



**Hummingbird House**

Queensland's only children's hospice

# the humm

Autumn 2021 edition

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Hummingbird House is a joint initiative  
of Hummingbird House Foundation and  
Wesley Mission Queensland.



## A note from our GM

It's been a big 12 months at Hummingbird House as we've adapted to doing what we do under the shadow of a global pandemic, but like so many others, we have been overwhelmed by the kindness, generosity and support of our community, who have allowed us to continue to walk alongside the families we support.

In our first issue of The Humm, we share some of our highlights from 2020. These include the expansion of our Hummingbird House @ Home and Family and Community Support services, and the incredible results of our Coles and LIFT UP Giving Day community fundraising campaigns, which combined, raised nearly \$750,000!

As a service, the last 12 months have tested our agility and resilience in ways that we have never experienced before. As we enter our fifth year of operation though, it's been rewarding to watch the ease and confidence with which our team has adapted – marking our transformation from a new service, to a more mature one, that possesses the experience and capability to respond to any challenge thrown our way.

Most importantly, we know from the feedback received from our families that Hummingbird House has continued to be a safe sanctuary for families during these uncertain and troubling times. A place that they have continued to stay connected with through short stay breaks, home visits, virtual check-ins, morning teas, hydrotherapy, art therapy, harp therapy, and more. And none of this would be possible without you.

So, on behalf of all of us at the House, and every Queensland family we support, thank you.

Dr Fiona Hawthorne  
General Manager



**Hummingbird House**



**22** morning teas, filled with conversation, laughter and tears



**23** batches of freshly baked scones, served with jam, cream and a smile



**700** hours of giggles, splashes and smiles in our pool thanks to our hydrotherapy program

# 2020:

## A snapshot

# 256

families were  
provided care  
and support

**69** new families  
were welcomed  
into our warm  
embrace



## Supporting families at every stage

**17** guests and their families were provided  
end of life care and support

**15** guests and their families were provided  
after death care and support

**12** funerals and memorials were held at  
Hummingbird House

**32** families were provided funeral support

**74** families were provided ongoing  
bereavement support



# 2,682

volunteer hours filled our house  
with joy (time worth \$90,000)

**12** creative art  
therapy workshops  
provided families  
a safe space to  
reflect, grieve and  
reconnect



## Meet our families

# Rani's story

**On the 26th of April 2020, the lives of the Macdonald-Johnson family changed forever.**

It was an average Sunday afternoon, Steph was in the kitchen preparing dinner and having a late afternoon tea with her three-year-old daughter Millie, and eight-month-old daughter Rani, while Rogan was in the backyard working on a cubby house for their girls.

Suddenly, Rani began to choke on a piece of mango, sending her quick-thinking parents into action who, after several unsuccessful attempts to dislodge the fruit, called 000 and commenced CPR on her, while they waited for an ambulance.

Rani was rushed to Emerald Hospital, where she was intubated and placed in an induced coma, while a retrieval team was flown in to air lift her to the Queensland Children's Hospital (QCH) in Brisbane.

Over the next five days Rani underwent numerous tests under the care of the Paediatric Intensive Care Unit (PICU) at QCH. The outcome was every parent's worst nightmare – Rani had sustained an extensive brain injury from a lack of oxygen to her brain, otherwise known as a Diffuse Hypoxic Ischemic Brain Injury.

After nine days in the PICU Rani was transferred to a children's ward, where she remained for six weeks, while Steph and Rogan began to learn her new care needs.

By this time the young family had been living in a motel room for nearly two months, amidst the COVID-19 pandemic, not knowing what Rani's future would hold. One thing was for certain though, their lives were forever changed, and the parents felt totally overwhelmed with fear and grief for the journey ahead.

"It was such a difficult experience," remembers Steph. "We were in the middle of COVID lock-down, my family was in New South Wales and Rogan's in New Zealand.



We spent seven weeks living between the hospital and the motel, as QCH's usual family accommodation had limited capacity because of the pandemic."

Finding time together was an impossible task during that period. "It was hard to care for a 3-year-old in a hospital/motel setting, as all the parks were closed and there was only so much art and craft we could do," recalls Steph.

"So, we took it in turns to be with our girls... me with Millie, Rogan with Rani, and then we'd swap, which was incredibly draining."

Steph and Rogan first learnt about Hummingbird House during this time, when their options were to move to a rehabilitation ward or a children's hospice. "Once we visited Hummingbird House our choice became clear, we needed a breather, a place to be together, a home away from home – and Hummingbird House was that saviour," reflects Steph.

A week later the family was moved to Hummingbird House, where they were finally reconnected and supported to discover what their new normal looked like.

"When we first arrived at Hummingbird House, they took over all care of Rani and Millie, allowing us to have a break and process everything we had been through," says Steph. This included arranging physical therapy for Rani, daycare for Millie, and family support for Steph and Rogan.

"Then, when the staff at the House felt we were ready, they slowly started to teach us how to care for Rani, giving us the confidence that we could do this, but letting us get there in our own time."

"Hummingbird House also allowed us to spend time with Millie during this time, which was so special, because her little life had been turned upside down, and she was taken away from everything she knew and loved," reflects Steph. Millie was able to cook in the kitchen, run around the backyard, and get creative in the arts and crafts space, which was a welcome distraction for the three-year-old.

After two and a half months away from home, the family made the 10+ hour road trip back to Emerald, to get ready for Rani's return home. Rani remained at Hummingbird House during this time, while her parents equipped their home to meet her new care needs.

Days later Rani was flown back to Emerald with her parents by her side, to find herself embraced by the kindness, generosity and support of friends and the local community. A community that continues to stay deeply connected with the family, helping with cooking, cleaning, and emotional support in ways that never cease to amaze Steph and Rogan. Rani has even had a song written in her honor!

The family have also found themselves embraced by other families at Hummingbird House, who provide them with the kind of understanding and support that only parents of a child with a life-limiting condition can provide.

Today, almost 12 months after Rani's accident, the family are continuing to adjust to their new life with their cheeky four-year-old and smiley one-year-old, who fill their hearts with laughter and joy.

"We're manifesting miracles," smiles Steph, as she reflects on where they are today, and their endless pursuit to help Rani live her best and most comfortable life.

When asked about the bond between Millie and Rani, Steph's face lights up with joy. "The connection between the girls is just beautiful, they have their own little way of communicating and playing, and Millie is constantly kissing Rani."

In the meantime, Hummingbird House continues to be the family's home away from home, and the place they know they can count on 24-7. The family's most recent stay at the House even extended to include Steph's family from New South Wales, which gave them quality time together without worrying about Rani's medical needs.

“ “ **To the people that support Hummingbird House, your support means the world to us. Hummingbird House picked us up and got us back on track at a time that we didn't think we could do it. We truly can't imagine our lives without them.**

## Meet our team



### Name:

Heather Rapkins

### Position:

Entertainment and  
Volunteer Coordinator /  
Chief Officer of Fun

### Time with us:

1.5 years

# Heather Rapkins

## Tell us about yourself and what drew you to Hummingbird House?

I'm a Brissy girl that grew up on the South side and crossed over to the North side 22 years ago, when I married my husband Michael. We have two dogs that I love with all my heart, and an old and sometimes naughty horse!

My background is in the corporate and not for profit space, spanning manufacturing, construction, communications and finance. I volunteered with Camp Quality for 20 years and worked at the Children's Hospital Foundation for 10 years, leading their Volunteer and Entertainment Service. I came to Hummingbird House through an unplanned career change. I love my role and that I can make a real difference to guests and families while they stay at the house.

## How would you describe Hummingbird House to someone who has never visited us?

Warm, inviting, safe, unique, restful, peaceful, lively, supportive, compassionate and kind. We are a one of a kind service that supports families in a truly unique way.

We allow families to take respite, create memories, develop friendships, gain support, and walk some of their hardest days in our corridors wrapped in our warm embrace. Our services give families some control over the last days of their child's life and in the days, and sometimes weeks, following their child's death. We listen, respond with kindness and respect, and let families know that they are not alone.

## What does a typical day 'in the office' look like for you?

I love that my days start with "good mornings!" and chats with guests, families and staff. My calendar varies depending on what's happening in the House. March, for example, is all things Easter! Like egg and spoon races, salt dough decorations, egg hunts, biscuit decorating, musical guests, and Easter bonnet making followed by a bonnet parade. I also liaise with our guests and families about their stay and coordinate our volunteers to support their needs.

## What's one of your favourite memories at the House?

It's really difficult for me to pick a favourite memory. I love any opportunity I get to put a smile on a child's face and create love and laughter in the air. I also love the simple moments that bring our families, staff and volunteers together, like pumpkin carving or baby animals in our back yard.



## What's your favourite spot in the House and why?

I honestly don't have a favourite spot, because each area of the House has its own qualities and the ability to create moments and memories. I do however have my eye on our courtyard and green space on the roof top, which I hope I'll have a chance to transform into something amazing and exciting one day!



## Meeting families when they need us, where they need us



When Hummingbird House opened its doors in late 2016 we had a dream. A dream to reach into the farthest corners of Queensland, to ensure no family caring for a child with a life-limiting condition was alone. As we approach our fifth birthday, we are excited to share our plans for Hummingbird House @ Home, the community arm of our service, that will meet families when they need us, where they need us.

Right now, through NDIS, Hummingbird House @ Home is piloting a service delivery phase across the greater Brisbane area, covering Moreton Bay, Ipswich, Brisbane, and Logan. This will allow us to develop a best practice model for the delivery of paediatric palliative care services in our families' homes, with a focus on clinical safety and quality of care. Once complete, the service will extend to reach the Gold Coast and Sunshine Coast before being rolled out across rural and regional Queensland.

In the meantime, thanks to our supporters, every child requiring end of life or after death care will be prioritised to ensure they are cared for and supported by our entire Hummingbird House team. This may involve us physically walking alongside them or dropping into their homes via telehealth.

And so, Hummingbird House remains focused on our dream, but we now have a clear path forward to make it a reality.

### LIFT UP Giving Day 2020

Last year we launched LIFT UP, our very first giving day aiming to raise \$150,000 in support of Hummingbird House @ Home. While COVID-19 forced us to cancel all of our fundraising events for the year, the reality was that the needs of the families we support were increasing. Thanks to your generosity, our LIFT UP giving day raised over \$180,000 in just 12 hours! Thank you for showing our families that no matter how tough life gets, you care, and they are never alone.



# Coles staff & customers help raise \$560k in 2020

Since 2014, Coles Queensland has raised over \$2.5 million for Hummingbird House, through its annual community fundraising campaign.

From the get go, our 2020 campaign looked different to previous campaigns, with COVID-19 restrictions in place, and limits placed on when, where and how teams were able to interact with their communities. Despite this, the passionate and dedicated staff from 182 Coles stores across Queensland rallied together with their communities, and raised a phenomenal \$560,658 for Hummingbird House! That's over \$110,000 more than the previous year, during a pandemic, in what will no doubt be remembered as one of the toughest years the world has ever seen.

To every Coles staff member that dressed up, hosted an event, or simply asked "would you like to buy a \$2 token in support of Hummingbird House?" – thank you! And to the incredible communities who have stood by us since 2014, a heartfelt thank you, from our families to yours.







*Bunnings Queensland*



*ConocoPhillips Australia*



*Brisbane IT Social*

# Our champions in the community

Thanks to our wonderful community of supporters who tirelessly fundraise for Hummingbird House! Here are just some of our many highlights from the past 12 months.

Follow us on Facebook to read more about their stories!



*Brisbane Convoy For Kids*



*Loganlea State High School*



*Aspley Hornets*



*Cooper & Abbie*



*Bellissimo Coffee*



*Inspire Health Services*



*Mt Pleasant Freemasons Lodge & Hand Heart Pocket*

# Your donations make a difference



Thank you for supporting Hummingbird House, Queensland's only children's hospice, and one of only three children's hospices in Australia. Your generous donation will extend the reach of our service and help provide vital services to families loving and caring for a child with a life-limiting condition.

## Please accept my gift of

- \$30       \$60       \$100       \$.....
- One time gift       Monthly       Quarterly       Yearly

## My details & payment information

Full name

Postal address

Phone number

Email address

Please email my receipt     Sign me up for email updates

Card type     Visa     MasterCard     American Express     Diners

Card number

Expiry & Signature  /

Please remove this slip and post to **Locked Bag 7005, Chermide South QLD 4032.**



## Growing our team to better meet families' needs

The Hummingbird House Family and Community Support team has more than tripled over the last 18 months, increasing our ability to be more responsive to families' needs.

Our team now includes family support workers, therapists, community development workers, a chaplain, and of course, our volunteer coordinator a.k.a. chief officer of fun.

While our team works on various projects, in various settings, our commitment is collective, which is to ensure our families are supported in every way possible and to extend this support to their broader community.



Hummingbird House is a joint initiative of Hummingbird House Foundation and Wesley Mission Queensland. Wesley Mission Queensland (ABN: 28 746 881 862) is a Public Benevolent Institution (PBI) with charity tax concessions, endorsed as a Deductible Gift Recipient (DGR) and covered by Item 1 of the table in section 30-15 of the Income Tax Assessment Act 1997.

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# How we transformed family and community support during COVID-19

Last March, as the world adjusted to a new normal, Hummingbird House made the decision to remain open for emergency short break stays, symptom management, end of life, and after death care during our first lockdown – which has remained our approach as we have navigated the ups and downs of this pandemic.

During this period, our team was faced with the challenge of how to deliver care to families unable to access the House for short break stays and in-person support, which was critical to ensuring they remained connected and supported during this incredibly isolating time.

Within a fortnight of the pandemic being announced, our Family and Community Support team successfully transitioned all of our existing services online, and began to offer weekly webinars to families, who were trying to make sense of life amidst COVID-19. These webinars provided a place for families in lockdown to connect and share expressions of hope and resilience, as well as discuss their common concerns and fears. Our regular creative arts therapy sessions and morning teas were also held online, connecting families who lived across many hundreds of kilometers, in some instances for the very first time!

“ **What was striking was how well prepared families were for the outbreak of COVID-19, because caring for a young person with palliative care needs requires the same daily vigilance. Many families felt that the ‘rest of the world’ was getting a small glimpse into their everyday reality.**

*Elham Day, Family and Community Support Manager*



Thanks to some significant grants and project partnerships, particularly with the Queensland Children’s Hospital’s Paediatric Palliative Care Service, we also adopted the use of telehealth to ensure our families are supported from a clinical and psychosocial perspective.

Telehealth also opened up new opportunities for our team. We now provide specialist advice to school teachers supporting bereaved siblings, facilitate bereavement support groups and offer individual creative arts therapy and counselling sessions for our guests.

In many ways the COVID-19 pandemic has acted as a catalyst that has shifted our team to a new way of working and connecting with our guests and families. For us, it has certainly been a silver lining during an incredibly challenging year.



# Hummingbird House

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