



The Tuberous Sclerosis Association

### **Behaviour in adults with Tuberous Sclerosis Complex**

Tuberous Sclerosis Complex (TSC) is a multi-system disorder which can affect almost any organ of the body. It is the calcified tubers on the brain (i.e. lesions that become hardened or sclerotic) which give rise to its name. Cortical tubers are thought to be associated with epilepsy (affecting about 80% individuals) and learning disability (affecting about 50%).

Cortical tubers are areas of disorganised tissue and can occur in any or all areas of the cerebral cortex. The effect they have on the individual may vary according to number, position and size of lesions. Tubers in the temporal lobe may be associated with autistic behaviour and future research will need to examine whether there are any correlations between other psychiatric and behavioural disorders and the presence of lesions in the corresponding parts of the brain. Behaviour typical of TSC may not be wholly attributable to the tubers however; research into the effects of TSC within brain cells themselves may provide helpful information e.g. how certain aspects of memory are affected.

Many adults with TSC, particularly those without learning disabilities, report feelings of anxiety, depression and/or anger. Other problems well recognised in TSC include socially impaired behaviours such as autism and Asperger's Syndrome as well as Attention Deficit Hyperactivity Disorder (ADHD). Aggression, self injurious and impulsive behaviour are also associated with TSC and in adults with epilepsy schizophrenia-like psychoses and hallucinations can also appear. There is also a higher rate of depression (sometimes with suicidal tendencies), paranoia and other psychiatric problems compared with the general population.

Treatment of psychiatric and behavioural disorders in TSC requires a well co-ordinated multi-disciplinary approach. Any adult with depression, anxiety, persistent feelings of anger or indeed any psychological difficulties is advised to visit their GP for assessment. In some cases medication or counselling may be appropriate; in others referral to specialised psychiatric or psychological services may be necessary.

In conclusion behavioural and psychiatric problems in TSC are common and are frequently the biggest problem for families. The Tuberous Sclerosis Association liaises and works closely with the clinics and research projects around the country. Contact details below:

**Cambridge TS Clinic**, Jane Taylor, Clinic Co-ordinator, University of Cambridge, Developmental Psychiatry, Douglas House, 18b Trumpington Road, Cambridge CB2 2AH Tel 01223 746090.

**London TSC Clinic**, Ginny Attard, Genetic Nurse Counsellor, SW Thames Regional Genetics Service, St George's University of London, Cranmer Terrace, London SW17 0RE, Tel 020 8725 0334

**Institute of Psychiatry TSC Clinic**, Diana Acklom, Professor Bolton's PA, S6DP Building IOP, De Crespigny Park, London SE5 8AF, Tel 020 78485256

Further information on TSC and the work of the Tuberous Sclerosis Association can be obtained from: PO Box 12979, Barnt Green, Birmingham, B45 5AN. Tel/fax 0121 445 6970  
[www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)