



HeartKids

Support and guidance for parents and carers of children with childhood-onset heart disease

Caring for a loved one who is unwell is something that most people will experience, but when that loved one is a child, the role of carer can be particularly stressful.

This resource details why it's so important for you to still take the time to look after your own wellbeing during stressful periods. It also includes strategies for supporting your own wellbeing and resources you can access for additional support.

HeartKids support staff can help you navigate your journey as you care for your child, and connect with your critical support resources. You can contact our helpline on **1800 432 785** for tailored, empathetic advice.

Why your wellbeing is important Identifying that you need more support

As a carer, you play a critical role in your child's CoHD journey – providing advocacy and support, administering medication, keeping track of appointments.

All of this is on top of the normal pressures of parenting – school, meals, social events, milestones – for both your heart kid, and any other children for whom you are responsible.

Fulfilling all of these duties can be overwhelming. In order to be able to provide your family with the support they need, you need to ensure your needs are also being met.

It's normal to feel overwhelmed, tired and emotionally drained while caring for a sick child – but there are things to look out for, that may indicate that you're in need of additional support and coping strategies.

Some of those things include:

- Changes in sleep patterns
- Changes in appetite
- Withdrawal from social networks
- Disinterest in things that previously gave you joy
- Increased anxiety
- Heightened emotions
- Decreased emotions

“ People dropping off meals was fantastic. Those that rocked up with a lasagna on your doorstep and walked in, said, “Do you want to have a cup of tea or have coffee?” You knew they cared because they dropped in that food for you, but they didn't sit there and press you on how you felt. They just were there.

- Alan and Rohini, Heart Angel parents ”



Strategies for wellbeing



Sleep: Getting enough sleep is crucial for your wellbeing - even if it feels impossible during times of stress.

Practicing good sleep hygiene can help. Keep a consistent bedtime routine, avoid caffeine and electronics before bed, and optimise your sleeping environment. White noise apps can help.



Eat well: Stress can affect appetite and it's common to reach for comfort foods. When you're able to, try to include some nutritious options too, it can make a real difference to how you feel.



Get some exercise or time outdoors:

Regular exercise promotes better mental health and emotional wellbeing. You don't need to spend hours in the gym to reap the benefits - just finding time to go for a walk each day can do wonders for your mental health.



Stick to routines: Having routines for things can help reduce the build-up of stress. They can provide a sense of structure and rhythm. And in times of uncertainty, they can remind you that

there are things within your control.



Lean on support networks: Accept help from your existing network, while building connections with people who understand what you're going through.

Online communities like **HeartKids Connect** can help you meet other parents of children with CoHD.



Scan the QR code to join HeartKids Connect



Get practical support: Identify the day-to-day tasks you're lacking time or energy for, and seek external help with those items. That may involve hiring a cleaning service, asking a friend to

assist with school pick ups or relying on meal kits or delivery services.

Identifying where you need support also means that when loved ones ask how they can help, you have an answer.



Make time for the things you enjoy:

It might be something as simple as catching up with a friend for coffee, but finding ways to fit in time for friends, hobbies or other things you love can help you stay grounded and connected.



Breathing and mindfulness: Take moments when you can to pause and breathe deeply - even short mindfulness breaks can help centre you.

“

We had the most incredible community around us, as you do in rural communities, and I'm really grateful for that. At five o'clock each day, someone would arrive with a meal for our family. No questions asked—they simply helped. I might be feeding the baby or helping with one of the other children, and they would fold washing or do whatever was needed. That happened every night for months while we found our feet. We will be forever grateful for our rural community and the support they showed us.

- Louise, Heart Mum

”

How HeartKids Can Help

Our support team can offer both emotional and practical support, including mental health support. You can access assistance through the following channels:

HeartKids Helpline

The HeartKids Helpline is open Monday-Friday, 9am-5pm AEST and is the easiest way to get connected to the most relevant support for you.

Call: 1800 432 785

Webchat: heartkids.org.au

heartkidsconnect.heartkids.org.au

HeartKids Connect is a safe, supportive online community for all people impacted by CoHD, with a dedicated space for parents and carers.

Follow us on social media

 @HeartKidsAustralia

 @HeartKids



