



PHOTO: REUBEN MAHAFFY

Merrill Tanner, an Edmonton-based speech pathologist and classical singer who helps people manage symptoms of Parkinson's disease.

A DOSE OF SONG

An alternative therapy offers hope for the growing number of Albertans with Parkinson's disease.

By CHERYL MAHAFFY

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THEY ENTER THE ROOM IN ONES AND TWOS, choosing spots around the semicircle of music stands while the pianist repositions her instrument for a better view of the action to come. This could be any group gathering for a morning of music-making, except that these singers find it nearly impossible to stand still. A head bobs, a back writhes, hands twitch nonstop. Various skilled as nurses, engineers, teachers, musicians, researchers, now they're connected by something they neither wanted nor trained for: Parkinson's disease (PD). Men and women, walking and wheeled, middle-aged and older, they're here in hope that the singing techniques they're about to learn might help keep this cruelly degenerative disease from stealing their voices.

At the hub of the semicircle is Merrill Tanner, a speech language pathologist and classical singer intent on adding to the evidence that art, and in particular singing, deserves space on the shelf of PD therapies alongside medication and surgery. As part of her doctoral studies at the University of Alberta, Tanner designed this six-week class to test what she observes in her practice: that people with PD can use the parts of their anatomy as a cellist would use strings, bow and body to speak with more power and volume. Not to fill a hall with elegant

music, but simply to be heard.

I had never stopped to think that the same degeneration of neurological systems that causes people with PD to shuffle, shake, stoop, fall and freeze in mid-step also impairs their ability to speak. In fact nearly 90 per cent of people with PD lose vocal capacity, and if anything the surgery and medication used to improve limb control exacerbate the loss of speech. Yet I'm not alone in focusing on what's most visible; it's telling that the most comprehensive PD therapy in Alberta occurs at "movement disorders" clinics in Calgary and Edmonton. But the people I meet in this sun-filled room at Edmonton's Glenrose Rehabilitation Hospital express equal urgency about hanging onto their ability to speak.

“When you're sitting in that nursing home, and you hurt, and you can't tell them...”

Take Violet Jeffrey, for example. Years before learning she has PD, Violet watched a friend lose his voice to the disease. “It was heartbreaking,” she says, recalling how he struggled to make himself heard and at the end couldn't communicate at all. “So I know that's coming, but most people don't, especially when they're first diagnosed. And it's more serious than anything else. Because when you're sitting in that nursing home, and you hurt, and you can't tell them...” Her voice trails off, clogged by tears.



Tanner's class tests her observations: that people with PD can slow or halt the disease and learn to speak with more power and volume.

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“PUT YOUR HANDS ON YOUR RIB CAGE AND BREATHE in as deeply as possible. Feel like you’re expanding your whole body, getting really big, inside and out. You want sound to initiate from the diaphragm, as if you have a voice button there.” With video and audio recorders running, Tanner leads her subjects through a series of exercises gleaned from various therapies, using imagery to implant the rationale for each. Her slender body sways and bends; the others follow suit as each is able, vibrating out of time as if controlled by a jerky electrical current.

“People with PD have less breath support than before, so you’re all going to have to put more physical effort into speaking and singing,” Tanner says. “But if you push from your throat, your voice wears out and loses its vibrancy. We’re trying to build up your muscles and train you to use the whole system, so you can have a nice, loud, vibrant voice.”

She urges them to speak like a cello sings, with the resonance and power that come from deep breathing, relaxed vocal cords, plenty of space in the mouth and accurate articulation. “You don’t want your shoulders going up; that’s a sign of shallow breathing,” she says.

At Tanner’s urging, they breathe deep and moo like cows, hoot like owls, yawn like cats, howl like monkeys. They hold notes loud, soft and long, up and down the scales as pianist Judy Loewen plays arpeggios to match each task. They practise elongated vowels, since vowels carry sound, and try to make their consonants short yet precise.

Finally they tiptoe into song, attempting to employ what they’ve just learned. It’s not easy, but that’s intentional, Tanner tells me later. “Spontaneous speech is a very complicated task; we need to decide what to say and coordinate our breath and voice. Singing gets the whole mechanism into shape faster because it is more vigorous than speech, making deeper breathing and voice coordination more automatic and natural.” Among the jaunty tunes and medleys she’s chosen for this group, I’m struck by some that, intentionally or not, are painfully pertinent. One line in particular loops through my brain: “Will you still need me / will you still feed me / when I’m 64?”

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ALTHOUGH PARKINSON'S DISEASE CAN APPEAR in mid-career or even earlier, it is more typically a disease of the elderly. Striking on average in the late 50s, it eats away at nerve cells' ability to make dopamine, an essential ingredient in the body's message system. People can live for decades with the disease, while the brain becomes less and less able to tell body parts what to do. Although hope for a cure rose with the diagnosis and subsequent philanthropy of such prominent individuals as actor Michael J. Fox, the puzzle is proving more complex than expected. Alberta's rate of PD is high for reasons still unconfirmed, although exact comparisons are impossible because data are incomplete and out of date. Estimates of the number of Albertans living with the disease range from 8,000 to as high as 14,000, with incidence tripling after age 60. Given our aging population, the stage is set for PD to double in less than a decade.

The cost implications are significant. The most recent Public Health Agency of Canada calculations (2001) put the total annual direct and indirect cost of PD at \$447-million. Slowing the progression of the disease for even a quarter of the 100,000-plus individuals across Canada with PD could save \$112-million a year in direct healthcare costs and reap even greater gains in productivity and quality of life for both patients and caregivers.

A key concern for people with advanced PD (and many others who are elderly and/or frail) is the ability to swallow. Swallowing therapy is now recognized as a life-or-death aspect of speech pathologists' work, but mere decades ago this wasn't the case. Instead, people who couldn't swallow were syringe-fed, raising the risk of aspiration, pneumonia and death. Having been at the forefront of the shift to swallowing therapy while working in Saskatoon, Tanner now sees an opportunity to take another step forward by incorporating singing. Buoyed by her earlier singing study in which subjects spontaneously reported improved swallowing as well as improved speech, she hopes to track those changes during a second six-week singing session this fall. "If swallowing disorders were reduced or put off until later in the disease," she says, "no doubt it would reduce hospital admissions and aspiration pneumonia, which could be a very big money-saver."

Tanner's fascination with the healing power of music has personal roots. She burst into song almost as soon as she could speak, uses music to lift her own spirits and watched her mother, architect Doris Newland Tanner, enjoy singing familiar tunes even after Alzheimer's disease robbed her of other capacities. Perhaps it's no wonder Tanner added a masters in voice performance to earlier training in speech pathology and healthcare administration and has been spreading the gospel of singing as good medicine through research, publications

and presentations to a broad span of audiences.

Yet singing has not become mainstream Parkinson's therapy, despite a growing body of scientific literature documenting its healing potential. Through her studies, Tanner hopes to hasten the day when singing is recognized as not just an artistic pastime, but a means to health preservation. "It should be a part of healthcare," she says, "especially proactive healthcare in a community setting."

Tanner is buoyed by a singing study in which subjects reported improved swallowing and speech.

I'M IN AN OLD STRATHCONA COFFEE SHOP WITH Helen Mak and Alison Wood, two women whose teaching careers were cut short by Parkinson's disease. They've entered this world decades younger than most, becoming part of a small but growing subset termed "early onset." Both are relatively free of the monotone voice and masklike face that characterize more advanced PD, but Mak trembles visibly and Wood concentrates hard to control involuntary swaying.

Active members of the Parkinson's Society of Alberta, they have turned their considerable research skills to charting the unwelcome journey ahead. So they're well aware that, especially for individuals struck earlier in life, it may be as little as five years before the medication that now controls their symptoms begins to cause involuntary jerks and bobs. They also know the hazards of being at the mercy of healthcare workers who refuse to recognize that PD patients need medication on schedule or chaos ensues. No wonder their antennae are on alert for alternative therapies.

More than anything, Mak seeks ways to exercise her brain. "Quite a few people with PD get slower in their thinking," she says. "I can sit in a room being unable to talk, but being unable to think is absolutely unacceptable." A participant in Tanner's singing study, she appreciated that it engaged her brain while giving her "the guts to sing out," at least in the shower.

Mak has also taken Lee Silverman Voice Therapy (LSVT) LOUD, a US-based approach that hammers home one simple command: "Say it louder." LSVT is proving that (contrary to previous belief) speech treatment can make a lasting difference for people with PD—if intensively taught and religiously practised. Two years after treatment, brain scans show positive change and clients continue to enjoy improved speech, facial expression and swallowing ability. Mak, too, found LSVT surprisingly effective. "My husband's hearing has improved greatly," she says with a twinkle in her eye.

Wood has dipped into an even broader range of treatments. A musician who terms her ability to communicate vital to life, she credits voice lessons with enabling her to remain in Richard Eaton singers even after giving up a position as handbell conductor. She also speaks highly of the Alexander Technique, which was developed by an actor who found that neuromuscular tension was robbing his voice by affecting his



Violet Jeffrey (left) and Helen Mak, both of whom have PD. Jeffrey watched a friend lose his voice to the disease. “So I know that’s coming.”

posture. “With physio, chiropractic and exercises, I could stand up straight one minute and then be back into my usual slouch,” she says. “Now I can wake up in the morning as my Parkinsonian self, shuffle stoop-shouldered toward the bathroom, stop and make myself stand straight.” Living alone, she spends a sixth of her income on medical needs and worries that lack of resources will force a fateful decision when she can no longer look after herself. “If I can afford, it, I’ll hire a nurse,” she says. “But if not, I will make sure I don’t go to a seniors home.”

Whatever the financial consequences, it’s important to take advantage of promising interventions as soon as possible after diagnosis, Mak says. “And if the activities tie into enjoyment at the same time, chances are you’ll keep them up.”

That’s exactly why Tanner layers music and explanatory notes atop other voice therapy techniques. “For the rest of your life with PD you have to concentrate on your voice,” she says. “Singing is fun and maybe even a social event if you’re in a choir. And I want them to understand the whole process, so they can trick their body. The more they understand, the more they’re in control.”

I’M BEING SERENADED SOMEWHAT QUAVERINGLY by Joyce Pinckney, musician, poet, former belly dancer, retired nurse and advocate for art as PD treatment. Diagnosed in 1997 and a participant in Tanner’s singing study, she invited me to her home to demonstrate why the healthcare toolkit needs to expand.

Piano students may know Pinckney as the author of jazz-style music books aimed at making learning playful. The work that brings me here today, however, is a chapter by Pinckney in the book *Parkinson Disease: A Health Policy Perspective*. Authored by Alberta leaders in the field, the 2010 publication is rapidly gaining global notice. Pinckney’s chapter, “Can the Art of Medicine use Arts as Medicine? A Personal Perspective,”

draws on numerous studies as well as her own experience.

It’s not uncommon for people affected by PD to discover or expand their artistic talent, Pinckney says. Whether due to brain changes or medication, art becomes an avenue to replace and/or reflect on what’s being lost. Even though her professional belly dancing days are over, she often plays dancing music when she’s overly stiff and in pain. “Suddenly I’m moving with grace and ease,” she says. “I know that music helps me. It gives me freedom from the symptoms for a short time and I can move more naturally. I believe it has actually slowed down the progress of my PD.”

Rather than waiting for more evidence, Pinckney concludes, the healthcare system could prescribe “participation in the arts” in addition to medication—and actively encourage the programs and training needed to fill those prescriptions. “If people with PD who use arts are happier or perceive themselves to be happier, if they bring pleasure to others by adding culture to society, and if they prevent their own depression and minimize their symptoms, then why not use the arts? What harm could it do? In my opinion, the subjective views of afflicted persons should hold as much weight as any objective measures of improvement.”

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THE ELEVATOR IS OUT OF SERVICE, SO I’M SEARCHING for the stairs to the third-floor office of Kathy Kovacs Burns, associate director of the U of A Health Sciences Council. After watching Joyce Pinckney laboriously manoeuvre through her split-level bungalow, I’m wondering how she and others with PD would cope with this climb. Being a resourceful lot, they’d

figure something out.

I'm here for a bird's-eye view of how our province is coping (and should cope) with PD, particularly in light of the coming spike in numbers. Besides authoring key parts of the Parkinson's book that Pinckney contributed to, Kovacs Burns is integrally involved in related provincial and national initiatives. She's frank in her assessment: "A lot of things have to change, and much of that has to do with the way we align services."

Issues begin with diagnosis, which is not often obvious with PD. Ideally, everyone with neurological symptoms would have access to the diagnostic expertise available at Alberta's two movement-disorders clinics. But each clinic caters to a spectrum of neurological conditions and can serve only 500 patients a year, and wait times stretch to as long as nine months. More often, family doctors refer patients with likely symptoms to neurologists outside the clinics, who may or may not be skilled in recognizing PD and may or may not help locate key services. It's the rare patient who returns home with a comprehensive care plan.

Rural settings are a particular problem. Services have been centralized in urban centres, but many with PD cannot drive, making travel challenging, Kovacs Burns says. "People end up having to move to the city if they want to access the services that make a difference in their quality of life."

What's more, provincial health coverage excludes many of the therapies that have potential to manage PD, including singing and artistic pursuits. Nor are essential supports for caregivers, including respite, readily available and covered. Households without supplemental medical coverage spend as much as \$2,500 a month on drugs and services. Were other promising therapies and caregiver supports widely available and prescribed, that figure could be even higher.

"We don't know the cost/benefit of any interventions and therapies; we don't even know the cost/benefit of the drugs, to tell you the truth," Kovacs Burns says. Yet she has sat with enough PD patients and caregivers to know that certain individuals respond to certain therapies amazingly well. "Ideally, people with PD would be able to test out a whole variety of therapies. Does it stop the progression? No—none of these therapies do. Would their quality of life improve? Definitely. Many by 100 per cent."

The resulting burden on caregivers can become excruciating, she adds. While working on one study, she was entrusted with the diaries of spouses who recorded their daily struggles as PD ate away at the ones they loved, in some cases leading to depression and abusive behaviour. Even now, recalling those stories nearly brings her to tears. "There needs to be more respite and time for caregivers to have personal space and look after things, including themselves," she says.

The consolidation of nine provincial health regions into Alberta Health Services offers an opportunity to fill service gaps, Kovacs Burns says. Ideally, the primary health networks being set up in as many as 80 Alberta communities will include specialists in Parkinson's and other neurological conditions. Telehealth could be better used as well, although not to the

exclusion of in-person care. Given adequate support, the Parkinson's Society of Alberta, which already coordinates support groups in several communities, could become a more central player in facilitating funded access to diverse therapies. "We're trying to think of better ways to get around some of these gaps we've identified," she says, "but it's tough to get there."

The healthcare system could prescribe participation in the arts in addition to medication—and actively encourage the programs and training needed to fill those prescriptions.

In the broader picture, work is needed to ensure that the \$8.8-billion a year spent on all neurological diseases across Canada is achieving best results. Already involved in research aimed at building a national strategy for the most common neurological conditions, Kovacs Burns is seeking funds for a similar strategy in Alberta. Among the key pieces needed (and currently absent) is a provincial registry of patients, researchers, specialists, treatments and care providers.

Perhaps someday every person diagnosed with PD will take home a service plan—one that pays attention to the importance of vocal communication.

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SIX WEEKS HAVE FLOWN BY, AND I RETURN TO observe Tanner's singing class in its last hurrah. Spouses, friends and caregivers are invited as well, for the group is finishing up with a concert and potluck tea—evidence of Tanner's focus on the social side of singing.

As we mingle, I ask the key question: did singing help? A few say no, including a woman whose voice remains a mere whisper. But others report increases in volume and endurance. "I've got more duration, so I can finish off that last word without running out of breath," says Violet Jeffrey, whose memory of a friend's lost voice propelled her into this room. "I'm not a singer, but I've got it all on tape, and I'm going to practise so I don't lose it."

As they make plans to meet again, it's clear friendships have formed. "A lot of people don't realize that being able to be heard is not only just mechanical," Mak says. "It also builds confidence and helps us engage, so we're less likely to be depressed or get sick. Each of us is different. But we're all comrades, whether we like it or not." ■

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