

ARTS & LIFE

A place to find comfort

PATH helps patients, families make their way through complex health decisions

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Dr. Laurie Mallery helped found the Palliative and Therapeutic Harmonization (PATH) Clinic at the Queen Elizabeth II Health Sciences Centre in Halifax. (Christian Laforce / Staff)



Carole Ann MacDonald shares a happy moment with her common-law husband Hugh Gauntlett, who has Alzheimer's disease. MacDonald says the PATH clinic at the QEII Health Science Centre makes her feel so much less alone in caring for her husband. (Peter Parsons / Staff)



Hugh Gauntlett, who is an Oxford University graduate, former Royal Air Force intelligence officer and former CBC-TV executive, now listens to music eight to 10 hours a day. He has Alzheimer's disease and can no longer read or write. (Peter Parsons / Staff)

HE'S THE CONDUCTOR of a mysterious orchestra, the maestro of a fading tune. His arms rise in reveries. His head sways to symphonies.

But the synapses in Hugh Gauntlett's brain are almost broken, like a violin string pulled too tight, or a thread unravelling too soon.

The 85-year-old smiles as strangers enter his bedroom, which is lined with rows and rows of classical CDs: Mozart, Brahms, Verdi and many, many more.

"A whole series of bing, bang, bong!" he exclaims, taking off his headphones, trying to explain his love for the music — and for life.

These days, the music is most of his life.

Eight to 10 hours a day, he sits here, in this room, wearing those headphones, letting the great composers fill the spaces that used to know history and science and the great authors: Graham Greene, Proust, Orwell, or the thousands of others whose books line the den of his Halifax home.

Today, the Oxford University graduate, former Royal Air Force intelligence officer, former CBC television executive, can't read or write.

And often, he can't remember — the details of his Second World War service, his age, his bladder cancer or, as he puts it, "my great lady," Carole Ann MacDonald, the common-law wife he mistakes today for the daughter he doesn't have.

Sometimes, he doesn't know her at all.

But for some reason, the music remains.

"Never a dull moment," he theatrically proclaims, as if announcing an aria of his own. "Yes, yes, yes!"

"I'm too old to do anything else, you know. I think I'm very glad. All the guys I had known before died, you see, quite early on, and now I've had these bings and bangs and I'm perfectly delighted!"

So there's still joy for this distinguished and learned gentleman who still has his music, who still dresses daily in his suit jacket, who has lost so much else to Alzheimer's disease.

And that comforts MacDonald, who has loved Gauntlett as a woman loves a man. And now loves him as a mother loves a child.

"It's like, I put him as a three-year-old child," she says a week earlier, sitting in the office of Dr. Laurie Mallery, co-founder of a Halifax clinic that tries to help people like this longtime couple — "soulmates" who in many ways have become strangers.

"(He's) happy, you know," MacDonald says about Gauntlett, a former world traveller, history major and avid reader who once served as head of arts, music and science for CBC-TV in Toronto.

"He can walk and talk, babble, not quite making sense. But that's where he is now."

THE 69-YEAR-OLD Halifax woman never thought she'd be where she is now, in this "all-consuming" existence of doctor's appointments and life and death decisions and loneliness — all without the help of the man she used to talk to about everything. The man she first saw more than 30 years ago and instantly thought: "That's my guy."

MacDonald was overwhelmed with her responsibilities for her guy when she first came to the Palliative and Therapeutic Harmonization (PATH) Clinic in Halifax in September.

Gauntlett, diagnosed with bladder cancer two years ago, had been receiving maintenance treatments involving injections of medicine directly into his bladder. It was painful and confusing. He lost urinary control and he kept resisting the procedures. So MacDonald cancelled his last appointment, then wondered what in the world she had done.

"I had a huge guilt trip about cancelling that," she recalls. "Am I going to be responsible if the cancer comes back? And I came in here feeling terrible."

"I spoke to Dr. Mallery about the bladder and the number of treatments that we'd been going through and how he's feeling and how I'm feeling."

"She talked about the goals of PATH . . . and how I could get help. I needn't feel that way, and with other staff members, we went through what could be done, what should be done, to make his life pleasant and . . . he's already had three peaceful months."

Making life — usually the end of life — as pleasant, peaceful and pain-free as possible is among the goals of this one-year-old clinic, founded by Mallery and Dr. Paige Moorhouse at the Queen Elizabeth II Health Sciences Centre.

Mallery, a geriatric specialist, says she saw the need for the clinic when watching so many patients with dementia and multiple physical ailments suffer and decline further after hospitalization and surgeries or other treatments.

The clinic isn't about limiting treatments, she says, but rather taking a comprehensive look at the multiple conditions of these "frail" elderly patients and how treating one illness might actually hurt another.

PATH — the place MacDonald says makes her feel so much less alone — often sees patients with cognitive impairment like Alzheimer's, plus conditions like heart failure, diabetes and cancer.

"So one alone would be enough to be serious, but together it produces a situation that's even more fragile," says Mallery, who is also in charge of the geriatric medicine division at Dalhousie University.

"They're vulnerable because when they get sick, they have decreased reserves and their body can't respond. So for instance, when they come into the hospital they get confused, and that confusion doesn't always resolve, so they don't always go back to the way they were before.

"Thirty per cent of people who are frail will . . . have some decline in their function or mobility while they're in the hospital, so they're vulnerable to . . . being in the hospital in general and to medical interventions in particular."

Clinic staff try to help patients with this "illness burden" weigh all the risks before they make a decision. If they're too cognitively impaired, the responsibility falls to family members, who often face an emotional burden as well.

"We want . . . to help families make the best decisions possible as they consider what their family members would want for treatment," Mallery says. "Basically, we're on a fast track toward decision-making in health care where we just very quickly decide on treatments that have a lot of risks. So really what we want to do is just slow that process down a bit, to give

people a chance to really fully understand where they are in their health and then to make decisions based on that."

Doctors and staff at the clinic, on the first floor of the Camp Hill building, start a three-step process by giving patients — who Mallery says "deserve a lot of attention" — a comprehensive geriatric assessment of their medical condition. Then they lay out all the facts in what she describes as a detailed, no-holds-barred fashion.

"Instead of saying you have heart failure, we would say, 'Well, this is heart failure that's really serious, it's going to get worse over time, and typically . . . an illness like this will shorten life.' So we describe each illness, the stage and the expected progression of the illness."

Then they ask patients or their families to consider a group of key questions, among them: Which health conditions are easily treatable and which are not? How will frailty make treatment risky? Will the proposed treatment improve or worsen function or memory? Will the treatment allow more good quality years, especially at home? What can we do to promote comfort and dignity in the time left?

COMFORT AND DIGNITY in the time left. This is what MacDonald wants now for Gauntlett, the man with whom she has shared "a wonderful life."

His comfort has improved substantially since he stopped the maintenance treatments for his bladder cancer. Recent tests haven't shown any signs of new malignant cells, Mallery says, explaining that Gauntlett initially received BCG (Bacillus Calmette-Guerin) immunotherapy, which research shows can delay tumour growth and improve chances of survival.

He then started followup known as "maintenance BCG immunotherapy," which four of five clinical trials have shown provides no benefit. And Gauntlett experienced significant side-effects: pain, loss of bladder control and cognitive decline.

So his quality of life is better without the therapy, even though he doesn't know it.

"Did I have bladder (cancer)?" he asks MacDonald when the subject comes up.

"Remember all the treatments . . . the doctor was giving you?" she prompts. "All those treatments and we're not having any more."

"Oh, vaguely, I suppose," Gauntlett says, often speaking in meandering story bursts that aren't quite right, in sentences that don't so much finish as trail off into musical flourishes: "Brumph, brumph, brumph!"

Even the war comes down to "bombs and bangs and crashes and all that stuff."

"I find my memory . . . it's kind of worn out," he says. "Bits and pieces I forget about, some I will never forget — notably, wars — you know, things like that.

"And my daughter and friend," he says, smiling as he motions toward MacDonald. "Not my daughter," he corrects himself. "My wife — that's what they're called, aren't they?"

"You'll never forget me," she teases.

"I'll never forget you," he says.

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