



A bond for life: CHEO, Roger Neilson House and our community

Life is made up of moments, and by celebrating and supporting each and every one, we acknowledge how unique and precious all life is.

Overview

Despite continuous advancements in research, obstetrics and pediatric medical care, miscarriage, stillbirth, life-limiting and terminal illness still affects our community. As do conditions that cause babies, children and youth to be medically complex, fragile and technology dependent throughout their lifetime. Whatever path leads families and caregivers through the doors of CHEO and Roger Neilson House to access palliative care services, and however long their time with us may be, they will find support, community and dignity.

The History

When Roger Neilson House opened its doors, it marked a new era. This eight-bed pediatric residential hospice is as much a home as it is a world-class palliative care facility. And for families and caregivers facing the turmoil that complex medical conditions, life-limiting illness and death can bring, it is a safe haven.

Roger Neilson House offers a multitude of services that cater to the unique needs of a medically fragile population in an environment that celebrates life by enabling kids to be kids. It has become a special place of comfort and compassion where children, families and caregivers can cherish and celebrate moments together.

The inter-professional team of doctors, nurses, social workers, therapists and support staff working together in a new state-of-the-art, homelike setting brought to life the family-centered care at the heart of a vision to enrich the quality of lives, no matter how short.

Growing Needs

Today, demand for palliative care and respite services continues to grow and Roger Neilson House and CHEO are working together to offer new services and expand access to current programs. Knowing how important it is to provide solutions that will ease suffering and struggle, the palliative care teams are tenacious, creative and relentless in their work. But the need is great, and we rely on the community who built both CHEO and Roger Neilson House to be our cornerstone.



The CHEO Foundation has the privilege of raising the funds that will ensure the health and prosperity of Roger Neilson House today and long into the future. Through events, fundraising campaigns and direct donations there are many ways to be a part of the team standing with us to bring respect, celebration, dignity and community to those facing the most difficult times. **Palliative care at CHEO and Roger Neilson House is about living, and your generosity is what breathes life into everything we do.**

A. Strengthening the circle of caring

This fund provides the critical support for the various programs and services offered by Roger Neilson House every year. These are the resources that children, youth and families rely on and that make Roger Neilson House the special place that it is. This includes counselling, respite, recreation therapy, end-of-life care and more. The capacity to do this work depends on donor dollars that can enable dedicated staff to make sure every family caring for a child with a life-limiting condition has access to the supports they need.

B. Securing the future for RNH

A special fund was established in 2006 with the long-term goal of raising \$10 million to build a pool of money large enough to generate annual interest at a level capable of paying the portion of operating costs not covered by other sources. Thanks to the inspiring and devoted support of the donor community this goal has been met, and those dollars will never be spent. The full amount of gifts will be preserved and professionally managed in perpetuity. With this stability comes deep gratitude as well as the recognition that past budgets won't cover current or future increases in costs. It is crucial to keep adding to, and diligently stewarding, the protected nest egg as maintenance bills, core program needs and day-to-day expenses will continue to increase. Every dollar added to this endowment fund will literally and figuratively reinforce the foundation of Roger Neilson House.

C. Preparing to weather any storm

This capital fund will ensure that Roger Neilson House can maintain the facility and improve the physical environment for patients and families as needs arise. Having capital available allows for scheduled maintenance and planned improvements as well as providing a safety net for any unforeseen capital costs which can come up suddenly. A recent assessment suggests \$1 million should be on hand at all times to cover capital needs for Roger Neilson House. Every home requires diligent maintenance to keep the roof from leaking and pipes from rusting, but at Roger Neilson House the specialized medical care available onsite also means meeting all health and safety codes while providing homey and welcoming spaces for the children and families.



When you donate to Roger Neilson House, you support families in a variety of ways.

Respite Care:

The word respite is synonymous with pause. The provision of respite care at Roger Neilson House is a form of support for families coping with the many challenges of their child's life-limiting illness. It gives a family time to rest and rejuvenate so they are better able to care for their child. It also provides an opportunity for staff to monitor a child's health and support the family in dealing with challenges they may be facing in the community. The children benefit from being in an environment built for them, interacting with peers and having some fun. During the respite visit, children may be offered or require symptom management, recreation therapy and counseling.

End of Life Care:

End of life care is available at Roger Neilson House when it is determined by the medical team that death is imminent. Staff works collaboratively to ensure that the final wishes and needs of each child and family are met in the weeks, days and hours leading up to a child's death and beyond into the bereavement phase. This involves helping family members make difficult decisions around end-of-life plans, creating memories and sharing mementos as well as addressing emotional and spiritual care needs. Heartfelt guidance and compassionate support are offered to help with transitions at end-of-life for children and their families.

Grief Support: Individual, Couples, Grand Parents and Group Counseling:

The death of a child is a life-altering tragedy for the families who love them and who must accompany them through this difficult journey. Roger Neilson House provides support throughout the highly individual experience of grief. From a child's diagnosis, throughout their illness, and after their death, grief support and specialized bereavement care are offered to the entire family, from young siblings to devoted grandparents.

Spectacular Incredible Brave Siblings (SIBS):

S.I.B.S is a program to support siblings of children with life-limiting illnesses. Siblings can often be an invisible population who suffer in silence while dealing with the same amount of worry and stress as a parent. S.I.B.S creates a safe environment for peer-to-peer support among young people going through similar experiences. This is an invaluable resource to both children and their families. With additional community funding this circle of caring could grow to include more families within our community.

Memory and Legacy Building Activities:

Throughout a child's involvement in the palliative care program, Roger Neilson House helps families make lasting memories and keepsakes, which can include handprints, photography, artwork, referrals to wish-granting organizations, and participation in special events.



Every family, if they so choose, will be given a star after the death of their child and a book of remembrance including their child's name will be available at Roger Neilson House always.

Visiting Hospice:

The In-Home Volunteer Visiting Service is available to families whose child is receiving palliative care through Roger Neilson House. This is a new program where trained Roger Neilson House volunteers go into the home of a Roger Neilson House family and offer supervised respite by playing and spending time with the child while parents can tend to other children, rest, and do household chores. This is an important program to support our families in their own home.

The Perinatal Hospice:

The loss of a baby during pregnancy or after birth is devastating and impacts those involved forever. Perinatal Hospice and Bereavement offered by the Roger Neilson House team is provided to parents and families in cases where there is a prenatal, perinatal or neonatal diagnosis of a life-limiting illness or a life-ending diagnosis. It is specialized care that prepares parents for the birth, death and sorrow of the impending loss of their deeply loved child. Care is provided in a timely manner and is dependent on parental/family needs and wishes.

Recreation Therapy Program:

The children accessing Roger Neilson House services often miss out on parts of their childhood due to being medically fragile. The Recreation Therapy program gives these children the opportunity to experience normal childhood life, as well as fulfill their wishes however big or small. Developing this program will mean more dreams can come true for these children, improving their quality of life and creating a greater sense of legacy for each family Roger Neilson House supports.

Symptom Management:

Symptom assessment and management is available at Roger Neilson House and is coordinated by the CHEO Palliative Care Team in consultation with the family and members of the care team at CHEO. A child is admitted to the hospice for a period of time to evaluate symptoms, implement treatment modalities and evaluate responses.

Transition Care:

A transition to home admission at Roger Neilson House is coordinated by the CHEO Palliative Care Team. Children leaving hospital with new treatments, equipment and/or medications may be admitted to the hospice for a period of time to support families as they become familiar and comfortable with the new plan of care. Families assume the responsibility for their child's care while also receiving support and reinforcement of the teaching they received at CHEO.



A Lasting Impression

Meet the Otto family who benefitted from services offered at Roger Neilson House...

<https://youtu.be/db-VQ5vFuD0>

Sunday July 15, 2007, was a beautiful sunny day at the lake where Jeanine and Dean Otto were building their family cottage. That afternoon, their daughter, Maddy, went for a nap, and when she woke up her speech was slightly slurred and physically there was something about her that the family could not put their finger on. They made the decision to take her to CHEO. What they would learn later was that she had a seizure during her nap.

On the drive back to Ottawa, Maddy's condition worsened. Upon arrival at CHEO the family had just been admitted when Maddy started to seize again. The staff rushed her to the trauma unit where they put her in an induced coma to run tests. The Otto's felt helpless. What was happening to their little Maddy? The results of a CT scan followed by an MRI brought the family's world to an abrupt halt – their beautiful 5-year-old had a tumor on her brainstem. It was inoperable and terminal.

Their lives changed forever in that moment. How could this be possible? Had they made a mistake? They were forced into decisions that no parent should ever have to make. Would they like to donate Maddy's organs? Do they want to put her on life support? Would they like to take her to Roger Neilson House? At the time, they had no idea what Roger Neilson House even was.

The Otto's took the short walk from CHEO to view Roger Neilson House. Instantly the warmth of the facility and its' incredible staff were a comfort to them, and they knew this was where Maddy would spend the rest of her short life. Around 3:00 p.m. on Tuesday, July 17, 2007, while the rest of the world continued as normal, Jeanine and Dean walked with Maddy in their surreal world along with their family and friends through the park, to Roger Neilson House. They settled in quickly thanks to the caring staff, so all they had to do was focus on their little girl. They reassured her it was okay to let go of this world.

Roger Neilson House supported them through this horrific ordeal, and the family still feels that support to this day. The bereavement counselling and group therapy was instrumental in helping the family survive the first stages of what they refer to as their "new life". They are now a part of a very different family. Their darkest days were to come, but they had a safe and special place where they could go to endure those days, and this was vital to their survival.



The Otto's wanted to dedicate part of their "new life" to Roger Neilson House. It was six short weeks after Maddy passed away that "Maddy's Superheroes" was born! They formed the largest team at that time to participate in the Roger Neilson House's Walk, Roll & Run event and they raised close to \$26,000 in honour of our Maddy! This achievement made the family feel like they had a purpose again and they wanted to do more.

A simple idea blossomed over a glass of wine: a gala in Maddy's honour. There was a small and intimate evening on February 1, 2008, which raised almost \$10,000. Feeling rejuvenated, the Otto's decided this should be an annual event, so "Maddy's Gala" was born, and each year it continues to exceed the success of the previous year!

"Our Angel Maddy gave us wings and we are using them to soar. We miss you every day Maddy Moo. xoxo" ~ Mommy and Daddy (a.k.a. Jeanine and Dean Otto)

