



END OF LIFE CARE

It's more about quality of life than it is about death.

Serious illness, death and dying are hard things to talk about. It is important to find a support who you trust and who will take time to listen to you and your family. At Roger Neilson House, the team of care providers is available to assist you, your child and other family members to achieve your wishes as the child approaches end of life.

What we offer?

- Stay for the whole family when the child is approaching end of life with a team to take care of the child.
- Collaboration in developing a plan of care for the end of life – called palliative care directives.
- Support child 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 and provide 24 hours of care 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 when the time comes?

Each child's journey to death is different. Your role is to be present, provide comfort, and reassure your loved one with soothing words and actions that help maintain their comfort and dignity. And it is our responsibility to make sure that your child receives highest quality of care which is consistent with their values and desires. Our goal is to make sure the child is as comfortable as possible in his or her final hours.

- Your nurse will notify the palliative care physician to declare your child's death.
- 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.

Helping you get through grief.

You may have a lot of feelings as you grieve, you may feel angry, sad and confused. Your partner or other loved ones may cope in different ways. It is normal to have questions about all parts of the care and experience emotions. Your nurse or social worker will speak to you how we can support you in coping with your grief 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, siblings and grandparents.

How to obtain services?

Each child and family referred to the Palliative Care Team at CHEO has access to Roger Neilson House end of life services. For more detailed information please refer to the contact information on this brochure.

LEARN MORE

For more information please contact us at CHEO Locate and ask them to page Palliative Care Nurse/Physician on-call, 613-737-7600 ext. 0 or email at info@rogerneilsonhouse.ca.