



PANS PANDAS UK
awareness support education



In Conversation With **Tina Coope**

PANS PANDAS UK Education Lead.

Let's start from the beginning. Can you tell me a bit about your professional background and previous experiences in education?

I trained as a teacher in Birmingham and started my teaching career in Birmingham, which I absolutely loved. Following a family move and having completed a master's degree, I then started working in a special school. It was a fantastic role supporting the children and watching them develop and thrive.

Some of our students had experienced a difficult time in school, and there was a lot of focus on building trust and using a child led approach. When severe neuropsychiatric symptoms subsequently struck a close member of our own family, it eventually became impossible to continue to work in the classroom.

Did those experiences motivate you to work with PANS PANDAS UK? What specifically drew you to the cause and made you passionate about supporting children and families?

As with so many things in life it wasn't part of an ordered plan. Families had been regularly posting in the PANS PANDAS UK Facebook support group about the difficulties that they were experiencing in education, and I gradually started to respond to some of those queries.

I feel really passionately about supporting families affected by PANS and PANDAS as we have been on our own journey as a family, and during that time, there were no PANS or PANDAS specific educational resources at all. It sounds like a cliché, but I really would like to make the educational journey for other families and their children better. We have had some very supportive teachers in our lives, and that has been important on so many different levels.



Written by Ceridwen Clark.

Ceridwen is a recent Sociology graduate from the University of Birmingham, currently undertaking an internship with PANS PANDAS UK.



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Tell me a bit more about your current role as an educational lead professional. What does your position involve?

No two days are the same and there are lots of different strands to the work! Some of these include creating resources and delivering teacher training alongside meeting with a wide range of professionals, such as educational psychologists and designated clinical officers. The work is very varied from creating an education video to share with Maria Caulfield, writing health and education briefing documents, and of course talking to families or creating education posts to share on social media.

Opportunities to raise awareness arise frequently; for example, we recently presented to educational professionals who are leading courses to train SENCOS at University College London. This (already fantastic) opportunity, then led to an invite from Manchester Metropolitan University to deliver workshops at their education conference. One step leads to the next. These are brilliant opportunities to network across wider groups of professionals and geographical areas.

We are now also in the early stages of exploring potential offers to undertake the university-led educational research into PANS and PANDAS which is so desperately needed. The conditions should also soon be included in forthcoming education books. The educational landscape is slowly improving, but I'm acutely aware that there is a very long way to go.

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The work around education doesn't happen in isolation and is heavily influenced by the work across health and social care. It is so important that we all work as a team and join up. Our own charity team and community works tirelessly making connections and building networks and relationships, and these all feed into the strands of work. Our strength lies in our numbers and families have been brilliant at sharing the education resources far and wide.

As a charity we are also working to improve the landscape in UK countries other than England and are very much hoping in future to increase our education team capacity.

I definitely see my main responsibilities and duties as supporting families, validating their experiences and providing information for a wide range of professionals. Listening to the families and children is the most important thing that any of us can do. We need to make things better.



Tina Coope with education volunteer Helen Huitson attending the recent SEND conference at Manchester Metropolitan University.

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That sounds really rewarding. Can you tell me more about the challenges children with PANS/PANDAS face in an educational setting, and how do you help meet their needs?

This is a huge question and could fill a book. There are multiple challenges currently, and the individual stories of children and their families are truly heart-breaking and have a lot to teach us about improving the educational support for children with PANS or PANDAS.

Some of the main barriers include the low levels of awareness across the board of professionals, the fact that the conditions have got lots of unusual characteristics and that it is very easy to misinterpret the symptoms. Add in the large number of PANS and PANDAS context-specific vulnerability factors that are giving rise to so many families being subject to safeguarding concerns alongside the medical context, and it all comes together to create a perfect storm. Our children and families get caught in the middle.

These challenges need to be addressed on several different levels, and as we are such a small team, we always need to consider carefully how to use our resources wisely to achieve the maximum impact for our families. For example, we did lots of work recently as a team exploring the safeguarding issue and produced the FII guide in conjunction with wider professionals. The aim was to have a resource that both families and professionals could refer to. We are aware it is just a drop in the ocean, but each step takes us forward as a community.

You're playing a vital part in the whole journey. Do you have any success stories or rewarding experiences you can share from your time working with PANS PANDAS UK?

There are rewarding experiences every single day. Children who feel safe again in school, families who feel listened to and that their educational experiences have been validated, attendees at the teacher training who have then said "I think we may have missed children with this", or "I am going to share all of this information with my colleagues" or who share that they will do something differently going forward.

Sometimes families write to say that their child has now got an effective Education Health and Care Plan or a working Individual Health Care plan and that it is making a difference. Families are also brilliant in our community at generously sharing their own educational experiences and knowledge and the importance of this cannot be overestimated.

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Your work is essential for PANS PANDAS UK, but also difficult. How do you handle the emotional challenges that may arise when working with children and families affected by PANS PANDAS?

When things are difficult, I always remind myself of what my own family member is going through, and that if they can manage those symptoms, I can keep on going. The courage and tenacity of our families, and the way that they support each other is truly amazing.

There is always somebody in the group with the capacity to give and provide support to other members. It is not a group that any of us would have ever chosen to belong to, but we are there together, and we are a community.



That's great to hear. When it comes to supporting children with PANS PANDAS in their educational journey, what strategies do you think are the most effective?

I feel like I say this a lot but no one size fits all, and that is particularly true for children with PANS and PANDAS. The conditions cover such a wide range of symptoms and severity, and even within the same child, the symptoms can vary enormously from flare to flare.

Some key things though include:

- School/education support is 'needs' rather than 'diagnosis' led.
- Listen to your child - if possible, ask them what they find tricky and what would help.
- Ensure that the child's timeline and breadth, scope and impact of the symptoms are accurately documented.
- Your feelings as a parent/carer are there for a reason - please listen to them and let them guide you in terms of knowing what is right for your child.
- Build your supportive team at home and at school - positive relationships and understanding are worth their weight in gold. Keep open channels of communication and respect that the child may be presenting differently in school to at home.
- Always prioritise your child's well-being and focus on creating a positive environment. Have their long-term engagement with education in mind.
- PANS and PANDAS are medical conditions - ensure that the school are following the guidance and ask about having an Individual Health Care Plan. These can be enormously helpful in documenting an often complex and shifting landscape of symptoms.
- The conditions very often impact attendance. Decide proactively how absence from school will be supported. The difficult decision of when a child's symptoms are overwhelming or too distressing to cope with in school needs to be made by those that have genuine insight into the extent and scope of the child's symptoms. Children who have been in school whilst experiencing a multitude of distressing symptoms have subsequently reported trauma.
- Have a key/contact adult in school.
- Ask any professional supporting your child to have a working knowledge of the conditions.
- Be aware of the different education options available.
- Find your tribe! There is a wealth of advice, wisdom and support out there.

Is there anything else you would like to share about your role as an educational lead, PANS PANDAS UK, or the importance of education in supporting children and families?

It is a huge privilege and a position of trust. I'm aiming always to keep the children's educational experiences at the centre of everything that I do. Our children will not get their childhood back. We have enough information now, and we need to get on with it ■

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