



# Shawn Quest

## Caring with Courage

### Submitted by Dana Young

Shawn is a perfect example of caring with courage. When her young son Jude, who has dual diagnoses and is non-verbal, was diagnosed with cancer she stayed by his side at Sick Kids hospital. As a single mother, she took a leave of absence to support her son through his treatment.

Knowing the complex details of her son's care needs and health history, Shawn was able to pick up on small changes in Jude's health and behaviour. Recognizing a cause for concern, she advocated for her son to the medical staff. During his hospital stay he suffered many complications including an infection that led to hemiparesis, a weakness of one side of the body. Unfortunately, Jude did not respond to treatment as was expected and once again, Shawn advocated for further investigation and alternate treatments. She was persistent and because of her efforts, Jude received, physiotherapy, occupational therapy, speech therapy and behaviour therapy.

She knew what her son was capable of prior to his cancer diagnosis and empowered him to regain as much of his abilities as possible with the help of these therapies, ensuring they were practiced consistently. Eventually Jude was discharged from Sick Kids with the support of several services from Holland Bloorview Kids Rehab, Surrey Place, HSC Pediatric Oncology Group of Ontario program and Ontario Health atHome. Day in and day out, Shawn continues to empower her son, ensuring the people involved in his care are experienced in caring for a child with special needs and a cancer diagnosis.

It was because of Shawn's tenacity that over time, Jude was able to stand with support and began to communicate through sounds, including some words as well as through movement and assistive devices such as communication buttons. Eventually Jude was able to return to school and she was able to secure adaptive devices and specialized after school care part of the week, allowing Shawn to return to work.

This journey has been incredible to witness. Through Shawn's tireless efforts, Jude has completed his treatment, attends school full time and with the use of assistive devices is able to walk once again!

In speaking with Shawn, she shared, "Jude has taught me, and by extension Dana, to listen and to be quiet and still. If you are constantly going and going and talking for him, you're not hearing." It is important to Shawn that Jude has a "voice" in his own care and sees her role as preserving his dignity and his voice. She continued, "Jude has a desire to live and as long as I am there, I'm his safety blanket."



Dana agrees, remarking, “Shawn is a force to be reckoned with and I believe that is why Jude is doing well today. I am inspired by Shawn’s ability to persevere through incredibly stressful times.”