

Emily's House

Family Handbook

Information for Children, Youth and their Families



45 Jack Layton Way
Toronto, Ontario
M4M 0B7

Tel: 416 363-9196
Fax: 416 363-6153

Table of Contents

Introduction & Welcome to Emily's House	Page 3
What is Emily's House?	Page 3
History	Page 4
Emily's House Program	Page 5
Eligibility for Services	Page 5
Emily's House Team & Services	Page 6
Consent	Page 8
Confidentiality	Page 9
A Healthy Home	Page 9
Visitors	Page 9
Siblings & Young Friends	Page 10
Pets & Guide Dogs	Page 10
Family Rights & Responsibilities	Page 11
Emily's House Facilities and Guidelines	Page 12
Parking	Page 14
Safety & Fire Regulations	Page 14
Other Information	Page 14
Lost & Found	Page 14
Complaints and Compliments	Page 14
Frequently Asked Questions	Page 15
Contact Information and Map	Page 17

Welcome to Emily's House

Emily's House is here to support you and your child living with a life-threatening serious medical condition. Our goal is to ensure family-centred care and the delivery of integrative services while improving quality of life. Our support is provided with the purpose of helping to live full, active lives for as long as possible. And, when this is no longer possible, to help manage life closure and the dying process.

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

This booklet will familiarize you with Emily's House programs and services. Given we share this house with many families we ask that you follow the basic guidelines outlined in this handbook. Together we will ensure a comfortable stay for all. We are always available to answer any questions you may have before, after or during your stay with us.

What is Emily's House?

Emily's House offers a colourful, comfortable and homelike environment.

Emily's House is dedicated to caring for children with life-threatening and serious medical conditions while supporting their families. With around-the-clock nursing and medical support, Emily's House offers specialized clinical care, creative therapies and recreational programs.

Our staff and volunteers are dedicated to helping you and your child(ren) achieve the best possible quality of life together. We understand that our patients and their families each face unique circumstances and challenges and we strive to provide support in all aspects of your experience.



History

Emily's House is a division of the Philip Aziz Centre (PAC) home hospice visiting program. Through trained volunteers, case management, music and recreational therapy, and spiritual and bereavement care we PAC has been delivering hospice care to adults, children and families for the past 25 years, in the comfort of their own homes.

PAC 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 help build an organization that would support others living with the challenges of a life-limiting illness. Years into our programming in the community, it became evident that the complex and diverse needs of the children and families we supported were greater than what we could address through our visiting hospice. Many families were exhausted, and in need of medical respite. Children who were at the end of life were often being cared for in acute clinical settings. The need for a children's hospice was critical to ensure families had a more enriching and better support experience and option in the location of care, outside of home or hospital.

This led to the building of Emily's House a Children's Hospice, named in honour of a courageous young woman (Emily) living with a progressive life-limiting illness, who we had supported for several years through our visiting hospice programs. Emily and her family represent hundreds of children and families who daily face the challenges and uncertainties of dealing with complex, life-limiting illnesses.

Our primary goal is to ensure your family is comfortable, safe and well cared for in a home-like, child-friendly, professionally staffed facility. A special place where parents can be parents and kids be kids.

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



Rauni Salminen CEO

Founder of Emily's House

Founding member of Philip Aziz Centre for Hospice Care

Eligibility for Services

Emily's House services are available to children:

- 0 - 18 years of age (exceptions can be made)
- Have a valid Ontario Health Insurance Plan (OHIP)
- Eligible to receive enhanced respite funding
- Have a serious or life-threatening medical condition

Respite Care

Respite is offered to children who qualify for enhanced respite funding. We offer enrichment opportunities while also giving temporary relief from the high physical, psychological and emotional demands that often accompany caring for a medically fragile child. Respite can be booked in advance for a pre-determined duration. There is an expectation that at the time of admission your child will be in good health and at their baseline. Care is provided by nurses, PSW's and volunteers. Care providers at EH will seek to maintain health and comfort by implementing your child's usual home routine to the best of our abilities.

This also provides an opportunity for ongoing health evaluation and access to supportive counselling and informational resources. Your child could benefit from therapeutic programs and have the opportunity to socialize with other visiting children.

Each child within the program is eligible for 28 days in any calendar year.

Your child when admitted to EH for respite will not be admitted by a physician and will not receive physician coverage during their stay. If your child is admitted in this category and becomes unwell, you will be called by staff for direction as to how to proceed. Emily's House staff and you will decide together on the best way to manage the situation, which may require you or a designated individual to pick up your child and bring them to their doctor or home. If the situation requires, or we cannot get a hold of you, EMS may be called, and your child will be transferred to an acute care facility.

Transitional Care

Transitional care is offered to children who meet Emily's House criteria of having a severe medical illness and for the purpose of avoiding unnecessary admissions to SickKids inpatient beds for a predetermined duration. The care needs of your child admitted under this category may fall outside of their baseline and for many reasons care at home may not be manageable but admission to a SickKids bed isn't needed. In these cases, Emily's House will work with the primary team to support you and your child with transitional care. Your child will continue to receive support from their Primary SickKids MD or NP.

Transition care is available for up to 14 days. If you require further support, it will be reviewed at this time. Emily's House will collaborate with the nursing agency in your community to ensure a safe transition home.

Symptom Management

Children known to and followed by PACT, whose primary goals of care are focused on comfort, are eligible for admission to EH to address uncontrolled symptoms. Only SickKids PACT may admit patients under this category. PACT is available to EH staff to address concerns 24/7.

End-of-Life Care

Children admitted into this category will be admitted for End-of-Life care by your referring PACT physician. The goals of care for these admissions are focused on comfort. You and your child are coming to EH with an understanding that death is the expected outcome and a 'no CPR' order must be on file.

Perinatal Hospice

Our perinatal hospice is a program that offers 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 your baby. Services provided focus on the development of a specialized birth plan, legacy building, memory making, and ongoing bereavement support.

Emily's House Team and Services

Emily's House interdisciplinary team includes:

- Nurses
- Doctors
- Personal Support Workers
- Recreation Specialists
- Volunteers
- Spiritual Support
- Bereavement Coordinator
- Music Therapy
- Art Therapy

Our team is committed to providing the best possible comprehensive care for your child and family. Regular communication with your family and our team is one of the best ways to ensure this can happen.

Nursing Care

Our team consists of compassionate and knowledgeable Registered Nurses and Registered Practical Nurses who are experienced and skilled in pediatric palliative care. They provide 24-hour nursing care and work as part of the interdisciplinary team to deliver medical and therapeutic care to your child and your family.

Physician Care

Emily's House will work with your child's paediatrician, family physician, or designated specialist to provide care during his or her stay at Emily's House. With the exception of respite care, 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 energetic, warm, and hardworking individuals who are trained to provide personal care, as well as cooking, cleaning, and interacting with guests.

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 devote their time, efforts, skills and talents to enhance the quality of life and care 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 can spend time with your 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
- All volunteers respect confidentiality
- Volunteers who prepare or handle food have received their Food Handlers certification

Spiritual Care

The goal of the Spiritual Care and Bereavement counselling team is to provide support to you and your family through all the different stages of your personal journey. Our team of professionals are committed to respecting everyone's unique spiritual journey, understanding that spiritual needs and expressions differ.

Spiritual care may not necessarily involve any particular religious expression or system, although for some people it naturally will and we are committed to facilitating connections to religious communities if desired.

Spiritual care includes:

- A spiritually supportive, non-judgmental and caring presence where positive or difficult emotions and questions can be expressed
- Offering spiritual direction and encouraging a sense of emotional and spiritual well being
- Visiting in-home or at Emily's House
- Responding to concerns relating to loss and grief
- Planning funerals, celebrations of life and memorial services

Bereavement Support

Using skills from the disciplines of social work, spiritual care and expressive therapies, the counselling team works with your child(ren) and family members in a way that is supportive. Art, music, play and recreational therapies are prominently incorporated into the counselling support program at Emily's House.

Bereavement programs focus on:

- Helping family members in the grief process by facilitating their expression of thoughts and feelings and helping them identify or develop and utilize healthy coping strategies
- Addressing social and spiritual concerns
- Assisting survivors to adapt to an environment without the decedent while experiencing a continued (transformed) relationship.
- Memorial services

Expressive Art Therapies

Coming alongside families, our expressive art therapy programs enable families to create memories in music, art, and recreation.

Other Services

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

Consent

You and your child are actively involved and included in ongoing discussions with the team for the provision of care and involvement in activities. You will be made aware of all aspects of your child's life at Emily's House. We will obtain written consent for any significant changes or new treatments that may arise.

Written consent is required for:

- Admission
- Special outings
- Occasions where your 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 your child when it is not the parent or legal guardian
- In the event that parents or legal guardians are leaving the GTA an **Emergency contact and/or Alternate Decision Maker** must be appointed to make medical/personal decisions for your child/youth during your absences.

All aspects of care, treatment, and activities are documented in your 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 health information. All information concerning children and families, staff and volunteers is kept strictly confidential. Personal Health information is only shared with those 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.

Nursing report takes place in the nursing station room in order to respect patient confidentiality. This takes place at 7am, and 7pm, 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.

A Healthy Home

Our home and now your home too. With any home we hope you feel safe, free to rest and well cared for in the same way you take care of your own home we ask that you respect ours.

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

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

Visitors

We welcome your visitors to Emily's House. Visitors should ring the doorbell upon arrival and wait to be admitted. 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.

Overnight accommodations are made for two family members per child. Please advise the nursing staff of any changes and if you require further accommodation. Emily's House will do our best to meet the needs of the family, however, extra accommodation will be dependent on availability.

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.

Quiet Hours are between 11 pm and 7 am. So that all guests in the house may have a restful sleep we ask you to keep visitors and noise to a minimum.

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.

Service Dogs

Service dogs are admitted to Emily’s House and must have documentation indicating:

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

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

Family Rights & Responsibilities

Families are important members of the health care team at Emily's House. Staff and Volunteers will work with you and your community to make sure that children receive the best care possible. All staff will do their best to make sure families are informed, respected, and supported.

As a Patient or Family Member, I have the right to:

Respect

- Receive safe, compassionate, and quality care that is patient and family-centred
- Be treated with dignity and respect
- Receive equitable care that considers my culture, background and identity
- Have my privacy respected

Communication

- Be fully informed about my diagnosis and treatment plan in a language I understand
- Ask questions, voice concerns and receive answers
- Expect that the members of my healthcare team will talk with one another about my care

Partnership

- Participate in decisions about my care
- Know the name and role of each member of my healthcare team

As a Patient or Family Member, I have the responsibility to:

Respect

- Respect the rights, privacy, property and diversity of staff and other patients and their families
- Not verbally or physically abuse staff, patients and visitors

Communication

- Share information to help my healthcare team develop the best plan of care
- Let my healthcare team know if I can't attend an appointment

Partnership

- Work together with my healthcare team to achieve best possible health outcomes

Sharing a Home-Like Environment

We make every effort to create an environment that is 'home-like' however, 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:

- 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.
- Keeping all common areas clean and tidy. Among other things, returning used dishes and cups to the kitchen, washing up when able and putting away arts and crafts supplies, and turning off computers/televisions after use is appreciated
- Respect the privacy and belongings of others in the house.
- Reduce the noise level after 9 p.m. for those trying to relax and settle to sleep.
- Use the kitchen and/or dining areas for eating.

Emily's House Facilities and Guidelines

Main Floor Living Room & PlayRooms

The living room is a multipurpose room used for family gatherings, quiet reading, and small memorial services, interdisciplinary rounds, or general staff meetings and playroom. Children and youth, including guests, siblings and visitors must be supervised at all times by a responsible adult when using the small playroom attached or in the basement.

The Snoezelen Room

The Snoezelen Room is a multi-sensory room that offers visual, auditory and tactile stimulation. The Recreation Coordinator supervises therapeutic sessions for stimulation and/or relaxation. You may accompany your child(ren) in the Snoezelen room under supervision. Shoes must be removed and socks worn during Snoezelen times. Staff are encouraged to utilize the area on a daily basis.

Kitchen and Meals

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

If you would like to plan a special dinner or event that will require exclusive use of the kitchen, please speak to the Client Care Coordinator to schedule.

Laundry Facilities

Emily's House Staff will routinely wash the house linens. A washer and dryer are on-site and available for use by families every day until 6pm. Please place all soiled laundry in the bags found in your room. If you need any assistance please feel free to ask any staff who will be pleased to help.

Telephone and Call Bell Use

- Call bells are located in each room if you require immediate nursing assistance
- Telephones are located in each room and in the nursing station
- The 2nd-floor nursing station extension is 225
- 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 speak to the nursing staff

“The Jeffrey Dawson Lifeline to Palliative Care Program” was created to honour Jeffrey Dawson. A leadership gift made in Jeff's name has made it possible for Emily's House to install a new Nurse Call Communications System. This system enables real-time, crisis / risk communications from patient rooms to nurses. Additional funding, in Jeff's name, is designated to clinical equipment costs for Emily's House.

“Where hospitals and established charities have secure funding bases, it is vitally important to consider new projects and grassroots initiatives where there is a gap that needs to be filled – to build awareness, core funding and sustainability. I can't even fathom having a child of our own in a similar situation. However we can help ... we will. Our hearts go out to all families with children who have life-limiting illnesses. We are grateful that Emily's House is there for them.”

~ Jeffrey Dawson, Champion Advocate and Leadership Donor, Emily's House

Guidelines for Internet Use

The guest computers at Emily's House are available for your use and enjoyment. If you have your own computer or device, please ask the staff for the Wifi password. Emily's House computers are not to be used for gaining unauthorized access to any computer system on the internet.

- Accessing sites or email that may contain profanities and or pornography will not be tolerated
- We encourage our guests to save their files on a USB stick so files are not lost or deleted
- If you require assistance with accessing wifi, Netflix or the cable please ask the nursing staff
- Unplugging/switching wires can cause the Internet connection to have disruptions

Wheelchairs

Emily's House is 100% wheelchair accessible.

Smoking and Vaping

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.

Intoxication

Intoxication by alcohol or drugs is not permitted at EH. Intoxication could result in you being asked to temporarily leave the premises until a time of sobriety.

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, the nurses 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. hairdryers, razors, etc.).

Other Information

Lost and Found

Personal items are periodically left behind. Please check our Lost and Found Box for any missing items.

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 programs. 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. All compliments and complaints will be reviewed by the Client Care Coordinator, Director of Clinical Programs and the Chief Executive Officer.

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 a 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.

- **Is there a cost to families for using Emily's House services?**

Emily's House relies on the generous support of donors and corporate sponsors in partnership with the Ministry of Health and Long Term Care to offer our programs at no cost. Families accessing respite or transitional services are responsible for providing the child's medications, diapers, special food, and other supplies required by the child.

- **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 Client Care Coordinator to find out how Emily's House can accommodate your child.

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

Please contact the Client 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 Client Care Coordinator.

- **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. Please respect the quiet hours between 11 pm and 7 am

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

Bring clothing, books, any special toys or games, and anything that makes you or your child feel more at home. We also provide all food for your family, but you are welcome to bring in additional or special foods from home.

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

If your child is admitted for respite and becomes unwell or deteriorates, you will be called by staff for direction as to how to proceed. Together we will decide on the best way to manage the situation, which may require you or a designated individual to pick up your child and remove them from respite care. If the situation requires, or you cannot be contacted, EMS may be called, and your child transferred to an acute care facility. SickKids will not treat any respite children at Emily's House.

If your child is admitted for Transitional Care and becomes unwell or deteriorates, in consultation with the Primary Team a transfer to SickKids will be arranged for further assessment and/or treatment of the issue as indicated.

- **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.

For any additional questions, please contact us at 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.]

Emily's House
45 Jack Layton Way
Toronto, ON
M4M 0B7

Tel: 416 363-9196
Fax: 416 363-6153
www.emilyshouse.ca

