

Jennifer Johannesen

Author, speaker, blogger at Patient Advocate

Toronto, ON, CA

My talks are frank and unsentimental, yet lighthearted and engaging. No lecturing! Authentic patient experience illuminated through stories.

Biography

Jennifer Johannesen is a speaker, author, blogger and patient advocate whose main themes include the challenges and ethics of substitute decision-making in healthcare. Her expertise was earned through experience: her 12 year old son, Owen, passed away in October 2010 after a lifetime of undiagnosed, severe multiple disabilities. Jennifer speaks to large and small audiences comprised of healthcare and education professionals, parents of children with disabilities and patient groups. Her engagements include numerous talks for The Hospital for Sick Children, the University of Toronto and Holland Bloorview Kids Rehabilitation Hospital. Her blog and book are available at NoOrdinaryBoy.com.

Availability

Keynote, Panelist, Workshop, Author Appearance

Industry Expertise

Writing and Editing, Health Care - Services, Health Care - Providers, Health Care - Facilities, Education/Learning, Social Services, Mental Health Care

Areas of Expertise

Disability Advocacy, Ethics, Parenting Children With Special Needs, Patient Advocacy

Sample Talks

'Fake Work'

The over-administration of the lives of families with children with special needs not only threatens to completely snow them under with paperwork, but also creates an unnecessarily stressful environment of constant monitoring, surveillance, reporting, and goal-setting. Jennifer presents theories as to why these conditions exist and shares how she opted for an alternate route for her family.

A Patient/Parent Narrative and Perspective

Jennifer often speaks to new and experienced professionals in orientation, lunch-and-learn and professional development settings. Her 'Patient Perspective' talks are geared to the specific audience and healthcare or therapy-related discipline. Themes include experiences in healthcare settings, receiving bad news, communication styles and decision-making.

Redefine success: Decide for yourself what really matters

No Ordinary Boy author Jennifer Johannesen talks about society's expectations for constant improvement, how this plays into therapy for children with disabilities, and how families can be left shouldering more burden than they want or can handle. Jennifer explores how institutions, clinicians and parents alike contribute to the increasing pressures placed on families and shares her experiences as she leads a discussion on ways to redefine "success."

Ethics in Healthcare Decision-making

Ethics are often seen as an instrument to remedy conflict, but are in fact at play in every healthcare decision made in the pediatric healthcare setting. Jennifer discusses how all decision-makers and advisors, parents and clinicians alike, ought to consider more than just the clinical outcomes when making decisions - they should also identify personal motivations, family and cultural influences and other environmental factors--all lenses through which we filter and distort information.

Event Appearances**Ethics in Healthcare Decision-making**

Grand Rounds

Redefine success: Decide for yourself what really matters

Holland Bloorview Bloom Speaker Series

Author Appearance and Conversation

Silver Creek Preschool Professional Development Day

CBC Blue Sky, featured guest interview and call-in show

Blue Sky

CBC Alberta at Noon, featured guest interview and call-in show

Alberta at Noon

CBC Ontario Today, featured guest interview and call-in show

Ontario Today with Rita Celli

Presenter, Medical Student Program

Medical Student Home-visiting Program

Negotiating the Gray Zone: Ethical Issues in Health Care Decision Making

National Developmental Pediatric Update Conference

Panelist, Navigating Contentious Cases in the Public Eye: A Working Symposium

Navigating Contentious Cases in the Public Eye: A Working Symposium

Education

Ryerson University

Bachelor of Applied Arts Administration and Information Management

Accomplishments

Principal - Low to the Ground Consulting

Low to the Ground Consulting provides low cost, high value marketing, website and social media solutions for small businesses, entrepreneurs and services professionals.

Author

Twelve-year-old Owen Turney died on October 24th, 2010, of unknown causes. *No Ordinary Boy: The Life and Death of Owen Turney* is Jennifer Johannesen's extraordinary story of her profoundly disabled son, his family, his caregivers and his doctors. It is a sharply evocative, sometimes humorous, never sentimental chronicle—not only of perpetual crisis management, crushing disappointments and dashed hopes, but also one of love, spiritual growth, self-understanding, acceptance and maturity.

Testimonials

Dr. Golda Milo-Manson

"No Ordinary Boy is a must read for all health professionals. It reminds us why we do what we do?and inspires us to do better."

Avis Favaro

"...found it moving and inspirational. It may offer support and a new perspective for parents and doctors dealing with these especially vulnerable children. It was penned by a courageous and yet forthright mother who wants to help others learn the lessons that Owen's short life, offered."

Thom Ernst

"...a balanced, sometimes difficult, often amusing account of a real young man told, with an almost unbiased honesty, by the one woman who knew him best. Jennifer avoids the kind of finger-waving judgment calls writers with less skill tend to saddle on the ignorant, the curious and the well-meaning. Her observations are that of a young woman who lives in a world of contradictions, complications and revelations, including her own."

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