The Children’s Hospital of Eastern Ontario (CHEO) and Roger Neilson House (RNH) Integrated Palliative Care Program: A comprehensive pediatric palliative care delivery model

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THE INNOVATION:

- Development of an Integrated Pediatric Palliative Care Program that combines the services of the CHEO palliative care team and Roger Neilson House, a free-standing pediatric palliative care hospice, located on the grounds of the hospital
- Goal: Provide comprehensive pediatric palliative care services which enhance comfort and quality of life of children and their families
- Population: Children (0-19 yrs) with life-limiting illnesses from Eastern Ontario, Western Quebec and Nunavut
- Partners and Stakeholders: Champlain LHIN, MHLTC, MCVS, Ottawa Senators Foundation, CHEO Foundation

HOW DO WE KNOW?

The Integrated Pediatric Palliative Care Program improves care through:

- Seamless Integration: The team provides care in the hospital, hospice, and in the child’s home ensuring that the child and family’s needs are met in all locations
- Timely and Responsive: A team member is available 24/7, accessed through a single point of contact
- Holistic: Multidisciplinary team includes professionals with expertise to address all domains including physical, emotional, psycho-social and spiritual suffering
- Comprehensive: Services are offered from the time of diagnosis, at any point along the life-limiting illness trajectory, and bereavement supports after death

CULTURE AND CARE EXPERIENCE

Co-locating of Roger Neilson House on the hospital campus resulted in:

- Enhanced visibility and awareness of palliative care services among CHEO staff, patients, and families, leading to greater acceptance and integration of a palliative care approach
- Increased timely and appropriate referrals
- Reduced caregiver burn-out and hospitalizations for children with complex medical needs through provision of hospice respite admissions and symptom assessment
- Improved end-of-life services through ease of admission to hospice and ability of team to respond to emergencies in the community with home visits

IMPACT STORY: Ethan’s Legacy

Ethan was diagnosed in utero with a life limiting illness. His parents were referred to the Palliative Care Team when he was 20 weeks gestation. With gentle guidance, they planned for his birth and short life.

After Ethan was born, they spend time with Ethan at Roger Neilson House, bonding with him in a safe and supportive environment. They loved and lost precious Ethan while in the care of a compassionate team. They later healed with others while attending a Perinatal Hospice Support Group.

Wishing to give back, Ethan’s parents and sibling have become advocates for palliative care. This is Ethan’s legacy.

IMPACT AND RESULTS

Key Performance Measures

- Number of referrals to the CHEO program
- Number and type of admissions to Roger Neilson House
- Number of participants in bereavement program (sibling, parent, grand-parent and perinatal loss support)
- Satisfaction of children, families, staff and volunteers
- Development and piloting of new programs/services/supports

THE INTEGRATED PEDIATRIC PALLIATIVE CARE TEAM:

Core Team Members: Palliative care physician, Advanced practice nurse, RN/RPNs (with pediatric palliative care expertise), Social Worker, Recreation Therapist, numerous volunteers

Consulting as needed: Pediatric sub-specialists, Bioethics, Pharmacist, Spiritual care, Cultural Support, Child Life, Occupational and Physiotherapy, Respiratory Therapy

THE INTEGRATED PEDIATRIC PALLIATIVE CARE PROGRAMS:

- Pediatric Palliative Care Consultation
- Home Visits
- Hospice admissions for respite, transition to home from hospital, symptom assessment, and end-of-life care
- Perinatal Hospice Program
- Bereavement Support (individual, couple and group counselling) for parents, siblings, grand-parents
- S.I.B.S Group (Spectacular Incredible Brave Siblings)
- Summer day camp
- Research committee
- Family Advisory Committee

Trends and Growth

Qualitative Results

Surveys
- Staff, Family, Volunteer Satisfaction 2008-2010-2012
- Survey of Family Support 2016

Needs Assessment
- Family needs assessment 2010
- Program Evaluation and Planning
  - Palliative Care Survey for CHEO Staff 2007
  - CHEO Palliative Partner Survey 2009
  - Palliative Care program Evaluation 2012
  - Strategic Planning 2012 & 2017 (in progress)

Numerous Publications and Research ie:
- A Pediatric Palliative Care Program in Development: Trends in Referral and Location of Death, Vadeboncoeur et al, (2009)
- Aim: To describe the formation of a pediatric palliative care program providing care in hospital, at home or in hospice, ensuring continuity of care where the child and family desire.
- Charting the territory: symptoms and functional assessment in children with progressive, non-curable conditions, Steele et al, (2014)
- Aim: To describe these children’s symptoms, as well as how the children’s condition affects them physically.
- Perinatal Hospice Referral Review (in progress)
- Retrospective chart review of referrals to guide program needs going forward.

Family Quotes
- “I wish I had been referred earlier” Symptom Assessment
- “We could have never done this without you” EOL
- “...the best 7 days of our life” Perinatal Hospice
- “I could not help my son grieve the loss of his child... I was grieving too. Thank you for helping me so I can help him” Grand-parent bereavement

SPREAD PLAN

- The integrated palliative care model is flexible and can be replicated as a whole or adapted to local needs
- The CHEO Team and Roger Neilson House have been consulted by other programs wanting to replicate their services ie: Emily’s House; Rotary Flames House; and Le Phare. Resulting programs are similar and respond to local needs.
- A hospice and its availability of respite and other services is complementary and attractive but not required if alliance with adult hospice is available and suitable.
- A professional team with pediatric expertise or link with such is essential and home/community services ideal.

LESSONS LEARNED

- A dedicated professional team with pediatric palliative care expertise was essential from the beginning
- Team had to include a dedicated physician and nurse with 24/7 availability through on-call system
- The team focused on the best interests of the child and family, despite numerous perceived barriers
- Regular evaluations emphasized the need for an expanded clinical team and services, encouraging the team to develop proposals for increased funding and novel programming and services such as S.I.B.S Group and perinatal hospice