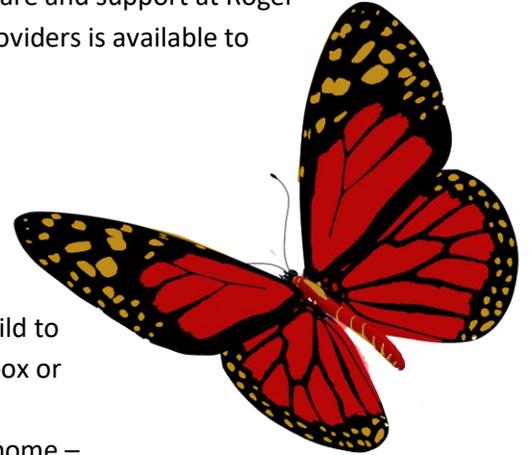


End of Life Care at Roger Neilson House

Each family referred to the Palliative Care Team at CHEO has access to care and support at Roger Neilson House as their child approaches end of life. The team of care providers is available to assist you, your child and other family members to achieve your wishes.

WHAT CAN YOU EXPECT?

- Openness and honesty about the belief that the end of your child's life is approaching.
- Collaboration in developing a plan of care for the end of life – called palliative care directives. This will include helping your child to fulfill his or her own special wishes such as creating a memory box or planning their own funeral or memorial service.
- Choices about your child's place of death – hospital hospice or home – with 24 hours of support wherever your child might be.
- 24-hour access to symptom control by qualified and experienced professionals.
- The opportunity to consider organ or tissue donation. If your child has had a long-term illness it may not be possible to consider major organ donation, but it might be appropriate to consider tissue donation such as heart valves and corneas.
- Emotional and spiritual support in talking with members of your family about the difficult decisions you are making.



WHAT WILL HAPPEN AT THE TIME OF DEATH?

- Your nurse will notify the palliative care physician to declare your child's death.
- Because Roger Neilson House is a publicly funded children's residence, the coroner is required to visit each child and family after a death. The coroner will be contacted and will talk with your palliative care physician, visit your child's body and speak with you about your child's illness and death. The coroner will also complete the death certificate.
- Unless a time-sensitive autopsy is planned, you can hold your child and spend as long as you wish together. You may want to have other family or friends with you or you may choose to be alone.
- You will be encouraged to take time to say goodbye to your child by bathing and dressing them, taking a lock of hair, making a handprint or footprint, taking photographs, playing music or lighting a candle.
- If you have planned for organ or tissue donation, a Trillium Gift of Life coordinator will be contacted.
- If you have planned for an autopsy, your child's body will be taken to the morgue at CHEO by your nurse. You can accompany your child to the morgue.

- The funeral home of your choice, or your Mosque, will be contacted to pick up your child's body. If you live outside of Ontario or a distance away from Ottawa, the funeral home of your choice may ask to have a local funeral home involved. Funeral home staff will assist you in making plans for a service and burial or cremation – you will be asked to contact them as soon as you are able to make these arrangements. A social worker can help advise you on financial issues associated with the funeral.
- The funeral home or member of your family will be required to register your child's death and obtain a burial permit from the City of Ottawa.

BEREAVEMENT SUPPORT

- Your nurse or social worker will speak to you about bereavement support available at Roger Neilson House.
- You will be contacted by the social worker about bereavement support within a month of your child's death. Individual counselling and support groups are available for you and your other children.