# ADAY and a bit INTHELIFE



OF A HEARTKIDS
COMMUNITY SUPPORT
COORDINATOR

# Meet Helen West, based in Victoria.

Helen's journey with HeartKids began as a mother, navigating her son Aidan's heart surgery when he was just 5 months old. Driven by her personal experience and armed with a background in Health Promotion, Helen found her calling in supporting



families facing similar challenges. For over 12 years, Helen has been the reassuring voice for countless families grappling with childhoodonset heart disease. Here is her personal account of an average day as a HeartKids Community Support Coordinator:

# **10pm**

I receive a call notifying me of a catastrophic event that occurred on the ward. I sleep fretfully, overwhelmed for the family, ward, and staff that this will impact.

### 6.25am

I receive a text from a family asking if the morning tea will occur today.

## 9am

The admission nurse stops me in the hallway to discuss ways we could reach more families.

We prep for the morning tea, ensuring there are options to cater for all sweet, savoury, gluten-free, vegetarian, and vegan options.

We visit the child on ECMO (a temporary form of heart lung bypass), CTs are booked in. Mum and dad are clearly distressed. A psychologist is sitting with the sibling, and as soon as he makes eye contact with me, he asks if they can come with us to morning tea.





### 10.30am

The Peer Support Group morning tea is so busy it is hard to navigate the room. Wheelchairs, VADs (Ventricular Assist Device, a machine that helps to pump blood from the heart to the rest of the body), prams, and oxygen tanks fill the room.

New families, families with outpatient appointments, and families who have been at The Royal Children's Hospital (RCH) long term sit together. Some are quiet and some overshare, families bond over diagnoses, state of origin, length of stay.

Babies are passed around, and when they cry they are handed back to mum. A teenage girl entertains a younger child. One teenager just sits in the corner, but even coming out of his room is a major achievement. A family gives us a thank you card.





# 1-3pm

A cardiologist walks beside me and tells me that the work I do is important, and that the families speak very highly of me. I explain that I love my job, but days like today are hard. He agrees.

We fulfil a family's wish to meet the Melbourne Storm by coordinating with hospital staff, bringing joy to a palliative family.

We assist a family with Travel payments through IPTAAS (Isolated Patients Travel and Accommodation Assistance).

Another family requests help setting up a GoFundMe page.

We offer support to a dad who must return interstate, letting him know we are available if his partner needs assistance. He texts me "Thanks...you're the best."



# 8<sub>pm</sub>

I receive a message from the family whose child is in a critical condition.

I try to spend time with my family (4 kids, 3 cats, a dog, and who knows how many fish!) and rest as much as I can for another day tomorrow.

Dear Helen.

I could fill this caid plus
Ten more with now amesome
I think you are!

Thankyou for being you and
all our chats and even
Celebrating phoebes 1st birthelay
with us.
Heart kids are Lucky to have
theart kids are Lucky to have
you and us parents are hucky
you work for heart kids!
you work for heart kids!
you work for heart kids!
we appreciate you so
much!!



Throughout the day, I must navigate emotional highs and lows, provide practical assistance, coordinate special moments, and offer compassionate support to families during challenging times.

Tomorrow will see a different set of challenges. But despite the difficulties, I know that my role as the Community Support Coordinator makes a real difference in the lives of the families we serve.



