

# **A Family Guide to Tourette Syndrome**

## **How can the family help the person with Tourette Syndrome?**

Usually, the first task of family members is to educate relatives and others about various aspects of the disorder. Often, neither the family nor the child with Tourette Syndrome (TS) thoroughly understands the full range of TS symptoms or how to manage them.

After gaining an understanding of the condition, an effort should be made to assess how TS might impact each member of the family. The family should try to promote the child's self-esteem and competency, and provide support in the challenges of work or school and in peer group relationships. The goal for family members should be to have flexibility to give special help when needed, but not to overprotect.

## **How can the family foster their child's positive self-image?**

Children see themselves through the eyes of their parents and will feel as much confidence in themselves as they feel valued. They will gain confidence through encouragement and praise.

One way that is often effective in encouraging good behavior and positive self-image is through the use of rewards. Too often we only punish for negative behavior. Rewards for good behavior can come in the form of treats, praise or just a simple hug. Simply saying "Thank you" or "Good job" will go a long way in cultivating your child's self image. Above all, always remember to follow through on your promises.

## **How do I know when to use discipline?**

Parents of a child with TS have to walk a fine line between understanding and overprotection. They are constantly faced with deciding whether or not certain actions are an expression of TS or just poor behavior. Parents must then determine the appropriate response.

The child should be encouraged to control what he/she can, when possible, and to try to substitute what is socially acceptable for what is not. Parents are urged to give their children opportunities for as much independence as possible while gently, but firmly limiting their child's attempts to use their symptoms as an excuse for unacceptable behaviors.

## **How can the family help in overcoming a child's developmental problems?**

Family members can easily become overwhelmed by the multitude of developmental challenges a child may face. The following guidelines may assist you in focusing on the areas that will most help the child.

- Understand everything you can about TS. Both you and your child should talk together about all aspects of your child's disorder so that you can make informed decisions when solving problems.
- Treat your youngster as a "normal child" whenever possible. Allow him or her to assume all the responsibilities needed to develop into a responsible adult.
- Have realistic expectations and set realistic goals. To allow for challenge and success, expectations and goals need to be reasonable according to the child's age, strengths and limitations.

- Allow your child to make choices. This helps children gain confidence in their ability to control their own lives and learn to take responsibility for their own actions.
- Encourage your child to continue participating in activities they enjoy, such as sports, computer, clubs, etc. This helps children build confidence and pride in varied areas of their lives.
- Make learning a part of daily life. Teach social skills and life skills on a day-to-day basis as situations occur. This teaches children to face their problems-not avoid them.
- Obtain needed therapy services. Supportive counseling, occupation, physical and speech therapists can help the child overcome a variety of problems.

## **Do children with TS have special education needs?**

While school children with TS generally have the same IQ range as other children, many do have special educational needs. These needs, combined with the problems inherent in dealing with the frequent tics, often call for special educational assistance. Discuss the possibility of special arrangements with your child's school, such as the use of tape recorders, typewriters or computers for reading and writing, as well as granting permission for the child to leave the classroom when symptoms become overwhelming.

When difficulties in school cannot be resolved, an educational evaluation may be needed. Your child is eligible for an Individual Education Plan (IEP) to address specific educational problems in school. Such an approach can significantly reduce learning problems that prevent children from performing up to their potential.

When it's time for homework, try to limit distractions. Create a quiet, secluded and organized homework area away from TV, games and other people. Additionally, when possible, break up long assignments into smaller segments. Once your child has learned to concentrate during the set time, you can then increase the intervals until the maximum amount of concentration is achieved.

## **What kinds of family services exist?**

The Tourette Syndrome Association sponsors local support groups throughout the United States. For a free catalog, publications and chapter information, call or write:

Tourette Syndrome Association, Inc  
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