

The journey to be understood

STORY BY ANISH MAJUMDAR
PHOTOS BY MATT WITTMAYER

The waiting room of Nazareth College's Aphasia Clinic is well stocked with magazines, but the people gathered here aren't reading them. They're engaged in something more fundamental: the seemingly simple yet incredibly complex act of trying to speak and respond naturally. Most of the faces are middle-aged, and a few show signs of deep exhaustion or anxiety in their eyes.

Aphasia is an inability to communicate—be it speaking, writing or comprehension—usually triggered by a stroke or traumatic brain injury. The 60 or so clients of the Pittsford clinic, one of only a handful in the country, are taking part in an experiment of sorts—one that melds cutting-edge technology with the primitive, repetition-based needs of the human brain seeking new ways to be understood. Along the way they're redefining what's possible for those struck silent, offering new hope to the estimated one million Americans grappling with this debilitating disorder.

"We focus on practical benefits," says Merideth Rao, clinical assistant professor of Speech-Language Pathology at Nazareth College and head of the clinic. "How can we increase a person's engagement with life?"

As they do, they're defying some conventional wisdom about how much progress people with aphasia can make.

Gary Neverett is a prime example. On June 11, 2006, Gary suffered a stroke. He and his wife, Mary, had been married less than six months when it happened.

"He couldn't speak," Mary says. "Nothing besides gibberish and a few Spanish words; he'd studied Spanish years ago."

A typical course of rehabilitation would last six months. "The doctors told us whatever Gary gets back in six months is it," Mary says. With the clock ticking, most people would want as much therapy as possible. But as Mary points out, "there was no way our

insurance was going to pay for daily therapy sessions."

Like many families in their position, the Neveretts went into debt to pay for extra sessions. Progress was agonizingly slow.

"I could understand OK," Gary says, speaking softly and haltingly. "When I spoke, in my mind, I was talking like normal...but it came out wrong." He shifts in his seat, appearing uncomfortable with returning to that time in the critical care wing of the hospital, brain swollen to the point where Mary had been forced to make arrangements for his passing. After he pulled through, he found his struggles were only beginning.

"Do you have any idea how many motor skills are involved in speech?" asks Mary, 37. "The positioning of the tongue, the lips...it's endless. I had to become an expert to help Gary. The whole family did. His mother still comes every Saturday to help with his reading."

Gary, 41, speaks in a low, mostly uninflected voice. Replies are frequently monosyllabic, and sentences often lack conjunctions such as "with" or "and." Christina Damin, the student clinician who works with Gary, leads him through exercises that seem like children's games: making the noise of a siren to improve how he makes the "r" sound; showing pictures of a dog playing with a Frisbee or a family having a picnic and asking him to describe it in full. He gets frustrated but continues on, displaying the obsessive drive that took him from a mostly mute shell to where he is today.

"I wouldn't accept it," Gary says of the time span his doctors originally gave him to improve. "They told me six months...I thought, 'You don't know me. You don't know who I am...what I can do.' He pauses for several moments to try to organize his next thought. "It's a lie...I was going to prove them wrong."

But as he wrestled with the intricacies of relearning pronunciation, their finances steadily declined. Insurance coverage ran out within the

A little-known clinic at Nazareth College is quietly changing people's notions about recovery after brain trauma.

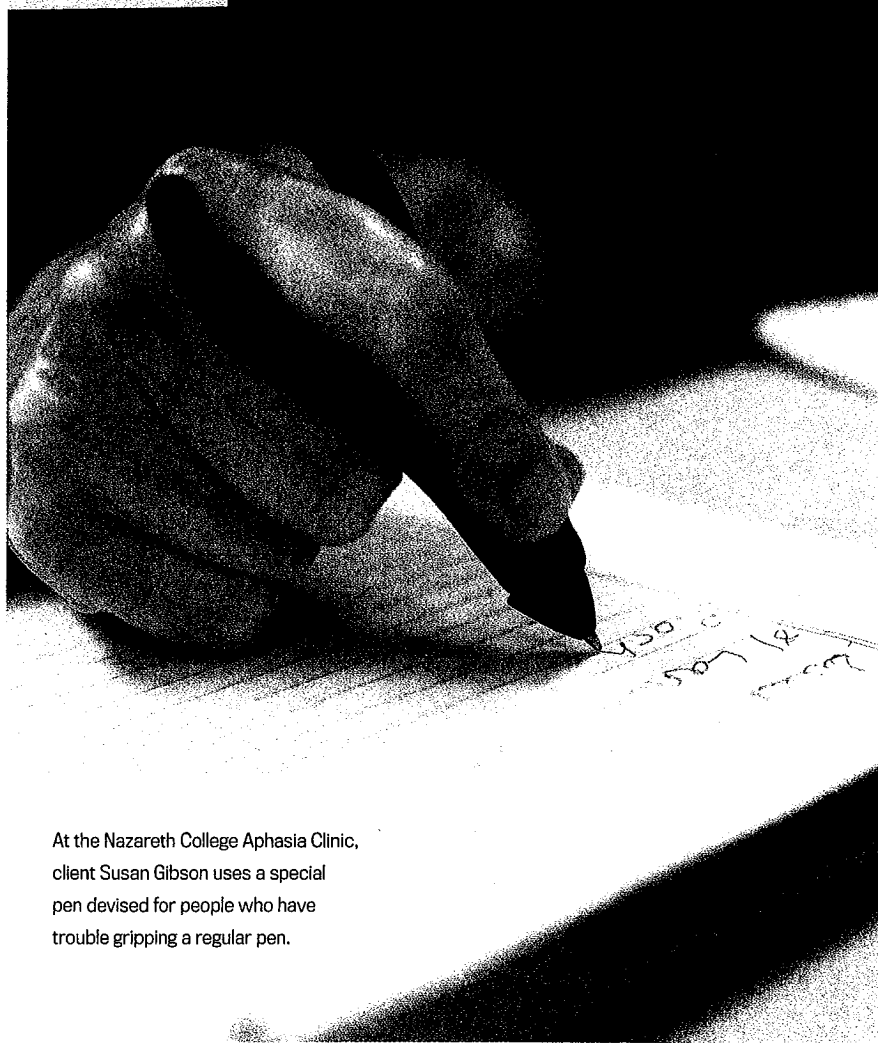
first year, forcing them to shoulder the full cost of Gary's rehabilitation. They had to ask the landlord for extensions. American Filtration, Gary's former employer, pitched in. The Salvation Army paid their electric bill. Grim as the situation became, the idea of stopping therapy and allowing Gary to regress wasn't an option. That's when they heard about a clinic in Rochester offering long-term therapy for little more than a token fee—roughly \$60 a semester.

"Our clinic is unusual because we're not reimbursed through third parties such as managed care and insurance payers," Rao says. "Many family services are limited to a specific number of visits for speech therapy, or else a client is discharged for having reached a 'plateau' in treatment when a third party is paying. We don't have those limitations. We find out what someone like Gary wants to achieve, and then we'll work together, as long as it takes, to help him get there."

Progress Report

And yes, says Rao, people do make progress beyond those first six months—especially what she calls functional progress. "For example, an individual with aphasia may always have word-finding problems, and that specific difficulty may not go away, but functionally the client learns to use a strategy to compensate effectively," she explains. "They start by using it in therapy, groups, home, community and even back to work. They functionally become more independent in their communication skill and effectiveness, even though the impairment persists."

Another client, Susan Gibson, 43, is at the clinic today with her mother, who prompts her to join a conversation about recent movies. She starts off enviably smooth, rattling off scenes and actors, but runs into trouble when someone asks about a particular show time. Unable to verbalize the numbers,

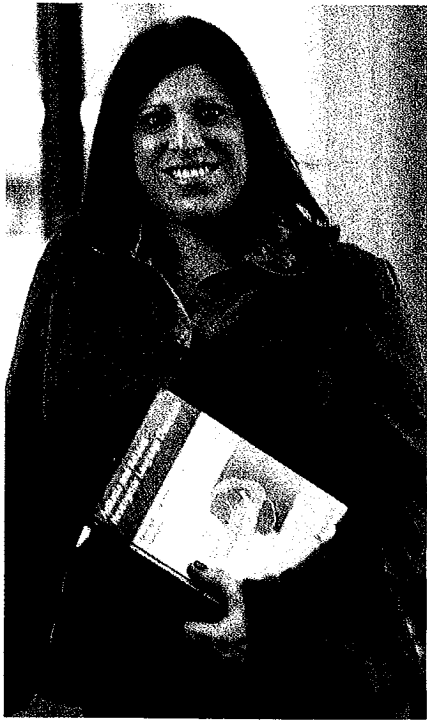


At the Nazareth College Aphasia Clinic, client Susan Gibson uses a special pen devised for people who have trouble gripping a regular pen.

she traces 3, 3 and 0 on her lap. Her mother says, "3:30" and the talk continues. Tactics like this are the direct result of the work done at the clinic, teaching clients coping strategies that ideally will, in time, create new pathways around a damaged section of the brain.

One client, says Rao, developed a script to follow when conveying basic information. Instead of searching endlessly for words, he used the script to call his physician's office and make an appointment—something he had relied on his spouse to do for four years after suffering a stroke. A seemingly small victory, but for someone who has lost independence, such progress represents true improvement.

These sorts of "external memory aids" play an important role. Nick deVries, a lanky 28-year-old sporting a track jacket and three-day growth of scruff, breezes into the clinic like a movie star, cracking jokes with the student clinicians, all women, who conduct therapy sessions under Rao's supervision. He's obsessed with his Motorola Droid smartphone, which acts as a defense against finicky short-term memory. When he speaks, his words come out slurred, which, combined with a pronounced weaving to his gait,



Meredith Rao, director of the Aphasia Clinic.

creates a very specific impression.

"I speak like a drunk," he explains. "Which, don't get me wrong, has its perks. But in general, it's a problem for a well-spoken man such as myself." He chuckles. "I was salutatorian of my high school class, you know."

On July 18, 2007, Nick was riding his motorcycle down State Route 57 in Southern California when he hit a truck in the exit lane. He woke up in the hospital, ending a coma that had lasted weeks and which his family feared might prove permanent. Moving his mouth was an effort. Gesturing, impossible. "The years I spent in California are just...gone," he says. "My life there..." shaking his head, "are like blank pages in the middle of a book." Sensing things have gotten too grave, Nick insists I show him my phone, a hopelessly out-of-date model he teases me about.

"Not even a QWERTY keyboard?" he asks, rolling his eyes. "Come on, man."

Hillary Gotham, the student clinician who works with Nick, says, "He recognizes how lucky he is to be walking, talking, breathing. There are parts of his speech that will never recover. Not without surgery or a prosthesis. But until then, we work on what we can improve."

"Today I'd like to work on enunciation," he says to her. "It's holding me back."

"The loss of language can feel like a death. Coping with that is the biggest challenge any of our clients face."

When I ask what his goal in therapy is, he exchanges a look with Hillary, who almost manages to hide a smirk.

"I want to pick up a girl," he says.

Some clients, suffering from severely impaired short-term memory, have used smartphones to help record activities of daily living, actually managing to go back to college and live independently. The Apple iPad and iPod Touch both have speech-therapy applications, and the Amazon Kindle e-reader can provide simultaneous auditory and visual information. Voice recognition software, for clients who can speak fluently but have lost the ability to spell, can translate their spoken words into e-mails.

The biggest challenge

Back in the waiting room, Gibson's mother is waiting for her daughter to complete a session. Her hands slowly twist and untwist the fanny pack on her lap. In some ways, the rehabilitation process seems harder on family members than those stricken.

"You never imagine having to help your daughter re-learn how to dress or walk or speak," she says, referring to the brain aneurysm Gibson suffered three years ago. "We had our separate lives and then suddenly it was over, and it feels like we've just been running nonstop ever since." She talks about Gibson's difficulty with picking up social cues since the aneurysm; recent sessions have consisted of group conversations with a "turning stone" to signal that the possessor has the right to speak.

"We're trying to get to a point where she can work again, and there has been a huge amount of improvement, but it wears you out. She's living with me now, and that's no way for either of us to be." She takes her glasses off and begins rubbing the lenses with the end of her T-shirt. "There's all this sadness, anger that neither of us allowed ourselves to feel. But it's starting to come out now."

"People grieve in different ways," Rao explains. "The loss of language can feel like a death. Coping with that is the biggest challenge any of our clients face."

Rao is sitting in the clinic's "control

room," keeping tabs on multiple therapy sessions playing out on rows of black-and-white video screens. Since taking over the clinic in 2004 from founder Shirley Szekeres, dean of the School of Health and Human Services, she has seen clients throw tantrums, break down sobbing, walk out.

Yet she seems unfazed, driven by a stubborn curiosity to understand and address their challenges—a trait that transfers to the student clinicians, who constantly try new ways to help clients break through. They use everything from Wii video games to music and art therapy, which have helped produce new insights. The rhythms of communication are as complex as the psyches seeking to regain it, and just as unpredictable.

Miracles

"Many of our clients were followed by neurology services but aren't anymore," Rao says. "I wish they could have the opportunity to see the progress our clients are making. How do you make a stranger understand what a miracle Gary's transformation is?"

But the work continues; such miracles seem to bring not resolution but more challenges. As Mary puts it, her husband's stroke did more than affect his ability to communicate. "His brain changed, fundamentally. He's more sensitive now. Everyday phrases that mean nothing—sometimes he'll get hurt by them." She's quiet for a few moments. "When he was in the hospital and couldn't speak, I felt—looking into his eyes—that I could understand him better than anyone in the world. But it's different now. We're learning about each other all over again."

At a recent session, Gary runs into problems attempting to verbally spell out Neverett, his last name. He turns to a tactic learned at the clinic. After "N" and "E" he quickly runs through the alphabet until he discovers the next letter, then repeats the process to the end.

Mary takes his hand and gives it a squeeze.

"That's good," she says.

Anish Majumdar is a freelance writer living in East Rochester.