

Parkinson's hits old and young

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CONFERENCE:Speakers share latest information on debilitating disease

Parkinson's disease is not just a disease of the elderly.

Just ask Dr. Soania Mathur, one of the guest speakers at a conference held at Loyalist College over the weekend.

The event, hosted by the Parkinson Society Belleville Quinte Chapter in conjunction with Parkinson Society Central and Northern Ontario, attracted droves of people of varying ages.

The conference, dubbed 'Life After Diagnosis,' was staged to raise more awareness about the disease during April -- Parkinson's Awareness month.

Mathur told a crowded Alumni Hall she was just 27 when she was hit by Parkinson's disease. Mathur said she was rattled by the revelation the illness could affect her at such a young age.

"I really denied it and busied myself with my career and marriage," she said. "I avoided the topic for a very long time."

The mother of three, who has been living with the disorder for 12 years, said there is a perception that Parkinson's is an "old people disease."

Mathur was faced with the daunting task of caring for herself while treating her patients, forcing her to develop her own coping mechanism to fight the disorder.

She said the constant tremors created some barriers earlier in her career, but she quickly learned to adapt to those deficiencies.

She said until renowned Canadian actor Michael J. Fox made his diagnosis public, Parkinson's disease was a back burner issue.

"There aren't any really good test to check for Parkinson's, so it's often a clinical diagnosis," she said. "By the time your first symptoms appear, almost 80 per cent of the cells that produce dopamine have gone."

During her speech dubbed 'Shakin' But Not Stirred,' Mathur encouraged people suffering from Parkinson's to maintain a positive mindset in an effort to block the illness from taking control of their lives. She recommended exercise which reduces the symptoms of the debilitating disease.

Some of the other guest speakers at Saturday's event included a motivational speaker and lawyer, who advised the audience on ways to plan for life with Parkinson's. The keynote speaker was Dr. Stuart Reid, from the Movement Disorder Clinic, in Kingston. Reid gave an update on the latest treatment and research being done for Parkinson's disease before fielding questions.

Bev Hanna-Jones, head of the Belleville Parkinson Society, said the conference is aimed at providing a support system for people suffering from the disease.

The local chapter is one of two local Parkinson's agencies that cater to people dealing with life after diagnosis. The chapter also operates a young onset program that for people under the age of 50.

"We want people to know that they must see a neurologist," she said. "It's so individualized that a neurologist is the first step."

That program has about five young onset participants, who attend the monthly meeting. There is also an additional 40 people who are a part of the general group gatherings at the Quinte Living Centre.

She estimates the agency is only catering to about 10 per cent of the people in the community suffering from Parkinson's.

"A lot of people don't want to face it when they are diagnosed," she said. "Not everyone comes to a support group."

Stephanie Ossanna did. She started the young onset

program two years ago. She was a 35-year-old single mother raising a 12-year-old daughter, when she was diagnosed with Parkinson's five years ago.

"It was really difficult because I had a daughter and I couldn't let her see me fall apart," she said.

Ossanna shrugged off the litany of early warning signs that started popping up. She started experiencing an internal tension in her arm along with bouts of depression.

"You can feel the tremor inside the arm but you can't necessarily see it yet," she said. "From the internal tremor it became an external tremor. So you can physically see a very violent tremor."

She said Parkinson's can be marked by symptoms such as muscle stiffness, sleeplessness and depression. She said it sometimes takes several months before doctors can make a clinical diagnosis after eliminating a slew of other possibilities.

Ossanna said it takes longer for younger people with careers to come to grips with the disorder because of the stigma accompanying the disease.

Ossanna said the Saturday conference was geared mostly toward young onset information but it catered to everyone who attended.

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