

DEADLY QUESTIONS ABOUT RHD



What is the difference between RHD and ARF?

ARF (Acute Rheumatic Fever) is an illness that can happen after your body gets an infection from bacteria (strep A), like a strep (sore) throat or skin infection.

Sometimes, your body's defence system (immune system) gets confused and starts attacking its own healthy parts- like your body's joints, skin, brain, and heart. If ARF is treated quickly, most people can recover, especially if the heart valves are not damaged.

RHD (Rheumatic Heart Disease) is what can develop if ARF damages the valves in your heart. The heart valves are like doors inside your heart. They keep blood moving through the heart in the right direction. If valves get damaged, they do not open and close properly. They can leak and cause your heart to not pump as well. RHD is life long and does not go away.

What is RHD, and how can I explain it to my friends and family in simple terms?

Rheumatic heart disease (RHD) is when there is damage to one or more of the valves in your heart following Acute Rheumatic Fever. RHD happens because your immune system, fighting Strep A infection, accidentally attacks the heart valves, sometimes causing permanent damage.

You can say: "I have RHD which means my heart has been damaged after my body fought off a strep infection, like strep throat. The infection confused my immune system, so instead of just fighting the germs, it also hurt my heart. I now need regular treatment to protect my heart".

Can you play sports with RHD and a leaking valve? What are the limitations?

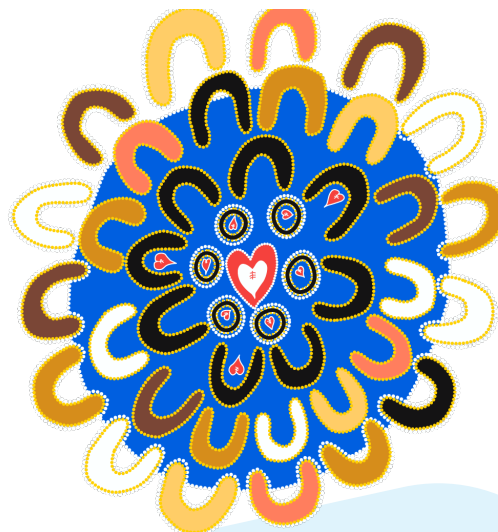
Yes, most people with RHD can play sports, but it depends on how badly the valve is leaking. Some people may need to avoid intense or contact sports if their heart is under too much stress. Always check with your doctor or heart specialist to find out what's safe for you so you can stay healthy and active.

For Bicillin treatment, is it better to have the needle or to take tablets — what is the difference?

Getting the injections (called Bicillin) is the most effective way to prevent ARF from coming back.

Needle: You only need one needle every three or four weeks. This medicine stays in your body for 28 days to kill any Strep bugs, and will prevent another episode of ARF which can cause more damage to your heart.

Tablets: For some people, the tablets are a good option, but for many, the needles are more effective. Chat to your doctor or nurse.



Why is the LA Bicillin injection long term?

Acute Rheumatic Fever (ARF) which causes heart damage can come back if you don't get regular treatment. Your Bicillin injections will stop you getting ARF and prevent any further damage to your heart.

You may need Bicillin every month for 10 years or until you are 21 years old or 35 years old depending on how your heart is functioning. Make sure you attend all your appointments with your heart doctor or nurse so they can keep checking how your heart is going.

What happens if I miss my bicillin injection or don't take it on time?

If you miss or are late with your treatment your body isn't protected from strep infections, and you can get ARF again. This can cause more damage to your heart. That could mean possible hospital visits, or needing heart surgery later on.

How can I make the needle less painful?

You are the boss of your body. Talk to your health worker, tell them where you would like your needle to go and if you would like an ice pack or to look at your phone or listen to music to be distracted.

Your health worker might have some good ideas too!

How many times does ARF need to occur for RHD to develop?

Just one episode of ARF can cause RHD, especially if it's not treated quickly. But repeated episodes make it more likely that damage may build up in the heart valves over time.

Why is RHD more common amongst Aboriginal and Torres Strait Islander people compared to non-Aboriginal and Torres Strait Islander people?

RHD is more common in Aboriginal and Torres Strait Islander communities for a mix of reasons:

- ♥ Some Aboriginal and Torres Strait Islander people may have a higher chance of getting infections from Strep A bacteria, which can lead to Acute ARF and then RHD.
- ♥ In some communities, more people live together in smaller spaces. This makes it easier for germs like Strep A to spread from person to person.
- ♥ Less access to healthcare or early treatment. Sometimes, it's harder to see a doctor quickly or get the right treatment in remote or rural areas. This means infections might not be treated early, increasing the risk of ARF and RHD.

What other ways are there to manage RHD instead of the Bicillin injection?

The most important thing you can do to prevent ARF is to take your Bicillin every three to four weeks. Other ways to help manage RHD is by:

- ♥ Eating healthy foods and staying active
- ♥ Avoiding smoking and drinking alcohol
- ♥ Taking care of your teeth and skin (to reduce infections)
- ♥ Keeping up with check-ups and heart scans
- ♥ Visiting the clinic or hospital if you are ever sick with skin sores, sore throat, fever or painful or swollen joints.



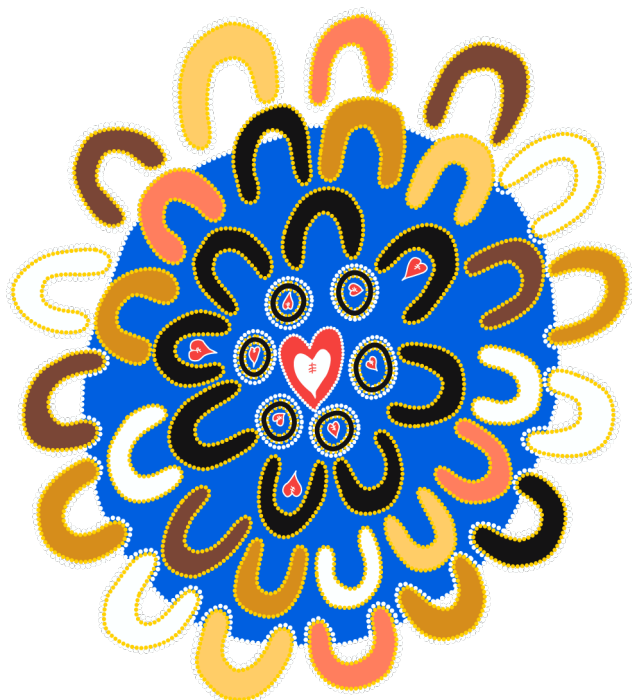
Are there any risks involved with pregnancies or birth control while having RHD?

Yes – pregnancy puts extra pressure on your heart, especially if you have RHD. You'll need special care during pregnancy.

Some birth control pills can also raise risks for people with heart problems, so talk to your health worker about safe options.

Can I pass on RHD to my children?

No, RHD is not genetic, so you can't directly pass it on. But your children can get strep throat or skin infections, which can lead to ARF and RHD if not treated early. So, it's more about being aware and preventing infection early for your kids.



Who should I speak to if I have more questions?

You can talk to your doctor, nurse, Aboriginal health worker or Aboriginal health practitioner, or your local hospital or health service. You can also access support and information through [13YARN](#), the [Heart Foundation](#), and [WellMob](#).

How HeartKids Can Help

Our support team can offer both emotional and practical support, including mental health support. You get help 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

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Find resources and information specifically for Aboriginal and Torres Strait Islander children, young people, families and communities impacted by childhood heart conditions here.

This resource was developed by HeartKids with input from registered nurses and Aboriginal and Torres Strait Islander health workers and practitioners. Content was informed by young people living with Rheumatic Heart Disease (RHD) and reviewed by the HeartKids Clinical, Research and Support Advisory Committee.