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## Frequently asked questions

### Will my baby have a normal life?

There are many definitions of 'normal' and the types of CHD vary. This is something you should discuss with your cardiologist.

### Will I have to change LMC?

In some cases, you will continue with your LMC and deliver at your local/regional hospital. If it is determined that your baby may need specialist attention within the first few days after delivery, you may be advised to deliver at Auckland City Hospital to ensure you are close to the specialist services. The cardiac and obstetric team will determine how long before your due date you need to be transferred. Your LMC will continue providing ongoing, routine care in your place of residence.

### What extra precautions do I need to take while pregnant?

Every pregnancy is different. Continue to maintain a healthy lifestyle as advised by your LMC.

### Can I still have a normal delivery?

Normal delivery is preferred; however, if obstetric issues arise, other options will be discussed.

### Where will my baby go after delivery?

Most often, your baby will be taken to the neonatal intensive care unit (NICU) and be observed, and a plan of care will be determined and delivered.

### How will I cope?

Everyone has different coping strategies, and it is important to find what works best for you. Whichever option and pathway of care you choose, there is support available for you and your family.

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## Useful contacts

### **/ Nurse Specialist - Paediatric Cardiac Service (Starship Children's Hospital)**

Telephone: 09 630 9972

Mobile: 021 774 606 or 021 614 348

Email: [hspin@adhb.govt.nz](mailto:hspin@adhb.govt.nz) or [jstubbbs@adhb.govt.nz](mailto:jstubbbs@adhb.govt.nz)

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## How Heart Kids can help

Heart Kids NZ is a non-profit organisation that provides support services to families that have had a diagnosis of CHD. Heart Kids believes that no family affected by CHD should travel the journey alone or unsupported. We are there every step of the way.

### We provide practical and emotional support

Heart Kids NZ has a dedicated team of Family Support Workers providing support to our families. We listen, provide information, help connect with community services, and provide practical support as required.

### We can connect you with other families

Heart Kids knows how important it is to have someone to talk to, who understands, and has had similar experiences.

We can facilitate 'family matching', which enables families to share experiences.

Heart Kids understands the practical, emotional and psychological impacts expecting a heart baby can bring. We are here to help you through this process and provide you with appropriate support that you may be looking for.



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## Information and support for PRENATAL parents

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## Heart Kids NZ

Freephone: 0800 543 943 (0800 KIDZ HEARTS)

Website: [www.heartkids.org.nz](http://www.heartkids.org.nz)

Email: [info@heartnz.org.nz](mailto:info@heartnz.org.nz)

Facebook: [www.facebook.com/heartkidsnz](https://www.facebook.com/heartkidsnz)



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Supporting heart kids through life.

Finding out that your unborn baby has a cardiac condition.



Finding out your unborn baby may have a cardiac issue can be overwhelming. In most cases the cause of a congenital heart defect (CHD) is unknown.

## You are not alone

CHD is the most common congenital birth defect, affecting 1 in 100 babies. In New Zealand, 12 babies are born each week with some form of CHD. It is important to know that this spans a wide range of severity. Some babies present no symptoms at all, while others may require surgery to manage their everyday activity. There are a range of CHD conditions requiring specialist treatment. This will always be assessed and determined on an individual basis.

## Specialist Service

If a problem is detected you will be referred to the local fetal medical specialist who may then refer you onto the fetal cardiologist. New Zealand's National Paediatric Cardiac Service is located in Auckland at Starship Children's Hospital. It is the only paediatric cardiac unit in New Zealand, treating approximately 1,000 children every year.

## Heart Kids NZ

Heart Kids NZ is the only organisation in New Zealand dedicated to providing lifelong support for all those affected by a childhood heart condition.

Heart Kids is committed to providing support and information in an unbiased and non-judgemental manner, whatever your decision or needs.

## Healthcare professionals involved

Throughout your journey, you will meet different healthcare professionals. They can help answer your questions and concerns.

- /// **Midwife** - Provides support, advice and care during pregnancy, labour and the postpartum period. They facilitate birth and provide care for the newborn.
- /// **Obstetrician** - A doctor who specialises in pregnancy and works with pregnant women with complications.
- /// **Fetal Medicine Team** - A team of healthcare professionals that specialise in the care and treatment of pregnant women whose babies have abnormalities.
- /// **Fetal Cardiologist** - A cardiologist who specialises in the diagnosis, management and treatment of unborn babies with cardiac issues.
- /// **Paediatric Cardiologist** - A doctor who specialises in the care and treatment of babies and children with heart conditions.
- /// **Paediatric Cardiac Surgeon** - A doctor that specialises in child heart surgery.
- /// **Neonatologist** - A doctor who specialises in the care and treatment of newborn babies.
- /// **Cardiac Nurse Specialist** - Coordinates care between healthcare professionals, supports families and educates about cardiac conditions.
- /// **Sonographer** - A health professional who performs ultrasound scans.
- /// **Other professionals:** the Consult Liaison Team, social worker, chaplain, counsellors, Heart Kids Family Support Workers, and Maori and Pacific support services are available.

## Things to consider

### Questions to ask healthcare professionals

Finding out your child has a heart condition can be very upsetting and it may be hard to make sense of all the information you are given and the decisions you may have to make. You will have many questions. Health professionals are there to help you work through the issues. If you have more questions after appointments, take the time you need, book another appointment with your doctor or find someone else to speak with. Some questions you may need answers to:

- /// *What is the name of the heart condition?*
- /// *What will happen when my baby is born?*
- /// *Will my baby need surgery?*

### Before you leave an appointment with a healthcare professional, consider:

- /// Writing down the contact details and names of people you have seen.
- /// Writing down the name of the heart condition.
- /// Asking the doctor or nurse specialist to draw a diagram to help the explanation.

### Finding out more

If your baby has been identified as having a heart condition, you can expect your doctor (paediatric cardiologist) to explain:

- /// The precise nature of the heart condition.
- /// The treatment that may be needed after birth.
- /// The long term outlook or prognosis.

### Where can I go for further help?

You can contact your Lead Maternity Carer (LMC) who will refer you to a cardiac nurse specialist. These two key people will facilitate your care with your obstetric and cardiology teams.

**Join Heart Kids, membership is free - [www.heartkids.org.nz](http://www.heartkids.org.nz)**