

## Where there's smoke, there's sickness

Ontario's firefighters are falling prey to ALS at a rate much higher than the general population

JESSICA LEEDER

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The problems started for Al Pettit five years ago with a nagging weakness, and a peculiar feeling beneath his skin.

"One day I was sitting on the toilet. I looked down, and I noticed my calf was wiggling," the former Mississauga firefighter said. At the time, he was on a seven-week trip to the Philippines. He attributed the twitching to his tiring travels and to overindulging in foreign beer.

But at home a couple of months later, he still felt weak and his calf was still wiggling. He tinkered with his heart medication, but "then both calves started," he said.

While waiting for doctors to figure out the problem, Mr. Pettit, a 238-pound firefighter who had been having trouble mustering the strength to pick up a ladder, did a little Internet research.

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"I diagnosed myself with ALS," he said.

Eventually, Mr. Pettit's doctors came to the same conclusion: He was battling amyotrophic lateral sclerosis, or Lou Gehrig's disease, an incurable neurodegenerative disease.

"Basically, if they tell you you've got ALS, you're screwed," he said. "... It's just a matter of time."

A small collection of Ontario firefighters know that all too well.

At least seven out of the province's 10,500 full-time firefighters have recently developed ALS, including two pairs from the same stations. One of the pairs, who worked most of their lives together at Mississauga's 500-person fire force, are in the midst of losing their battle with ALS. The other pair, from a 30-person fire hall in Owen Sound, Ont., have already succumbed to the disease.

There's no medical consensus on what causes ALS. But the fact that so many firefighters have contracted it - and that their relationships overlap - is a contravention of incredible odds: Statistically, only one or two people in 100,000 get the disease.

"The fact that this has happened in seven firefighters is a concern," said Lorne Zinman, director of the ALS clinic at Sunnybrook Hospital in Toronto. "It certainly bears further investigating."

Complicating the issue is the fact that occupational health and safety statistics are not tracked in Canada. Partly as a result, wary scientists caution that the deaths of the Ontario firemen could be no more unique than those of the 3,000 others felled by ALS in Canada each year; the link between their quick demise and the toxicity of their jobs could be sad happenstance.

The counterargument is backed by a small but increasing number of firefighters who feel their brethren wouldn't be perishing from this cruel disease if they'd worked jobs that spared their lungs from vacuuming in toxic chemicals.

While science doesn't yet support their case - no major studies have explored the link between firefighters and ALS - it's buoyed by an increasing amount of anecdotal heft.

### **The second in his generation**

The wheelchair ramp - a sturdy wooden bridge from the gravel driveway into the house - took up most of Nancy Blair's garage for a month more than she needed it.

It was something to hang on to after her husband, retired Owen Sound Fire Captain Jim Blair, died in June, at 59, of ALS. In his final days, the gruff, 240-pound firefighter, hardened by a military background, was reduced to 90 pounds, with no voice. The disease ate him up in 2½ years: about half the time doctors originally suggested.

Mr. Blair's diagnosis in 2005 prompted the family to plunge with warp speed into retirement activities they once planned to pursue leisurely. They managed a European bus tour and a Hawaiian cruise. Then the impossibilities began for Mr. Blair, including travelling, even walking up a few steps into the house.

That's when a large team from the city fire hall showed up to build the ramp. Doug Barfoot, one of the squad's health and safety representatives, said the support was not surprising: The small fire hall has been historically tight-knit.

They may also have been propelled by the alarm bells Mr. Blair's sickness set off among their ranks. He is the

second fireman from his generation at the 30-person hall to come down with ALS.

The first, Ron Muzzell, died in 1990 at age 52, although the bulk of his working years overlapped with Mr. Blair's. Mr. Muzzell's death came just seven months after he started experiencing the weakness, muscle twitching and loss of motor skills that are the early markers of the disease.

Still, his wife Gerri recalled, at the time little thought was given to the possibility that his ALS was connected to his job. But Mr. Muzzell's death wasn't lost on his friends, who immediately suspected a link between ALS and firefighting when they heard, in 2005, that it had hit Mr. Blair, too.

Mr. Barfoot, a quiet, mustachioed fireman who prefers to spend days off in his workshop with his dog - far removed from office work - began devoting his spare time to an exhaustive hunt. Combing through files of decades-old fires, Mr. Barfoot was hoping to unearth a noxious blaze that both his comrades had attended, and a clue to the cause of their disease.

"I went through all the fires back to 1958. I couldn't come up with anything."

Frustrated, Mr. Barfoot turned to a pair of occupational disease representatives at the Ontario Professional Firefighters Association, the provincial firefighters' union.

While much of their work in recent years has focused on amassing a cache of files on firefighters suffering from job-related cancer - with a longer-term goal of helping them win rights to workers' compensation - it turns out the pair had also come across a small handful of ALS cases.

One of them was Al Pettit's.

### **Making it a big deal**

On a recent July morning at the home in Orangeville, Ont. where he retired, Mr. Pettit, a white-mustached, bald man with a rounded belly, is wearing blue jeans and a golf shirt with the Mississauga firefighters logo.

"There's a lot of firefighters who aren't kind of making a big deal about it," said Mr. Pettit, propped up in an electronic wheelchair and clutching a coffee mug with disobedient fingers. "I'm trying to make a big deal about it. I really do feel in my particular case ALS was caused by firefighting."

Mr. Pettit, 58, spent almost 33 years with the Mississauga Fire and Emergency Services in relatively good health, save for some heart trouble. The end of his career began when he failed a routine physical test.

"I couldn't pick up the ladder. My heart was supposed to be in good shape, but I just couldn't pick up the ladder."

Mr. Pettit was relegated to light duties. Frustrated and growing weaker, he left the force. Shortly after, in November, 2003, he was diagnosed with ALS. By January, 2005, his breathing was so bad he couldn't lie back without his lungs threatening to collapse.

"It feels like something's pushing on your chest - like you're smothering. It does give you a certain amount of fear that if you go to sleep, you might not wake up."

When he found out about his disease, Mr. Pettit had difficulty staving off depression. But he's learned to manage. By night, working patiently with deadened hands that no longer have the muscle to lift a piece of tissue paper, let alone a fire hose, he clicks away at his computer with the help of special software, administering an ALS chat forum. Through his flaming "Grampa Al" fireman avatar, Mr. Pettit has built a virtual haven for thousands looking for comfort and answers about the disease. By day, he often lobbies for research dollars to nudge along the murky science around ALS.

"I don't necessarily think I'm going to beat this. I know I'm screwed," he said. "But I'm actively trying not to get into the 'woe is me, I'm going to die' routine. ... I'm living with it the best I can."

Mr. Pettit is one of two firefighters from the Mississauga detachment now suffering with ALS. He has a hard time believing more names won't one day be added to the list. He said that for most of his career, he - and many others from his era - shied away from using air masks at fires.

"The idea was, you get in, you get low, you stay down out of the smoke. You didn't use a breathing apparatus for just general firefighting. It was heavy, it was constricting. As soon as the air was sort of breathable, you'd have the thing off. It was a macho thing."

There's no way to know for sure whether the chemicals Mr. Pettit, Mr. Blair, Mr. Muzzell and the others took in at fires had anything to do with their ALS. But the provincial firefighters' association is willing to hedge its bets.

"I would be very surprised at the end of the day if there is not a relationship," said Paul Atkinson, a former Toronto firefighter and one of the provincial association's occupational disease representatives. "I don't think it is a local problem that we're going to see just in Owen Sound. I think we'll see, just like cancer ... that it cuts across the board of firefighters. It wasn't too many years ago that there wasn't science out there on cancer and firefighting. Now, it's becoming blatantly obvious."

### **Pushing the pieces together**

That's in part due to the gumshoe tactics Mr. Atkinson and another representative, Hamilton firefighter Colin Grieve, used in their efforts to force the province to recognize the link between a collection of cancers and firefighting. For seven years, the pair have been collecting cancer claims from firefighters across Ontario and flooding the provincial compensation board's system with them to try to establish a pattern of sickness on record.

While they knew it would be hard to establish a definitive causal relationship, their hope was to push the puzzle pieces close enough together to persuade provincial politicians to change compensation laws.

Last spring, their efforts finally paid off. Queen's Park voted unanimously to recognize eight types of cancer as job-related when contracted by full-time firefighters. It was hailed as an important gain in the union's ongoing crusade to establish the connection between middle-aged members "dropping like flies," as Mr. Atkinson puts it, and a plethora of diseases now thought to be contracted on the job.

"It's not about the money," Fred LeBlanc, head of the provincial firefighters' association, said. "It's about ... recognizing there's a lot of hidden risks our members are suffering from in greater numbers." The victory also opened the door to add more diseases to the roster of those applicable for compensation. ALS has since entered the running for the next frontier.

Already, seven firefighters have logged ALS claims with the board. All have been rejected because firefighters cannot prove they contracted the disease through their job: an impossible task, given that the specific cause of ALS remains unknown.

While about 10 per cent of ALS cases can be traced to family genetics, the litany of potential causes of non-genetic cases has doctors and scientists divided.

Various studies have suggested intense physical exercise might cause ALS; others have identified high incidences of the disease in Italian soccer players, people exposed to pesticides, industrial workers and Persian Gulf war veterans. More point to aluminum toxicity. But for every study that suggests a clear environmental link, there seems to be another that muddies things. "In the literature, we're chasing our tails," Sunnybrook's Dr. Zinman said. "You do a study, another one contradicts it. It's complicated. This is not a trivial disease."

Dr. Zinman belongs to a faction of ALS specialists who believe the disease is caused by a complex mix of genetics and environmental exposure. Simply put, their theory is that if a person has a genetic flaw that

predisposes them to ALS, the engine of the disease can be turned on with the right environmental keys. But what constitutes such a key?

Encountering a cluster of patients suffering from the disease can help researchers narrow potential causes. However, the question of whether these firefighters constitute a cluster is contentious; the broad menu of chemicals they're exposed to on the job further complicates things.

"Firefighters have a higher rate of heart attacks, respiratory problems and cancers. They're exposed to so much toxic crap that it's probably not enormously surprising there would be a neurological component," said Chris Shaw, a professor in the department of ophthalmology at the University of British Columbia. "But proving it is going to turn out to be a real problem. They're exposed to so much stuff. Proving any one of those molecules is responsible is going to be impossible."

Mr. Atkinson is doing his part. Whenever he hears another firefighter has been stricken with ALS, he asks the family to log a claim with the compensation board - even though it will be rejected - in hopes of laying a foundation upon which future claims will some day be upheld.

"To be able to function with this disease, it's very expensive," said Mr. Pettit, who added that he doesn't expect to live long enough to see progress on the compensation front. Right now, he's looking forward to the fall, when his grandchildren from the Philippines are scheduled to visit.

"Hopefully," he said, "I'll still be able to move my arms enough to put them around my little granddaughter and hug her."

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### **ALS primer**

ALS is a disease that affects motor neurons, which control voluntary muscle movement. As upper and lower motor neurons degenerate, the brain is unable to control muscle movement. Muscles waste away. In late stages of the disease, patients can become fully paralyzed.

Early symptoms often include persistent muscle weakness in the arms, legs and hands; difficulty speaking, swallowing or breathing.

There is no known cause of ALS.

ALS is difficult to diagnose because there are no definite disease markers: Typically, ALS is diagnosed after all other diseases are ruled out.

There is no cure or effective treatment.

Eighty per cent of people diagnosed with ALS die within two to five years, unable to breathe or swallow.

Statistically, men are slightly more likely to develop ALS than women.

Most people who have ALS are diagnosed between the ages of 40 and 70.

About 2,500 to 3,000 Canadians currently have ALS.

*Source: The ALS Society of Canada; United States ALS Association*

END OF MACHISMO

Tough guys in masks

"There are no old smoke eaters. Wear your mask."

This is the advice Bill Sullivan, acting division chief for professional development and training for Toronto Fire Services, bestows on new recruits. It's meant to be interpreted as an order.

Air masks, or self-contained breathing apparatuses (called SCBAs in fire hall lingo), have come a long way since the days firemen were known as "smoke eaters" and grew long beards they could wet and stuff into their mouths to use as filters during fires. The only alternative was to stay low to the ground, where gravity was feeding cleaner air into the fire.

To help ease that approach, a special smoke hood was patented in the 1800s. It featured air tubes that fit into the firefighter's mouth and ran down his back to the ground.

"The idea was you could stand up in smoke and breathe air that was down low," said Peter McBride, a health and safety specialist with the International Association of Firefighters. "These were hard men."

By the time Mr. Sullivan joined the fire service 30 years ago, fire halls had been stocking modern air packs - steel compressed air canisters firefighters harnessed to their backs - for more than two decades. However, they were used grudgingly.

"There was a real smoke-eater mentality in the fire service, meaning tough guys don't wear masks," he said.

That mentality led the tough guys to some hard lessons, and many to early deaths. Now, Mr. Sullivan tells his recruits there's no excuse not to wear a mask.

The steel canisters have been replaced with lighter carbon fibre models, and many fire halls have had the packs built right into the seats of their trucks so firefighters can easily strap them on en route to a blaze.

"We all know the dangers associated with firefighting. There are diseases attributed to our job," Mr. Sullivan said. "There is no rational reason not to wear a mask. The machismo that goes with the job should not go in that direction."

*Jessica Leeder*

### **'Smoke-eaters' a thing of the past**

A sophisticated breathing apparatus reduces smoke-related health problems.

Alarms: LED display and vibration alert the firefighter to low air-tank levels.

Transceiver: Sends and receives information between firefighters and base command unit.

Alerts others when a firefighter is incapacitated.

TONIA COWAN/THE GLOBE AND MAIL: SOURCE: SCOTT AIRPACK

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