

Rheumatic fever and rheumatic heart disease



Welcome

If you have been given this booklet then rheumatic fever or rheumatic heart disease has touched your life. **You are not alone.** These illnesses affect many Māori and Pacific families/whānau. Rheumatic fever and rheumatic heart disease mainly affect children aged between 4-19 years old, but can also happen in adulthood.



It was a shock for **Tina** when she was told that her young son **Braydon** had two valves that were leaky and the cause was rheumatic fever.

Despite problems with his first heart surgery, Braydon is now back to playing sports and is really active. He takes Penicillin each month to help keep him well.

Misty-Blue's 11th birthday was not the average birthday celebration but a day in hospital coping with learning she had been diagnosed with rheumatic fever.

After having very little energy in the first few months, Misty-Blue is now coping reasonably well with her monthly Penicillin injections and manages to live a reasonably normal life.



Acknowledgements

The Heart Foundation wishes to extend a huge thank you to Tina, Braydon, Misty-Blue and their families for generously sharing their experiences with rheumatic fever.

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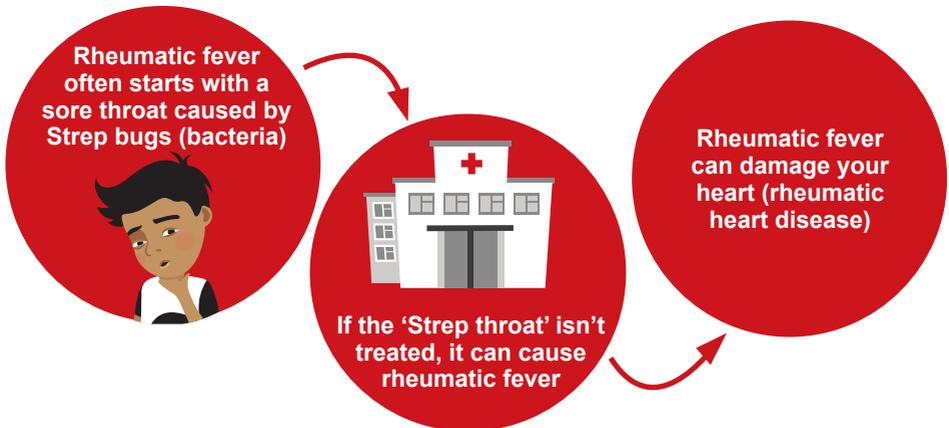
About rheumatic fever

What is rheumatic fever?

Rheumatic fever is a serious illness that can cause damage in your heart as well as swelling and pain in your elbows, wrists, knees, and ankles. You may also notice a skin rash, fever or jerky movements.

Over time, most of these symptoms will go away **but any damage to your heart may stay.**

How did I get rheumatic fever?



You can get rheumatic fever more than once and this can cause more damage.

How can rheumatic fever affect my heart?

The heart is a pump with four chambers (rooms) and four valves.

A heart valve acts like a one-way door. It makes sure that blood pumped by your heart flows in one direction only.

If rheumatic fever damages the heart valves, this is called **rheumatic heart disease**.

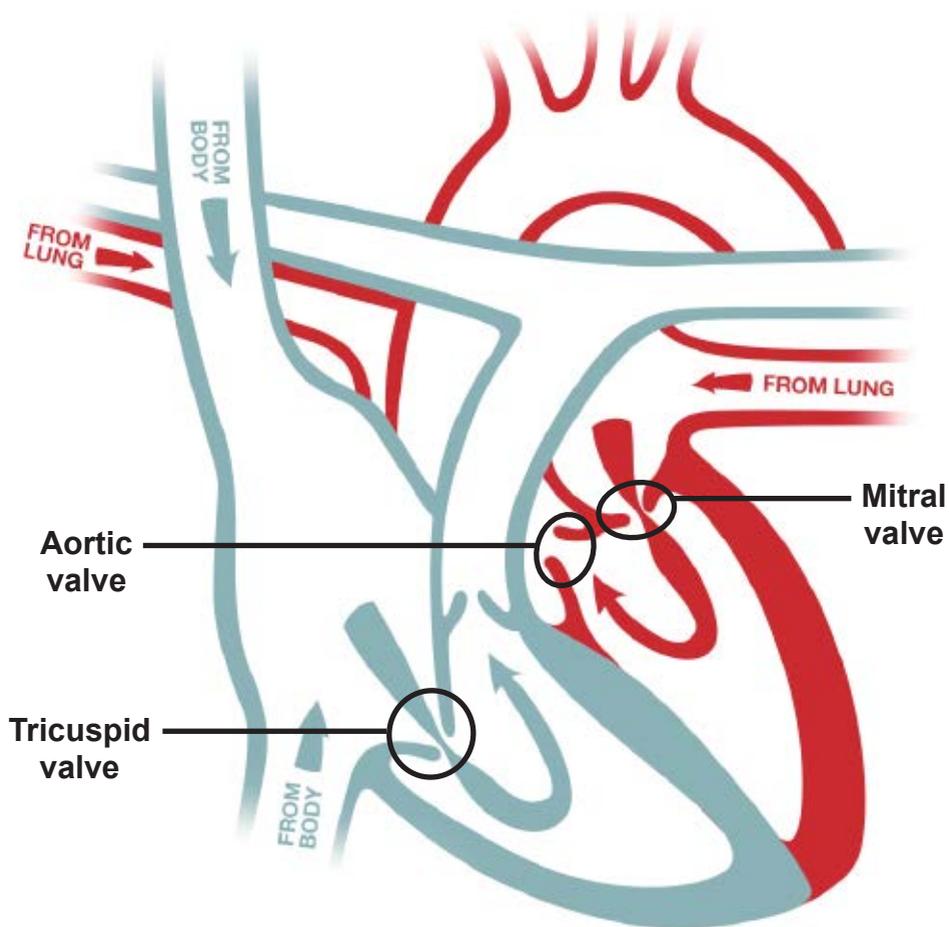
When the doctor listens to your heart, they may hear extra sounds called murmurs. A murmur is the sound of some blood flowing the wrong way through a leaky valve.

Leaky heart valves - rheumatic heart disease

Not everyone with rheumatic fever will have heart valve damage, but people with badly damaged heart valves may need heart surgery.

When rheumatic fever damages your heart valve, your heart cannot pump properly and you may feel:

- short of breath when lying down flat, needing to sleep with more pillows
- more short of breath than others when doing the same exercise
- short of breath when doing nothing
- a lack of energy



Ask your doctor or nurse to explain what rheumatic fever has done to your heart.

Getting well

What happens in hospital?

During your stay in hospital, you will have many tests, including blood tests and an echo scan (echocardiogram) to check on your heart.

Sore joints are treated with rest and pain relief.

You will be treated with Penicillin to get rid of the Strep bug and receive your first injection of Penicillin before leaving hospital.

Depending on your symptoms and test results, you may need to stay resting in hospital for some weeks or months.

People with badly damaged heart valves may need heart surgery.



“One of the nurses said Braydon’s heart sounded a bit funny, like a train. They referred us to a specialist in Auckland hospital to get checked out. After an ultrasound (echo) and more blood tests, we were told that Braydon had two valves that were leaky and that the cause was rheumatic fever.”

Tina, Braydon’s mum



There was some time spent in and out of hospital before it was confirmed Misty-Blue had rheumatic fever. This was a stressful period of time for Misty-Blue and her whānau.

“There was lots of travelling to and from the hospital and sharing the care of Misty-Blue and the kids at home, while she was in hospital.”

Misty-Blue’s mum

What happens when I go home?

The doctors will let you know how long you will need to rest when you go home. As soon as the doctor says it is safe for you to be active again, it is important to start exercising regularly and to lead a healthy lifestyle.

With proper care and regular Penicillin injections, most people who have had rheumatic fever lead a normal life.

Penicillin is the best antibiotic to prevent rheumatic fever. If you are unable to receive Penicillin, another treatment will be offered.

It is very important that you don't get rheumatic fever again.

Every strep throat has the potential to lead to rheumatic fever, which can cause more damage.



To stop you from getting Strep throat, which can cause rheumatic fever again, make sure you have regular Penicillin injections.

Talk with your nurse about options you have to get your Penicillin injections, to see what may work best for you.



The experience of spending months in hospital and now going through the ongoing treatment has completely changed the course of **Misty-Blue's** young life. As a result, Misty-Blue wants others in her community to be aware of what a simple sore throat can lead to.

Staying well

How can I avoid getting rheumatic fever again?



The best way to prevent rheumatic fever is to make sure you have regular Penicillin injections on time.

Penicillin kills the Strep bugs that trigger rheumatic fever, stopping any further damage to your heart valves.

Penicillin injections:

- are usually given every 28 days
 - are given in a muscle near your bottom or hip
- can be painful. Nurses can use local anaesthetic, distraction techniques and other therapies to minimise the pain
 - are given by your Community Nurse, District Nurse or Public Health Nurse. The nurse may come to your home or your school clinic or work and give the injection. There are also community nurse clinics available.

“I said to the nurses every time when they give his injection please bring some pain relief for Braydon. At the moment, he uses the buzzy bee and that works. He knows now, he’s used to getting his penicillin, his injection.”

Tina, Braydon’s mum

How long will I need to have Penicillin injections?

You will need to have injections every 28 days for at least 10 years, or until you are 21 years old, whichever is longer. In some cases, particularly if you have heart valve damage, you may need to continue Penicillin injections for longer.

You should never stop Penicillin treatment without discussing it first with your doctor, as you could get rheumatic fever again which can cause more damage to your heart valves.

Remember to tell your nurse if you are moving house, going overseas, on holiday, or going away. You may need to get your injection early, or your nurse may be able to arrange for you to receive your injections elsewhere.

Don't be late - plan the date!



Write it on your calendar



Ask your nurse to text you a reminder



Ask your family/whānau to help you remember



Write a reminder on your fridge

Common questions about Penicillin injections

Why do I have to have injections for so long?

The injections protect you from Strep bugs at the time in your life when you are in close contact with many people who could have a Strep infection.

Why do I need to have an injection every 28 days?

One injection gives you enough Penicillin to fight the Strep bug for up to 28 days. Having an injection every 28 days means that there is enough Penicillin in your body to help stop you from getting rheumatic fever again.

Is it true the injection puts weight on you?

No - the injection doesn't cause you to gain weight. Eating too much and not doing enough activity are the main causes of weight gain.

Can I have my injection early if I'm going away?

Yes - it is better to be early than late. Talk to your nurse to arrange to have your injection early.

What happens if I miss an injection?

It is very important that you don't miss a Penicillin injection. Missing one means that you could get Strep throat which can trigger rheumatic fever again.

If you forget an injection, ring your nurse to arrange to get your next injection as soon as possible.



Why do I need to tell people I've had rheumatic fever?

Heart valves damaged by rheumatic heart disease can occasionally get infected during certain types of operations and dental work. You may need extra antibiotics to help protect your heart. This is why it is important to remember to tell every doctor, dentist or dental therapist that you have had rheumatic fever before you have any medical procedures or operations.



Ask your doctor for a copy of this wallet card. It has important information about your rheumatic fever. You should show it to any dentist, dental therapist or doctor before they treat you.

At the dentist

Everyone has tiny bugs in their mouths. These bugs are usually harmless, but sometimes when the dentist is working on your teeth, the bugs can get into your bloodstream. If they reach your heart, the bugs can cause more damage to the heart valves. This is called endocarditis.

You can look after your teeth and help to avoid any infection by:

- having your own toothbrush - don't share with anyone
- brushing your teeth twice a day with fluoride toothpaste
- avoiding having sweet food and drinks too often
- having dental checks every six months



If you are younger than 18 years old, you can get free dental care. Call 0800 825 583 to find out more.

Women and pregnancy

Did you know that when you are pregnant, your heart has to work 50% harder all day every day? The heart's hard work starts very early in pregnancy and keeps increasing until about seven months pregnant. Ten extra beats a minute doesn't sound very much but that is 14,000 extra beats a day. That's a lot!

If you have had rheumatic fever or rheumatic heart disease, you should have a heart check-up before you fall pregnant. Make sure you tell your midwife and doctor that you have had rheumatic fever.

Depending on how badly your heart valves are damaged or if you have had surgery, you may need extra monitoring and sometimes treatment to ensure you and your baby stay healthy throughout the pregnancy.

Most women who have had rheumatic fever or rheumatic heart disease will want to have children at some time. You can plan when the time is right for you and using contraception is the safest way.

It is safe to have Penicillin when you are pregnant.



Your family doctor, local family planning clinic and/or cardiologist can talk to you about the best options for you when planning a family.

What else can I do to stay healthy?

Even after you have been told by your doctor that it is safe for you to stop having your regular Penicillin injections, it is important to get every sore throat checked.

Because rheumatic fever can cause rheumatic heart disease, it is important not to add further stress on your heart.

- Avoid smoking or being exposed to smoke
- Manage your weight
- Eat heart healthy foods
- Exercise regularly as soon as the doctor says it is safe for you to be active again.



When Braydon first came home, Tina had to make sure he didn't play like usual. He had to sit down and relax and avoid sports. But a year on from his heart surgeries, Braydon is doing well.

“At the moment, he's really good. He's really active. He likes playing sports but I still keep an eye on him.”

Tina, Braydon's mum

For parents

As a parent, what else do I need to know?

Sometimes parents will feel guilty and responsible for their child having rheumatic fever. You may experience feelings like:

- Guilt
- Anxiety or feeling over-protective
- Sleep disturbances
- Inconsistency with discipline or parenting

Remember, it is not your fault. If your feelings of guilt are strong or you feel overwhelmed then please talk to your nurse about what support may be available for you.

Misty-Blue's mum found it challenging to see her once 'chirpy, bouncy girl' in a wheelchair and having very little energy in the first few months.

Helping to make the Penicillin injections more comfortable

As a caregiver or parent it is important you take a few deep breaths and relax yourself, because if you are feeling very afraid and upset then your child will find the experience more difficult.

Supporting your child for the first few injections can help them feel more confident. You may like to think about giving encouragement like "Try counting to 10", "you can do it", "let's look at this game". This is more helpful for most children than saying things which make them focus on the injection.

If they are saying it is sore you can acknowledge their feelings by telling them they are doing a good job and they are trying really hard.

"I think that supporting Braydon helps him with what he's going through. Just helping him by being by his side. He likes that. It's just to support him throughout the days and times."

Tina, Braydon's mum

What about the rest of my family?

Does rheumatic fever run in the family?

There is no good evidence that the risk of rheumatic fever is passed down to your children. However, some families get rheumatic fever more than others.

If **anyone** in your household gets a sore throat, they need to go to the doctor and ask for a throat swab. If it is a Strep throat, the doctor will give antibiotics. These antibiotics must be started straight away and taken for 10 days to fully kill all the Strep bugs (even if the sore throat feels better).



Everyone should get every sore throat checked. To find out if there is a free sore throat swabbing clinic near you:

- phone Healthline on 0800 611 116 (**all calls are free**, even from a cell phone if you are in New Zealand) or
- visit the Ministry of Health website www.health.govt.nz

“You don’t want to see other people go through it. I even said to my sisters and brothers, make sure if your kids have sore throats or other symptoms, take them to the hospital. Because you don’t want them to go through what Braydon’s gone through.”

Tina, Braydon’s mum

Can you catch rheumatic fever?

You cannot 'catch' rheumatic fever from another person, but you can easily catch the Strep bug that triggers rheumatic fever through:

- coughing
- kissing
- sharing cups
- sharing toothbrushes

Bugs are often shared while you are sleeping close to other people. To help to stop the spread of Strep bugs and keep yourself and your family/whānau healthy, try creating your own 'sleep space' by:

- sleeping in your own bed
- or 'top and tailing'.



Keeping Strep bugs away

People are more likely to be exposed to Strep bugs when living in an overcrowded, damp house. Keeping your house warmer and drier can help prevent your family from developing a Strep throat and rheumatic fever. You could:

- open windows in the kitchen and bathroom to let steam out
- wipe down the inside of your bedroom windows if they are wet when you wake up
- dry your washing outside or in the garage.



If you need help to make sure your house is dry and warm speak to a social worker to find out if you qualify for assistance.

Rheumatic fever care plan

After going through this booklet with your nurse, you should be able to check off the following statements:

- I understand what has happened in my heart and the heart diagram on page 6 has been labelled for me
- My nurse has given me a wallet card about infective endocarditis and I know that I need to show this card to all the doctors, dentists and dental therapists I go to
- I have talked to my nurse about local support available to help me make my home warmer and drier
- I have talked to a social worker, and a Māori, Pacific health and cultural support worker about what support is available for me and my family/whānau
- I know what to do to get my next Penicillin injection

My next Penicillin injection

Time and date:

Place:

Nurse name:

Nurse contact details:

Hearts fit for life, for this generation and the next

The Heart Foundation is the charity that works to stop New Zealanders dying prematurely from heart disease. We are committed to helping people with heart disease live full and productive lives through better support, care, research and prevention.

If you would like to assist us to help other people like yourself, please consider donating

To donate:

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