

# Cutting through the fog of young onset dementia

by Cindy McCaffrey

Nine years ago, at age 42, my husband John came home from work for what would be the last time and said, "I can't figure it out any more." A few weeks earlier, he had complained of being in a "brain fog" and mentioned that his martial arts instructor had started commenting on his muddled footwear.

The red flags shot up for me when John admitted that at work he couldn't keep his clients straight and didn't pass the new software tests. He had always been both savvy and had never failed anything in the twenty-plus years that I had known him.

A lengthy medical investigation into John's cognition problem began with a battery of lab tests. We patiently waited for — and dreaded — their results.

Nothing was found to be out of the ordinary so he was sent for brain imaging and neuropsychological tests. Upon receiving the results, John's physician said, "This is rare." Quit your job at the bank and shovel snow for a living.

I quickly learned to get second, third and even fourth medical opinions. Early on, John's issues were diagnosed as depression or "moodiness" and possible causes ranged from Supranuclear Palsy, Mild Cognitive Impairment and Young Onset Dementia (YOD).

Our new physician eventually referred us to a neurologist who determined through a PET scan that John has Frontotemporal Dementia (FTD), a disorder where the brain cells responsible for executive functioning skills — planning, problem solving and managing time — atrophy and die. Believing that John would not work again, the neurologist signed off on his long term disability and CPP paperwork.

Like all other forms of dementia, FTD is progressive and fatal. It usually strikes people between 50 and 70 years of age but can affect those in their 30s. There is no cure for FTD and no way to slow its progression; the life expectancy is between three to 10 years after diagnosis.

The news was a major blow to us and our two children.

John, aged 12 and 17. The first few months we lived in a fog, forcing ourselves to be a normal family while downsizing to a new house, taking on new roles, and creating new goals.

Looking back, I realize that with the help of a supportive family, friends, the medical community and agencies such as the Alzheimer Society of Calgary, we've come a long way and have even grown in positive ways.

Because of the stigma around dementia, many families turn inward and deny there's a problem. However difficult it seems, it's important to start the dreaded conversation early, and to discuss honestly the symptoms and prognosis.

I've only met a few people who flat out asked me what John's disease is, about and how best to communicate with him. Understandable, people are uncomfortable in an uncomfortable situation but it's more important to prevent the person with dementia from feeling isolated and without purpose.

The Alzheimer Society has a "Let me reintroduce myself" template that families can use to start a conversation with friends on what is going on with their loved one and how to stay connected.

The document can easily be tailored to include whatever information the family wishes to share: a description of the dementia and its symptoms, their loved one's favorite activities and what they like to talk about, or where they'd like to have a visit. This communication breaks the ice, takes away the awkwardness and helps friendships stay vibrant.

Relationships and communication within our own family also needed nurturing. Thankfully we were



referred through Seniors' Health to social workers and psychologists who helped us re-frame our situation, teaching us that we can still have a somewhat regular and even fun life with dementia in our midst.

A social worker told our kids at a family meeting, "Your dad's not stupid," and proceeded to compare John's faulty/neuro connections to bridges that had been washed out in a storm. I'm thankful that he helped the kids understand the problem and how best to deal with it, because I was at a loss.

Considered firmly remind me of the many ways to take care of myself as a caregiver and new breadwinner, including changing priorities and standards, the dust can wait, but our time as a family won't. I was to say "No!" to guilt, and not to beat myself up for ending take-out, having a nap, or losing my cool.

One of the best pieces of advice was to keep up friendships and stay active in the community, because the sad reality is that friends often disappear when a diagnosis of dementia occurs.

I was also encouraged to do things I enjoy such as taking art classes and to

learn new things like drawing. Of course they had to mention that exercise is a perennial stress reliever (I'm still working on that one).

Throughout this journey John's motto has been, "I just try to have a good day every day." It's often hard to follow his motto, but reframing helps. We try to make the best of every situation — things can always be worse. At first I was miserable, realizing that we will never travel to Europe and Asia, but happily we have found respite many times in our own beautiful backyard of Kananaskis Country and British Columbia.

Caregivers suffer from a tremendous amount of stress and because of it, often die before their loved one does. I joined the Young Onset Dementia Caregivers' Support Group to commiserate with other people my age. It has been a blessing to have the opportunity to vent and learn from others who have shared this miserable journey.

A common issue among the members of our group is trying to find enough things

for our spouses to do during the day. They are young and still want to hike, garden, paint, and otherwise be busy in their community, but most of us are still working and can't be at home to plan and supervise.

There are limited options for supporting people with YOD in Calgary so a volunteer and I are developing a full time day program to fill the gap. We will provide stimulating, purposeful activities for people with YOD, while giving time for caregivers to work, play or take a much-needed rest.

My advice to anyone taking the role of caregiver is to be kind to yourself, find out what support is available in your community and take any help that's offered (ask for it if it's not). Learn as much as you can about the disease and who else is suffering from it so you can build a strong network. Having an arsenal of support and strategies will get you through the stress healthier and more resilient.

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