

# THE LIGHTHOUSE AND THE DISSEMINATION OF KNOWLEDGE IN PALLIATIVE PEDIATRIC CARE

In addition to the support we provide, The Lighthouse, Children and Families has another mission: to share knowledge and transfer skills in palliative pediatric care. That's why we develop tools to pass the expertise we have gained on to others, especially frontline caregivers, families, and natural caregivers. Quebec's Ministère de la Santé et des Services sociaux has asked The Lighthouse to develop an online training program in palliative pediatric care. This Web-based training program is intended for CLSC caregivers and their colleagues within local community service networks. Although primarily designed for CLSCs, the 36 modules can also be used to train regular hospital and adult hospice attendants where there is a need to care for a terminally ill child. It's a way of improving the access, quality, and continuity of support available to families of sick children in their area—a growing challenge for families of children whose lives are prolonged beyond previous expectations.



The training program focuses on updating the attitudes, knowledge, and organization of services as observed in eight partner regions during a volunteer home respite program that ran for The Lighthouse from 2011 to 2014. One of the key contributors on the project is Carole Tétreault, a healthcare e-learning specialist, who is optimizing the program for online distribution through various learning activities. Reviewing the clinical content we have Marie-Claude Proulx, a management-level consultant in pediatric palliative nursing at the Montreal Children's Hospital.

The online program is designed to be interactive, dynamic, and visual. The goal is to offer a reliable and enjoyable course that can be adapted according to the learner's prior experience and the caregiving situation. Since pediatric palliative care can be a highly emotional topic, awareness and interpersonal skills are an important focus of the program.

Promising experiences in the Quebec City, Lanaudière, Laurentians, and Saguenay regions have provided specific solutions for critically ill children. These cases are presented along with the tools developed in the regions. Other modules offer examples taken from The Lighthouse's end-of-life care and long-term family support (respite services). One module suggests ways of moving support services closer to the family's home town, regardless of where the child is being treated. Dedication and kindness—central values of The Lighthouse—are reinforced throughout the training program. The goal is to establish quality, timely regional services, with The Lighthouse guiding and supporting caregivers, organizations, and families from afar.

### The training program has five sections:

- 1 Pediatric palliative care in Quebec: particularities and practices
- 2 New ideas on the organization of pediatric services in Quebec
- 3 An itemized care guide for children dying at home
- 4 Modules to be shared with outside professionals who may have little experience with end-of-life pediatric care (pharmacists, doctors, spiritual caregivers, etc.), as a primer for working with CLSC caregivers
- 5 Long-term family support

Quand vient le temps d'annoncer la mort d'une sœur ou d'un frère, les adultes hésitent, et utilisent des mots moins lourds tels que : on l'a perdu, il est parti...

On place les enfants dans un mode de recherche de son frère ou de sa sœur et c'est pourtant ce qu'on doit éviter.

Dans l'avion pour Disneyworld, j'ai regardé par la fenêtre, tout au long. Je voulais revoir son petit coucou. Mais le nuage de ma petite sœur n'était nulle part dans le ciel. Et il y avait quand même beaucoup de nuages. M'a-t-elle déjà oubliée?

On camoufle la mort derrière des images abstraites et derrière des croyances qui empêchent souvent les jeunes de vivre la réalité.

La sécurité réside dans la vérité un concept simple, mais souvent malmené

On dit à nos jeunes de ne pas nous mentir dès qu'ils sont tout petits.

Nous voilà à leur mentir au sujet d'une personne qu'il aime de tout son cœur. On commence souvent dès la maladie : on cache la gravité, on parle de bobo au lieu de cancer.

Nos jeunes gagnent tellement à accompagner dans la vérité la personne qu'il aime et qui va mourir. Aider nos jeunes endeuillés commence bien avant la mort.