

Social challenges surrounding prosopagnosia

Face blind and socially deprived

Face blindness or prosopagnosia is a neurological disorder that disrupts the processing and recognition of faces. For those who struggle with it, it mainly means a challenge in the social field. As far as I know I have always been face blind, but my social problems only started after I became aware of it.

Face blindness has nothing to do with your eyes, your mental faculties or your memory in general. Those who are face blind have difficulty processing and registering people's faces. To remember and recognize faces. This can be mild or very extreme.

Face blindness is not a rare condition. It has long been assumed that about 1 in 50 people (2 percent) has some degree of face blindness. Yet there is a lot of misunderstanding about it. Often, if you don't have prosopagnosia, you don't know about it. It often appears to people that they are being deliberately ignored by someone who is face blind. As a result, that face blind person can be found to be conceited, or stubborn when they do not recognize other people.

It is not incomprehensible that people misunderstand face blindness. I would probably be that way myself, if I wasn't familiar with it. But when you are completely left out socially, in the street or neighborhood where you live, or in your work environment, it can be very tough. Especially in a tight built-up working-class neighborhood or in the 'office garden' at work. (office garden meaning; one large space with work places - no rooms or walls) I can't think of any good reason for deliberately ignoring acquaintances or other people in general. The consequences are familiar to everyone who struggles with the challenges of face blindness. People are surprised, angry, or offended. In fact, no one ever says anything directly to you about it. Much more often a change is noticeable in the approach towards you. People react surly next time, or they stop responding themselves when they meet you. And those are the nicer responses; things can get a lot less nice also.

Barbecue

For example, it can happen that the entire (working-class) neighborhood is barbecuing right in front of your house, from early in the evening until after midnight - and you were not invited. Or that boy next door from a few houses down yet another street. With a colleague of his - he worked for a sewage unblocking company - I talked about the collection day for the garbage. "Then they can come and pick you up right away", said the boy from next door. Apparently I had missed him once or more. I thought it was a very insulting comment that went way too far and decided to ignore him in the future, even if I did recognize him. Which did not improve relations.

Then the neighbor with the pit bull like dog that I noticed too late at the gas station. I only slowly realized it was my neighbour when I saw the dog. After that my living comfort was apparently no longer of value to her and her boyfriend. The dog was indifferent about it, I expect. Nevertheless, at frequent parties, the music went on all night long, as did the endlessly repetitive and incomprehensibly loud 'ping' of the (then) MSN chat program. The bedroom wall shook at every PINGGGGG!!!! A few weeks later, in my absence, the separating hedge between our backyards had been trimmed down to knee height.

In some neighborhoods, your rights are worth as much as your popularity. I have since avoided living in crowded, small or narrow streets. There are too many people to recognize there and the social consequences are much greater there, when people think you are deliberately ignoring them. When purchasing our first home - I was already almost 50 - I paid particular attention to the space in the street and the free access to the front door. The above are just a few examples of experiences gained over several decades. Much more often, subtly or less subtly, I was made fun of, or insulted, because of my face blindness.

Understanding

So why would anyone consciously choose to ignore others? In that sense, the fact that 2 percent of people suffer from some form of face blindness is very surprising. Why, then, does a face blind person encounter so little understanding? It is also surprising that there are so few experience stories or tips to be found. About a multitude of brain abnormalities or -disorders you can find the world of forums, associations, trainings and researches; not about prosopagnosia. At least, nothing that transcends the general. Nothing that really helps. The translated article about face blindness on the website of the Netherlands Institute for Neuroscience refers for more information to a 2011 English article in the New York Times (which you have to pay for to read) and a 2006 English story from Time Magazine. On the website of the 'Hersenstichting' in The Hague, face blindness or prosopagnosia does not appear at all in the endless alphabetical list of brain disorders.

Hereditary or brain damage

According to science, prosopagnosia can be hereditary, but it can also develop later in life after brain damage. If you can sustain this kind of specific brain damage from a slap in the face, falling from your bike, a fight in the street or (youthful) excessive alcohol consumption then there are many options for me. I myself have not noticed any major changes after these types of incidents.

Hereditary perhaps? I once asked my mother, but she said she was not aware of the problem. So it could have been with father. Hopefully my kids don't have this problem.

By the way, many more reasons are mentioned that could cause face blindness. It almost looks like guesswork by the scientists, because in-depth studies into it are untraceable.

Neighbors

When I think about it, my face blindness problem definitely goes back to my younger years. In elementary school I already had trouble recognizing parents I met in places other than my friends' homes. Or a neighbor with a face or appearance that was too general for me. I never thought about it at the time; as a child, the need to behave socially towards everyone is not yet as great as later in life.

It is said that prosopagnosia can become problematic with major life changes; incidentally, this is also said in the case of autism. Think of the transition from primary to secondary education, the step from education to internship or work, or when people start living on their own.

That is recognizable to me. I lived alone for the first time when I left home at the age of 25. After that, the facial recognition problems definitely increased. If I didn't recognize neighbors in the store, for example. Or teachers from the university of applied sciences I met outside of school. At first I didn't think about it; I thought I just 'hadn't seen it at that moment', or that I was busy with my thoughts or distracted another way.

Also, I have bad eyes. Despite maximally improving spectacle lenses, I see poorly in the distance. Perhaps part of the problem with recognizing others lies in this. I can only judge who is coming when he or she is a little closer. And so I have no way to save people I see from a distance in my memory anyway. When I see someone in my street at a house, I sometimes just assume that person is a neighbor and say hello. Sometimes without actually knowing who it is.

Between the ages of 30 and 35, I had a lot of social difficulties because of the problems recognizing people, especially when I lived alone for several years. At that time I worked hard and long days to make ends meet as a starting, independent entrepreneur (editor/journalist) and to build up a business. It was also the time I developed RSI and my chronic sinusitis started; another 'invisible' condition. I really struggled with the sinusitis for 15 years; I still have to take into account the RSI. Neither did contribute to the social resilience I so needed as a 'face-blind' person.

Moviestar

Brad Pitt has prosopagnosia. In an interview he indicated that he has difficulty remembering and recognizing people's faces. He feared that this would make people think he was distant, inaccessible and self-centered. "But no one believes me," he said.

That is also recognizable. People don't understand that you don't (always) recognize others. Because everyone can do that, right? Pitt said he preferred to stay at home instead of going out: "You meet so many people. And then you meet them again. ... So many people hate me, because they think i'm disrespecting them."

For Brad Pitt, who meets a lot of people, prosopagnosia must be extra hard to deal with. But then again he is a movie star. And he probably doesn't live in a cramped working-class neighborhood. The main conclusion here is of course that I resemble Brad Pitt. Well, at least as far as prosopagnosia is concerned.

Handhold

Face blindness comes in shapes and sizes. If you have it a little bit, it might just be 'a bit of a problem'. If you have extreme difficulty recognizing faces and people, the problem is obvious. In between, however, are many degrees of people looking for what's wrong with them, or practicing tricks to do better; which most likely will not work.

I often don't recognize people myself. Very regularly that happens in the fleeting passing, when I don't expect to meet someone. On the street, for example, but also in line at a shop, or on a busy terrace in the city. Often I don't recognize people at all. I also often recognize them too late and the realization dawns too slowly. Sometimes the other person's reaction when I don't say anything is a clue. Sometimes three seconds later I think, 'hey, maybe that was...' Usually then I don't find out at all whether or not it was that person.

Of course, people with prosopagnosia try to find something unique in a face, but even if someone has a pronounced nose, a special hairstyle, or a birthmark on the face, it is not unique and cannot be seen (very well) in passing. Other references are, for example, someone's height, a way of walking/acting, clothing, a car/bicycle or a dog. But with that you also easily go wrong with face blindness. What if someone has a different car, left the dog at home, has a new coat, or a different haircut?

All blonde teenage and twenties girls with long hair look very similar to me. In fact, this also applies to boys. However, girls change their appearance faster, with a new hairstyle, different

clothes or make-up every day. Then it really becomes an impossibility. All the older men with gray beards are like clones to me too. I can't find anything to hold on to, and it gets even more difficult if the beard has recently been cut or groomed. And so there are many, especially difficult groups and aspects.

Winters are challenging because of scarves and hats and summers because of caps and sunglasses. If you don't recognize uncovered faces, you really don't stand a chance then. Not to mention the face masks during the Corona period.

Greeting everyone

Whatever you want to try; greeting everyone does not work; it is also physically impossible if there are more than just a few people. Looking at everyone until they're reasonably close isn't a solution either. Even then I often just don't see it, or on the other side someone else passes by whom I do know. Or people get annoyed that you 'stare' at them. 'What are you looking at', will not come as a grumpy response the first time.

Telling (certain) people in advance that you are face blind is a tactic that you can use with prosopagnosia. If you want to do that, do it on time. Otherwise - when you have already missed someone several times - you have less chance for understanding. And even after that, there is no guarantee of lasting success. People still find it difficult to understand that you do not see them when you pass them at a distance of 1 meter, or are standing behind them in the queue for a cash register.

When someone is aware of your face blindness, things can certainly become easier. Sometimes also uncomfortable, when out of nowhere someone jumps right in front of you to say 'Hello'. Even then it is still switching gears for me, a few seconds. As a result, I already lost the first words of a possible conversation. But we don't have to strive for perfection. And understanding is fantastic.

Application

My life might have been completely different if I was better at recognizing people. For example, I could have had another job. When I was about 35 years old, I had a conversation with one of the two owners of a communications agency. At the time I was working for myself as a copywriter/journalist and could use some 'stability' for a few days. The co-owner of the agency was impressed with my experience and invited me to his office for an interview a week later. I rang the doorbell and a man who I thought was him answered the door. I kindly said hello and walked in. Slowly the thought came over me - also because of the bewildered reaction of the person who opened the door - that this could be the other partner. The three of us started talking, and I looked closely from one to the other owner and really couldn't determine who I had spoken to the first time. Except from the reaction and attitude of the partner who opened the door and who clearly showed what the outcome of this application would be.

Should I have said something about it? I was hesitant, especially since the situation was so awkward. But also because I wasn't even sure myself. The situation also happened to me unexpectedly, as always with prosopagnosia. I'd had problems recognizing faces before, but not like this. Later I thought; the partner could also have introduced himself to me, or could have said something himself. But all these years later it is 'water under the bridge', I have also found my way without that job.

Neurodiversity

Everyone is (even) different, also in the brain. The standard brain does not exist. This fact is encompassed by the concept of neurodiversity. The concept was introduced in the 1990s by sociologist Judy Singer and journalist Harvey Blume. In the years that followed, this has contributed to a greater understanding of various behavioral characteristics that arise from, for example, autism, ADHD, Tourette's and dyslexia. People with such a 'brain that works differently' are called neurodivergent. The terms disorder or condition are preferably avoided. Those who are not neurodivergent are neurotypical, or average.

The concept of neurodiversity invites us to look at a person's full capabilities and not just one deviant aspect. If all human brains are different, then all people are equal. Of course, this also applies to prosopagnosia; which should receive more attention in this regard.

30 years

Based on when I started living on my own, I have been dealing with face blindness and its social consequences for 30 years now. At first I didn't know that I didn't recognize people. Later I didn't know why. I only came into contact with the concepts of face blindness and prosopagnosia around the age of 45. It was an eye opener, but not a solution.

The examples given here - of dealing with face blindness - are just a small selection. It's something you have to deal with on a daily basis and sometimes struggle with. As such, it has influenced and changed my life. Socially it can have major consequences. I can also imagine that someone falls into a 'deep, lonely pit' because of this. Family life, as well as a small group of people around me, protected me from this. But with prosopagnosia you have to have a thick skin at times and be able to put things into perspective. It's not always easy.

Social anxiety

Prosopagnosia leads to social insecurity. The extent to which this has a negative influence largely depends on the face blind person himself. This has not only to do with face blindness, but also with character. One can be very outgoing; another introvert. And one worries and the other puts things into perspective. However, face blindness can create or exacerbate (major) social problems.

If I were single, the problems would certainly have been much greater for me. I lived alone for several years and noticed that the face blindness was playing an increasingly important role. So big that a social anxiety came out of it.

For example, I went to the supermarket or the shopping center in another neighborhood. Then I was less likely to run into someone I should know. I was then not only afraid not to recognize someone, but also afraid of the reaction of people I had 'missed' before. In fact, I preferred not to meet anyone at all. Before I went out the door, in the cramped streets where I lived before, I looked outside to see if anyone was on the street. If necessary, I waited on an empty street.

In another city, or on vacation, a weight was lifted off my shoulders. Because of my social anxiety I started avoiding people, avoiding looks and avoiding situations. This did not improve anything, but only confirmed and increased the social discomfort.

Although I am aware of this now, I still struggle with the social anxiety from my face blindness. Just when you are avoided or ignored by other people because of your prosopagnosia, it has major consequences in your life. Because your social situation is so precarious, you therefore look for confirmation in a friendly attitude towards you in a social

contact, even if it is only a very small one. Noticing it can really brighten your day and mood; but if you get a stiff or downright nasty reaction, it can really get you down.

To school

Waiting for primary school, for my son or daughter, was a big challenge for me. I've tried not (always) avoiding it. Of course you have already seen some of the parents, at your front door when picking up or dropping off after playing, at a children's party, or during an activity or conversation at school. Some of the parents, however, I do not recognize. The social anxiety then sets in and even makes it so that you prefer not to get to know parents - or people in general - because you then have to recognize them later in other places. Added to that is the fear that people will think you're crazy or weird because, in their opinion, you've ignored them before - or more often. Sometimes I think I recognize that too, in an attitude towards me.

Autism

According to studies, face blindness is relatively common along with autism. There may be a link in that to social anxiety. But are you socially anxious because of your face blindness or your autism? Perhaps you show autism-like behavior because you are face blind and find that socially difficult? Without giving a personal opinion here, I will briefly quote some information from the website of the Dutch Association for Autism.

What exactly is autism? According to the Dutch Autism Association, autism is 'a collective term for behavioral characteristics that indicate a vulnerability in social interaction, communication, flexibility in thinking and acting and the integration of information'. Where there used to be a subdivision into subtypes of autism, such as PDD-NOS and Asperger's, according to the most recent version (DSM 5) of the American manual of mental disorders, there is now only one autism diagnosis: the 'autism spectrum disorder (ASD)'.

To get the diagnosis, you must in any case show deficits in social-emotional reciprocity, in your non-verbal communicative behavior that is customary for social interaction, and have deficits in establishing, maintaining and understanding relationships. In addition, you must also meet at least 2 of the following characteristics: 'stereotyped or repetitive motor movements, use of objects or speech', 'insistent adherence to the same thing, rigid attachment to routines or ritualized patterns of behavior', 'severely restricted, fixed interests that are abnormally intense or focused', or 'over- or under-responsiveness to sensory stimuli or unusual interest in sensory aspects of the environment'.

Mild forms

According to the Dutch Association for Autism: "The NVA sees the advantages and disadvantages of the new diagnosis ASD for our 'supporters'. We find the term autism spectrum disorder an improvement in relation to the different forms and names of autism in the previous edition of the manual. The new term better indicates that these different forms are essentially similar. In our opinion, the distinction between 'mild' and 'severe' also offers more possibilities than before to indicate individual differences in the severity of the limitations experienced by people with ASD."

The NVA is concerned about what psychiatrists will mean in practice by 'mild' forms of autism and also about how health insurers will deal with this. "To what extent will people with an existing diagnosis of PDD-NOS or Asperger's and high intelligence still fall within the criteria and be able to claim autism help? Or will people wrongly be given a 'label' without needing psychiatric help?"

Just as autism comes in degrees, prosopagnosia also comes in degrees. In order to meet the current 'diagnosis rules' for autism, a number of characteristics must be met. A social anxiety alone, or problems in contact with other people, are not enough. In that respect, it is enlightening that there is still only one autism diagnosis, without the subtypes.

Less sensitive

What problem, or what cause, underlies social problems and fears? When I think about it, my social problems only started when I became aware of my social behavior. This was mainly due to the reactions of other people. This made me feel insecure - and more and more insecure - which actually exacerbated the problems in social interaction. Everything became difficult and uncomfortable.

In general, people with prosopagnosia should take a less sensitive attitude about poor recognition of people. If you can't help being the way you are, why should you suffer the judgment of others? Very regularly I come across people - without prosopagnosia - who behave socially very rudely or inappropriately, but who are completely unaware of this. No self-reflection; no problem. Prosopagnosia may at least also be experienced more lightly by the 'face-blind'. One certainly does not have to succumb to social fears to waste away in solitude.

The face-blind finds comfort by looking around. Even without prosopagnosia, everyone muddles along socially. Not only differences in appearance and character make people versatile, but also differences in brains. You can give each other a little space, even when someone is different, or when you don't 'click' with someone at all. The awareness of neurodiversity can and must become much more commonplace.

Reception desk and office garden

In addition to waiting for primary school, the reception desk and the office garden were - and are - social challenges for me. For example, the office garden (being one open space without rooms or walls) at an editorial office in daily newspaper journalism was a big challenge for me - more than 25 years ago. When I entered the building, I had to pass the reception desk first. Then of course followed a 'good morning' to the ladies who were sitting there. But I never knew what to do if I passed that counter again; and sometimes several times a day. Should you say hello or not? If I didn't do it, I felt burdened and if I did, after a few times it was so uncomfortable that people thought I was weird.

Same with the editing room. I had to cross half the office garden to get to my workplace. Do you greet all the people you see, or just a few, or no one? And if you went for lunch at noon? Or had to go outside for a writing assignment and come back? When I left at the end of the day, I said bye to my closest colleague in the office garden, but what about the others, whom I walked right past to the door?

It was a social problem, but I could deal with it, as long as I could count on some understanding. And I could from most of my colleagues. But not from everyone.

I'm pretty sure I could have gotten a permanent job with this employer, without my social discomfort. It didn't happen here either and I went and found my way.

Although I had never heard of face blindness or prosopagnosia, I had to deal with others' reactions to not recognizing people. My social discomforts arose after the social fears about

this started. I had never experienced these problems before. They probably arose because I was insecure about my social environment. And because I was far too aware of my own social actions and behaviour. I so want(ed) to do everything right, but i could never get there.

Reception desks, which I have to pass regularly over a longer period of time, remain a challenge for me. I was 49 years old when my mother was forced (by health problems) to live in a nursing home. So I regularly passed the reception desk, sometimes several times a day. Initially, people greeted me very warmly every time and this gave me the idea that it was desirable to say something when coming and going. After a while I decided to only greet with eye contact, because if people were busy doing something else, I found it uncomfortable. After three quarters of a year I came in one afternoon and walked on without saying anything, because the reception lady was busy on her computer screen. Then 15 meters away I heard the canteen employee shout: 'Now he doesn't say anything!' Apparently I had been a topic of conversation for some time. It was a blow to my self-confidence, although I was also offended by the rude way I was approached.

My social challenges around open plan offices and reception desks were not because I did not recognize faces there, but because of my insecurity in social interaction with others. That uncertainty arose - at least in part - from other people's reactions to my face blindness.

Advice

There is no treatment for face blindness. There are no medicines either. For practical advice, I may not be the best person to rely on. I myself have enough social challenges. From now on I will carry this article in my inside pocket and hand it out at every acquaintance. And when I encounter misunderstanding, I will read it again myself.

Fortunately, face blindness is not a fatal condition, but it can be a very annoying one, with a major impact on your (daily) life. The well-known Dutch scientist Erik Scherder, professor of neuropsychology, is not face blind, but suffers from several irrational fears. Despite being a professor in the field of the brain and aware of the irrationality, he cannot shake his fears. He did find a way to deal with it however. The most important thing is that he is not constantly worried about it, but has given the irrational fear a place in his life.

With face blindness, a lot also depends on how you deal with it yourself. That again depends on what kind of person you are. How easy you are in social interaction in general, for example, and whether you can easily put things off and put things into perspective. If you're a 'social beast', you may experience fewer problems with a mild form of face blindness. If you're a bit more introverted, you may not even need a lot of social contacts. Everyone has to find their way in this.

Understandable misunderstanding

If I have to say something general about it, it's that you just have to keep going your own way. Even if not everyone understands you - or even everyone doesn't understand you. Go to that party or meeting, the supermarket during rush hour or your child's school. You can avoid it occasionally, but don't always. Life as a hermit doesn't get any better either. As described before; be a little less sensitive and don't worry too much about how other people react to you. After all, you can't do anything about it yourself. Misunderstanding from others stems from unfamiliarity with the phenomenon of prosopagnosia and the concept of neurodiversity.

Misunderstanding is therefore understandable. And misunderstanding will remain. But really nasty reactions towards you - think of insulting, taunting or gossiping - come from nasty people who aren't social themselves.

It would be nice if science would take the problem of prosopagnosia more seriously. Just more awareness about the phenomenon would be a big help. As well as more attention to neurodiversity. It would also be nice to read more experience stories. Or if more stars and other 'role models' come out about their problems with face blindness. When Brad Pitt says it, it comes across very differently to people than when the neighbor - who always 'ignores' them - says it.

If a serious collective, self-help group, or face-blind association comes along in future, you might join them for support or peace of mind. There promise to be only interesting group meetings then, where everyone sees many new faces every time.

R.S. 2023