



THE HISTORY OF TS TREATMENT

Part 1—The (Not So) Good Old Days

Life with Tourette Syndrome has always had difficult moments. We're lucky to live in a time when TS is acknowledged as a neurological disorder. That wasn't always the case. TS had been mistaken for everything from insanity and demonic possession to a lack of willpower or the result of poor parenting. Some of the earlier misconceptions are funny, others are sad, and some proved to be dangerous to innocent individuals. The treatment of TS has reflected the changing nature of medical

care as doctors and patients moved through waves of different approaches to this mysterious disorder. As the 21st Century begins, pieces of the genetic puzzle are fall-

ing into place and a new era—with new approaches to the treatment of TS—is on the horizon.

A Short History

Most histories of TS begin in 1825 with Jean Itard's descriptions of the Marquise de Dampierre. The then twenty-six-year old noblewoman was notorious for shouting inappropriate or obscene words in the middle of conversations. Itard, who was the chief physician at l'Institution Royale Sourds-Muets in Paris, vividly described her inability to control these outbursts. In 1885, one year after the Marquise's death, Georges Gilles de la Tourette used Itard's descriptions of the Marquise's symptoms as a case study for his paper on what he termed the "maladie de tic." The disorder was then named for Tourette.

There were, of course, many people with TS before the Marquise. The confusing nature of this neurological disorder—the range of tics, the waxing and waning

of symptoms and associated disorders—Obsessive Compulsive Disorder (OCD), Attention Deficit Disorder (ADD), and Attention Deficit Hyperactivity Disorder (ADHD)—made TS a mystery to both doctors and patients. Individuals with TS symptoms were mistakenly considered insane, possessed by demons, weak-willed or simply eccentric. Some of them thrived but others suffered at the hands of misguided health care professionals.

The misdiagnosis of people with TS has continued until relatively recently. Dr. Ruth Bruun (former Chair, TSA Medical Advisory Board) comments, "I've had some older TS patients who were diagnosed as schizophrenic and spent time in mental institutions. I'd assume that in early times there were more of them." In the past, some people with TS were confined to mental institutions or subjected to exorcisms and other strange treatments. "I wouldn't be at all surprised if some people had been persecuted as witches," Dr. Bruun speculated. She confirms how far we've come in both the treatment of people with TS and in understanding the nature and variety of the human condition.

Historical Figures with TS

Although it is difficult to look back and diagnose historical figures, contemporary descriptions of both the composer Wolfgang Amadeus Mozart and the writer Samuel Johnson (best known for his *Dictionary of the English Language* published in 1755 and as a famous raconteur) lead some people familiar with TS to conclude that both men had Tourette Syndrome. It is far more likely in the case of Johnson.

James Boswell met Samuel Johnson and traveled with him in 1773. Boswell then wrote a biography of his friend entitled *Life of Samuel Johnson* in 1791 which included various descriptions of what he viewed as eccentric behaviors.

"... while talking or even musing as he sat in his chair, he commonly held his head to one side towards his right shoulder, and shook it in a tremulous manner, moving his body backwards and forwards, and rubbing his left knee in the same direction, with the palm of his hand. In the intervals of articulating he made various sounds with his mouth,

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"Everything from restraints to arsenic were used as treatments for TS-related tics."

Awareness 2002

Marking TSA's 30th year, the theme of the 2002 TSA Awareness Campaign is "Building with Basics." Chapters and support groups across the U.S. will hold events that emphasize the hands-on work of the chapters. Awareness is not just about explaining tics and associated disorders, it is making sure that every child with TS receives the best education available, that every adult with TS will have the opportunity to succeed in a chosen field and that every person with TS will be able to live, shop, travel and relate to other people without prejudice clouding their encounters.

Local events include family days at ballparks and amusement parks; tag sales, car washes, book signings, gift wrap booths at malls for Mother's and Father's Day shoppers and picnics. Chapters will also reach out to local educational and medical institutions with seminars, mailings and meetings. Call your local chapter to find out what is planned in your town and how to get involved.

