



ROGER NEILSON HOUSE

We hope you will feel a sense of pride in knowing that your support ensures we can continue to offer a compassionate place of comfort, a place where loving and skilled care is offered each and every day and where families know they are forever a part of the Roger Neilson House and CHEO family.

Thank you for your support!



Roger Neilson House

Since the start of the COVID-19 pandemic we have witnessed massive changes to our daily lives, our work and the choices that we make for ourselves and our families. Things we have always cherished have become even more precious, and while this time has been one of uncertainty, it has also been one of regeneration and heightened focus on what makes life truly special.

The mission of Roger Neilson House is deeply rooted in the idea that by embracing the beauty and dignity of each life, and celebrating the special moments each day, we can create a more generous and humane world that prioritizes kindness, compassion, laughter and a love for children. This vision reflects our values, and our donors help us bring that vision to life.

In the early days of the pandemic staff were working very hard to ensure that clinical care continued, that support for those grieving was available and that end-of-life plans were carried out as loved ones wished. Without knowing how the situation would evolve, the guiding principles of Roger Neilson House and the generosity of people in our community helped staff to continue delivering expert care and we are confident that our standards never wavered.

What we did not know during those tumultuous early days was that the challenge of shepherding our families through COVID-19 would usher in a time of inspired creativity. Every member of our staff was able to find ingenious ways to strengthen the bonds of community within the new safety guidelines. As new protocols were adopted and diligently followed, programs such as in-person respite could reopen in late June. On-site day respite was implemented across from the House at the Children's Treatment Centre. The technology that has revolutionized meetings in the business world became a lifeline for those in need of professional bereavement counselling as well as children and youth seeking an outlet for their energy through activities organized and facilitated by Recreation Therapists.

Through play, arts and crafts, talk therapy, movement, music and more, life blossomed inside Roger Neilson House and as far afield as we could safely go. When families couldn't come to us, we went to them, redeploying medical staff into private homes for much-needed visits and launching an online guest speaker series sharing tools to enhance resiliency and mindfulness. With the constant guidance and input of a dedicated family partner, with a view to breaking down barriers and escaping isolation, new programs and services were discussed and implemented.

Thanks to your support, Roger Neilson House can continue its vital work safely and help to lift families out of loneliness and despair. Your support funds the innovative approaches that keep our community vibrant and engaged. That sense of togetherness is more important than ever as we come to more fully understand how much we rely on each other.

Best regards,

Megan Wright
Executive Director, Roger Neilson House
Director Palliative Care, CHEO

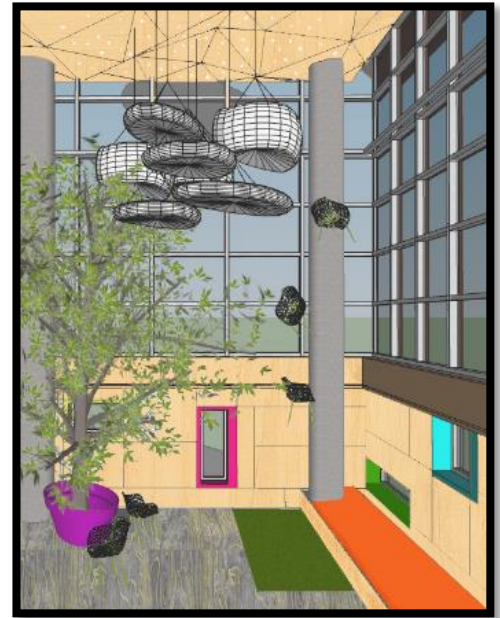
Jacqueline Belsito
Vice President of Philanthropy
CHEO Foundation



Thanks to donor support we were able to renovate our Playroom!

Roger Neilson House's playroom has been a focal point for its children and families since it opened its doors 14 years ago. It's a place where kids can go to do arts and crafts and where parents of children who have passed can go to visit their child's star on the memory wall. But just like any well-loved and used space, it became clear that the playroom was in need of a renovation. Thanks to a donor who left a generous gift in their will to Roger Neilson House, a redesign and renovation of the playroom and legacy star wall installation was made possible.

Under the leadership of Anne Carlyle of Carlyle Design Associates, a group consisting of Roger Neilson House parents, staff and volunteers designed this space for play and fun for children of all ages and abilities that also accommodates, with special sensitivity, a new legacy installation honouring the lives of children and families who have passed through the house. This new playroom will be fully accessible year-round and provide a sensory experience and opportunity for the kids to connect with nature and light. The playroom is named in honour of Louise Birkett Krapf and Rolf Krapf.



[READ THE FULL STORY HERE](#) on how we brought this playhouse in the trees theme to life while still beautifully honouring the memories of the children who have passed on the star wall.

As demand for palliative care continues to grow, your donor dollars also helped with services and programs offered at Roger Neilson House such as:

Counselling: Individual, Family Support, Bereavement

Our organization was impacted greatly by the COVID-19 pandemic. We had to make many changes, including to the services and programs we offer. As a team we were swift to respond and we have remained nimble as directives have changed. Unfortunately, it has meant suspending some activities in the house, including pre-booked respite admissions; however, we have remained open and available for our patients and their families in many other ways. We have shifted to providing online support for families, including for both bereavement and support programs, which is a first, and may make services more accessible to all. This will be an area that we will focus our research on in the future. The upcoming year will be full of challenges, but we are well positioned to be adaptable and flexible, while continuing to provide care for children, youth and families in need through:

- **Individual Counselling:** offered to the entire family from diagnosis all the way through bereavement. This supportive environment gives family members the opportunity to share challenges, experiences, and develop coping strategies.
- **Ongoing family support:** we offer support groups for the whole family to help them navigate the challenges associated with having a child/sibling with complex needs. These programs include our Parent Support Group (brings a sense of community where parents discover they are not alone), as well as S.I.B.S. (Spectacular Incredible Brave Siblings). S.I.B.S. allows siblings to receive support from peers going through similar experiences.



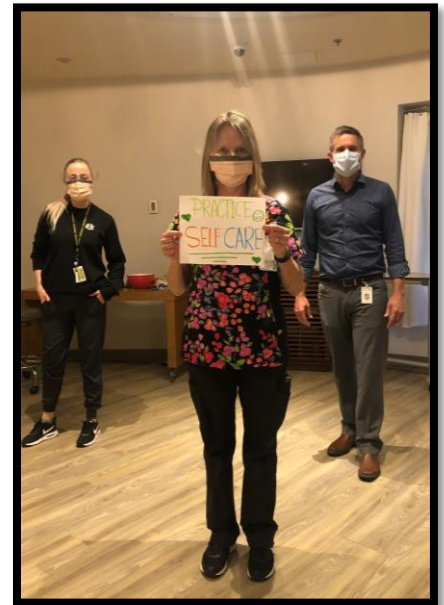
- **Bereavement Counselling:** we take every measure imaginable to support the family after the death of a child. We offer a safe and healing environment to share their experiences and grief through support programs like:
 - Parent Bereavement Support Group
 - Grandparent Bereavement Support Group
 - Perinatal Loss Parent Bereavement Group
 - Siblings Bereavement Support (S.I.B.S.) Group
 - Pregnancy After Loss Support Group (PALs) - *new in 2018*
 - Drop-In Bereavement Support Group - *new in 2018*

CHEO's Palliative Care program and Roger Neilson House

Losing a child is an already unthinkable tragedy - during COVID-19, it is much worse.

Children with palliative care needs and their caregivers are often isolated from family members, friends, schools and social support networks, and this isolation is only compounded by the threat of COVID-19 infection and the associated fear and anxiety. To make an already difficult time worse, families may not be able to have the end of life care previously planned e.g. the opportunity to make memories or have the funeral and send off, due to the COVID-19 pandemic. Families who have been caring for children and young people with serious underlying health conditions for many years have often had 'near misses' leaving them in fear of their child dying from COVID-19, potentially alone and in isolation.

CHEO and Roger Neilson House staff are doing everything they can to help these families, but we need community support more than ever to do so. Grief and bereavement support has always been made possible through donor dollars.



Visiting Home Hospice

Please note: This service is subject to COVID-19 restrictions and guidelines (see COVID-19 Update section)

The Visiting Home Hospice Service is available to families whose child is receiving palliative care. This is a new respite program, in its 4th year, that brings Roger Neilson House volunteers into the home of a family. By spending a few hours with the child parents can tend to other children, rest, or do chores around the home. Providing services to parents and children in the convenience of their own home relieves the stress and burden of having to come to the House for respite time. Our volunteers have reported that seeing these kids in the comfort of their own environment makes it easier for them to observe progression or regression in their development and skills, which they can then report back to the care team. Last year, we anticipated helping 14 families, but the need was so great that we were visiting the homes of 17. As requests for this support increase, we plan to expand the program. We are currently projecting a 20% growth in demand year over year as more families access and benefit from this unique service.

On behalf of Roger Neilson House, Thank you for your support!

