



ILLUSTRATIONS BY LOUISE REIMER

When kids become the caregivers

Nearly 2 million Canadian children are tasked with caring for loved ones. Here's what you should know

BY ABIGAIL CUKIER

Danielle Clayton is an A-average high school student, lacrosse player and ski instructor who loves to volunteer. But unknown to most people in her life, she has another role: The 15-year-old is also a young caregiver to her 16-year-old sister, Stephanie, who was born with an omphalocele, which means her organs were growing outside of her body.

Stephanie has had 16 surgeries and hundreds of procedures. While surgery successfully put her organs

are in remission, she loves water sports and hiking—but there are also days when she can't get out of bed. The girls' father, Greg, and mother, Denise, both work out of the home. If Stephanie is struggling and neither parent can take time off, Danielle or the girls' eldest sister, Sydney, 19, will stay home and care for Stephanie, bringing her medications and meals in bed.

Danielle says it can be stressful keeping up with schoolwork, helping care for her sister, trying to get teachers to understand her situation and organizing the occasional hangout with friends. "It feels like there is not enough time in the day to get everything done," she says.

Danielle isn't alone in her experiences. According to Statistics Canada, 27 percent of Canadians between the ages of 15 and 29 provide unpaid care for loved ones with physical or mental illness, disability, injury or addiction. Outside of these stats, there are also young caregivers who look after younger siblings when parents have to work long hours to make sure there's food on the table and a roof over everyone's head. And some of these caregivers first assume their responsibilities at ages much younger than 15.



“In one of my studies, one person talked about caregiving being her earliest memory—she believes she was three years old,” says Dr. Grant Charles, an associate professor in the School of Social Work at the University of British Columbia and a researcher on the issue. “Many mentioned being caregivers by age 10.”

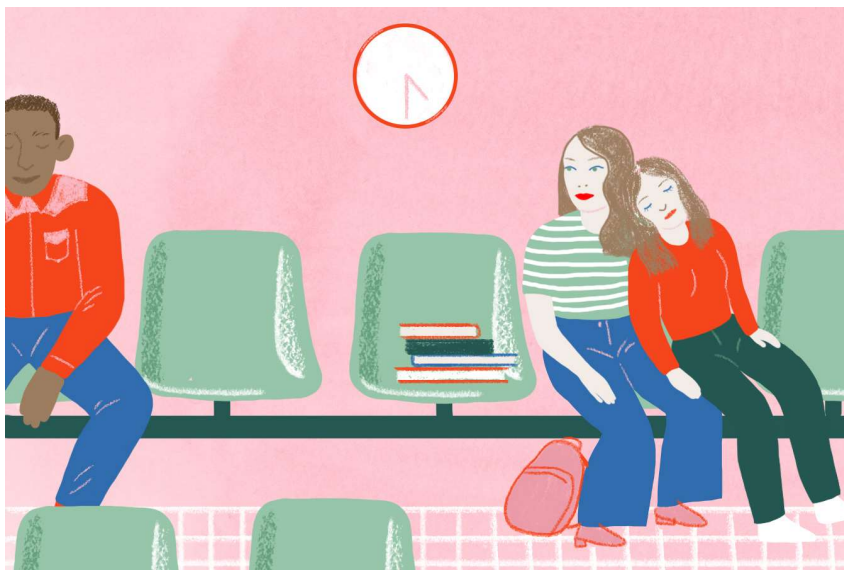
Some of the tasks young caregivers take on would be emotionally overwhelming even for adults: tasks like suctioning breathing tubes, acting as translators at medical appointments, and picking up family members who have fallen. “These young people go through so much. It can affect their physical and mental health,” says Chelsea-Anne Alex, facilitator of the Young Carers Program, an inter-agency initiative designed to meet the needs of young caregivers and their families in the GTA and surrounding area.

Being a young caregiver can lead to a sense of isolation, since classmates can’t relate to the heavy responsibilities their friend is shouldering. And like any teens, young caregivers just want to fit in. “I wish I could say I want people to know and I want to spread awareness, but school is my escape,” Danielle says. “Stephanie goes to a different school, so, school is a place where Sydney and I can just be us—at other times, people tend to treat us differently.”

aged five to 18. The workshops they offer build skills in areas such as cooking, self-care and mindfulness. And their outings to sporting events, holiday parties and games nights give participants a chance to relax, have fun and vent about their challenges with people who get it. “They always have a safe environment, where you can talk about what’s going on and not a single person will judge you,” Danielle says.

Finding support and sharing common experiencing can be hugely helpful for kids in caregiver roles. Another resource is the FAME Strengthening Families program at Reconnect Community Health Services, a United Way-funded agency. This program offers support and education to family members to help them care for themselves and their relative, even in the face of mental health challenges.

“It is easy to overlook the needs of these young carers, because there is typically a higher-need person in the family,” says Jenna Nelson, coordinator of the Young Carers Program. “But it brings a lot of comfort to them knowing they are not alone in their circumstances.”




wouldn't have had otherwise, if they weren't caregiving," says Charles. Danielle says she believes her silver lining is the closeness she has with both her parents and her siblings. "My sisters and I have such a strong bond," she says. "My family has spent a lot of time either too far apart and missing each other, or very close together in a hospital room, so we have grown together."

Nelson says, "Young carers are some of the most mature, super-compassionate, empathetic, resilient people. So many say, 'Caregiving changed my life, and I wouldn't change that—it has made me who I am.'" Nonetheless she stresses that there are too few supports and services for young caregivers. In fact, many kids don't even know there is a name for what they do.

Alex says that simply validating a young caregiver's experience can go a long way. Telling young people with big responsibilities that it's OK to feel overwhelmed or stressed helps take some pressure off. "Some young caregivers don't get recognized for all they do—it's about saying, 'you are doing a good job.'"

Through his research, Charles is seeing a promising growth in Canadian's awareness of the invisible work done by young caregivers. "But I am not sure it is translating into action," he says. "In the UK, if a young person comes in contact with the system, it is mandatory that health professionals ask if they have caregiving responsibilities, and then they are assessed to determine what support they need," he says.

Neighbours, friends, extended family, teachers and health professionals can help relieve some of the pressure by being mindful that a significant number of

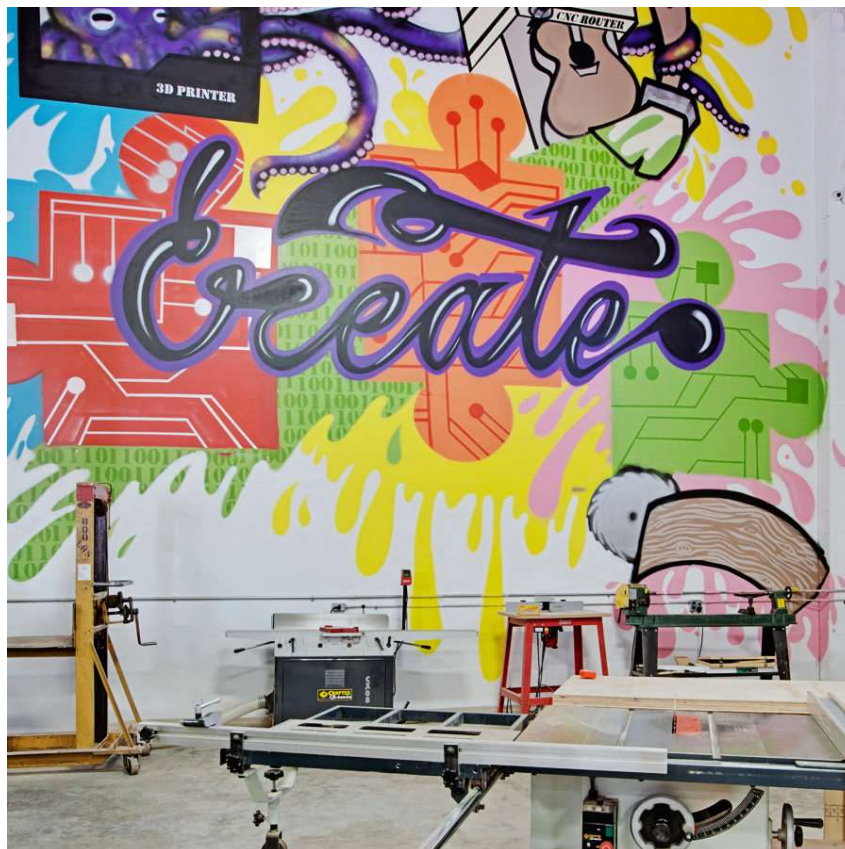
absences or talk about it in front of other students,” Danielle says. Charles would like to see professionals who work with youth be better informed. “If a teacher gets frustrated because a student is falling asleep or falling behind; if they are seeing symptoms of stress in a young person, they need to ask questions,” he says. “We all need to notice what we are seeing in front of us.” 

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