

## Symptom Assessment at Roger Neilson House

Each family referred to the Palliative Care Team at the Children's Hospital of Eastern Ontario (CHEO) has access to care and support at Roger Neilson House as their child experiences distressing symptoms during the course of illness.

## WHAT CAN YOU EXPECT?

- At your request, a meeting with the Palliative Care nurse and physician to ensure understanding of the concerning symptoms you or your child are observing.
- Admission to Roger Neilson House for assessment and evaluation of those symptoms. (The length of stay will be determined by the severity of symptoms and response to treatment).
- Palliative Care Team consultation with you, other members of the care team at CHEO and community caregivers. If changes to medications prescribed by other physicians are required, this would only be done after consultation with the prescribing physician.
- Recommendations for a revised plan of care.
- Assessment of your child's response to the revised plan of care before discharge home.
- Discharge instructions that summarize revisions made to the plan of care.
- A follow up call from the Palliative Care nurse or physician after discharge to provide continued care and support.
- Communication with your child's primary care physician at the time of discharge.

## WHAT ARE THE COMMON SYMPTOMS THAT CAN BE ASSESSED?

- Pain
- Feeding intolerance requiring an adjustment in the timing, rate or volume of gastrostomy tube feedings.
- Changes in responsiveness that require observation.
- Sleep problems including requiring more or less sleep than usual, disrupted sleep or day-night reversal.



- Poorly controlled seizures that might require monitoring while medications are being adjusted.
- Constipation (infrequent, large bowel movements or discomfort in passing the bowel movement).
- Pressure areas (redness or open areas of the skin over bony prominences).
- Spasticity and dystonia (increased muscle tone that causes discomfort and muscle contractions that cause twisting and abnormal postures).

If you or your child are concerned about other symptoms, consult with the Palliative Care physician or nurse on call (see contact numbers below).

## HOW CAN YOU REQUEST AN ADMISSION FOR SYMPTOM ASSESSMENT?

- Contact the Palliative Care physician or nurse on call via CHEO locating at 613-737-7600, extension 0. Ask to have the nurse or doctor on call for Palliative Care paged.
  - Contact the admissions coordinator at Roger Neilson House: 613-523-6300, extension 619.