



The Tuberous Sclerosis Association

This document can be found at www.tuberous-sclerosis.org

It reports on a presentation at a meeting of the TS Alliance in San Diego in July 2001.

Behavioural and Emotional Disorders in TS

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These disorders include

Autism	Obsessive Compulsive Disorder
Attention Deficit Hyperactivity Disorder	Anxiety and Panic
Tourettes and Tics	MDD, dysthymia, bipolar
Oppositional Defiant Conduct Disorder	Psychosis (schizophrenia)

ADHD

This often co-exists together with autistic features. There are a number of interventions which can help, including

- Physical exercise often works, in particular high intensity exercise
- Music often works, especially with earphones, so that the person can be in their own little world with music)
- Distraction often works (don't explain things too much since this can make things worse, but do distract. Talk less, not more, since talking too much can confuse).
- Stimulants sometimes work (but maybe not if the child is severely cognitively impaired)
- Neurosurgery for epilepsy sometimes works (at least for a year or two)
- Some anti-epileptic drugs may work (such as lamotrogine or sodium valproate).

Tourettes and other Tic Disorders

To suffer from Tourettes you need 2 or more motor tics and one or more vocal tic. About 1% of the school population have Tourettes, and the percentage is higher in TS. Many more have just some motor or vocal tics, probably 25-30% in the TS population.

Tourette's coexists with ADHD in 50-70% of the general population, and with Obsessive Compulsive Disorder in 40-60%. Severe and incapacitating tics should be treated with atypical neuroleptics. Risperidon is also helpful for aggression but weight gain is a side effect. Most tics should not be treated medically. SRI's (for OCD) and stimulants (for ADHD) may be important adjuncts.

Obsessive Compulsive Disorder

(e.g. turning lights on and off, dressing and undressing) affects 1-2% of the general population – more in TS. It is comorbid with tics. SRIs and cognitive behaviour therapy

can help. It is difficult to implement cognitive behaviour therapy in low functioning children.

Anxiety and Panic attacks:

SRI (such as LUVOX) and CBT can be helpful (again, not with lower functioning children, for whom physical exercise is the best treatment).

Depression and Bi-polar:

For all children with TS who show marked behavioural change, depression should be considered. There will be hypothalamic symptoms – they will appear frozen, slow (with a slow heart rate), listless, with dull hair and a change in appetite). SRI (Prozac) and CBT will be only moderately helpful. It is important to look for the causes of depression.

Tubers in TS contribute to the bipolar problem. Bipolar problems are characterised by mood swings, unpredictability, violent behaviour, ADHD turning to aggression. There may be a family history, and AEDs can help, as can lithium.

Dysthymia

Involves someone being irritable, sulky and bored.

Oppositional Defiant Conduct Disorder:

This can be very anti-social and involve severe criminality. It is very early onset and is usually comorbid with ADHD, often from the age of 3.

Psychosis:

This is uncommon, affecting 0.6% of the general population and is probably uncommon in TS, too. It is often linked to epileptic discharge on the EEG or to actual seizure disorder. It may be corrected by AEDs, surgery or neuroleptics (such as Risperidone, Clobazine). There is anecdotal evidence linking it to a left-sided discharge. It is rarely seen before the teenage years, and incidence increases at puberty.

Self-Injury:

This may be due to a communication failure, may be used to protest, or in exaltation! It is common in those with autism, 30%. If it is measurable resulting in physical injury, something needs to be done. If it's attention seeking, then the message is to DISTRACT! Physical exercise is a good preventative treatment, and atypical neuroleptics such as Risperidone can also be helpful to break the vicious cycle.

Summary:

- A structured concrete education can help (such as TEACCH, ABA)
- Physical exercise, music, distraction, and talking less can help
- Medication can help, but try to remove the medication when you can. Only use if the problems are severe.
- Find a neurologist and a psychiatrist and get them to work together
- When a child with TS exhibits behaviour problems, the starting point should be that the child's behaviour is due to his TS.

