Advice for Parents of ProsoKids, from Parents of ProsoKids

We explicitly asked parents, “Is there anything else that you would like to share that might be helpful for other parents and their children?” This is what they had to say.

Your child is not limited

♦ “Just like any other child that has some issues, never hold them back…. I think the best thing is to allow the child to follow their goals and help your child when things happen due to the prosopagnosia. When my son was young, I would wave to him so he knew it was me. He did better at 1:1 sports than team sports, hard to follow all of the people in uniform. (Mostly when you have to pass a ball or puck). I encouraged him to go out, have fun, and enjoy life. He has been a boxer for many years and that has helped him gain confidence. He loves to swim and now has a passion for carpentry.” –Parent w/ 14-year-old

♦ “Your child will learn to cope and this diagnosis does not have to limit them.” - Parent

It depends on how you handle it

♦ “[The] level of tension [you feel] will instruct [your] child to [whether they should] feel broken or not.” - Parent w/ 7-year-old

♦ “Be open, honest and always look for humor in any situation!” - Parent w/ 18-year-old

Upon first finding out:

♦ “It is fine, breathe and do not become too anxious, look at all of the famous people who have paved the way. Chuck Close, Brad Pitt, Oliver Saks and Jane Goodall….not bad if they got through childhood and adolescence without even knowing about it...we are 100 steps ahead...” - Parent w/ 14-year-old

♦ “[Do not] worry too much (although that’s hard). It’s a disorder for which one can accommodate. Sometimes my son surprises me…. I think he has a lot of coping mechanisms of which I am not aware and that he may not be even be aware of himself. My son has had facial recognition difficulties his whole life, and he has great friends, is successful at school, and is a typical kid in all other ways. He has a great life!” - Parent

♦ “Make sure your child understands that having prosopagnosia does not mean that they aren’t "smart." Point out all the areas where their brain performs well. Help them understand that all our brains are different and that is one of the wonderful things that make us all so interesting and unique. Do this not just on a general level (for instance, you are so good in math) but on a specific level as well (for instance, you understand the abstract concepts of math really well). Model positive ways to deal with your own weaknesses. Demonstrate acceptance of other people regardless of ability.” – Parent
“I promise you that your child is still the child [s/he] ever was and now needs you to help them navigate their future. By knowing more, your son or daughter will understand that there is a reason why some things are difficult but there is usually a way around if you take time to seek advice. Also remember you are not alone, there is a whole community out there to meet with their experience to fall back on. The role is not always easy but it is rewarding.” – Parent w/ Secondary School Student

“This diagnosis can be a way to learn about your child and get to know them in ways that you never knew.” - Parent w/ 10-year-old

“Every parent reacts differently to this diagnosis and approaches how to support their child differently. The best thing we can do is support one another, even if we approach it differently.” - Parent w/ 10-year-old

“Yes it is real and don’t let anyone’s reaction cause you to doubt that, especially if your child has received a creditable diagnosis from a reliable source.” - Parent w/ 10-year-old

**Diet could be a possible trigger**

“My son has food intolerances, and his face blindness certainly improved when we found and removed his triggers. I have spoken with other parents of affected children who have had the same experience. Food is now known to sometimes have profound effects on autism spectrum, so why not face blindness too. As a child rarely has only one symptom to food intolerance, they stand to gain a lot by discovering their own trigger. (Our son learnt to read in 3 weeks, and overcame headaches, anger, anxiety, lack of focus and night waking upon removing his - his teacher said 'what have you done, he is a different child'). An elimination diet takes a lot of effort, but is something the parents can do for themselves. If they want to know more I would direct them to [www.fedup.au](http://www.fedup.au) as a starting place... Our son’s face blindness still exists, (though all his other symptoms have all but disappeared) but is reduced, and also as he is not anxious and tired, he has more energy available for coping mechanisms.” - Parent w/ Secondary School Student

**Educate yourself**

“There are very few resources on prosopagnosia, especially how it relates to kids. Don’t expect to do a Google search and find tons of information or sources of support available like you might with other kinds of disorders.... Parents of children with prosopagnosia are trailblazers in a way.” – Parent w/ 10-year-old

“Watch the 60 minute video.... Get to know the experts, get involved in research, reach out to other parents. Regarding school-- you need to advocate and educate. Do not expect staff to understand this deficit or how it impacts your child. Many will not believe you, especially if your child compensates well.” – Parent w/ First Grader
“Be prepared for people to display ignorance around this diagnosis, especially when a well-known celebrity publically announces that he thinks he has it too.” - Parent w/ 10-year-old

**Words of Encouragement for Parents**

- “Always remember: You are the best advocate for your child.” – Parent w/ 14-year-old
- “It's a struggle but you and your child will survive, it's all about strategies and communication.” – Parent w/ 14-year-old
- “Everything will work out.” – Parent w/ 14-year-old
- “[H]aving prosopagnosia just adds to your kid's uniqueness! Celebrate who they uniquely are and welcome to the proso family!” - Parent w/ 10-year-old

**In the home**

- Recognize your child may require personal time between activities where s/he interacts with others. - Parent
- “We just focus on general regulation/calming strategies that she can hopefully utilize in other situations.” - Parent w/ First Grader

**Maintain open communication**

- Create a signal for when a social situation begins to feel overwhelming. - Parent
- “Let [your child] know that it’s okay when [s/he] doesn’t recognize someone and that [s/he] can definitely ask [you] who they are.” – Parent w/ 10-year-old
- “Give [your child] full permission to talk about his/her experience with prosopagnosia, the good, the bad, and the ugly.” – Parent w/ 10-year-old
- Incorporate laughter and humor whenever you can. – Several Parents

**Remember that your child is the expert**

- “[N]either my husband nor I have facial recognition difficulties. We can read all we want about it, but we will never fully understand, 100%, what it feels like to live with it every day.” - Parent w/ 10-year-old
- “Realize that [you] can NOT ‘teach’ [your child] to recognize faces.” - Parent w/ First Grader
- “Help [your child] exploit the accommodations [s/he] already uses: clothes, shoes, etc. Remind [him/her] to do a quick scan of what kids are wearing each morning.” - Parent w/ First Grader

**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.