
Invisible No More - International Digital Health Tool Shatters Silence & Empowers Young Adults with an Incurable Illness

(Winnipeg, Manitoba/Sydney, Australia) – Young adults and teens diagnosed with a life-limiting illness have been virtually invisible in health systems and online – until today. A new Canadian digital tool launching in Sydney, Australia is harnessing their unique stories to help other teens and young adults with advanced or metastatic cancer and other life-limiting illnesses.

Living Out Loud’ features frank, deeply personal, often humorous video conversations and written vignettes by young Canadians. They share their experiences of pursuing education and their careers, navigating impacts on sexuality and fertility, managing relationships with family, friends and health providers, raising their children and confronting end of life.

Winnipegger Catherine Wreford Ledlow, a mother of two and former Broadway performer, was given less than 6 years to live when she was 32 years old. “How do I tell my kids why I’ll go bald and get tired so quickly when all they want to do is play.” Wreford Ledlow added, “Knowing that I’m not alone and can share my story with so many others, means the world to me. It’s OK to express how I feel and that people will **listen!**”

Leading health experts from Canada and the US have contributed content to help address a gap in trusted online content. Shelly Cory, Executive Director of the Canadian Virtual Hospice remarked, “The impact of teens and young adult diagnoses is being amplified by the fact that their needs aren’t understood or even recognized.” Cory added, “So we asked them to drive the process – they defined content, design and functionality. They’ve filled an international gap and given those living with advanced illness around the world a huge gift.”

Living Out Loud’ is the world’s first online platform dedicated to raising awareness of young adults with advanced illnesses while normalizing their experiences as they live their lives to the fullest while preparing for death. Families, friends and health care providers will also gain a better understating by viewing the stories. Future plans are envisioned to integrate interactivity and encourage other countries to engage teens and young adults to expand the repository or stories and perspectives.

Living Out Loud’ is a partnership between the Canadian Virtual Hospice, young adults with advanced illness, Young Adult Cancer Canada and Team Shan. Funding was provided by the Canadian Partnership Against Cancer and the Thomas Sill Foundation. To view a sample of some of the adolescents and young adults who have joined the *Living Out Loud*’ community, click the link <https://vimeo.com/294711857>.

About Canadian Virtual Hospice:

Canadian Virtual Hospice is a digital health care leader and the world's most comprehensive online portal for information and support on advanced illness, palliative care and grief. It serves the information and support needs of people living with life-limiting illness, families and caregivers, health providers, researchers and educators. It operates:

virtualhospice.ca, portailpalliatif.ca, MyGrief.ca, LivingMyCulture.ca, Methadone4Pain.ca, KidsGrief.ca, DeuilDesEnfants.ca and numerous social media platforms.

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