

FROM THE EDITOR

Over the past year there has been more interest in Tardive Dyskinesia by consumers as well as the medical community. More research and more accountability by the medical community has brought many consumers with TD out of the closet. Our TD Support Group has survived the past two years sharing personal experiences with mental health professionals who have been our members' care providers.

As project manager of our group I have met with members as a group and had 1-1 meetings. I have also attended the Academic Morning Rounds of Vancouver Community Mental Health services. The subject was Tardive Dyskinesia. It was interesting to hear from mental health professionals dealing with the problems of treating with Tardive Dyskinesia. It had its ups and downs but there appeared to be more accountability. One comment by the speaker to one of the doctors was that if he didn't take time to test for Tardive Dyskinesia in his patients regularly he could have to deal with a lawsuit. But overall it was encouraging.

At least more cases of Tardive Dyskinesia are being recognized and more attempts are being made to treat TD. More needs to be done as there are still many sufferers falling through the cracks of the stigma of mental illness and Tardive Dykinesia. More consumers need to admit they have it because it often goes untreated and when it

is left too long it is irreversible. We have to remember that we have the power.

A Personal Experience of TD

Tardive Dyskinesia has changed my life but not the psychiatric medicines that caused it. I no longer take neuroleptic drugs but my recovery from mental illness began the day I was finally supported by a health care team to stop taking the meds and engage in appropriate psychotherapy. Unfortunately, when I stopped the meds, the Tardive Dyskinesia symptoms appeared. Those neuroleptic meds had masked my early symptoms, so by the time I stopped taking them, the TD was well-established and permanent. Now I am learning how to live with the facial tics, sore mouth and throat and weakened voice caused by the TD, in addition to my mental health recovery work.

Through the CIF TD Support Group, I have learned how little research has been done on TD. I have found some relief with large doses of Vitamin E. I have also made important friends. We share our stories every month and look forward to seeing each other to talk about our experiences of Tardive Dyskinesia.

TD is shameful and unnecessary; Patients are not told about their TD out of fear of non compliance. I believe having safer medications, lower doses, and more emphasis on psychotherapy is the best treatment plan for mental health recovery.

By Susan Katz

