

The Tourette Syndrome Association of Australia can be contacted at;

PO Box 1173

Maroubra 2035

Tel: (02) 93823726

[www,tourette.org.au](http://www.tourette.org.au).

info@tourette.org.au



May 27 1996
English

Telephone numbers are correct at time of publication but are not continually updated. You may need to check the numbers in the telephone directory.

What is Tourette's Syndrome?

NSW Multicultural Health Communication Service

website: [www.http://mhcs.health.nsw.gov.au](http://mhcs.health.nsw.gov.au)

e-mail: mhcs@sesiahs.health.nsw.gov.au

phone: (02) 9816 0347 _____

What is Tourette Syndrome

When her daughter was ten years old and began constantly flicking her hair back, Sue Cameron would make jokes about getting it all cut off unless she stopped. Soon the hair flicking was replaced by something else. This time her daughter Fiona started sniffing constantly, but doctors could find nothing wrong. Then Fiona began making squeaking noises like a bird. She even kept herself awake making the noises, so that sometimes her mother would spend hours each night, gently stroking her to help her fall asleep. What was happening to her normally happy, healthy, intelligent daughter?

Eventually she found the answer. A brain specialist diagnosed Fiona as having Tourette Syndrome, a movement disorder caused by a problem with the brain. This problem, which affects thousands of people in Australia of all ethnic backgrounds, causes people to make repetitive movements and sounds which they can't control.

These movements called "tics" include things like eye blinking, shrugging the shoulders, jerking the head, facial twitches and other repetitive movements of the body. Sometimes people with TS imitate other people's movements repeatedly. Sounds can include sniffing, throat clearing, coughing, grunting, barking or shrieking. Some people with TS repeat their own or other people's words, or even use obscene language or insulting words without meaning to.

This is a very distressing condition for people who have the disorder and for their families. What makes it worse is that there is little public awareness of the problem and people with TS are often assumed to be mentally ill or badly behaved. Neither of these things is true. Yet for most people with TS, seeing a film is out of the question, says Sue

Cameron, who is president of the Tourette Syndrome Association of Australia.

"They would be thrown out of the cinema" she says. "If people with TS are in a situation where they are trying to control their "tics" and their speech, the stress of trying to do this can actually make the problem worse. Doing normal, everyday things is difficult for people with TS. They are sometimes asked to leave restaurants. Even buying clothes is a problem - imagine what it's like to go shopping with a teenager, knowing that everyone can hear her swearing loudly in the fitting room."

There are also many schoolchildren with TS whose teacher assume they are just naughty and disruptive, says Sue. This is why the Tourette Syndrome Association is trying to educate teachers and school counsellors so they can be more aware of the problem. But Sue is also concerned that there may be some people with TS whose families keep them isolated because they are afraid of the condition and don't know where to go for help.

So far there's no cure for TS, although for some people the problem can be controlled with medication and people with TS can lead normal lives. Because the movements and sound caused by TS are often a reaction to things like stress and excitement, stress management and relaxation can also help.

The Tourette Syndrome Association, which provides information and support for people with TS and their families, would like to hear from people of all ethnic communities who either think they may have TS themselves or have a relative with the disorder.

Besides helping people with TS contact health professionals who understand the condition, the Association will also try to put people with TS and their families in touch with others who speak the same language.