairly good reputation, did not know more about glaucoma. A similar story occurred when I went to

the pharmacy nearest to my home to get the medicine I need. At first, the pharmacist did not understand that I had come to get glaucoma drops for myself and not for some older relative or neighbour. I made it clear to him that I was a glaucoma patient and the next time I went there, he started to act strangely, at least in my opinion, because as soon as he saw me coming into his pharmacy, he took me by the arm to lead me to the counter, read out my prescription as if I had no idea what I had come to do and, asked me whether I could still get by, etc. All this started to annoy me after a few visits, until I realised that he probably did not understand what glaucoma is about. He probably thought that I was gradually losing my eyesight and that every time he saw me my eyesight was worse than the time before, although I understand and know by experience that the impact of glaucoma on your eyesight can be controlled, once you get the right treatment.

So, if you ask me, a lot of people in the health care sector have no idea what glaucoma is. For me, personally, this is not a disaster anymore. I have been diagnosed with glaucoma and I will point it out to everyone who needs to know it. But this lack of knowledge might turn into a disaster for someone who has not yet been diagnosed with glaucoma. This is because house-doctors and pharmacists are often the first ones to whom people - and especially older people amongst whom glaucoma is most widespread - address themselves whenever they experience a loss of eyesight. If these primary care providers then do not pick up on the symptoms in time, a lot of valuable time might be wasted.

It is not only primary health care providers who often seem to be ignorant about glaucoma, the same applies to specialists (trained experts). My best example so far - and I say this with a dose of irony - has to do with my annual visit to the gynaecologist. I tend to go to the university hospital for my annual check-up. Last time, I got a young gynaecologist (in front of me) who started the consultation by asking me various questions such as what I was doing for a living. I told him that I am an assistant-professor at the university college nearby and he said, "well then, in fact we are colleagues because our institutions are linked". I replied, "yes, in a

way we are but of course, I am not specialized as a doctor". Why did I say this? Well, when the consultation went on, I had some questions for him. But he almost immediately made clear to me that he could not answer them because he had no knowledge of glaucoma. But there was a simple solution, he said, because, after all, I have access to all the university databases so I could look up all the information I needed myself. Of course, I have looked up information before on the basis of which questions are in my mind and then I turn to the expert, as s/he is trained to explain and interpret findings on my behalf as a patient. At least, that is my opinion. That young gynaecologist clearly had another opinion... So, if you ask me, glaucoma is not known well enough amongst health care professionals. No surprise then that I will continue by saying that glaucoma is also not known enough amongst people outside the healthcare sector. People talk about HIV, they talk about cancer - with my friends I talk about breast cancer and the way to do breast cancer-screening. But talking about glaucoma? I have never ended up in a conversation about glaucoma, unless I have started it myself. I also have to admit that I rarely bring up the subject myself, just because, nine times out of ten, people have no idea what glaucoma is and I do not feel I need to put my whole medical history on the table. When I meet new people, I do try to let them know about my impaired eyesight - which is a result of my glaucoma - and that is already so difficult to do. Let me try to make this clearer for you.

As mentioned before, I work as an assistant-professor in a university college. A nice job, which I enjoy doing very much. A couple of years ago, I changed the academic institution I was working at, like so many people in academia tend to do. Shortly after arriving at my new place, I was introduced to a colleague with whom I was going to collaborate closely in teaching a specific course and I told him that I have limited eyesight. His first reaction was, "What are you doing here then? Why are you taking a job that requires you to teach and to use your eyes?" "Why not?" I answered. I will find ways around difficulties that arise, together with the students, and that is exactly what I try to do.

So, whenever a new semester starts, I inform my students about my impaired eyesight. I tell them that I might not always realize when they raise their hand and I suggest they help me by making an acoustic signal before asking a question. I also warn them that they might sometimes get confused by my eyes, especially when I am tired. My eyes might not appear to be looking straight ahead anymore and when I then look at somebody, the person next to him/her might think I am interacting with him/her. That is annoying for both me and the people with whom I interact. I therefore inform my students in advance about this and whenever it actually happens and they get confused, I explain it to them again and say that they have to focus upon my left eye. So far, students have responded well to this and they do help me out whenever there is a need to. But for me, it still is a bit of a barrier to overcome, each time I have to inform people about my impaired eyesight. It is particularly hard when I notice that people show little or no understanding or even start to accuse me of exploiting my situation. Let me give you an example that I found pretty hard to "swallow" at the time.

Recently, at work, I had to move office and was given a big modern desk in a new building. This desk was placed near the window (to one side of the room). This is a problem for me because as a result of the surgery that I have had, my eyes cannot bear too much light (I have become very sensitive to light). I therefore went to my departmental head, whom I had told on day one that I have impaired eyesight, and asked him if I could get a smaller desk that I could place in a darker corner of the room, as well as a desk lamp that I could direct myself. He said that this would not be possible because everybody was appointed the same furniture. I then proposed to him that I buy the office furniture myself. He again refused because no exceptions were allowed and "everyone would, and should be treated equally in his department". I tried to counter-argue his argument of equal treatment by saying that I am not entirely equal to other people due to my visual impairment. In his opinion, I was exaggerating and just trying to get myself nicer furniture than the standard equipment and so on. I ended the conversation angrily, walked away and started to find

out what I could do in order to have a workplace that is adapted to my needs. In the meantime, I have seen our occupational doctor who immediately decided - on the basis of information provided by my eye specialist - that my workplace should be adapted to my needs. So she did what she is legally entitled to do on my behalf and advised my departmental head to approve the necessary adaptations, leaving it again in his hands to decide. For a moment, I thought, "well, this is it now. I will have to get by with my workplace as it is." But last week, I was surprised by the news that all the adaptations needed had been approved by my departmental head. Amazing, don't you think? Especially if you also knew that he is currently extremely busy as he is running to get re-elected for another four year-term to head our department next June.

Anyway, that whole situation at work caused me quite a lot of stress at the time. Stress is something I tend to suffer from regularly and I cannot separate it entirely from the situation with my eyes. Because if you suffer from impaired eyesight, you have to and want to prepare yourself more than others whenever you are going out into the world. That so-called "going out into the world" can be going to a conference or a study day - things that I do on a regular basis. I do enjoy this, although it can be stressful for me to get somewhere on public transport as I cannot always read timetables clearly, spot conference indicators or read people's nameplates. When presentations are projected or panel conversations take place, it is often not easy for me to read everything. But going out into the world can also be for something as simple as buying a newspaper or a piece of bread. Soon after we met, my partner made the joke that he finally understood why women need big handbags. "After all, you all tend to fill your wallet full of coins!" I then explained to him that the mass of coins in my wallet was no female fancy in my case because I tend to pay with notes in a shop and then get a lot of coins back in return. I do this (paying with notes) because it takes me more time than others to find the exact amount of money to pay in coins and I have noticed that people behind me or even people behind the counter get annoyed by that. For a while, I have even tried to

ask the people behind the counter to take the coins they need out of my wallet. But I often got negative reactions - people probably saw me as some kind of arrogant customer who wanted to preferential treatment. So I stopped doing this and now tend to pay with notes.

Maybe, this was a bit of a silly example but it clearly illustrates what life with limited eyesight is all about. Because it is stressful, I have always felt the need to search for ways to relax. But even this has not been easy. For example, it has taken me quite a lot of time and effort to find a type of sport I can enjoy doing in a group. It will not come to you as a surprise to read that I consider myself not really suited to ball sports. Going to a gym is no fun either if you want to have some social contact whilst doing sport. Anyway, I am now member of a jogging club and enjoy doing 'my miles' together with a small group of people. But even then, my eye problem is never really absent because sometimes, when roads are not lit very well, running is difficult for me. I then have to run behind somebody and have to trust him/her not to fall because otherwise I will probably fall as well. But, well, maybe that is what a good team is all about!

No, seriously, my eye problem creates barriers and overcoming those barriers sometimes starts to weigh down on me, at certain times more than others. I remember for a period as a student things becoming too hard for me. I started to feel down, I thought I was stupid be-

cause I was always the last one to notice things, the one who could not totally follow things. I felt ugly, isolated, and lonely. Luckily, an alarm then went off in my head that I could not leave things that way, I had to find help. So after a while, I was lucky to find myself a therapist with whom I could really address my eye problem. And I am still seeing the therapist, in some periods more than in others. We then discuss what situations have come up for me that are difficult to handle and how I can handle similar situations better in the future. Having that sort of help is very important to me even though I have a very understanding partner and family. Sometimes, they get too involved and suffer too much when they see me struggling. I am therefore better off with somebody more neutral who is not afraid of pointing out to me that sometimes I might be hiding behind my visual impairment or even running away from it.

So far, this is a short insight into my life as a glaucoma patient. I hope that this has opened your eyes further to what it means to live with impaired eyesight. Hopefully, next time, a patient is naked in front of you as the eye doctor, you can understand and help him/her even better.

NOTE

- (1) For this reason, the author prefers to remain anonymous as well as to be able to write openly about her daily experiences as a glaucoma patient.