

# Emily's House

## Respite Family Handbook

**Information Guide for Children, Youth and their Families**



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## Introduction & Welcome to Emily's House

Emily's House seeks to support children and their families living with a life-threatening illness. Our support aims to enhance **client and family-centered care** and interdisciplinary service delivery in the community while improving the quality of living and/or dying. Our support, in whatever form, is provided with the purpose of assisting children and their families to live full, active, independent lives for as long as possible and when this is no longer possible, to help children and their families prepare and manage life closure and the dying process.

Staff and volunteers at Emily's House are compassionate and skilled in the provision of respite and palliative care for children, youth and their families, and are committed to respecting confidentiality, beliefs, choices, faith and culture.

The enclosed material will allow you to become better acquainted with Emily's House and our programs and services. We share this house with many families and therefore ask that you follow the basic guidelines outlined in this handbook. This will ensure a more comfortable stay for all our guests. We are always available to answer any questions you may have during your stay with us.

## What is Emily's House?

Laughter, learning, play, comfort, and care is what Emily's House is about.

Featuring a 10 bed, home-like, comforting environment, Emily's House is dedicated to caring for children with complex, life-limiting illnesses, while supporting their families. With around-the-clock nursing and medical support, Emily's House offers pediatric care, specialized programs, comfort and respite to help enrich the lives children and families through all stages of a child's illness.

Our staff and volunteers are dedicated to helping children and their families achieve the best possible quality of life together. We understand that our patients and their families each face unique circumstance and challenges and we strive to support them in all aspects of their experience.



## History

*"I alone cannot change the world, but I can cast a stone across the waters to create many ripples."* Mother Teresa

This statement truly reflects the journey to Emily's House, which began with one act of kindness expressed through a small community church in Toronto towards a man name Philip Aziz who was living alone with a terminal illness. The compassion, love, practical and spiritual support he received amidst this caring community led him to bequeath his estate to them. He requested his gift be used to establish an organization that would help others in our city struggling with the challenges of living with life-limiting illnesses.

Since opening our doors in 1995, Philip Aziz Centre Community Hospice (PAC) has continued this legacy of love, through a small professional staff team and over 250 trained volunteers, whose commitment to delivering compassionate and skilled hospice care has helped to make a difficult life journey more meaningful and manageable for hundreds of adults, children and families over the years living in our community.

The complex and diverse needs of the children and families we have supported over the past 19 years through our community hospice programs led us to expanding our services to families by building a Children's Hospice in Toronto. Our Children's Home is named in honour of a courageous young woman (Emily) who we have supported through our "hospice to home" programs for the past 8 years, and is living with a progressive life-limiting illness. Emily and her family represent hundreds of children and families who daily face the challenges and uncertainties of dealing with complex, life limiting illnesses.

At Emily's House we believe that whether a life is measured in days, weeks months or years, children living with a life limiting illness deserve the opportunity learn, play develop and grow...to just be kids. When there is no cure, there is still life, support, compassion and care...there is Emily's House.

Our primary goal of care is to ensure your family is comfortable, safe and well cared for in a home like, child friendly, professionally staffed place.



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Rauni Salminen, Executive Director

## Eligibility for Services

Emily's House services are available to children:

- 0 - 19 years of age
- Have a valid Ontario Health Insurance Plan (OHIP),
- Eligible to receive services from the Community Care Access Center (CCAC)
- Have a progressive life-limiting illness or a major medical disease that demonstrates a progressive decline
- Open to Advanced Care Planning discussion

### Respite Care

Respite care for family caregivers is designed to provide the child and family caregivers support away from home, time for their own rest and renewal, and time for other siblings. Respite involves temporary 24-hour in-house care with or without immediate family staying at the hospice. This also provides an opportunity for ongoing health evaluation and access to supportive counselling and informational resources. Respite is scheduled in advance for a pre-determined duration. The child should be at his or her typical level of health. In the event of an acute illness or sudden changes in the child's health, it is possible that respite may be postponed or cancelled.

Care providers will seek to maintain health and comfort by implementing the usual home care routine. Children can benefit from therapeutic programs and have the opportunity to socialize with other visiting children. Additional recreational, play, psychosocial/spiritual, and bereavement services are made available.

### Advanced Emergency Care

Advanced emergency respite is available to all the children in our program who suddenly need care and do not have an available caregiver (due to a family emergency, etc.). We try to respond to requests for emergency respite within 24 hours of the request and offer care for 48-hour blocks of time.

Stays may be extended at the discretion of the Emily's House Residential Care Coordinator, at the end of the emergency respite period, depending on family circumstances, available resources, and bed availability.

### Advanced Transition Care

Advanced transition care offers services when a child is ready to leave the hospital but the child's community is not yet ready to provide the services required (i.e. wheelchair access, education about new care procedures, nursing or physical therapy). Care is aimed at providing support systems to the child and family that enables a transition to home plan.

The goal of this program is for the primary caregiver/parent to learn how to take care of their child safely at home using the new medical equipment or intervention. During transition care, the family is responsible for the activities of daily living and supplies

needed for their child's care. Our team directly assists the child and their parents and caregivers in transition from the hospital/hospice back to their community.

Transition care is normally available for up to 14 days. The nursing team will evaluate the family's progress. If the family requires further support in the care of their child, it will be reviewed at this time. Emily's House will collaborate with the CCAC to ensure a safe transition home.

### **Pain & Symptom Management**

Children whose primary goal of care is comfort and are known to and followed by PACT (Pediatric Acute Care Team) are eligible for admission to Emily's House to address uncontrolled pain and other symptoms. An initial assessment and admission by a PACT physician is completed within 12 hours of arriving to Emily's House. Nursing support will provide in-house care and appropriately monitor changes in symptoms and responses to treatment. The PACT team will be available for consultation 24 hours a day to address related concerns.

### **Advanced End-of-Life Care**

Advanced end-of-life care (hospice admissions) offers comprehensive services for your child and family during the end-of-life period. The primary focus of end-of-life care is to provide pain and symptom management, comfort, and supportive care. Children will receive full nursing care and access to PACT consultations 24 hours a day. You and your child will be supported in returning home if you wish, or experiencing the dying process at Emily's House.

Children may be transferred from the Hospital for Sick Children or be admitted from the community and assessed on arrival to Emily's House. To ensure the smoothest possible transition, admission to Emily's House is encouraged during regular business hours (Monday to Friday, 0900-1700). However, exceptional circumstances may require admission outside these times. If your child is in need of end-of-life care, an in-house admission will be facilitated as soon as possible.

### **Perinatal Hospice**

Perinatal hospice is a program offering support to parents and families whose babies are likely to die before, during or shortly after birth. Care is provided from diagnosis and throughout pregnancy, death, and bereavement while honouring the life of the baby. Services provided focus on the development of a specialized birth plan, legacy building, memory making, and ongoing bereavement support for the family.

*Note: Emily's House provides end-of-life care for a child and family. Due to the acute nature and sensitivity for the child and family experiencing the dying process, your child's respite stay may be rescheduled. Emily's House will do its best to accommodate your respite needs and the Residential Care Coordinator will notify you as soon as possible.*

## Emily's House Team and Services

The Emily's House interdisciplinary team includes:

- Nurses
- Doctors
- Personal Support Workers
- Recreational Therapist
- CCAC Case Manager
- Coordinator of Volunteer Services
- Volunteers
- Spiritual Support
- Music Therapy
- Art Therapy
- Play Therapy

Our team is committed to providing the best possible comprehensive care for your child and family. Regular meetings with your family and our team are one of the best ways to ensure this can happen. At these meetings, we will work together to develop and review a comprehensive family-centered care plan. These meetings also allow for discussion and decision-making around issues including supports in your community, hospitalization, acute interventions, resuscitation, and progressive symptoms. You, your child or our team may request family/team meetings.

### **Nursing Care**

Our team consists of Registered Nurses and Registered Practical Nurses who are experienced and skilled in pediatric palliative care. They provide 24-hour nursing care and work as a team with other professionals to provide physical, psychological, emotional, and spiritual care to children and their families.

### **Physician Care**

Emily's House will work with your child's paediatrician, family physician, or designated specialist to provide care for your child during his or her at Emily's House. During the end-of-life period, Emily's House has access to a physician on-call 24 hours a day from Sick Kids.

### **Personal Support Workers**

Emily's House personal support workers are trained and certified in providing personal care, as well as cooking, cleaning, and supporting our guests.

### **CCAC Case Manager**

Emily's House works with the Toronto Central CCAC. We have our own Case Manager who will coordinate CCAC support in-house and also facilitate discharge back into the community.

## **Volunteer Support**

Emily's House appreciates the valuable contributions of volunteers who work alongside the professional team assisting with care to children, youth and families. Our volunteers consist of dedicated and compassionate individuals who continually devote their time, efforts, skills and talents to enhance the quality of life for our guests at Emily's House. Volunteers fulfill roles on the board of directors, with patient care, at reception and with daily activities in the house. Volunteers spend time with the admitted child and their siblings engaging in activities, from music to working with arts and crafts, to assisting on outings and other recreational activities.

- All volunteers have completed 30 to 52 hours of training to prepare them for their role
- All volunteers have completed a Vulnerable Sector Police Check and must give three references
- All volunteers respect confidentiality
- Volunteers who prepare or handle food have received their Food Handlers certification or are supervised by someone who has
- Volunteers are flexible and have your best interest in mind. If you ever feel you want some private time and don't want to socialize they are happy to give you space
- Volunteers are familiar with the emergency and fire safety protocols

## **Spiritual Care**

The work of the Spiritual Care and Bereavement counselling team is to provide support to children and families through all the different stages of their personal journey. Our team of professional chaplains are committed to respecting everyone's unique spiritual journey, understanding that spiritual needs and expressions differ.

Spiritual care includes:

- A spiritually supportive, non-judgmental and caring presence where positive or difficult emotions and questions can be opened expressed
- Exploring the meaning of life and death
- Offering spiritual direction and encouraging a sense of spiritual well being
- Visiting in home (within GTA only) or Emily's House
- Reflection on faith, God, sacred readings, music, prayers and sacraments
- Exploring non-religious spiritual meaning and connectedness
- Connecting you with a faith or spiritual tradition that has personal meaning
- Responding to concerns relating to loss and grief
- Planning and officiating funerals, celebrations of life and memorial services

Spiritual care may not necessarily involve any particular religious expression or institution, although for some people it naturally will. In some ways, we might say that everything that happens in a place like Emily's House is an expression of spirituality, sacredness, and love.

## **Other Services**

Additional counseling and therapy services can be arranged for an Emily's House child during admission. These services may include physiotherapy, occupational therapy, and other forms of supportive therapies.

## Consent

We assume consent through a comprehensive assessment of a child and family. The family and child are actively involved and included in ongoing discussions with the care team for the provision of care and involvement in activities. They are made aware of all aspects of the child's life at Emily's House. Through discussion with the child and/or family, we will obtain formal consent for any significant changes or new treatments that may arise.

Written consent from the family and child is required for:

- Admission
- Special outings
- Occasions where the child may be photographed, filmed or included in media events for use outside of Emily's House
- Pet Therapy
- Interdisciplinary communication sharing
- Pick up and drop off of child when it is not the parent or legal guardian
- In the event that parents or legal guardians are leaving Toronto, an **Alternate Decision Maker** will be appointed to make medical/personal decisions for the child/youth during your absences. The alternate decision maker will be responsible to accompany the child/youth.

All aspects of care, treatment, and activities are documented in the child's health record by members of the care team.

## Confidentiality

Emily's House staff, volunteers and administration protect the privacy of your child and family's personal and healthcare information. All information concerning children and families, staff and volunteers is confidential. It is only to be used by individuals who require access to it in order to provide care or service to the person to whom the information belongs, or for another approved reason that has been consented to by that person/guardian.

Nursing report takes place in the nursing/medication room in order to respect patient confidentiality. This takes place at 07:30, and 19:30, as well as at other times when confidential information needs to be shared amongst the team. Should your child or family require our assistance during these times, please approach staff and we will be happy to assist you. Our goal is to protect confidential information for all our guests and families and we appreciate your assistance with this. Many private phone calls and discussions take place at the nursing station and we appreciate your efforts to respect the confidentiality of all of our guests.

## Communicable Diseases

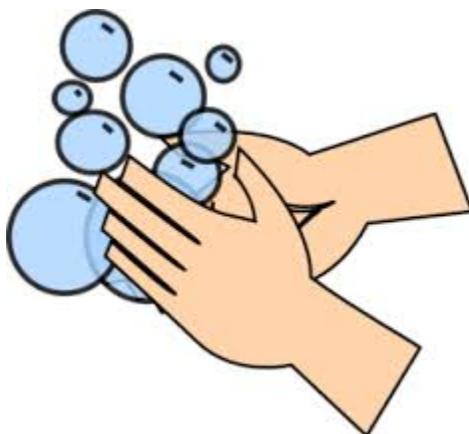
For the safety of all children staying at Emily's House, you must inform us if your child, or any family member, has been exposed to any of the following within three weeks of an in-house admission:

- Chicken Pox
- Measles
- Tuberculosis
- Whooping cough
- Mumps

If your child is experiencing an elevation in body temperature, vomiting or diarrhea, please inform us prior to your child's admission. If so, it may be necessary to reschedule your respite visit due to the fragile health of other guests in-house. If your child develops any of the above signs or symptoms while in-house, your child's remaining stay may be cancelled and rescheduled for another time.

**HAND WASHING** is the most important way to prevent the spread of infection. Hands should be washed thoroughly with warm soapy water at the following times:

- Upon arrival to Emily's House
- Before and after contact with shared house items and areas
- Before mealtimes
- After contact with a contaminated source (e.g. diaper change, bathroom use, drool, cough, sneeze, etc.



## Respite Booking Guidelines

Each patient admitted into our Standard Respite program is eligible for 7 days per quarter/**28 days per year** of planned respite. This may include up to **2 holiday stays per year**. These stays are considered **guaranteed respite**. A guaranteed respite stay is encouraged to be booked at least **2 months in advance**, to ensure we can accommodate your needs. These stays will not be cancelled, unless your child becomes ill at the time of admission or during their stay.

**As-needed respite** can also be booked at Emily's House, and we will take these requests at any time. These stays are considered "flexible" and are based on bed availability and staffing resources. These as-needed stays can be booked in advance, but are subject to rescheduling or cancellation if the beds are required for a more urgent admission.

- When you would like to book respite time, send your request by phone, fax, or e-mail. If your requested dates are available, you will be notified by email/phone from the Residential Care Coordinator confirming the availability. At the time of booking, please indicate which days are priority dates (guaranteed respite) and which days are flexible.
  - ❖ Phone number for bookings: 416-363-9196 Ext. 209
  - ❖ Fax number for bookings: 416-363-6153
  
- You will receive a pre-admission phone call from nursing staff to confirm:
  - Respite dates
  - Admission and discharge time
  - **\*\*Who will be dropping off and picking up your child**
  - Review of care plan
  - Discussion of respite events
  - Reminders of what to bring
  - Review emergency contact information
  - **\*\*\*Pre-screen your child for Fever, Respiratory issues, vomiting, diarrhea**

*\*\* To protect the safety of your child, it is Emily's House policy that you identify who is dropping off and picking up your child if it will not be you (the parent/guardian). In these cases, Emily's House requests a signed letter identifying:*

- *The name of the person picking up and dropping off your child*
- *The relationship to the child*
- *Your evaluation of this person's competency/ability/skill level in caring for your child*

*In cases where it is another person dropping off and picking up your child, Emily's House staff will request photo identification (driver's license, citizen card, or passport) to verify the identity of the person picking up or dropping off your child.*

*\*\*\* Remember to indicate exposure of your child or family member to any communicable diseases at that time. To protect the Health and Safety of children accessing hospice programs at Emily's House, all children are screened for fever, respiratory symptoms, vomiting, diarrhea or increased seizure activity. If these symptoms are present, the planned admission may be rescheduled for another time.*

- On the day of admission, the admitting nurse will confirm the following with the parents/guardian:
  - Consent
  - Care Plan
  - Up to date and correct medication summary

*Please allow for this time (**approximately one hour**) for this process.*
- While you are at Emily's House or before your child visits for respite care, please complete the "**Personal Belongings Checklist**" to avoid personal items being left at the hospice after your child returns home.
- On rare occasion, your child's respite visit may be **rescheduled** if a bed is required for end-of-life care. This need is very unpredictable, but we will do our utmost to prevent any inconvenience. You would be notified as soon as possible in this event in order for alternate arrangements to be made. We acknowledge that this may be of great concern to some families, and we will do our best to avoid any disruption to pre-arranged plans. You may indicate when booking a respite stay which dates are priorities, so that we can best meet your needs.
- Admission for Standard Respite will take place from 0800h – 2000h. No admissions will be scheduled from 1830h – 1930h.

## What to Bring for Respite



When planning a visit to Emily's House, we suggest that you bring all that your child requires on a daily basis, such as medications, equipment, supplies, and suitable clothing. Pack as though you were going to visit grandma. Like her, we do not have all the necessary items that your child requires for his/her activities of daily living. A **"Personal Belongings & Respite Packing List"** is available to assist in preparing for your child's respite stay. Completing a "Personal Belongings Checklist" prior to admission may reduce the number of lost/misplaced items not returned home on discharge. Extra copies are always available for families to take home in preparation for your next visit to the house. We suggest that you keep at home any personal items of great sentimental or monetary value that may potentially be lost or damaged. Please let us know if you have any questions regarding your child's medication, equipment, or supplies.

### **Please double-check that you have:**

1) An adequate supply of medication for the duration of the visit. Medication needs to be properly labeled\*\*\* and in the original container (including name and concentration of drug). Liquid medication must be in a **labeled** pharmacy bottle or nurses will not be able to administer them.

*\*\*\*It is Emily's House policy that medication must be in a pharmacy container, and labeled by a pharmacy. Orders must be up-to-date. In addition, nursing staff will **not** accept pre-loaded medication in syringes or pre-poured doses.*

2) Please fax or mail a copy of your child/youth's pharmacy profile to Emily's House and bring the original copy with you on admission. This will include all medications he/she takes routinely including prescription medications and over-the-counter drugs.

3) Please ensure you bring all necessary equipment and supplies (e.g. wheelchair, charger, splints, nebulizer, suction machine, communication aids, etc.). If your child is receiving oxygen, please inform Emily's House so we can arrange for an adequate supply to be available in advance.

4) If your child is on tube feedings, please bring a sufficient supply of formula, bags, syringes, pump, battery pack, extra Mickey, G-tube and NG tube.

5) Please bring toiletries (e.g. 'Attends' or diapers, special soaps or shampoos, toothbrush, toothpaste, etc.)

6) Please ensure that your child has enough clothing to last him/her the length of his/her stay as we may be unable to do laundry during the stay.

7) Clearly label all personal items, clothing etc.

8) Ensure that a plan is in place for educational activities. It is preferable that your child/youth brings his/her own books and schoolwork. If you are making arrangements for your child to attend school during their stay please ensure we have the necessary pickup and drop off schedule and bus and school phone numbers.

9) If parents/guardians are planning to be out of town during your child's visit, you must leave a phone number where you can be reached in case of an emergency.

**You must also leave the name and phone number of an Emergency Contact who is familiar with your child's condition and needs should we require their assistance during your absence.**

10) Please bring your child's favourite play and comfort items (e.g. toys, videos, tapes, CD player/radio).

11) Ensure you have an up to date copy of your child's Immunization Record with you when you arrive.

## Visitors



We welcome your visitors to Emily's House. All visitors are required to call ahead to inform staff that they will be visiting and we ask that they ring the doorbell. Once in the hospice, visitors must sign in the sign in book. Emily's House will request that you provide a visitors list for your child, so staff can assist in screening visitors.

Please use discretion regarding the number of visitors and the times at which people come and go. If you plan to have large groups visiting please inform the staff. If available, the multi-purpose living room on the main floor may be used to better organize visits. We recognize the interest of your visitors to "look around" the home. However, out of respect for other children and families, please ask your nurse before showing your guests around. Coffee and tea are available for your use. We generally cannot provide meals or overnight accommodation for your extended family or friends.

To protect the health and safety of children at Emily's House, all visitors will be screened for fever, cough, vomiting, diarrhea, etc. Please advise visitors that if they are experiencing these symptoms, their visit must be rescheduled for another date.

### **Siblings and Young Friends**

Please do not leave young children unsupervised. Siblings are the responsibility of the parents/guardians and must be supervised at all times. If, for any reason, you are experiencing difficulty in meeting this requirement, please let us know and we will do our best to access resources or assist with alternative arrangements

### **Pets**

The family pet is permitted to visit a child admitted to Emily's House, but is restricted to the child's room. Pets must have up-to-date vaccinations, be free of parasites and fleas, and have no open sores or lesions. Visiting pets must be on a leash at all times. Pets are not permitted on the beds, and female dogs in season are not permitted to visit.

The parent or family member is responsible for care, feeding, and walking the family pet while at Emily's House.

### **Guide Dogs**

Guide dogs are admitted to Emily's House and must have documentation indicating:

- A guide dog's status
- Location of the guide dog jacket at all times

The family is responsible for outlining the guide dog's responsibilities, supplying food, feeding dish, and providing for the guide dog's routine etc.

## Returning Home

- Ensure all personal clothing, toiletries, equipment/supplies, and medications are safely packed away with you upon discharge.
- Please take the time to go over the Personal Belongings Checklist with staff. Compare the **“Personal Belongings Checklist”** from admission and discharge. Communicate with Emily’s House staff of any discrepancies.
- If you find an item was not packed upon return home, please phone the Emily’s House nursing station and staff will assist you in locating the item.
- Obtain copies of the ‘Personal Belongings Checklist’ for your child’s next stay.



## **Family Rights & Responsibilities**

Families are important members of the health care team at Emily's House. Employees will work with families and the community to make sure that children receive the best care possible. All employees will do their best to make sure families are informed, respected, and supported. Families have a responsibility to:

- Respect the rights of other patients, their families, visitors, and staff
- Provide complete and accurate information about past and present matters relating to their child's health
- Learn and follow hospice policies and procedures
- Discuss any concerns with the health care team
- Respect right and privacy of other patients and visitors

## **Sharing a Home-Like Environment**

We make every effort to create an environment that is 'home-like'. Unlike a home, we have a number of families who reside here at any given time, along with staff and volunteers working at the house. Given this, it is important that everyone assumes the responsibility for creating an environment of sharing, respect, and collaboration.

### **The following guidelines are promoted:**

- 1) Unexpected drop-in visits are discouraged if your child is not in-house. We urge families in the program and any friends or relatives to please call ahead. An effort will be made to accommodate your visit, but due to various circumstances on a particular day, a drop-in may not be appropriate. We appreciate your understanding in this matter.
- 2) Keeping all common areas clean and tidy. Among other things, placing CDs in their appropriate cases, returning used dishes and cups to the kitchen, putting away arts and crafts supplies, and turning off computers/televisions after use is appreciated.
- 3) Respect the privacy and belongings of others in the house.
- 4) Reduce the noise level after 9 p.m. for those trying to relax and settle to sleep.
- 5) Use the kitchen and/or dining areas for eating.

## Emily's House Facilities and Guidelines



### **Main Floor Living Room**

The living room is a multipurpose room used for family gatherings, quiet reading, and small memorial services, interdisciplinary rounds, or general staff meetings and play room. Children and youth, including guests, siblings and visitors must be supervised at all times by volunteers or a responsible adult when using the playroom. Guests and siblings will be given access with appropriate supervision.

### **The Snoezelen Room**

The Snoezelen room is a multi-sensory room that offers visual, auditory and tactile stimulation. The Recreation Therapist coordinates supervised therapeutic sessions for stimulation and/or relaxation. Children will be assessed, in consultation with the family for suitability of various activities. Siblings may be included after an assessment by the child life or nursing staff. Parents may accompany their children in the Snoezelen room under supervision. Shoes must be removed and socks worn during Snoezelen times. Staff is encouraged to utilize the area on a daily basis.

### **Kitchen and Meals**

The kitchen and dining room areas are the focal point of the house. Anyone who wishes may eat there. This includes children, families, staff and volunteers.

Our Personal Support Workers (PSW) or kitchen volunteers prepare meals for our in house guests at designated meal times.

Meal times are:        Breakfast @ approx 09:00  
                                 Lunch @ approx 12:00  
                                 Dinner @ approx 17:00

### **Laundry Facilities**

There is a washer and dryer on site at Emily's House. For respite admissions, it is Emily's House policy to send the child's worn clothing home unwashed. Emily's House staff will do the laundry in the event the child's clothes became soiled when possible, and will wash the clothes separately from other children's clothing.

### **Telephone Use**

Telephones are located in each room and in the nursing station.

- To access an outside line, please ask the nursing staff and they will assist you- local calls only please.
- To make a long distance telephone call - please call collect or use calling cards.

**Guidelines for Internet Use**

Please feel free to use the computers at Emily's House. They are available for your use and enjoyment. Please note that there are some guidelines we ask you follow regarding their use. We ask that our guests avoid having food or drinks around the computer station.

- Emily's House computers are not to be used for gaining unauthorized access to any computer system on the internet.
- File sharing or peer-to-peer programs (ie: BitTorrent, Kazaa) is not permitted.
- Downloading copyrighted music/movies is prohibited.
- Accessing sites or email that may contain profanities and or sexual content will not be tolerated.
- We encourage our guests to save their files on a USB stick or CD so files are not lost or deleted.

Please note that computer privileges will be revoked should guests not comply with the above conditions. The computers at Emily's House are the property of Emily's House and removal of any equipment is strictly prohibited. Please do not hesitate to contact a staff member or volunteer should you have any computer questions or difficulties.

**Wheelchairs**

Emily's House is 100% wheelchair accessible.

**Daily Routine**

The nursing staff at Emily's House will endeavor to follow your child's routine at home. The child's bath, morning routine, feeding routine, and sleeping routine will be followed while they reside at Emily's House. The nursing staff will assess and monitor the child each shift (day and night).

There will be scheduled group activities for children in the morning, afternoon, and evening. Nursing staff will inform you of special events during the pre-admission phone-call.

**Smoking**

Smoking is not permitted inside Emily's House. You may smoke outside, at a distance of 9 meters from the building. Please do not leave your butts on the property, and please be considerate of the other Emily's House guests.

**Parking**

Individuals are encouraged to use the drop-off area at the front entrance of the house to load and unload people, equipment and supplies. Visitors may park at the parking lot at Bridgepoint Hospital. Parking is also available along the residential streets and along Gerrard Street East and Broadview Avenue. It is the car owner's responsibility to be mindful of the designated parking times. There is also a Green P parking lot on the south end of Gerrard, directly across from Emily's House.

## Safety & Fire Regulations



### Fire Regulations

In case of fire or other emergencies, families are requested to report to the Nurses who will direct you on what to do. By each exit door there is an emergency plan posted. Electrical devices that are brought into the house should be CSA approved, (e.g. hair dryers, razors, radios, etc.).

## Other Information

### Lost and Found

Personal items are periodically left behind. Please check our Lost and Found Box for any missing items. This is located in the supply room on the main floor.

### Staff Acknowledgement

We recognize that you may want to thank Emily's House staff for the care they have given your child and family. We respectfully request that you do not give individual gifts to staff. A gift that would benefit all families who use Emily's House would be appreciated. You may also make a donation to Emily's House.

### Gifting

Emily's House staff and services can be recognized by making a donation to Philip Aziz Centre. The Philip Aziz Centre works together with Emily's House to determine needs. Your generous donation will be applied to the purchase of items on our wish list. For other donations, please consult Philip Aziz Centre's Development office at 416-363-9196 EXT 212.

### Compliment and Complaint Policy

Emily's House staff will treat all compliments and complaints as opportunities for growth and development. Family Feedback Forms will be given to you after your child's first admission, and then again each year following, where you can express your thoughts on our care and services. You can also write an email or letter. All compliments and complaints will be reviewed by the Residential Care Coordinator, Clinical Nurse Manager, and Executive Director, and you will be contacted within 24 hours upon Emily's House receiving the compliment or complaint.

## Frequently Asked Questions and Answers



- **What is the difference between Emily's House and Ronald MacDonald House?**  
Unlike Ronald McDonald House, which provides a temporary home for families who have children receiving medical care and treatments in a hospital, Emily's House provides a home-like environment in which children with life-limiting illness can receive medical care.
- **Where is Emily's House located?**  
Emily's House is located in beautiful Riverdale neighbourhood at 45 Jack Layton Way (Gerrard St. East/Broadview Ave.) There is paid street parking along Gerrard, as well as some free street parking on side streets nearby between certain designated times. It is serviced by TTC Streetcar Routes 504, 505, 506 and by Bus Routes 306 (blue night streetcar route).
- **Do I need a referral to access services from Emily's House?**  
A referral to Emily's House can come from a parent/guardian, specialist physician, family physician, nurse practitioner, nurse, social worker, or case manager. Admission guidelines, referral and application forms can be found [here](#).
- **Is there a cost to families for using Emily's House services?**  
Families accessing Standard Respite are responsible for providing the child's medications, diapers, special food, and other supplies required by the child's condition. Emily's House is responsible for supplies related to our palliative care programs as well as all direct costs of care. Emily's House relies on generous support of volunteers, individual donors and corporate sponsors in partnership with the Ministry of Health and Long Term Care to offer our programs at no cost.
- **How is Emily's House funded?**  
Emily's House receives government funding that is further supported by fundraising efforts and generous private donations.

- **My child has complex medical needs, can he/she be cared for at Emily's House?**

If your child can be cared for at home with medical complexities, then they can be cared for at Emily's House. Please contact the Care Coordinator to find out how Emily's House can accommodate your child.

- **How many guests can Emily's House accommodate at a time?**

Emily's House can accommodate a maximum of 10 children at a time. However, capacity may vary at any given time based on the unique needs of our patients and their families.

- **How long can my child stay at Emily's House?**

Children receiving Standard Respite are permitted up to 28 nights per year. Emergency respite care is dependent on availability. End of life care is a priority and will be provided for as long as necessary.

- **How do I make a booking at Emily's House?**

Please contact the Care Coordinator to make a booking at Emily's House. Please be sure to complete all the appropriate forms prior to admission.

- **Can the families of patients stay at Emily's House?**

Immediate family members are welcome to stay with their children at Emily's House. Depending on available space and other resources, siblings may stay overnight. Permission must be requested and arrangements made ahead of time with the Care Coordinator.

- **What does my child do while he/she is at Emily's House?**

Emily's House is staffed by a play therapist responsible for planning recreational programs according to your child's preferences and abilities. Emily's House aims to provide a "home away from home". A care plan will be developed with you and your child prior to or at admission that will include appropriate activities to meet your child's needs.

- **What are visiting hours at Emily's House?**

There are no formalized visiting hours, but if you have guests after 2100, we recommend that you visit with your guests on the main floor. Visitors must sign in at the reception desk and obtain a visitor's badge that must be worn at all times.

- **What are the admission and discharge times?**

Admission times for Standard Respite are 0800h – 2000h. No admissions will be scheduled from 1830h – 1930h.

- **What should I pack for my child to bring upon admission?**

Please review the Personal Belongings Checklist as well as our "What to Bring for Respite" section of the Family Handbook. All medications, special equipment, clothing (labelled with your child's name), toiletries and special toys that your child requires should be brought

from home. The personal belongings checklist can be found here and can be used as a guideline of things to bring for your child's visit.

- **What if my child is missing a piece of clothing or equipment upon their return home?**

Please review your Personal Belongings Checklist prior to discharge from Emily's House to avoid forgetting any items from your stay. Should any items be forgotten, please contact our nursing station and they will assist you in locating the item(s).

- **What happens if my child becomes sick while staying at Emily's House?**

If your child becomes sick while receiving Standard Respite care, you will be contacted by staff for direction as to how to proceed. Together with you, Emily's House staff will determine the best way to manage the situation. This may require for you or a designated individual to pick up your child and remove him or her from respite care. If the situation requires, or Emily's House staff is unable to contact you, EMS would be called and your child would be transferred to an acute care facility.

- **Can my child continue their schooling while staying at Emily's House?**

Emily's House is in the process of establishing arrangements with the Toronto District School Board to support children continuing their schooling while at Emily's House.

- **I do not live in the Greater Toronto Area, but I have a seriously ill child. How can Emily's House help us?**

Emily's House provides services for children all across Ontario. Please contact us directly to discuss how Emily's House and the Philip Aziz Centre for Hospice Care can best support your family.

- **My child and I were in the neighbourhood. Can we drop by for a brief visit?**

Please call ahead and speak with the staff if you would like to visit Emily's House. Every effort will be made to accommodate your visit, however, it may not be appropriate given the activities and circumstances occurring in the house at that time.

*For any additional questions, please contact us at [info@philipazizcentre.ca](mailto:info@philipazizcentre.ca) and you will be forwarded to someone who can assist you [**Note:** due to the volume of requests, we may not be able to respond to all inquiries in a timely manner.]*

## Contact Information and Map

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M4M 0B7

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Fax: 416 363-6153  
[www.emilyshouse.ca](http://www.emilyshouse.ca)

