

When everyone



...e's a stranger

Being told she was faceblind led **Monica Zenonos** to re-evaluate her entire life. Now she facilitates a support group for others with faceblindness and is committed to raising awareness of the condition

'I shouldn't know you again if we did meet,' Humpty Dumpty replied in a discontented tone, giving her one of his fingers to shake: 'you're so exactly like other people.'

'The face is what one goes by, generally,' Alice remarked in a thoughtful tone.

'That's just what I complain of,' said Humpty Dumpty. 'Your face is the same as everybody has...' Lewis Carroll¹

I was waiting at a bus stop when I first realised there was something wrong. I was standing next to a young lady. After a couple of minutes she turned and said, 'Mum, aren't you going to say hello?' It wasn't until she spoke that I realised she was my daughter. At that point I imagined the worse scenarios in terms of my health and mental wellbeing. My GP sent me away, saying there was nothing wrong. Eventually I was directed to a website where I contacted the research team at University College London and was tested for faceblindness. I was found to be in the bottom one per cent of the population in terms of facial recognition.

The incidence of faceblindness in the general population is estimated at between two and three per cent. The impact of research in the field of neuroscience, and increasing media coverage, have led to dramatic increases in the numbers of people found to be faceblind. In addition, high profile celebrities including Brad Pitt, Duncan Bannatyne, Stephen Fry and Oliver Sacks have recently 'come out' as faceblind. This has led to an increase in people seeking support from counsellors and psychotherapists for faceblindness. Furthermore, many people are undiagnosed and present in therapy with an array of symptoms and behaviours that are attributed and dealt with inappropriately. I have heard stories of clients being told that if they simply had therapy regularly they would remember their therapist's face. Clients are left dismayed. As one lady put it: 'I've seen my husband's face every day for 20 years but I still can't recognise him!' Needless to say, these clients rarely return and do not get the help they require.

I believe it is essential for counsellors and psychotherapists to grasp the emotional landscape of people with faceblindness. When I was tested seven years ago, there was no specific support available for people with the condition, so I decided to train as a therapist and I set up a support group called the London Faceblind Group in 2011. As a result I have become a key contact for people who suspect they or their children are faceblind; counsellors and therapists wanting advice and information; and an increasing number of journalists, students, artists and writers. More recently I completed my master's in psychotherapy at the Psychosynthesis and Education Trust by writing a dissertation on the psychotherapeutic landscape of developmental prosopagnosia (faceblindness). It was a political act to become involved in awareness raising and this has led to careful ethical consideration of my role as a therapist as I share some of my experiences publicly in order to support others in 'coming out'.

Coming out as faceblind is similar to other coming out processes: embedded in shame, internalised oppression and insecurities about whether people will accept you or even believe that such a thing as faceblindness exists. The inherent cruelty of this impairment means that often, after telling people, you will be met with comments such as, 'But you will remember me, won't you?' Worst of all are those who insist on testing you: so next time they see you and you say hello, they say, 'See, you do remember me.' I often wonder what their reaction would be if I told them I had another type of impairment. If I said I were hard of hearing would people whisper to see if it were true? If I were visually impaired, would they ask me how many fingers they were holding up? The support group I facilitate helps by normalising and validating the day-to-day faceblind experience and supporting the coming out process.

The faceblind experience

It is not uncommon to hear about faceblind individuals walking past people they know, mistaking one person for someone else, being unable to follow films and TV programmes, having difficulty coping with hot-desking and unpredictable working environments, avoiding social gatherings, and struggling to pick themselves out of a photograph. They live in a state of mild confusion and vulnerability, often questioning their visual reality, having thoughts like, 'is that my partner I'm about to sit next to?'

My own realisation and subsequent testing happened after having spent most of my life oblivious to the condition. I had learnt ways of recognising people that did not involve faces. At the beginning of my career I taught English to adults and could very quickly learn names and recognise students in the classroom but never knew who they were if I saw them alone in the street. I now realise that one of my coping strategies was to remember what differentiates one person from the next, so when they were on their own there was no comparison to be made. At the time, I would put this down to my being ditsy or anxious. I was unaware that I did things differently to others, and assumed that people around me were extraordinarily gifted rather than that I had a problem. As my own responsibilities grew and I had a family I became anxious about not recognising my own children but I did not realise this was unusual. I remember watching school plays and anxiously scanning the children's faces, hoping my daughter would speak so I could identify her. Once I'd picked her out, I'd then try not to take my eyes off her for a second in case she disappeared again amongst the sea of faces.

The only way to be diagnosed with faceblindness is to be tested at a university that has funding to do so. Tests are non-invasive and often include recognising famous and ordinary faces. For example, the Cambridge Face Memory Test asks the participant to learn a number of faces and then select the known face from a wider group of faces. Other tests involve EEGs, which show which part of the brain is active when looking at faces, or eye-tracking equipment, which follows where the research participant is looking when gazing at a face. More information on testing can be found on the websites listed at the end of this article. Diagnosis can be important for people with faceblindness because it provides a non-blame explanation for a lifetime of embarrassing misunderstandings and mistakes.

Neurocognitive impairment

The term prosopagnosia was coined by neurologist Joachim Bodamer² in 1947 and referred to acquired prosopagnosia,

which is the result of brain injury or illness. Developmental prosopagnosia, which occurs from or around the time of birth, was not recognised and studied until the 1990s. Prosopagnosia or faceblindness is one of various associative visual agnosias in which perception 'is adequate to allow recognition but recognition cannot take place'.³ Associative agnosias are towards specific categories of object. Prosopagnosia is an impairment of the ability to recognise faces. Other associative agnosias include: topographical agnosia (not recognising landscapes and landmarks), object agnosia, facial and emotion recognition agnosia, alexia (not recognising written words), age and gender recognition, and colour agnosia. Prosopagnosia is a neurocognitive impairment like dyslexia, dyspraxia, Asperger's and ADHD. It is not uncommon for people to have more than one neurocognitive condition, and so some people with developmental prosopagnosia may have a combination of neurocognitive conditions, whilst others may only have faceblindness.

Research from neuroscience explicitly looks at the condition of faceblindness and explains its existence in terms of genetics and neurobiological structures in the brain.^{4,5} Family and twin studies suggest a strong genetic contribution to face recognition impairments.⁴ Some researchers⁶ further hypothesise that there may be two forms of developmental prosopagnosia: one that is heritable and one that is not. The psychological theories most often used as a basis for testing focus on the interaction between memory and perception and more recently on information processing. Cohan et al⁷ have found that people with developmental prosopagnosia holistically process the mouth but not the eyes.

Impact on child development

To date no research has been done into the impact of developmental prosopagnosia on the infant's emotional or psychological development. For my small research project I interviewed two experienced therapists who have the condition and also drew on my own experience in order to understand the implications. If we apply Stern's⁸ model of the infant, then the basic understanding of physical presence, affect and continuity may be impacted because the infant's impaired visual memory will affect the sense of continuity (object constancy) and understanding of physical presence. This may create a disjointed and episodic narrative and shaky sense of reality and self. The same developmental issue may also mean that the individual develops a wider, less restrictive understanding of others.

There are further implications for attachment styles, which may swing between over- and underattachment. My supposition is that this is linked to not being able to hold people in mind. When early caretakers are not consistently visible, the child may have a sense of an unknown person each time they see the parent. This sense of being a stranger can create underattachment, which can quickly switch to overattachment once familiarity is established. It needs to be recognised that

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this type of attachment pattern is the result of neurology but the impact on forming and maintaining relationships may be profound. It is also important to consider how the caretaker responds to the faceblind infant and whether or not the caretaker is also faceblind. The potential for wounding when the infant is not easily recognised by the caretaker, and the potential for co-producing a reactive caretaker when the infant does not recognise the caretaker, can create a complicated dynamic.

A person's sense of identity is deeply affected by the condition, and the consequence of not having the ability to visualise faces internally has an impact on feelings of isolation and connection to others. The person with faceblindness often cannot recognise himself and will have no internal visual self-image. One participant in my study spoke of sitting on a bus and staring at the CCTV: 'There were three people on the top deck, so I knew one of them had to be me!' This lack of a visual self-image can blur the idea of sameness/difference to another and may ultimately affect a person's sense of belonging and exclusion. It may even set up a type of body dysmorphia, as there is no comparison to be made between a mental construct of body image and a visual one. One of the therapists in my study talked about how she knew her own smell and believed this was one of the ways in which she recognised herself. She distinguished between having a strong sense of her inner self rather than her visual self-image but wondered whether or not it was always like that while she was growing up. Another participant made several links to self-perception and self-esteem while growing up. I can identify with these links from my own experience.

A purely relational interpretation would see the faceblind baby's inability to recognise himself as his having internalised the mother who does not 'see' him or recognise his own separate internal world. In this way the baby will learn not to see himself as a unique embodied individual and will struggle to separate himself and his own response from the mother's gaze. This view would suggest that faceblindness can act as a defence strategy to early relational trauma. However, I would argue that it fails to account for neuroscience, which finds that faceblindness is often genetic and due to biological structures in the brain. This argument resonates with debates surrounding relational causes for autism, which have now been replaced with neurobiological explanations. Yet this seems the most likely explanation for the experience I outlined earlier, where the therapist tells a client that coming to therapy regularly will enable her to remember the therapist's face. I believe that a strong and intimate therapeutic

relationship can help the faceblind client immensely, but a miracle cure for neurodiversity it is not.

Relationships with others

Faceblindness impacts relationships with others. The only other psychological study about faceblindness,⁹ conducted by a research team that included Dr Brad Duchaine, the world's leading authority on neurocognitive research relating to faceblindness, found some long-term effects involving loss of confidence, embarrassment, dependency on others, restricted social circles, and behavioural changes which seek to avoid occurrences repeating themselves. The team found that recognition difficulties interfered with the development of relationships. There were added problems in career and working environments, which resulted in various degrees of occupational disability. The researchers suggest that there is risk of people developing social anxiety disorder.

The therapists I interviewed also talked about work. One therapist talked about how not recognising clients out of context is interpreted by clients as 'maintaining boundaries'. I have had a similar experience. The therapist also talked about feeling upset when they are greeted warmly by ex-supervisees whom they cannot recognise and the other interviewee spoke about how it is not easy to approach some colleagues, even after years of working together, because they are not certain of who they are. As someone with faceblindness, I can testify that approaching anyone is always a risky business. You never know if you have ignored them on a previous occasion and can often expect to be met with retaliation and anger.

Coping mechanisms

Working in therapy with coping mechanisms and strategies is important. It is useful for the person with faceblindness to gain awareness around their particular methods for self and other recognition. From my experience I have come across many types of coping mechanism and often the faceblind person will use a variety of ways. Some of these relate closely to the early sensory mechanisms that a neurotypical infant uses to recognise their caretaker before they develop visual recognition: smell, movement, touch, sound, colour and proprioception. Others relate to visual recognition of objects and not faces: contexts, memorising clothes, hairstyles, jewellery, mannerisms and distinguishing features. Some relate to a heightening and sensitivity of other functions: intuition, somatic responses, instinct, imagination, reading body language and unconscious communication. Heightened responses and sensitivities are not 'magical powers' but simply the result of repeated use and reliance on methods other than facial recognition.

When these coping mechanisms are finely tuned they are often seen as a gift by therapists with faceblindness, who talk about skipping the first layer of visual recognition and seeing the client with a fresh pair of eyes each time they meet, as well as the ability to quickly form deep empathic connections and holding. As a transpersonal therapist, I believe that these gifts provide clues as to how to work with clients who are faceblind. And that increasing self-awareness and focusing especially on somatic and sensory awareness – learning to trust their gut feelings and intuitions – can improve their sense of self and their ability to cope with everyday life.

Coping mechanisms are important in the therapy room; as Winnicott said: 'Many patients need us to give them a capacity to use us.'¹⁰ People with faceblindness often find maintaining



eye contact difficult or unnecessary, others may have learnt the social norms and do so out of politeness and fear of rejection. They may not actually be getting information by maintaining eye contact and in fact some faceblind people complain that looking at a face is distracting. The client may be connecting to the therapist using a non-visual coping mechanism and may be trying to reduce the level of 'background noise' or distraction. If the therapist or client are not aware this is a frequent symptom of faceblindness then the risk of misinterpretation of the client's behaviour is increased – remembering, of course, that people may not be aware of their own faceblindness and will probably have learnt to hide it so as not to offend others or be ridiculed. In that case, they may need the therapist to name it and bring it into the room as a possibility. If the client knows they are faceblind, it is useful to say it is OK if they don't immediately recognise you and allow time for the client to reconnect at the start of each session.

In addition, the therapist needs to think carefully about how the client can keep them in mind between sessions, especially during absences and holidays. Maintaining context – for example, using the same room – is helpful and the therapist may be more easily identifiable by wearing particular clothing. The therapist may find that it is necessary to be more vocal about their countertransference and not rely on their facial expressions so heavily. Cognitive techniques work well for improving practical skills, for example, starting a new job or school. Psychotherapeutic techniques need adaptation to suit the client. For example, visualisations may need to be more sensory-based and the use of some affective objects (like photos) may not be as successful. Lastly, the client may respond well to techniques involving touch, movement, felt-sense and sound.

In conclusion I believe developmental prosopagnosia is a condition that needs to be acknowledged in psychotherapy and counselling. By highlighting the condition we can move on from what we can learn from neuroscience towards more discussion on how to adapt our practice to meet the needs of clients with neurodiversity. ■

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ABOUT THE AUTHOR

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Find out more

Brain & Behaviour Lab, Department of Psychological Sciences, Birkbeck College

www.brainb.psyc.bbk.ac.uk

Prosopagnosia Research Centres at Harvard University (USA), Dartmouth College (USA) and University College London

www.faceblind.org

Prosopagnosia Research at Bournemouth University

www.prosopagnosiaresearch.org

City University London, University College London, King's College London

www.troublewithfaces.org

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