

WHAT TO DO IF YOU THINK YOUR CHILD HAS TOURETTE SYNDROME

- 1. There is no need to panic. TS is not an emergency and the news is probably not as bad as you may fear.
- 2. Contact your local Tourettes Syndrome Association for information. They can provide you with:
 - a. Description of TS and its various manifestations
 - **b.** General Information
 - c. Names of Doctors in your area who have experience in diagnosing TS.
- 3. Get educated abut TS yourself it is vital in being able to help your child. You can source information from libraries, websites, medical reference books and of course, the Tourette Syndrome Associations. Be careful with websites. Make sure they are put together by reputable organisations. Often personal websites contain sensationalised reports which make good reading, but will not contribute to your understanding of the condition as experienced by the majority.
- 4. TS is **not a rare** condition and many people are affected by it. fortunately, the majority of cases are mild. TS often occurs in individuals accompanied by other conditions, such as Attention Deficit Disorder or Obsessive Compulsive Disorder. This makes TS an individual and complex condition. No two people have it the same.
- 5. Before racing off to the doctor to get a diagnosis, it is recommended that you observe your child's symptoms from a distance. Before TS can be definitely diagnosed, the symptoms must have been present for at least one year, and generally have a waxing and waning character. Additionally, there is no 'test' to say you have or do not have TS. Diagnosis is based on the information you provide to the doctor and an observation of the symptoms. Other conditions must be eliminated first as they can produce TS-like symptoms.
- 6. Keep a short journal of symptoms so that you can accurately report them to your doctor. A detailed clinical history is necessary before TS can be diagnosed. TS symptoms notoriously vanish in the doctor's surgery, only to reappear in the car on the way home! Many parents have videotaped their children to verify the symptoms they have seen. A journal is usually good enough.
- 7. Remember, TS tics are involuntary and as such, a child has little or no control over them. Trying to stop tics by correction or punishment will lead to anxiety and stress for the child, which will definitely cause aggravated symptoms! It is like blaming a child for having diabetes or asthma! — It is unfair.

- 8. Don't blame yourself if you have already erred as in number 7 above. All parents of children with TS have done this in ignorance. Your are not alone. Just stop now.
- 9. Remember this most children who develop Tourettes go on to live productive and happy adult lives. This condition is not degenerative and won't change the intellect, lifespan or potential of your child.
- 10. Join your Tourette Syndrome Association. TSA's provide information and help that is very hard to get elsewhere. Most TSA's offer support groups as well as opportunities for social interaction, which will benefit your child. Take advantage of these opportunities by becoming a member. The greater the number of members, the more chance your TSA can affect government policy on TS disability. The more recognition TS receives, the better the public can learn to accept the behaviours that are common to this condition.
- 11. Love your child as much today as before you thought about TS He or she is the same as before TS and needs your help to manage this condition in life. Children with Tourette Syndrome are often advantaged in other ways they can have lively personalities, boundless energy, can develop enhanced musical and artistic ability and love life. They often grow into compassionate and interesting adults. Some children with TS will get moderately severe symptoms. There is treatment available and a good doctor will be invaluable. Your TSA will support you with knowledge and practical help in managing TS in your family.

Tourette Syndrome is a neurological disorder that affects thousands of Australians and is characterised by involuntary body movements and vocalisations called 'tics.' People with TS are normal in every other way.