How a new clinic offers a better approach to chronic care

Barbara Binert, who has 22q112 deletion syndrome, welcomes the new clinic

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Think about the biggest issues facing the health-care system. Chances are, unnecessary emergency-room visits and crowded hospitals are among the first things that come to mind.

But what if bed shortages and jammed ERs are symptoms, rather than causes, of the problem?

Patients with chronic health conditions that need continuous, consistent care drive a significant portion of health-care spending. Although the system was designed to treat one problem at a time, such as appendicitis or a broken bone, medical advances and longer life expectancies mean that there are more patients with multiple chronic health problems who require ongoing care from several specialists. Without care that is geared to chronic conditions, these patients are often forced to travel

between specialists who may not be communicating with each other and face a heightened risk of multiple hospital stays, among other challenges.

In recent years, however, a growing number of health-care organizations have started to recognize the need to care better for patients with serious, chronic illnesses. One example of how organizations are moving to bridge gaps in the system came on Tuesday, when the University Health Network in Toronto announced the opening of a clinic solely dedicated to patients with a relatively rare genetic condition.

Patients with 22q11.2 deletion syndrome are a prime example of why the health-care system could benefit from a stronger focus on continuous treatment for patients with complex care needs. The condition occurs when a small piece of genetic material is missing from chromosome 22. It happens in one out of every 2,000 to 4,000 births. In the majority of cases, the genetic change is spontaneous and not inherited from family members. The syndrome is linked to dozens of chronic health issues, including heart problems, endocrine disorders, learning disabilities, defects of the palate and psychiatric illness.

Although other institutions, such as the Hospital for Sick Children in Toronto, have units dedicated to 22q11.2 deletion syndrome, they are all geared toward children. The new UHN clinic is the first of its kind in the world to focus specifically on adults.

This is critically important, particularly as more patients with this genetic syndrome who might have succumbed to heart defects as children in the past are now living well into adulthood as a result of advances in medical technology, said Dr. Anne Bassett, Canada Research Chair in Schizophrenia Genetics and Genomic Disorders, a professor of psychiatry at the University of Toronto and the director of the clinical genetics research program at the Centre for Addiction and Mental Health.

"This is bringing it all together," said Bassett, who will become the new Dalglish Family Chair in 22q11.2 Deletion Syndrome at UHN.

Patients will be referred to the clinic, which will have an array of medical specialists on staff, including a dietitian, as many patients have feeding issues.

Bassett highlighted the fact the clinic will allow researchers studying this condition to translate their findings directly into care for patients with 22q11.2 deletion syndrome. "In a way, it's like a symbolic or a … crystallized example maybe of personalized medicine," she said. "It's an overused word, holistic, but it's a more holistic [approach]."

Before, patients with the syndrome would have to see multiple specialists, many of whom may not be familiar with their condition or be aware that the patients have multiple health conditions. This poses "special barriers" to patients, according to Bassett. Instead of being treated for tremors caused by a thyroid problem, for instance, patients may be given anti-anxiety medication.

"Rather than being thrown from pillar to post … we will absolutely make their health care more efficient," Bassett said.

The unit could also serve as a model of a "full-service facility" that can be used for other patient groups, she said.

One woman living with the deletion syndrome says having all of her specialists under one roof will make life much easier. "I think it's absolutely wonderful that it will be here," Barbara Binert said.

News of the new clinic is a welcome development in the eyes of Linda Ger Walters. Her daughter, Melissa Ger, had the syndrome and the family faced major challenges navigating the health-care system. "It was exhausting," she said. "It's frustrating. When she died, it was very clear to me there needed to be multidisciplinary co-ordination."

Melissa passed away in 2001 at the age of 18 after developing pancreatitis following a probe. Ger Walters stresses that her daughter's outcome is not typical for people with 22q11.2 deletion syndrome, many of whom can live well into adulthood.

She believes that the new unit will provide better care to patients and be a substantial improvement on the patchwork care many currently receive. "To be able to have it under one roof is incredibly important," Ger Walters said.
