Finding out about Prosopagnosia Later in Life

Some of the adults we surveyed didn’t “find out” about prosopagnosia until they were adults. These individuals had a few comments to share about their adult experiences . . .

Now that I know...

♦ “I would have loved to have known [sooner]; maybe I would not have been so shy and quiet. Most people I need to trust before my real personality is shown. I wish for all of my life I could be as funny in groups as I am with my friends.” - Adult
♦ “The ones who want to be your friend will be the most understanding and most helpful if you tell them about your face blindness. The people I tell now would have been the kind of people who I wish I could have told as a kid. I think I probably would have had a much larger friend base growing up if I did. Also, just knowing about the disorder would have been helpful.” - Adult
♦ “[I wish I had known] how to get a diagnosis. It should have happened at 4 years old instead of 10. With it our son's education would have been very different.” - Parent w/ Secondary School Student
♦ “I just wish I had found out about Prosopragnsia during my teacher training. Looking back through my career I’m sure that I have taught others with this condition. Luckily I was able to find solutions for my family in isolation but that was probably my teaching background and personal philosophy.” - Parent w/ Secondary School Student
♦ “I think I wish someone had told me that professionals don’t know anything about this condition (or didn’t - I hope things are changing).” - Parent w/ Secondary School Student
♦ “I wish I’d heard that prosopagnosia isn’t a sentence to a lonely life. I wish I’d known that he’d develop amazing ways to cope.” - Parent

Affects on academics or career

♦ “Academically, I have done well. It is easier to surround yourself with ‘likeminded people’ and books. Career wise, I am a teacher and see over 500 students in a week. If I have them that day and see what they wore I know who they are outside. I chose to teach older students, this way I do not send the wrong student with the wrong parent.” - Adult
♦ “At a large work party, I decided to duck out early without telling anyone. I figured no one would notice I had gone as I wouldn't have noticed anyone else leaving. The next day, I had a dozen people ask me where I had disappeared to the previous night. Oops.” - Adult
♦ “In high school, I was more focused on my work. It was mostly independent work and since I rarely knew anyone in my classes, I spent any spare time in class either doing homework or reading a book. In college, I think it became detrimental as I was unable to form necessary study
groups for reviewing the information and when learning complex concepts, the conversation with other students is what helps you learn. Without that, I struggled. Career-wise, I have not had too much difficulty, though I think it effects my customer service and possible promotions, since I'm not always able to sensor what I talk about based on who is around me, which may be detrimental.” - Adult

♦ “I have [told employers]. So far, it hasn't prevented me from getting a job. It might be that they see it as 'equal opportunity' or something. Usually, the other person is interested and asks questions. I like to think it helps me stick out from the crowd, but there's really no way to know.” - Adult

DISCLAIMER: There is no research to confirm or deny any benefits to you or your child that may result from the information included in Project ProsoFamily. The University of Minnesota does not endorse anything on this page. It is simply words of wisdom from individuals and parents based on their personal experiences for you to adapt as you see fit.