

GROWING OLDER WITH TS

Tourette Syndrome waxes and wanes in unpredictable cycles. Symptoms may also disappear only to resurface decades later. Growing older is never an easy process and TS presents a special breed of complications and challenges. But awareness has changed the way individuals with TS are perceived, at school, at work and in social situations. The next generation to grow into old age with TS will have an easier time explaining it and a wider variety of treatment options, but there is a great deal they can learn from members of today's older generation. For this story we've tapped members of the TSA family ranging in age from 49 to 91 and two expert physicians.

The Disappearing and Reappearing Act

Ruth Bruun, M.D., has treated many individuals with TS during her long career. She notes that for most people with TS, symptoms lessen in late teens and early twenties. "Most of the people I've treated as children are doing very well, but, unfortunately, for some people there is a reoccurrence in their mid-forties. I've looked into reasons, but haven't found anything consistent. By and large, most of these people have learned to cope with their tics."

Cathy Budman M.D., Director, Movement Disorder Center in Psychiatry, North Shore University Hospital-LIJ Health System in New York, said that, "Adult patients with TS are often surprised when their tics dissipate or improve for years and then suddenly return with a vengeance. It's very demoralizing and often unpredictable."

When asked what Dr. Bruun would suggest to doctors treating an individual experiencing such a recurrence, she said, "... the first thing to do is find out if anything else is going on. Treating that (other condition) will sometimes take care of the tics."

Professor Donald Donin, 65, of Kingsborough Community College in New York,

experienced both the hiatus and the return of symptoms. "From approximately age 14 until 44, the TS had let up a bit. Therefore, this enabled me to start my career."

Time and TS

Other people with TS never experience this "break" in symptoms. They go on with their lives coping with the same kind of waxing and waning they experienced as children and adolescents. For some, the experience of years of tics has a cumulative cost on their general health.

Years of head-jerking tics have taken their toll on Paul Devore, national TSA Board Member and Chief Executive Officer of Financial Management Services, Inc. and President of Pacific Insurance Management Corp. Paul said he may need surgery to repair the injuries to his neck. Professor Donin said that repetitive movements exacerbate the pain in his arthritic joints and that after years of squeezing his eyes too tightly, "...my contact lens damaged one of my retinas."

Retired pilot David Larson, 72, did not receive his diagnosis of TS until a few years ago, but he has had symptoms for most of his life. He describes his squirming and jiggling tics as having "... parts of my body in constant motion. The TS symptoms are always with me. They can get bad enough to bother my sleep, but I try to ignore them and avoid taking medication."

Medications used to treat TS symptoms may also have an impact on long-term health and well-being. Some adults who have had mixed experiences with drug therapies in the past are reluctant to try new ones. Dr. Budman said that, "Many adult TS patients have had years of unpleasant medication side effects and may be even less willing to consider medication intervention but are often very keen to learn about the latest findings. I find they are sometimes more enthusiastic about taking the initiative to embark on non-pharmacological interventions such as exercise or meditation and

relaxation to help cope with their tics."

As reactions to the medications used to treat TS varies widely from individual to individual, each person's experience is different. Professor Donin had a very specific complaint about the impact one particular drug, Topamax, had on his general health, causing metabolic acidosis, increasing nearsightedness and softening his bones. He now has arthritis in his feet where bones had broken and then healed.

If I'd Only Known Then What I Know Now...

Today, children routinely receive an accurate diagnosis of TS after a year or two of symptoms. Many adults in their forties, fifties, sixties and up didn't learn they had TS until decades after the onset of symptoms.

Richard Milo, 50, exerted a tremendous amount of energy controlling his tics. Without a diagnosis, he had no help in this struggle. "Unfortunately when I was young there was not much known about the illness. It was a time when I was looked at as 'strange' even by my own parents who at times would threaten to put me away if I would not stop the tics and grunts. I knew that they would never do this; they were loving people but they thought it was just a habit that I refused to stop. I eventually learned to restrict my tics to a localized area such as a constant twitch of the right hand and jerk of my stomach muscles when I was around them as well as other people. But of course when left alone I would explode in every jerk twitch and grunt imaginable to release the pent up urges."

According to Mr. Milo, the years of effort keeping his tics, and symptoms of related neurological disorders, under control eventually led to the loss of his business and family. Diagnosed at 44, he has rebuilt his life with a focus on his artwork.

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