

Caring for your Child

You are doing this already! By reading this leaflet and trying to find the answer to why your child has changed.

A family often needs to learn a whole new way of life when dealing with PANS and this can be difficult for the whole family. Please remember that this is often a temporary illness and with quick and effective treatment you can have your child back.

Caring for yourself

Feelings of isolation, grief and accusations of bad parenting are reported by the majority of parents, especially those who have been dealing with this condition for some time. Finding a trusted counsellor or friend to talk to, who has your best interests at heart and is prepared to listen, may offer some release from mounting anxiety.

Parents and carers often forget to take care of themselves. If you have a partner, try and take turns in having some time out if you can. See your doctor to make sure your own health needs are met and ensure that if you feel you are not coping with your own stress and anxiety that you ask for help.

Join our Facebook support group PANS PANDAS UK Support Group where you can share your story, ask questions and join our community of supportive and knowledgeable parents. They are waiting to welcome you to the group and sometimes it is only those who have been in your shoes who truly understand.

Caring for your other children

This condition is hard on siblings. Try if you can to spend time alone with your other children, no matter how short that time is, making sure they understand that they are loved and valued too. Consider approaching Young Carers, an organisation which offers support to children with ill siblings.



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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Parent Information Leaflet (September 2020)

c/o Baldwins, Pegasus House, Pegasus Court, Tachbrook Park,
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Charity number: 1178484

Parent Information Leaflet

PANS PANDAS UK

PANS

Paediatric Acute-Onset Neuropsychiatric Syndrome

PANDAS ICD-11: 8E4A.0

*Paediatric Autoimmune Neuropsychiatric Disorder
Associated with Streptococcal Infections*



PANS PANDAS UK
awareness support education

Does my child have PANS/PANDAS?

If you suspect PANS or PANDAS then it is likely that your child has undergone a dramatic personality change, is displaying some OCD, tics or issues with food, together with a number of other symptoms (see diagnostic criteria adjacent) usually following some kind of infection. In very young children, OCD can display as very intense anxiety or fears.

PANS and PANDAS are closely associated with infections and viruses. Both the initial onset and subsequent exacerbations are usually incited by a variety of childhood infections. The specific microbe most commonly recognised has been streptococcus (PANDAS). However, mycoplasma pneumoniae, as well as influenza, chicken pox and other common viruses have also been noted.

Symptoms may fluctuate as a child heals, but can often return or worsen if the child is exposed to another infection.

JOIN OUR FACEBOOK GROUP!
(PANS PANDAS UK Support Group)



Diagnostic Criteria

For a patient to be diagnosed with PANS or PANDAS, she or he must have experienced a sudden onset of OCD, tics or severely restricted food intake where the symptoms are not better explained by a known neurologic or medical disorder; with 2 or more similarly severe accompanying symptoms from the list below:

- Anxiety (particularly separation anxiety)
- Sensory and/or motor abnormalities
- Emotional lability (extreme emotions which can fluctuate rapidly and are not always appropriate to the situation) and/or depression
- Irritability, aggression and/or severe oppositional behaviours
- Deterioration in school performance:
- Memory deficits, cognitive changes, hyperactivity, inattention, impulsivity
- Behavioural and/or developmental regression
- Sleep disturbances, enuresis, or urinary frequency

Additional symptoms often reported by parents include

- Hallucinations and/or psychosis
- Phobias / concerns that their food is contaminated
- Trichotillomania (Hair Pulling)
- Enlarged pupils

“It’s like my child woke up as a completely different person!”

Tests your GP may consider

First step is to go and see your GP. Take the PANS PANDAS UK GP Information Leaflet with you. (This can be downloaded and printed from our website.) Taking detailed notes of daily behaviour since onset can help. Your GP may perform a number of tests and/or may refer you to CAMHS or to a paediatrician for further assessment and investigation.

It is important however, to note the following:

- PANS/PANDAS is a clinical diagnosis.
- There is no medical test to prove or disprove it
- You do not have to have a positive strep result to have PANS
- You do not have to have a current infection
- You do not have to have tics
- You do not have to have every symptom
- There is no age requirement
- An MRI and EEG may be required
- Children will present with differing symptoms

Tests your GP may perform

- Throat, nasopharyngeal or peri-anal swab to rule out strep on a 48 hour culture.
- ASOT, Anti-DNase B and Mycoplasma titres
- Vit D3, U+E, LFT, FBC, CRP, TFT, ANA
- Immunoglobulin and Immunoglobulin sub-sets
- Tests to rule out other infections based upon medical and family history