



PANS PANDAS UK
awareness support education

In Conversation with Rosie



PANS PANDAS UK had the privilege of interviewing Rosie Saxon to learn more about her journey with PANS PANDAS. We spoke with Rosie about her diagnosis, the impacts of the condition on her school experience, and heard more about some of the advice she would give to other young people and their families who may be facing a similar diagnosis.

Can you share with me the journey of how you were first diagnosed with PANS PANDAS? What were some of the initial symptoms you faced that led you to seek medical attention?

I was 17 years old when I was diagnosed with PANS PANDAS but I had experienced symptoms from the age of 14. I started having OCD thoughts, followed by vocal and motor tics. My mom did a lot of research, learning everything she could to try and understand why I was experiencing these symptoms and what she could do to help. She found out that I have a condition called PANS PANDAS but because it was something we had never heard of before and such a rare condition, we weren't sure what to do. We took leaflets from the PANS PANDAS UK charity website and took them to the doctors. After some tests, we discovered that I had glandular fever and this had triggered the onset of PANS PANDAS.

How did this affect your education? Was school more challenging and did it affect your friendships, grades and attendance?

School definitely became more challenging, and the condition really affected my education. Although I was determined to keep going, it was very difficult to comprehend what was going on and I struggled to maintain my energy levels. I feel like because there is such little awareness, it was quite difficult for my friends and teachers to understand something that they had not heard of before. Explaining and repeating myself multiple times to friends and teachers was one of my biggest challenges.



My grades and attendance stayed the same because I was fully committed to achieving the best possible results I could, even if it meant going against the advice from the nurse to only do half-days at school!

“ Before I was diagnosed with PANS PANDAS, my school experience was amazing. I was really motivated, and I loved being at school! ”

It is great to hear that you were so motivated! Did you have any periods of isolation or challenges and how did you overcome them? Did school and college offer any support to help you with the challenges you experienced?

Constantly feeling tired was my biggest challenge. I had to take one day at a time and could not plan too far ahead as I did not know how I would feel the next day. I also struggled more in college because I had previously put so much effort into my GCSEs and had tried to mask the problems at school. This took its toll on me and when I started sixth form, I had to seek support. However, the support from my sixth form was brilliant, and instead of having full days, I could attend my lessons and then go home. This level of support during my time at college has definitely helped with my educational journey and has made me feel less scared about going to university.

How did you find that transition into university? How did you first approach the university about your condition?

Going to university can be a scary thought, especially when you have a condition like PANS PANDAS. However, the university was extremely helpful and receptive, and really wanted to understand my condition to try and help in any way possible.

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Having PANS PANDAS has made me more aware of the struggles people go through. I would say I am now more empathetic towards others, especially because we are all so different and the symptoms people experience differ from person to person.

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From your experience in education, what would you say to other universities about what they should put into practice for young people with PANS and PANDAS?

It is crucial that support is offered to students and their families. Without the support that was offered to me during college and university, I would not be where I am now. I would also say that raising awareness is key. Perhaps it would be a good idea to start introducing awareness events about PANS PANDAS in education so other students and teachers can understand what the condition is.

What insight or advice would you give to other young people and their families who may be facing a similar diagnosis whilst in education?

I would suggest contacting and getting in touch with the charity because they are so helpful. The educational resources on the PANS PANDAS UK website helped me understand the condition and how to find support. It was also reassuring to find out that I am not alone and that lots of people have experienced the same challenges I have faced.

What are some of the positive achievements or moments you have had?

My journey through education is something I am very proud of. I have never let my condition get the better of me and I have always been determined to do the best I can. I have now completed a foundation degree in Early Education BA where I hope to work with children from the ages of 0-8. Also, although it took me a while, I was really proud when I passed my driving test!



Written by Daniel Hindle

Daniel is currently in his second year, studying History at the University of Birmingham and is undertaking an internship with PANS PANDAS UK.