

ROTARY FLAMES HOUSE

A REPORT TO THE COMMUNITY 2022 - 2023







LIVING FULLY AT ROTARY FLAMES HOUSE

Specialized care, comfort, and love found at Alberta's only pediatric hospice

While no one wants to think of a child needing a pediatric hospice, sadly this is the reality for many families in our community. And yet, thanks to generous community support of Rotary Flames House, families who rely on this special place for specialized respite and palliative care say it's hard to imagine our community without it.

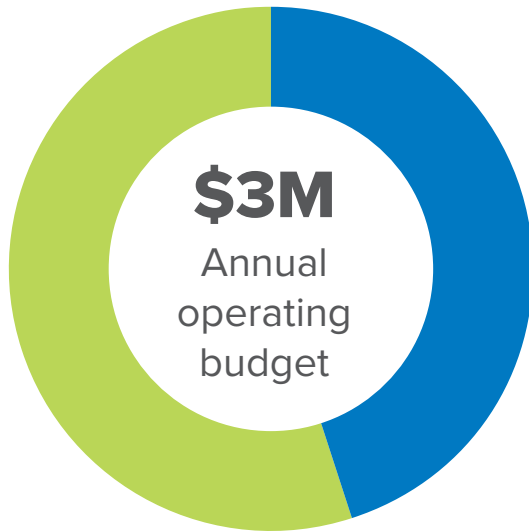
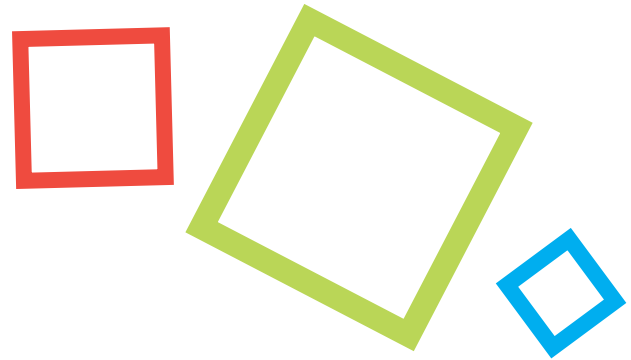
Fourteen years ago, this community, came together to raise the capital to build Alberta's first hospice dedicated to children. In this beautiful two-storey home, children with complex and life-limiting medical conditions and their families can access respite care, therapeutic programming, symptom management and transition care, as well as compassionate end of life care and grief support. The Alberta Children's Hospital, Alberta Health Services (AHS) and generous donors provide this complete continuum of care to help children live their best lives possible, however long or short.

"To a family, the idea of going to a hospice can feel really big, and yet when they get here, they feel this sense of relief," says Dr. Estée Grant, Pediatric Palliative Care Physician at Rotary Flames House. "They and their child feel so well cared for and the fact that they can trust these caregivers and just be present as a parent, that's what makes this place so special."

Care comes in other forms too. Here, there is an in-house chef cooking homemade meals for families as well as friendly volunteers always eager to make art, play games, and read stories to kids at the House. Parents can take some quiet time for themselves while their child explores the therapeutic lights and textures of the Sensory Room, takes a comforting bubble bath in the big tub, tries a science experiment in the playroom or joins their sibling in the Calgary Flames room for some table hockey or video games.

The following report provides a summary of the services provided from April 1, 2022 - March 31, 2023.

THANKS TO COMMUNITY SUPPORT



ACHF contribution from donors
\$1.36M



AHS
\$1.64M

While AHS funds many operational expenses of Rotary Flames House, including equipment, facility costs and some staffing costs, it is the additional community support which ensures the broadest range of services are available for this special group of children and their families.

Forty-five percent of annual funding for Rotary Flames House comes from fundraising by the Alberta Children's Hospital Foundation. Sources include memorial donations and events (often from grateful families), employee fundraising, events such as ECL Choppers for Charity, monthly donors, and lottery funds through raffles at third party events, WinWin Lottery and Flames Foundation. Every year, hundreds of donations and undesignated memorial gifts are directed to support Rotary Flames House programs and initiatives.

This philanthropic support is key to providing high quality respite and palliative care along with therapeutic and family support programming. A multi-disciplinary team including registered nurses, health care aides, Child Life therapists, social workers, spiritual health practitioners and pharmacy technicians provides round the clock care and is committed to ensuring each child and family's physical, developmental, emotional, spiritual, and cultural needs are met in a compassionate manner.

A shared government and philanthropic funding model for comprehensive pediatric palliative care services has been in place since 2012 and is consistent with funding models of other pediatric hospices across Canada.

Opening Rotary Flames House (RFH) enabled the expansion of the previous Pediatric Palliative Care Consult Team into the Children's Hospice and Palliative Care Service (CHaPS) and the enhancement of services and support available to children with life-limiting conditions and their families. The RFH-CHaPS program also consists of Aid for Serious Symptom and Illness Support (ASSIST) outpatient consult service.



Dr. Estée Grant, Pediatric Palliative Care Physician

Prior to caring for families at Rotary Flames House, Dr. Grant worked in the pediatric intensive care unit (PICU) at the Alberta Children's Hospital. Working closely with a child's specialist at the hospital, Dr. Grant is involved in all aspects of a child's care at the House, from respite care and symptom management to end of life.

"What is gratifying about this work is that I get to know children and their families throughout their whole journey," she says. "We have a unique connection with them and it's remarkable. The strength and spirit of these children is humbling."



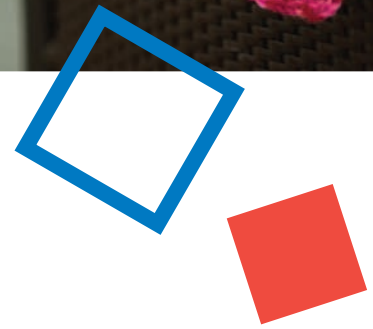
END OF LIFE CARE AND SUPPORT

Sadly, while not every child can be saved, every child can be cherished. Their parents, and the palliative care team at Rotary Flames House make sure of it. When a child's death is expected to be imminent, this team of doctors and nurses, while managing pain or other symptoms for the child, ensures a family can treasure final moments together in whatever way that brings the child joy.

Whether it's helping the child attend a concert at school, spend quality time playing with friends, or cross something off their bucket list, helping a child experience that joy during their end of life is one of the team's greatest privileges, says Dr. Grant.

"For a family, the whole medical journey right up to their child's death is their forever remembered story," says Dr. Grant. "We have an opportunity to have an impact on that. We get to focus on what brings them happiness, and that is what this building is all about. When we let the kids take the lead, and we respond, it allows them to live so fully."

When a child passes at the House, a social worker is there to comfort the parents however they need – making phone calls, providing grief support, offering a cup of coffee, or simply being by their side. A Child Life Specialist will help support siblings during this time.



10

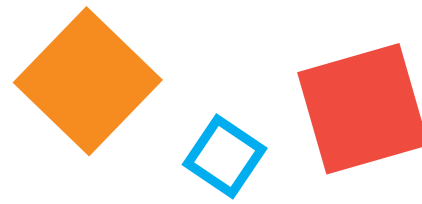
Admissions for End-of-Life Care this year



120

Total nights of stay

A Place Between Heaven and Earth



Even while bravely battling cancer, Govind could make people laugh. It's how his family remembers their sweet, courageous boy five years after his passing at Rotary Flames House where he spent his final days filled with happiness and love.

Govind was only four when a mass developed around his kidney and adrenal glands. Diagnosed with stage 4, high-risk neuroblastoma, the news was understandingly devastating for his parents, Deepak and Shilpa.

“It was like our world came crashing down,” says Deepak.



Kindergarten was put on hold as Govind began a year and a half of treatment at the Alberta Children's Hospital, including chemotherapy, surgery, a stem cell transplant, and radiation. While undergoing immunotherapy in May of that year, he was finally able to join his classmates who had been writing him cards in hospital. He fought courageously, however, sadly, the cancer spread to his skull and ribs. After exhausting all available treatments, his family had to make the difficult decision to move him to palliative care at Rotary Flames House. It was a place, his parents said, that would make him feel better, yet they had no idea just how special it would truly be for him and his family.

Govind's last few weeks were full of joy. Claiming the biggest room of the house, he enjoyed spending time with his friends, eating his favourite sweets and playing video games. Even though he never went home again, he didn't mind. Govind found happiness at Rotary Flames House.

“It's a place between Heaven and Earth,” says Deepak. “The nurses and doctors there are like family and the joy they give these kids, how they help them forget their pain, it can't be put into words.”

During his final days, Govind was surrounded by love. As he slept peacefully, his family gathered to say goodbye. That evening, unexpectedly, he woke up, seemingly to give his mom one last gift. As Shilpa helped him to the washroom, he held her and gave her a big hug. The longest, greatest hug in a beautiful moment she will treasure forever. A few days later, with his family by his side, Govind passed away. At his request, his tumour was donated to cancer research to support efforts to ensure no other child would have to go through what he did.

“He was a real fighter, and we miss him, we miss those hugs now,” Shilpa says.

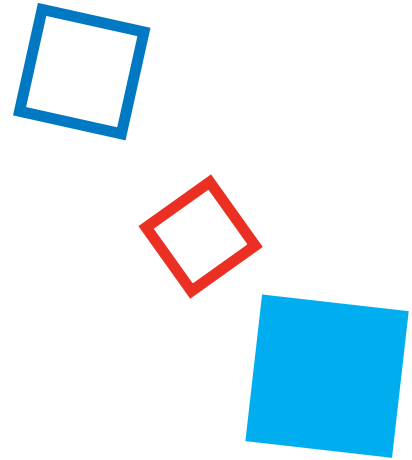
While they grieve, his parents are grateful for how the incredible people at the hospital and Rotary Flames House wrapped their arms around him and his family, too.

“There are no words to express the gratitude we have for how the hospital and Rotary Flames House cared for our boy,” says Deepak.



RESPIRE CARE AND SUPPORT

For parents caring for a child with complex medical needs, their daily routine may involve feeding tubes, oxygen tanks, power chairs, and medication schedules - on top of the usual responsibilities of being Mom and Dad. Being on alert for medical emergencies 24/7 can impact a parent's time or ability to do basic things, like sleep, eat, run errands, connect with their other children and with friends and family, or take time to relax. Thanks to your support for respite care, these loving, resilient parents can leave their child in the hands of highly specialized nurses, doctors, health care aides, respiratory therapists, Child Life Specialists and the Therapeutic Arts team at the House with peace of mind their child's care will continue uninterrupted. They can take some valuable time for themselves to rest and recharge, knowing their child is happy and safe.



93

Unique patients



231

Admissions



1238

Total nights of stay



63

Volunteers



2670

Volunteer hours

Parent Hope Group

No one understands the journey with a medically complex child better than another parent walking the same path.

The Parent Hope Group brings these families together to help reduce isolation and build connections.

Part of the Family ❤️



Melissa remembers the first time she dropped her boys off at Rotary Flames House. It felt like she could finally breathe. During a difficult journey, Rotary Flames House has been a light for her family.

Mikail, 19, was nine when Melissa first noticed he seemed clumsier than usual, falling off his bike and out of his desk at school. He would also tire easily. After meeting with genetics specialists at the Alberta Children's Hospital, Mikail was eventually diagnosed with Friedreich Ataxia, a debilitating, degenerative, neuromuscular disease. The family learned he would lose his coordination of his arms and legs as he grew and would experience other health challenges. Most devastatingly, his family learned his condition was life limiting.

About a year after Mikail was diagnosed, his younger brother Emerson started displaying similar symptoms. His parents' worst fears were realized when Emerson was diagnosed with the same condition. His speech began to slur, he started losing his fine motor skills in his hands and developed chronic nerve pain. When the high school athlete began losing the mobility of his legs, his sports were sidelined and dreams of getting his driver's license dashed as he felt control of his body slipping away.

As the boys become more reliant on their parents at home, including help with medications, making meals, and just getting around the house as they both become wheelchair bound, the whole family are grateful for respite care at Rotary Flames House. Their parents can drop the boys off in a caring place with peace of mind they are in good hands while they take time to rest or spend more time with their daughter.

At the House, the boys are spoiled with their favourite foods and activities. They love playing video games and air hockey with volunteers, checking out the stars through a telescope, and napping on the relaxing waterbed in the Sensory Room. The staff have also helped them learn how to do more accessible activities in the city like kayaking. Emerson loves to bike and now he can ride a three-wheel bike!

"This journey is a very emotional one, there have been a lot of milestones we don't get to experience, and the staff at Rotary Flames House are amazing at providing different experiences for our family," Melissa says.

"The team at Rotary Flames House is phenomenal, they have become a huge part of our family and we are so grateful to them."

Kaelyn McDonald-Wirasinghe has been volunteering at Rotary Flames House since the fall of 2021. As a Masters of Neuroscience student within the department of oncology at the Alberta Children's Hospital, her passion has always been working with and caring for children. She spends time with children at the House for respite care while their parents enjoy some time to recharge. She enjoys learning new ways of interacting with children who have communication challenges and helping make their stay full of fun.

"Rotary Flames House is such a bright spot during some difficult times for families," she says. "Caring for medically complex children is a full-time job for parents. Having someone care for their child in a place they know is safe and loving so they can tend to other children or needs around the house is so important, and it's rewarding for me to be a small part of that."





GRIEF SUPPORT AND BEREAVEMENT CARE

From the time of a child’s diagnosis, throughout their illness and after their death, grief and bereavement support is offered for families by compassionate social workers at the House. Upon receiving a referral of a child’s death at the hospital, Rotary Flames House, at home or other AHS sites, members of the team follow up with a supportive phone call. The team then sends a bereavement package with useful information, from how to talk about the death with another child and how to inform a parent’s workplace, to where to begin with funeral arrangements while offering ongoing support.

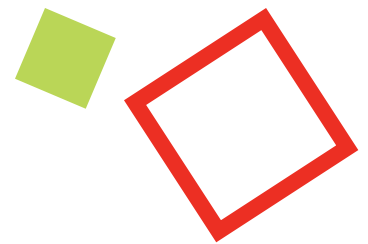
Megan Miller is a social worker and the Grief Support Coordinator who cares for grieving parents, helping them learn how to create an ongoing relationship with their child, honour their memory and manage feelings associated with grief and trauma.

“Death ends a physical life but not a relationship a parent has with their child,” she says. “Parents are still parents even after their child’s death, so we help them find ways to make them still feel like Mom and Dad.”

At Rotary Flames House, parents can participate in grief and trauma counselling and take part in monthly drop-in grief support group sessions to connect with other bereaved parents. These are offered virtually over Zoom to reach parents across Alberta. Other support offered includes a group for parents grieving a loss by suicide and a six-week Grief Group Program.

“The newly bereaved can see the hope in the families who are further advanced in their journeys and in turn, those families can see their own growth reaffirmed,” says Miller.

Child Life Specialists also offer a Sibling Grief Support program that focusses on coping and understanding the grief journey through a developmental lens. This past year, 200 parents, extended family and staff participated over Zoom in the Annual Celebration of Life Memorial Service to honour children who have passed.



190

bereaved parents supported in groups



10-25

Children supported in sibling grief groups each year facilitated by the Child Life team

Megan Miller, Social Worker, Grief Support Coordinator



Megan Miller joined the Rotary Flames House team in 2005 and began walking alongside families in their grief journey. She started her career at the Alberta Children's Hospital in the Infant and Preschool Treatment Team, Inpatients, and Brain Injury Program before earning her Master of Social Work in Clinical Bereavement when she saw a need to expand her skillset and knowledge working with bereaved parents.

"We are working with a family during the worst time of their lives. And then when you see them come out of the darkest days, see their resilience, and the beautiful ways they honour their child, it's a gift," she says.

"There is such tremendous growth for these families and to witness that is so rewarding."



Currently, Miller is co-leading a collaborative research study with the University of Calgary gathering feedback from bereaved parents about their end-of-life experience at Rotary Flames House.

SYMPTOM MANAGEMENT AND TRANSITION CARE

The care teams at the House also specialize in symptom management to help relieve the adverse physical and emotional symptoms of a child's condition and the side effects of treatments to avoid admissions to hospital. For those children who have been acutely ill and hospitalized, Rotary Flames House offers a safe place to fully stabilize before returning home.

During respite stays, the team helps reinforce teachings families have learned in hospital, regarding, for example, any new care needs for their child. The team also supports by phone and sometimes goes to the home when a child's condition changes to help families adjust and manage care in their home setting.



19

Admissions

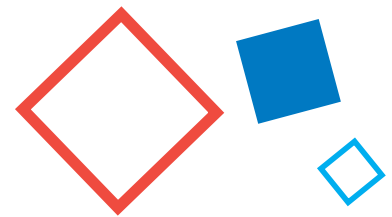


240

Total nights of stay



THERAPEUTIC DAY PROGRAMMING



Being a child with complex medical needs can often be isolating as many traditional recreational opportunities are not possible for them. At Rotary Flames House, children can take part in therapeutic and recreational programs adapted to their unique needs. The Child Life team, who develops these programs, complement the nursing team by focusing on the psychosocial needs of the child. From playing the drum in a music therapy group, to touching the soil with a horticultural therapist, to sensory activities with a Child Life Specialist, children are offered a wide variety of recreational and educational opportunities not readily available in their home communities. Five days a week, children can also enjoy sensory-based learning with a Calgary Board of Education teacher.

Children, families and staff alike were pleased to see a return of in-person field trips this year during respite care stays, including visits to the Calgary Zoo and Telus Spark and adventures in community parks.



194

Inpatient group sessions offered with Child Life Specialists (4-7 participants each program)

Debbie Rudd, Certified Child Life Specialist

Child Life Specialists have been part of the Rotary Flames House team since it opened. Rudd joined the team in 2018 after receiving a degree in Child and Youth Care and being certified as a Child Life Specialist. She supports the programs primary Child Life Specialist, Kate Ross, who has a Master of Child Life.

"I feel privileged to be part of a family's Rotary Flames House journey," Rudd says. "We build strong relationships with the children and their families. Supporting and adapting an activity that enriches a child's stay, and experience, is wonderfully rewarding. It's such a special place, full of light and hope and joy, and I'm honoured to work alongside our families."

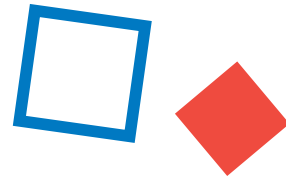


A Day in the Life at Rotary Flames House





LOOKING BACK



Rotary Flames House is always striving to improve care and expand programming to better meet the needs of children and their families. Over the last several years, thanks to our generous donors and AHS partnership, Rotary Flames House has been able to...

- Increase access to comprehensive pediatric palliative care for families of children with potentially life-limiting conditions
- Increase staffing, including health care aides to support respite care, a volunteer coordinator, and weekend Child Life support
- Enhance family supports including developing a Sibling Support Group and virtual Grief Support and Child Life programs during the pandemic.
- Offer advanced respiratory support at end of life that previously could only be provided in hospital
- Increase pediatric palliative care resources and capacity through training of other health care providers



A Home Away From Home

Thanks to your incredible support, children and their families feel loved and at home at Rotary Flames House.



LOOKING FORWARD

Quality Improvement Study

To explore enhancements to care and ensure Rotary Flames House is aligned with other pediatric hospices and palliative care services across the country, the team embarked on a Quality Improvement project this past year. It included benchmarking across Canada and connecting with similar palliative care programs, including Canuck Place in B.C., to help standardize services.

Work is currently underway to adopt recommendations from this project including:

- Moving to a nursing led model of care, where a nurse practitioner instead of a physician, will assume the role of managing the process of admitting children for respite, symptom management, and end of life care,
- Streamlining workflows and processes, and
- Implementing a family advisory council to provide feedback from parents about their experiences at the House.

Enhancing Support for End of Life at Home

Expanding palliative care services, including symptom management and end of life care, to more families who wish for their child's death to be at home remains a top priority.

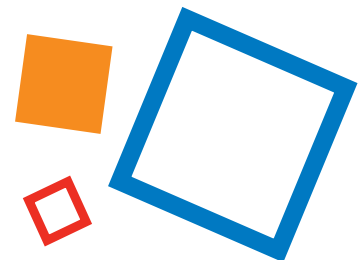
Currently, care provided at home to children at end of life is limited due to a lack of home care support and resources. Enhancing support for end of life at home would offer more options for parents and create capacity at Rotary Flames House for respite and those wishing to have end of life care. Future goals also include utilizing more beds at the House for respite care and reviewing the amount of nights children are spending at the House each year.

“We are relooking at how we provide care and how we can increase services in different ways, but what will remain the same at Rotary Flames House is how we help children live their best lives,” says Rachelle Van Vliet, Patient Care Manager. “We are grateful to all the generous people in the community who help us achieve that.”

Rotary Flames House Playground Renovation

Thanks to community support, a newly re-imagined recreational and therapeutic play space will be created at Rotary Flames House. While the current outdoor space has been well-used and enjoyed by countless children and families over the years, the complexity and needs of patients have changed since the playgrounds were first constructed.

This vital space will be redeveloped and address opportunities for increased wheelchair accessibility through wider ramps and wheelchair accessible play equipment, expanded physical and occupational therapy opportunities and improved patient and family connections.



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