

What lies beneath

Sarah Cannon wants people to look into the eyes of her daughter and other kids who are fighting mental illness and see their courage

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Emily Cannon's blue-green eyes dance when she chatters about some of her favourite things. Like Hilary Duff — she's been to three concerts, you know. Her weekly jazz and ballet classes. If only she could take tap too, she sighs. And the sleepover tonight. "We're all supposed to bring our favourite candy!"

But in a manner wise beyond her years, Emily can also converse about other things going on in her head that aren't such typical 9-year-old fare.

She calls them "the wiggles." And, she explains, "they are pretty much always there."

When they are blue and moving quickly, Emily feels nervous. Green mean she's calm. Yellow are silly, and red or black are very angry. Sometimes they stand still, other times they fight. "It feels like a war in the olden days." But now she's learned how to talk to them, tell them to stop.

Words are part of Emily's arsenal against the bipolar disorder she was diagnosed with at age 5, following three years of rages, hallucinations and night terrors. Bipolar is a serious but treatable neurobiological disorder that causes extreme swings in mood, energy and behaviour. And it is among the mental illnesses increasingly being diagnosed among children.

On a sunny July morning, Emily intermittently squirms and snuggles with her mother Sarah on the living room couch in her St. Catharines home, her stepdad Jim close by, as they talk about living with a childhood mental illness. It's hard at first. Emily is nervous. But then, as the sounds of her stepbrother Austyn, 11, sister Amy, 5, and the two dogs waft up from the playroom below, she remembers what she wants to tell kids like her who have distressing voices or pictures in their head. "Be brave," she says. "And if you have them, talk to them every day, and tell them to stop it."

Sarah Cannon, 36, wants to share their story for the sake of all families going through the fear, guilt and despair of trying to find help for a child in distress. Sarah has looked down at the fault lines in the mental health system and valiantly tried to leap, daughter in her arms, over them. Going from one specialist to another and starting all over again each time with detailed examinations and tests and medical histories. Taking parenting courses and wondering what she was doing wrong. Pleading with teachers and social workers and therapists to help her figure out where to get help and how to get extra support at school. Refusing to



STUART NIMMO FOR THE TORONTO STAR
Emily, 9, has bipolar disorder. It took three years before her mom, Sarah Cannon of St. Catharines, was able to get Emily diagnosis and treatment.

How to fix the children's mental health system

Psychologist Ian Manion says fixing the children's mental health system in Canada is a daunting task.

"It's like trying to build an airplane in mid-flight," says Manion. He is executive director at the Provincial Centre of Excellence for Child and Youth Mental Health in Ottawa and one of many advocates wrestling with the challenge.

There are huge gaps in services and care, inconsistencies across various regions of the country and a mishmash of federal and provincial responsibilities. But experts say many steps could be taken to address the long wait lists and lack of coordinated services. Among them:

- Developing a national strategy that would make the mental health of Canadians — including children and youth — a priority, following the footsteps of the other G8 countries. They say that would be the first step to drawing attention to the issue, educating the public and mandating funding for treatment and research.
- Education in schools and through public awareness campaigns to reduce the stigma of mental illness.

give up.

Emily is stable now, but still not a day goes by that her mother doesn't worry about the long-term effects of psychotropic medication, or grapple with the dilemma of managing the dosage for a growing child.

But most of all, Sarah wants the world to look into the freckled face of her daughter and other youngsters fighting the same battle and see their innocence, their courage and their gifts, and not write them off or turn the other way.

We've made adjustments for kids who have peanut allergies, she says. "Why can't we do the same for children with mental illness?"

Advocates have been sounding the alarm for years about the overburdened children's mental health system in the face of rising rates of depression, anxiety, bipolar and other disorders. Sarah and Emily's story illustrates the hurdles so many families face as a result of inadequate funding and poorly co-ordinated services.

The urgency of the situation was highlighted in the report from Senator Michael Kirby's committee on mental health this spring called "Out of the Shadows at Last," which noted that children and youth are the group most acutely and severely affected by lack of prompt diagnosis and treatment. Canada is the only G8 country without a national mental health strategy, and the report urged Ottawa to make it a priority.

Even the Global Business and Economic Roundtable on Addiction and Mental Health, a group of Canadian business and health care leaders focusing on workplace issues, has been trying to nudge kids' mental health up the political agenda. Kids are future employees, after all. At the same time, parents of children with mental illness need support, says co-founder Bill Wilkerson.

The group has issued guidelines for parents about risks and signs. It has also formed a joint task force with U.K. experts to learn about the integrated and streamlined system developed in Britain over the past decade, thanks to political commitment and mandated funding.

It's now known that mental illness most often begins in childhood or adolescence, which amounts to a "sea change" in how society must approach it, says Toronto community pediatrician Diane Sacks. And failing to intervene until adulthood is like waiting to deal with stage-four cancer and its secondary side effects. Not only does it threaten to bankrupt the health care system down the road, it puts too many young people at risk — for developmental delays and learning problems, social isolation, dropping out of school. Untreated depression and anxiety in adolescents can lead to self-injury, substance abuse, jail. Or worse. Suicide is the second-leading cause of death among Canadian youth.

The frequently cited statistic is that one in five children or youth has a mental illness. Experts say while about 5 per cent of kids have severe cases, as many as half will have mental health issues at various periods of their lives.

"If we pick it up earlier we can change it around dramatically and hopefully end up with fewer sick kids and fewer dead kids," says Sacks, past president of the Canadian Pediatric Society.

Early intervention is key to a child's development. But fear of discrimination and judgment can discourage families from seeking immediate help for their kids. Parents often say they feel blamed as they try to navigate the system.

- Incentives to attract more doctors into clinical child psychiatry. It is a complex field that involves treating patients who are growing and developing, as well as helping their families. Child psychiatrists take an extra year of schooling but are among the lowest paid of the specialties.
- Providing more resources and support to family physicians and pediatricians to screen and in some cases treat patients. That includes continuing education and more toolkits like those available for diagnosing ADD and adolescent depression. Some physicians with additional training are starting to offer cognitive therapy and treat patients with mild or moderate depression.
- Innovative systems to make better use of resources. Collaborative mental health care is already happening, where family-practice residents work with psychiatrists to assess patients to develop skills and knowledge. Tele-psychiatry initiatives in Ontario give pediatricians and family doctors access to child psychiatrists through regular phone consultations to help them diagnose and refer patients for appropriate help. In some regions, psychiatrists make monthly visits to rural areas to screen young patients.
- Incorporating a continuum of services into the health care system including counselling by social workers, psychologists and nurses. Not all children with mental or behavioural problems need to see a psychiatrist.
- Adjusting medical billing systems to reflect the growing demand for and importance of mental health consultations. Pediatricians currently earn more from seeing patients for coughs and earaches.
- Creating better links between the education and health care systems so they can provide co-ordinated and complementary support for children and youth. Many with mental illness also need extra school support. Mental health training for teachers would better equip them to identify possible problems and offer appropriate support in the classroom. The Canadian Psychiatric Research

'I am embarrassed to say it now but I resisted. I didn't want to have to say my child is crazy'

Sarah Cannon, Emily's mother

Foundation handbook *When Something's Wrong* is aimed at teachers, often the first people youth go to when they need help.

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"Every pediatrician will tell you their office is full of mental health consults," she says. Family doctors are also inundated. While more are starting to screen for mental illnesses, they are reluctant to label children when there is nowhere to send them for prompt treatment. Six months to a year is not uncommon to wait for an appointment with a child psychiatrist — a long time in a child's life. The result is a two-tiered system, where people who can afford to pay \$100 to \$150 an hour for psychologists or private counsellors can get help quickly and those who can't must wait.

"Thirty-five years into my practice I'm faced with huge numbers of children and youth who cannot get the (mental health) treatment they need, and their families are really hurting," says Sacks. "This is extremely frustrating."

According to Simon Davidson, chief of psychiatry at Children's Hospital of Eastern Ontario in Ottawa, child psychiatrists are retiring at a faster rate than the 10 to 12 entering the field each year.

Provincially funded children's mental health centres are trying to handle the onslaught but budget constraints mean they can't hire enough trained social workers and other specialists. Funding has barely budged in a dozen years, while demand has skyrocketed. Linda Sumner, clinical director of the Yorktown Child and Family Centre in Toronto, says it takes about eight months for patients to get into individual counselling there. Like other centres, they do what they can, offering parenting courses or group counselling in the meantime. Yorktown also runs a unique walk-in counselling service, which handled about 200 clients in the most recent fiscal year.

Seeking help through the school system is also an uphill battle, as Sarah Cannon discovered. It typically takes a year to have a child tested for psychological or learning problems unless you can afford to pay up to \$2,000 for a private assessment. Without that, it's hard to access support. In the meantime, kids like Emily wait and continue to fall behind, caught in a vicious cycle that eats away at self-esteem and their ability to fit in with peers.

It took Cannon three years to have her daughter diagnosed. For many families, the search for answers is much longer.

Emily was a happy baby and a good sleeper. But by about 18 months, it was clear to Sarah that her toddler's way of processing the world, the way she lined up her toys so perfectly, was unusual. Learning to talk was a struggle. When the tantrums started, they quickly went beyond the normal range of "terrible twos."

She ripped her room apart so often, including sheets and blinds and books, that eventually Sarah took everything out but the essentials. The rages seemed to come from nowhere. Or they might be provoked when Emily wanted a waffle for breakfast and there weren't any.

"You could see in her eyes, 'Help me,'" says Sarah. "It was like she was trying to crawl out of her skin from the inside out. It was just awful to watch." Then Emily would fall asleep and wake up overcome with remorse.

Once, she ran suddenly from a children's television program shrieking and toppling furniture. Other times she would start screaming at people to get away from her when no one was in the room.

In junior kindergarten, if she felt overwhelmed, Emily would retreat and wedge herself into her cubby. Soon after, when the pediatrician witnessed some of the outbursts, she suggested a psychiatric consultation. But Sarah was afraid. "I am embarrassed to say it now but I resisted. I didn't want to have to say my child is crazy." When she did eventually agree, it took eight months to get an appointment.

The psychiatrist diagnosed Emily with bipolar disorder and suggested medication. At first, Cannon said no way. Then she reluctantly agreed to try it, if it would give Emily some peace.

"The difference was night and day." The nightmares and hallucinations stopped. Emily was more relaxed, comfortable in her own

skin for the first time in years. But without a drug plan at the time, Sarah, a medical transcriptionist, had to take a second job just to cover the \$700 a month in drug bills.

The same year that Emily improved dramatically, mental illness struck the family with another tragic blow. Her father, suffering debilitating depression, took his own life. Mental illness has a genetic component, often affecting more than one family member and exacerbating stress levels for everyone.

Four years later, Sarah has joined Wilkerson's mental health roundtable to advocate for the mentally ill and their families.

Today, Emily has tools and relaxation strategies to manage the peaks and valleys of her illness. Still, Sarah worries about what adolescence may bring. Adjusting the drug dose is a delicate balancing act. Emily is already on her sixth combination.

"But without them, Emily has no quality of life. I'm convinced that without them she would die."

She sometimes fears for her perceptive, excitable child, who prepares to head off to the sleepover with her pyjamas, the Ring Pops she will share and her evening pills. She's a little girl who loves to write stories and watch *Canadian Idol* and finds it hard to know how to act in a group. A child who is so sensitive to people's feelings that she once hugged a stranger she sensed was sad, and who wants so much for other kids to like her.

"I'm fiercely proud of her. I think the world needs more Emilys," says her mom. "But instead of learning from them, we try to hide them."

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