**Telling Others: To share? Or not to share?**

As you will read below, there were varying degrees of advice related to whether or not to tell others about prosopagnosia.

**Telling others**

- “It is always a weight off my mind. It’s permission to not act like everyone else, permission to make a social mistake – and with that permission my anxiety goes away.” - Adult

**Who do you tell?**

- “If I have a great conversation with a stranger who I think I will see again or want to see again, I tell them about [my prosopagnosia].” - Adult

- “I only tell people when I have plenty of time for a full and private conversation, and only people whose integrity and discretion I trust.” - Parent w/ Secondary School Student

- “[My son’s] school is aware of his difficulties, and I have asked the teacher to simply be aware. We took him out of public school with 1000+ students and put him in a charter school with 500 students. Fewer students and teachers to identify has helped him.” - Parent

- “We are careful with who we tell due to safety concerns.”- Parent w/ First Grader

- “I am still unsure if it is best to disclose to others that you are affected. Young people can... be unkind, so I don't think it is wise now. But later - should [my son] tell a girlfriend, or employer? I see how having unrecognized FB has shaped my husbands personality, and I wonder how he would have got on if he had known. I think in the end it comes down to personal choice.”- Parent w/ Secondary School Student

- “If [the school] saw the child lurking alone on the edge of the playground, it would make more sense. But to see them busy and active, relating to their classmates and having friends - it is hard to grasp that they have face-blindness. I have come, over time, to have tremendous respect for the intelligence and sheer memory involved in my son’s coping mechanisms. So to an outsider, I feel they really need it spelling out - I sat and told [the school] the very weird situations we have been in, where there is no explanation for his behavior other than he did not recognize the person.” – Parent w/ Secondary School Student

**Who does your child tell?**

- “[My son] usually controls who knows about his prosopagnosia. He tells people he has trouble with faces if he needs to and leaves it at that.” - Parent

- “[My son tells] good friends only but there is a lot of curiosity about it. It is not an easy thing to explain as [he] can work out who most people are using other methods. His good friends do look out for him and always introduce themselves if necessary.” - Parent w/ Secondary School Student
“We made a big deal about the school staff not disclosing my daughter’s diagnosis without our consent and then my daughter independently told the entire class during a discussion about being unique that she “has problems with her eyes including facial blindness.” We don’t think that any first grader knows what that means and have encouraged her to carefully share with her friends things like “so I might not see you on the playground. Make sure you find me”. Right now, it does not seem to have helped. The bigger issue is getting our daughter to advocate for herself.” - Parent w/ First Grader

Ways to explain

Metaphor/ Simile

♦ “I usually explain that we’re strange in our ability to recognize faces and ask them to imagine trying to recognize everyone by their hands. You can see they are all different but it’d be hard to recognize people quickly and accurately.” - Parent

♦ “I often compare it to dyslexia—they see all the letters, cannot process it meaningfully into a word; she sees the face and its components, just can’t process it meaningfully to say ‘this is so and so’. We discuss how she uses other ways to identify people. Sometimes we use a very simple description ‘She has some visual deficits and might not recognize you next time she sees you.’” - Parent

♦ “We used the analogy of a camera (his eyes and brain) taking a picture but that his brain never filed that picture away so that he could use it to recognize someone again in the future.” - Parent w/ 10-year-old

Straight to the Point

♦ “I explain that while I will remember this entire conversation and how well we got along, I won’t recognize them later so please come up to me if you see me so I know you were there.” - Adult

♦ “At this point, since [my son] hasn’t wanted us to tell people, I just say that remembering faces and names isn’t his best strength. People seem to understand this. They don’t get the depth of his struggles, but they can relate. Nearly everyone has been in a situation where they can’t recall a face or a name that they should.” - Parent

♦ “If I need a particular person to understand the gravity of it, I just mention to them that [my son] has trouble recognizing me (his MOTHER), and tells his three brothers faces apart by their hair.” - Parent

♦ “My husband devised a computer program that took the faces of a celebrity (without hair) and rotated them through 360 degrees. I found that the faces went from unknown to known as they rotated. Also there was a blog that likened faces to rocks.” - Parent w/ Secondary School Student

♦ “When I tell people, I do usually acknowledge that it sounds kind of crazy and that it’s hard to wrap your mind around at times. I have found that this usually makes people feel comfortable asking questions if they have them,
because they know that, even for me as a mom, it’s sometimes hard to understand.” - Parent w/ 10-year-old

Reactions

Neutral

♦ “[Adults who are looking after him] panic but we ask them to give a location rather than a person when meeting up and then tell them that our son copes. He has been away with the scouts, school, etc without incident. Our son is open about it and others take their lead from him.” - Parent w/ Secondary School Student
♦ “They usually say, ‘Oh, I have trouble remembering faces too.’ They underestimate the difference in ability.” - Parent
♦ “People generally do not understand what that means. Even after the Brad Pitt hype this summer, there is still misunderstanding.” - Parent w/ First Grader

Positive

♦ “Most reactions have been very positive. Most people have actually been fascinated by it and have asked questions or wanted to know more. That is very encouraging.” - Parent w/ 10-year-old
♦ “I have found most people who hear about this condition are intrigued and curious about it.” – Parent w/ Secondary School Student

Negative

♦ “People think you’re a liar... but some people believe you.” - Adult
♦ “I think others sometimes think I’m stupid.” - Adult
♦ “We have definitely encountered our fair share of people who don’t think it’s a real thing, even among our closest friends and family. We can only explain it as best we can and let them decide if they really “believe in it.” I have told those people who don’t really ‘buy it’ that they may not express their disbelief to our son. If they have questions or doubts they should only address them to his dad and I.” – Parent w/10-year-old
♦ “[W]e have been told that we are coddling our son and that we should force him to act more independently. We have also been asked why we don’t ‘allow him’ to have more friends. I even had someone suggest that our son would be better able to recognize others if he wasn’t an only child. The vast majority of our friends and family have been very understanding and supportive and the ones that haven’t I think view prosopagnosia as a ‘diagnosis du jour’, especially after Brad Pitt said that he thinks he has it.” – Parent w/10-year-old
♦ “We have had a few of our friends and family members that didn’t really believe it was a real thing and questioned our parenting in how we’ve reacted to this. I won’t lie; that was hard and really hurt. We probably haven’t had as much contact with those friends and family members as we did in the past.” – Parent w/10-year-old
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