

Roger Neilson House



Family Handbook

Information and Guidelines for Children and Families



Roger Neilson House

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Rights and Fundamental Freedoms of Children and Their Families

Roger Neilson House promotes the integrity of the family and assures the best interests of the children we serve as outlined in the Children and Family Services Act of Ontario (1990).

In accordance with the act, Roger Neilson House strives to:

- Recognize the physical, cultural, emotional, spiritual, mental and developmental needs and differences among the children we care for.
 - Develop services that are responsive to the needs, values and customs of the diverse children and families we serve.
 - Recognize that, wherever possible, services to children and their families are provided in a manner that respects cultural, religious and regional differences.
-

Provincial Advocate for Children and Youth

The role of the Advocate's office is to ensure that children and youth, including First Nations children and those with special needs, are able to voice their concerns about their lives and the services they receive. The Advocate ensures that the voices of children and youth are heard and that systems respond accordingly.

How to contact an advocate:

- Toll free at 1-800-263-2841
 - Email advocacy@provincialadvocate.on.ca
-

Roger Neilson House Values

The Roger Neilson House program strives to be a safe, welcoming, refuge for both the families we serve and for the employees and volunteers who work here.

Together as a team we have acknowledged the importance of abiding by these values in our work, our ethics, and in our practice. These values need to be considered, adopted and demonstrated in our interactions with all others we encounter in our day to day tasks at Roger Neilson House. We are a multi-professional team and the values are relevant and inclusive to all of us. It is the goal of the Roger Neilson House team to work in an environment that promotes a high quality of service to children and families, while at the same time offering a safe, accountable, and pleasant work environment to the employees and volunteers of the program.

Our values include:

Safety

Respect

Accountability

Transparency

Engagement

Learning

and Performance

Roger Neilson House Team

The team includes, but is not limited to:

- Administrative Assistant
- Doctors
- Executive Director
- Nurses
- Nurse Practitioner
- Managers
- Pharmacist
- Personal Support Workers
- Recreation Therapist
- Social Workers
- Volunteers



The Roger Neilson House team is complemented by the **CHEO Palliative Care Program**. The CHEO team collaborates with the Roger Neilson House team to provide comprehensive care for children and families.

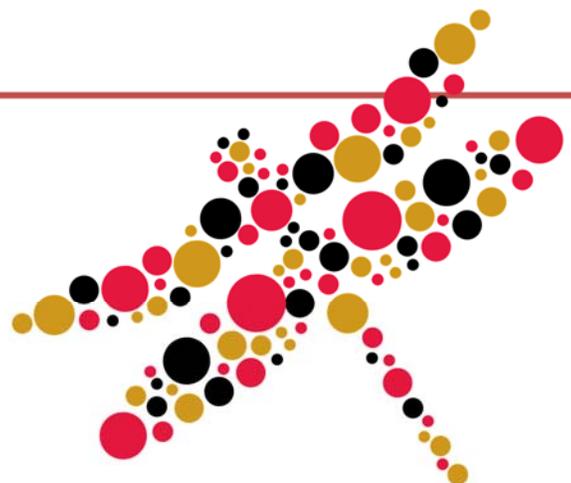
Yearly meetings are scheduled between individual families and the CHEO team. At these meetings, goals of care are reviewed and services are enhanced based on changing health status. These meetings allow for discussion and decision making around issues including supports in your community, hospitalization, acute interventions, resuscitation, and progressive symptoms. These meetings are held at Roger Neilson House yearly, during daytime hours.

At any time, you, your child or a team member may request a family/ team meeting. The meeting will be scheduled at everyone's earliest convenience.

If your child becomes ill at home and you need to contact the CHEO Palliative Care Nurse or Physician on call, they can be reached urgently through **CHEO locating at 613-737-7600 ext. 0.**

If you have any concerns at any time, please contact the Roger Neilson House Manager:

Helen Yoxon—613-523-6300 ex. 4603



Services Offered at Roger Neilson House

When your child is deemed eligible to receive palliative care services by the CHEO Palliative Care Team, you and your family will be introduced to the services offered by Roger Neilson House.

Admissions to Roger Neilson House are dependent upon the prioritized needs of all children in the program. Admissions are prioritized from 1 to 5 in the following order:

- | | |
|-------------------------|---------------------------------------|
| (1) End of life care, | (4) pre-booked respite, |
| (2) emergency respite, | (5) transition from hospital to home, |
| (3) symptom management, | |

RESPITE CARE:

Respite care is 24-hour care of your child at the hospice. The purpose of respite is to allow your family time to rest and rejuvenate. It is also an opportunity for ongoing evaluation of your child's health by the CHEO Palliative Care Team and Roger Neilson House staff. There are 2 categories of respite care:

1. *Pre-Booked Respite Care:*

- **During a calendar year, each child is entitled to 28 days of pre-booked respite.**
- While Roger Neilson House makes every effort to honour these bookings, it is important that families have a contingency plan in the event these admissions need to be cancelled due to a higher priority need.
- The maximum length of stay is **2 weeks at a time**. Each child is eligible to stay for 2 holiday weekends per year. 10 days over the summer months and either March break or the Christmas holiday.
- Families are encouraged to pre-book these stays well in advance to ensure the desired dates are available.
- While we will make every effort to honour these bookings, it is important that families have a contingency plan in the event these admissions need to be cancelled due to a higher priority need. We very much strive to never cancel and will continue to do so.

2. *Emergency Respite Care:*

- Emergency respite is available to children who require emergency care due to a crisis situation in the family.

TRANSITION CARE:

Transition care offers services when the child is ready to leave the hospital (CHEO-OCTC) but your family is not yet ready to take over their care at home. Your family may need support and assistance to become more comfortable with the changes of your child's care.

- During a transition visit, the primary caregiver is expected to provide care with the support of the Roger Neilson House nursing team.

SYMPTOM MANAGEMENT:

Symptom management is aimed at managing the distressing symptoms experienced during the course of illness. When symptoms are identified by the family, a meeting with the CHEO RN and MD on call is arranged and the child is admitted to Roger Neilson House for assessment. Recommendations about changes are then made after consultation with the family and other members of the CHEO care team and in the community. A new plan of care is agreed upon and re-assessment by Roger Neilson House staff occurs prior to discharge home. The following are some of the common symptoms that are assessed:

- Pain
- Feeding intolerance
- Changes in level of consciousness/ responsiveness
- Sleep disturbance
- Poorly controlled seizures
- 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



The length of stay will be determined by the severity of symptoms and response to medical management. A summary of the stay will be forwarded to the primary care physician at the time of discharge.

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. The Roger Neilson House team recognizes this and 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 the child's death and beyond into bereavement. 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. The goal is to enhance comfort support and family relationships.

PERINATAL HOSPICE:

Perinatal hospice offers services to expectant families when a prenatal diagnosis of a life limiting or life threatening illness is made. The family is assisted in developing a birth plan which details goals of care during and after the baby's birth. Memory making (photographs, plaster casting of hands and feet) is provided. Transfer to Roger Neilson House can be arranged if the health status of the baby and mother permits. Quality time spent with the baby is encouraged in the environment of choice; hospital, Roger Neilson House or home. Timely referrals are encouraged to permit the development of a therapeutic relationships with the care team.

GRIEF SUPPORT AND BEREAVEMENT CARE:

From the time of your child's diagnosis, throughout their illness and after their death, grief support and bereavement care are offered for you, your child and other family members.

Memory making and legacy building activities are available throughout your child's involvement in the palliative care program. This can include handprints, photography, art work, referrals to wish granting organizations, and participation in special events. All families are offered a memorial star on the Wall of Stars after the death of their child.

Support and Bereavement Services at Roger Neilson House

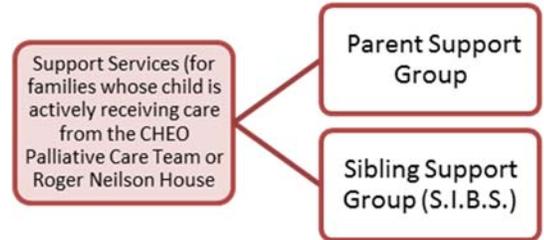
Roger Neilson House offers a variety of support services to families (parents, siblings, grandparents).

We offer counselling to individuals in addition to the group counselling outlined below. If you have any questions please speak with any one of our team members or contact Helen Yoxon, Manager, Palliative Care and Roger Neilson House at 613-523-6300 ext. 4603 or hyoxon@cheo.on.ca.

Please visit website for more details on services offered at Roger Neilson House, and the Events page for the updated listing of group sessions available.

Ongoing Support Services:

Parents whose children are currently receiving the services of the CHEO Palliative Care Team and/or Roger Neilson House have access to individual and family counselling over the trajectory of their child's illness.



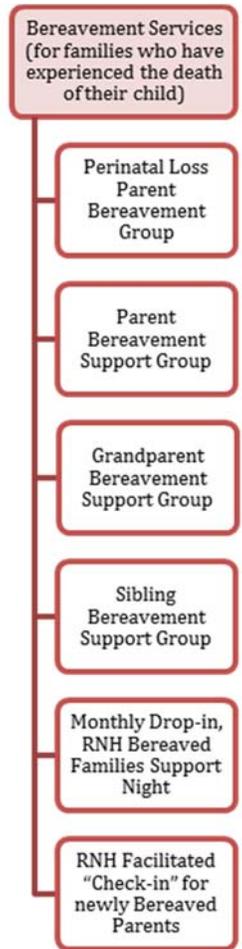
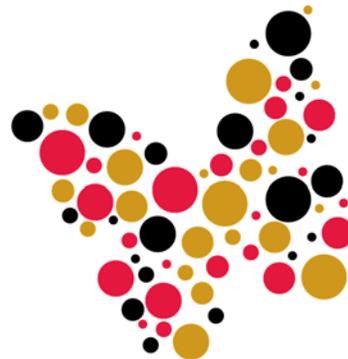
Bereavement Services:

Bereavement support is available for families who have experienced the death of a child (under the age of 19) at Roger Neilson House, CHEO/OCTC or in the community.

We offer a safe and healing environment. At RNH our philosophy is to accompany families through their grief journey. The following principles guide our services:

- Grief is unique for each family member.
- Sharing your experience with others who understand can bring comfort.
- Being part of a group helps reduce the sense of isolation common to bereaved families.
- All of our bereavement groups are closed and require advance registration.

Coffee Chat:
a non-facilitated "drop-in" time for all Roger Neilson House families, both past and present, to connect



Preparing for a Stay at Roger Neilson House

BOOKING YOUR STAY:

When you have chosen the type of stay and the dates you would like to request, please contact the Admissions and Care Coordinator. If no one is available to take your call, leave your request on voicemail – your call will be returned as soon as possible.

Communication:

Please note e-mail is our main form of communication with parents. Always ensure you have provided RNH with your current email address.

PRE-ADMISSION:

Prior to admission you will receive an e-mail from the Roger Neilson House nursing team entitled *Admission to Roger Neilson House*. Attached to the e-mail is a link to the pre-admission questionnaire on the RNH website. Please ensure this questionnaire is returned a few days prior to admission so the necessary paperwork can be prepared.

Please ensure a current Medication List is included. This can be obtained from your pharmacy.

Recent exposure to an infectious illness (such as chicken pox, measles, tuberculosis, whooping cough or mumps) or the presence of fever, cough, vomiting, diarrhea or rash may require postponement of the admission.

Because all children staying at Roger Neilson House are medically fragile, it is very important to report the presence of symptoms to protect others.

Emergency Caregiver/Contact:

You are responsible to provide the name and contact numbers of an emergency caregiver/contact at each admission. ***The role of this individual is to assume care for your child within 2 hours if discharge is required and you cannot be reached or are not immediately available.***

At each admission you will be asked to sign a Care Agreement and Consent which authorizes staff to give the necessary medical care as outlined in the Palliative Care Directives in the event that staff are unable to reach you.

Please Note:

If your child will be attending school during their stay at Roger Neilson House, you will need to coordinate this with your child's school and the busing program. Please let staff know what time your child will be picked up and dropped off from school. In addition, please let staff know what supplies are to be sent to school with your child on a daily basis.

Quick Reference to Book a Stay:

1. Select type of stay (see page 5)
2. Contact: 613-523-6300 ext 4611
3. Complete pre-admission questionnaire on the RNH website. Must be completed prior to stay.



What to Bring for your Stay:

Pack everything your child might need on a daily basis with the exception of sheets and towels.

Roger Neilson House is not responsible for loss or damage to personal items belonging to guest or family.



The following are the equipment and supplies required for admission:

Medications: Including prescription & over-the-counter medications, in adequate supply for the duration of stay .

- Please ensure the medication bottle is properly labelled & in the original container with drug name, concentration and date of expiry. This is also necessary for all liquid medications. Please bring pill crushers and splitters as needed. Bring an epi-pen if your child has a life threatening allergy.
- ***Improperly labelled medications cannot be administered.***

Respiratory equipment : Any respiratory equipment your child requires which may include portable suction and suction catheters, ventilator, Bipap, Cpap, ambu bag, nebulizer, in-exsufflator, oxygen saturation monitor, tracheostomy emergency kit (including extra tracheostomy tubes). If your child requires oxygen (please contact your provider prior to admission).

Communication devices

Mobility devices including wheelchair and splints.

Feeding Equipment:

- Feeding equipment including formula, pump, battery/charger pack, spare Mickey, extension tubes and feeding bags.
- Food for special diet (ex. Gluten, Ketogenic)
- Note: Roger Neilson House is a nut safe environment.

Toiletries: Including diapers, wipes, soap/ body wash, toothbrush & toothpaste, hairbrush, shampoo, creams & lotions.

Clothing : Labelled and in sufficient quantity for the duration of stay.

Personal play & comfort items : Example: toys, blankets, videos, CD's. **Please note: All staff take every precaution with your child's equipment.**

Day of Admission

Please note – admission time is between 1 pm and 4 pm.

The nurse admitting your child to Roger Neilson House will review consents, medication orders, care plan and daily activity schedule with you for accuracy. **This process may take an hour or so – please make arrangements to accommodate for this.** You will be asked to unpack your child's equipment & supplies before you leave.

Day of Discharge

Please note – discharge time is: up to 4:00pm

You will be asked to come in and pack your child's equipment & supplies. Your child may be discharged to the school bus if requested. Equipment and supplies will not be sent to school.

Please ensure you have all of your child's belongings and medications.

Infection Control

Anyone recently exposed to an infectious illness (measles, tuberculosis, whooping cough, mumps, chicken pox) or showing symptoms (fever, cough, vomiting, diarrhea, rash) is encouraged to avoid visiting until the incubation period has passed and/or their symptoms have resolved.

Any child who develops symptoms during their stay at Roger Neilson House may be discharged so other children staying at the house are protected. Children receiving end of life care are exempt from discharge due to the nature of their admission and their isolation.

Smoking

As of January 1, 2018, all Ontario hospital grounds will be smoke-free by law.

This includes Vaping/E-cigarettes.



Lost and Found

Please call the Nurses Station if you think something has been left behind at the House. Your family will be contacted if a team member discovers any leftover items at the House and make arrangements for pick up. Equipment, supplies and personal items that are left behind will be kept at reception in the front lobby.

Family Advisory Committee (FAC)

The Family Advisory Committee (FAC) provides families who use Roger Neilson House the opportunity to give feedback and advice to the Executive Director, leadership team and staff about programs, practices, policies and initiatives.

If you are interested in joining this important committee, please contact Roger Neilson House staff liaison, Bruno Perrier (bperrier@cheo.on.ca or 613-523- 6300 ext 4605). You will receive a formal application form which will be followed by an interview to determine your eligibility.

Please follow this link for more information on the Family Advisory Committee (FAC).

<http://rogerneilsonhouse.ca/families/family-advisory-committee/>

Roger Neilson House Facilities

In the event of fire or other emergencies, families should report to the nursing station for direction. Emergency plans can be found at each exit door.

Visitors

Your visitors are welcome at Roger Neilson House. Please provide the nursing staff with a list of visitors permitted to visit your child in your absence. Visitors are encouraged to call ahead. **The volunteer (or staff member) at the main entrance reception desk will welcome and register all visitors before they are permitted to go upstairs.**

Young children who are visiting (including siblings) must not be left unsupervised. A responsible adult is required to be with them at all times. Any child under the age of 18 may stay overnight with permission from their legal guardian if a responsible adult is available to supervise them.

Touring visitors through the house should also be discussed with the responsible nurse. The privacy of other guests and families need to be taken into consideration.

Notes on Providing Care:

- Community Caregivers may visit with your permission but they are not permitted to provide care.
- Friends and family may visit and provide care with your written permission. They are encouraged to speak with the responsible nurse before giving care.

Main Floor

Kitchen & Dining Room - Meals are prepared for guests (at no cost) and immediate family (low cost). Meal coupons may be purchased from the Coordinator, Strategic Projects and Governance, between 8 am & 4 pm in the main office. Families may use the kitchen to cook and store their own food. Please consult with the PSW on duty for times that the kitchen is available.

- Snacks can be purchased from the basket in the kitchen, Donations are gratefully accepted.
- Take out menus are available in the kitchen. You are welcome to order food to the house.

***Living Room** – available for family gatherings, services and meetings.

***Library** – available for family & friends. Books (including reference books) can be borrowed. Please return when you have finished using them. **All rooms must be booked prior with the** Coordinator, Strategic Projects and Governance.

Playroom – available for guests and families staying at Roger Neilson House. All children using the room should be accompanied by a responsible adult (parent, staff or volunteer).

Snoezelen Room – available for guests and families staying at Roger Neilson House. Designed to provide stimulation and/or relaxation for guests under the care of staff or volunteers. All children using the room should

Second Floor

The second floor contains the guest rooms, tub room, laundry room, nursing station and medication room. There are 4 single guest rooms and 2 double guest rooms, each with its own bathroom and wheelchair accessible shower, TV & DVD player.

Family Suites:

There are 2 family suites, primarily for use by families who want to be together as their child nears end of life. These rooms are furnished with a guest bed, a king-sized bed, table & chairs, couches, microwave & compact refrigerator, television & a DVD player. Towels & linens are provided: emergency toiletry packages are available if needed.

- Families have access to the laundry room as available.
- Telephones are located in all common rooms at Roger Neilson House. Dial 9 to access an outside line for local calls. Long distance calls can be made using calling cards or collect.
- Laptops & iPads are internet ready and available for use by families staying at Roger Neilson House.

Basement

The lower level contains offices and shared space. The Teen Lounge has gaming and movie-watching equipment in addition to games tables (foosball, table hockey). The Training Room has a mini kitchen, table & chairs for meetings and support groups. Please note that children under the age of 14 should be accompanied by a responsible adult at all times (parent, staff or volunteer). The music space includes a piano and guitars that guests and families are welcome to use.

Parking

Families are encouraged to load and unload their vehicles at the OCTC curbside where parking is permitted weekdays after 4 pm and on weekends. Those with disabled parking stickers are able to park in the disabled parking spots in front of the play park.

Roger Neilson House permits must be displayed at all times.

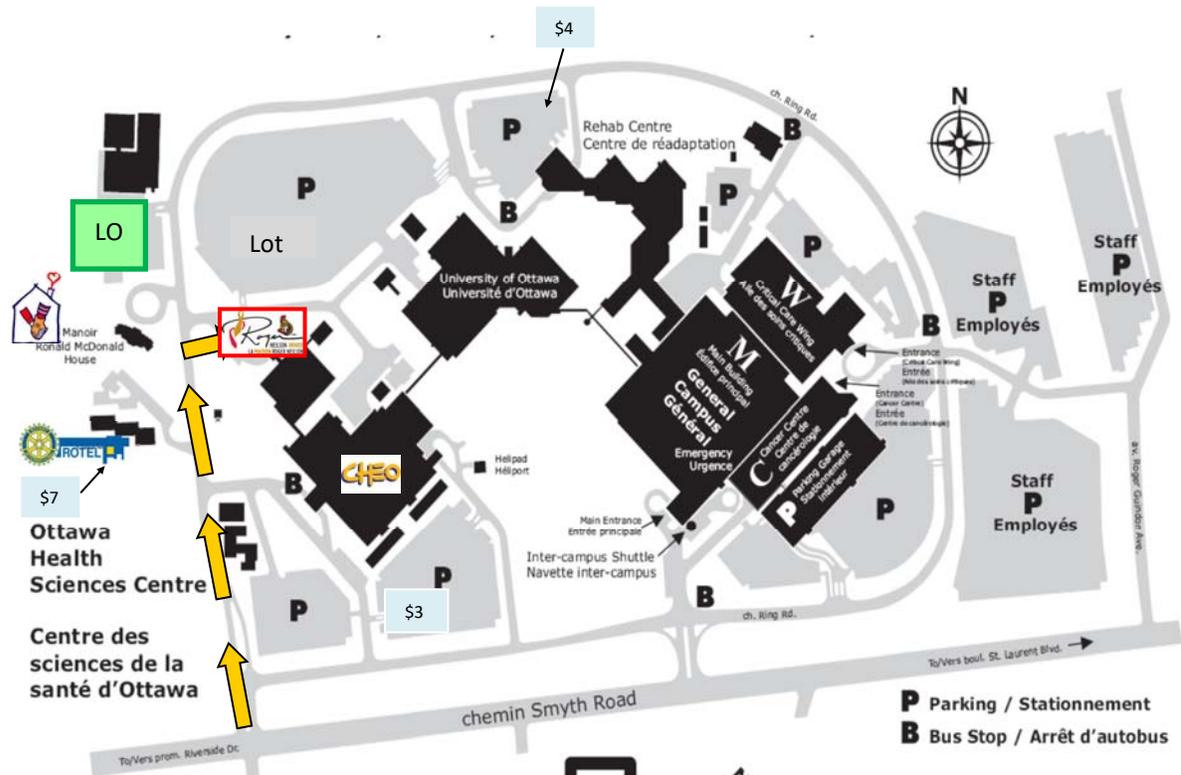
Temporary permits may be obtained from the Volunteer Receptionist (or any staff member).

Parking is available on a first-come-first-serve basis. If no parking is available, you must find parking elsewhere.

Families staying at Roger Neilson House should speak to their nurse if they require a long term parking permit.

A \$20 deposit is required to secure a permit and is refunded when the permit is returned. Parking is located in Lot C.

Parking



CHEO-OCTC / ROGER NEILSON HOUSE

15 minute parking/drop off area only
 School Bus Drop Off & Pick Up Zone
 Strictly no parking between the hours of
 0815hrs-0915hrs and 1415-1515hrs

Parking regulations are enforced 24/7
 Violators will be issued a City of Ottawa
 parking infraction notice.

CHEO-CTEO / MAISON ROGER NEILSON

Stationnement limité à 15 minutes /
 Aire de débarquement
 Zone d'embarquement et de débarquement
 pour autobus scolaires

Stationnement strictement interdit entre
 8 h 15 - 9 h 15 et 14 h 15 - 15 h 15

Les règlements concernant le stationnement
 sont appliqués 24 h/24, 7j/7
 Les contrevenants recevront une
 contravention de la Ville d'Ottawa.

CHEO-OCTC / ROGER NEILSON HOUSE RESERVED PARKING

Parking permits must be clearly
 displayed and are required at all times.

Parking regulations are enforced 24/7
 Violators will be issued a City of Ottawa
 parking infraction notice.

STATIONNEMENT RÉSERVÉ AU CHEO-CTEO ET À LA MAISON ROGER HOUSE

Les permis de stationnement
 doivent être clairement affichés
 en tous temps.

Les règlements concernant le stationnement
 sont appliqués 24 h/24, 7j/7
 Les contrevenants recevront une
 contravention de la Ville d'Ottawa.

Important Telephone Numbers & Extensions

Main Roger Neilson House number 613-523-6300

Extensions:

- Executive Director - 4604
- Manager – 4603
- Nurse Practitioner – 4610
- Nursing Station – 4651/4652
- Admissions and Care Coordinator – 4611
- Recreation Therapy – 4663/4667
- Coordinator, Strategic Projects and Governance – 4600
- Social Work – 4622/4607/4609
- Kitchen - 4615

Please feel free to call the Nursing Station 24/7 if you have questions about your

We asked RNH Parents what they would tell a new RNH Parent:

- Once you are a Roger Neilson House family, get involved in all that is offered to you. Stays at the House — even when your child is ‘well’ — give the team the opportunity to get to know your child. You are now an RNH family and all RNH families are entitled to the care and supports of the program. Try not to judge your circumstance as ‘not as bad as others’ or deny your family what RNH can give. In talking to the team and meeting other families, we found the support we were missing outside of Roger Neilson House. This was the best gift ever.
- RNH is different. They will listen to you and they understand that parents know their kids best. They know that parents are the experts when it comes to their children. The process is a joint effort between the child, parents and staff. The doctor does not dictate to you the plan. Rather, the plan is compromised of valuable input from the RNH team and the parents.
- Ask questions, understand and don’t feel intimidated. RNH does care about our kids.
- You are so brave for coming through the doors and asking for help. Hugs to you! This is a unique place with lots of love for the kids and helpful hearts for you too.
- Don’t be freaked out when another parent says hello. Embrace those moments - they remind you you are not alone and there is something comforting about that here.
- You are the best voice for your child - speak up and ask for help to support him or her and you on this journey.
- Best memories were sharing time in the kitchen with other moms as they cooked up a pot roast and cupcakes to celebrate with the families they knew - feel free to do that with new people or with your family and friends - this is your home.
- Like many RNH kids, our son has challenges communicating. We noticed that some parents attach a small booklet to their child’s wheelchair with information on likes and dislikes, and even include photos showing their child properly positioned in various equipment. We started to do this too before RNH stays. We sometimes also bring in a family photo book so that staff and volunteers can learn about our whole family.
- Many of our closest friends - the ones we can turn to in the tough times, who reach out to us without asking, and who really “get it” - are people who we met at RNH support groups and other events. We didn’t choose to be on this journey, but we feel privileged to have a network of role models, advocates, and leaders thanks to the RNH community.