

Hormone may be key to relief for patients, caregivers

October 13 2016, by Paul Mayne

Through the worry, Linda Jacobs welcomed the sense of relief she felt when doctors diagnosed her husband, Ray, with frontotemporal dementia (FTD). She finally had an answer for many of the questions she had regarding Ray's ongoing behaviour.

"The two qualities they say you need as a caregiver in dealing with someone with FTD are thick skin and a good sense of humour. I believe it – I'm just not entirely sure I always have them," Jacobs said. "Some days I have them; others I don't have enough to get through the day. (Ray) has a lot of frustration and I can't help him with that as much as I'd care to. All I can do is really love him and be there for him. At the end of each day, his biggest concern is asking me, 'We're still okay, right?'"

Patients with FTD develop deficits in fundamental components of social and emotional behaviour, including emotional blunting, apathy, inappropriate language and a loss of empathy for even their closest family members. The disease can go undiagnosed initially because of the subtle changes it brings to personality, decision-making and judgement.

Like most, Jacobs was unfamiliar with FTD and its symptoms. Looking back, she said there were clues she didn't pick up early on.

"It was like his personality was changing and he was trying to drive me crazy – and he was doing a great job. I was feeling like I was going to lose it," said Jacobs, who was also a caregiver to her father, who suffered from Alzheimer's, as well as her mother as she got old. "What makes it

different and more challenging from other conditions is the lack of insight they have. As my mom got older she had heart disease and arthritis, but I could reason with her. With FTD, Ray had no insight whatsoever."

While there is no cure for FTD, one Western researcher is looking to mitigate symptoms of the disease for patients like Ray and, in turn, lessen the heavy burden faced by caregivers like Linda.

Clinical Neurological Sciences professor Elizabeth Finger is studying the treatment possibilities of oxytocin, a hormone and neuropeptide in the brain that plays an important role in social behaviour and empathy.

The second most common dementia behind Alzheimer's, FTD boasts different symptoms. The disease affects personality rather than memory and presents itself in patients in their 50s or 60s, at least a decade earlier than most Alzheimer's patients.

"They can have perfectly normal functioning skills but start to be disinhibited and make comments that are rude, inappropriate, racist or sexist, which can come on gradually," said Finger, a Parkwood Institute neurologist and Lawson Health Research Institute scientist. "They can even lose empathy for other people, even their own children and spouse. As the disease progresses, it becomes more and more prevalent and frequent."

The average [frontotemporal dementia](#) patient goes about five years with symptoms before diagnosis because the disease can overlap with others issues, including depression. If there is no family history of FTD, it can be hard to diagnose early.

"It doesn't impact treatment. There currently aren't treatments to slow the disease or stop it," she said. "There are treatments in clinical trials at

the moment looking to slow or prevent the disease, so soon that diagnostic uncertainty is going to be problematic."

Finger, recently received a Canadian Institutes of Health Research (CIHR) 2016 Project Grant to look at the use of intranasal oxytocin as a treatment for these deficits of social apathy, empathy and related social behaviours in FTD patients. The funding is worth \$1.4 million over four years. Finger is the lead investigator of the 15-site study, which includes five locations in Canada and 10 in the United States. Her work is also supported by a separate grant from the Canada-based Weston Brain Foundation (Weston Brain Institute).

The body normally produces oxytocin but doesn't reach its intended target in FTD patients, said Finger. So its transmission is inefficient. By increasing the levels oxytocin in the patient's body, in a sense flooding the area, Finger hopes to increase its effectiveness.

Earlier studies found caregivers rated the behaviours of their patients better on the day of a dosage, as well as the patient's ability to recognize facial expressions.

If proven effective, oxytocin would be the first symptomatic treatment for patients.

"They (patients) often have no idea of the changes (after treatment) since they don't have insight into the problem," Finger said. "If you ask them how their social skills are, they think they're great. From a caregiver perspective, even a small difference would be great."

In the study, Finger wants to see how much improved the patient's empathy and social interactions are, as well as also look at caregiver distress and how it has improved.

Jacobs, who had been married to Ray for 44 years, said her husband realizes he is unable to do things like before. They don't go out in public much anymore; she is anxious about having the grandchildren over in fear of what inappropriate things her husband might say.

"I think he feels vulnerable. What an awful way for a man of 67 to feel – not being able to work or drive. He was an accountant and now his wife is giving him an allowance every day. Why would he be happy with that?" she said. "His emotions are so unpredictable. When I get home from work, I never quite know what I'm going to walk into."

Jacobs hopes she will be able to participate in Finger's ongoing study, if not to help her husband, but to help other families whose loved ones have yet to be diagnosed.

"We all know it's a downward journey we're on. But if you can get days where life can be a little more comfortable for him and for us, that would be wonderful," Jacobs said. "If there can be anything positive that comes out of this difficult journey that can benefit someone else in the long term, be it medication or treatment that will make their quality of life better, it helps me feel there is value in what we're going through."

Provided by University of Western Ontario

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