

What does this mean for families with a PANS/PANDAS child?

The family and child are often traumatized, frightened and exhausted. However with the help of a PANS literate Doctor and the correct treatment, a full recovery is possible.

“It is important for people close to the family to recognise the likelihood that it will be a long journey where symptoms wax and wane.”

Every day brings a different challenge for a PANS/PANDAS family. Depending on which symptoms are ‘flaring’ the family may be able to socialise with friends or may regularly need to cancel plans at the last minute. Sadly the nature of this illness means that this situation can change hourly and as a result many families find themselves becoming increasingly isolated as friends and families stop including them in social events due to their apparent unreliability.

Often, when out and about a PANS/PANDAS child can come across as ‘normal’ with no issues and it can be difficult to imagine what the family are experiencing on a daily basis. This does not mean that the family are exaggerating or that it is simply a disciplinary issue at home, or lack of routine. In many cases a child is able to ‘hold it together’ when in public. Often their triggers are primarily at home, for example OCD being around ‘their belongings’. Please show support and understanding even if the issues are not obvious to you.



Who we are

About Us

It is our mission to raise national awareness of these life changing conditions, create support networks for families who are affected and develop ongoing relationships with a network of doctors in order to encourage education in these conditions.

Contact Us

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Supporting a PANS/ PANDAS family (September 2020)
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Supporting a PANS/PANDAS family

PANS PANDAS UK

PANS

Paediatric Acute-Onset Neuropsychiatric Syndrome

PANDAS

*Paediatric Autoimmune Neuropsychiatric Disorder
Associated with Streptococcal Infections*



PANS PANDAS UK
awareness support education

What is PANS/PANDAS?

A brief outline...

PANS/PANDAS is a broad spectrum of acute onset neuropsychiatric conditions that may include obsessive-compulsive symptoms, tics, severe eating restrictions, cognitive, behavioural and neurological symptoms. Triggers may include strep throat, influenza, chicken pox, pneumonia, allergens, anxiety, trauma or other environmental factors.

In simple terms, instead of becoming ill with a sore throat, sore ears, temperature, etc, the immune system attacks a small area of the brain called the Basal Ganglia which controls voluntary motor movements, procedural learning, habits and emotion.

Children are often misdiagnosed with psychiatric problems, ASD or ADHD.

What are the symptoms?

Symptoms usually start with a rapid, acute onset of OCD, restrictive food intake or tics along with a number of other symptoms, some of which are listed below:

- Anxiety (particularly separation anxiety)
- Emotional lability (extreme emotions which can fluctuate rapidly and are not always appropriate to the situation) and/or depression
- Aggression and/or irritability
- Hyperactivity
- Severely oppositional behaviour
- Behavioural regression
- Developmental regression
- Sensory & motor abnormalities
- Enuresis and/or urine frequency
- Hallucinations and/or psychosis

How can I help a PANS/PANDAS family?

Supporting the PANS/PANDAS child

Their actions are not behavioural but are due to brain inflammation. Every child will experience a different combination and severity of symptoms. Speak to their parent to understand how the illness effects the child you know and what coping mechanisms they have found help to support the child. Normal parenting techniques and discipline are often not effective in managing the symptoms. It is important to remember that these children are ill and not naughty.

Supporting the PANS/PANDAS parent

Parents can often struggle both emotionally and physically with caring for a child with PANS/PANDAS.

- Sleep is often difficult and therefore offering help with daily tasks can be greatly appreciated
- Offer to cook some healthy meals
- Offer a safe place for the parent to talk and cry
- Offer to babysit so parents can have some much needed time out. Either during the day or evening
- Be understanding if the family repeatedly cancel plans last minute.

When offering support or favours to a PANS family, they may struggle to offer favours in return. Unconditional support will greatly ease pressure on the family.



Supporting the PANS/PANDAS sibling

Siblings often suffer the brunt of negative behaviours, and parents often have little time or energy to give siblings the attention they deserve. They can become very confused and scared. You can help by:

- Looking after the PANS/PANDAS child so that the parent can spend some 1-2-1 time with the siblings
- Take the sibling out for special treats
- Offer a safe space for the sibling to talk
- Help out with taking the sibling to after school clubs