

# 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.

We also wish to acknowledge everyone in the clinical community who provided input into the review of this booklet.

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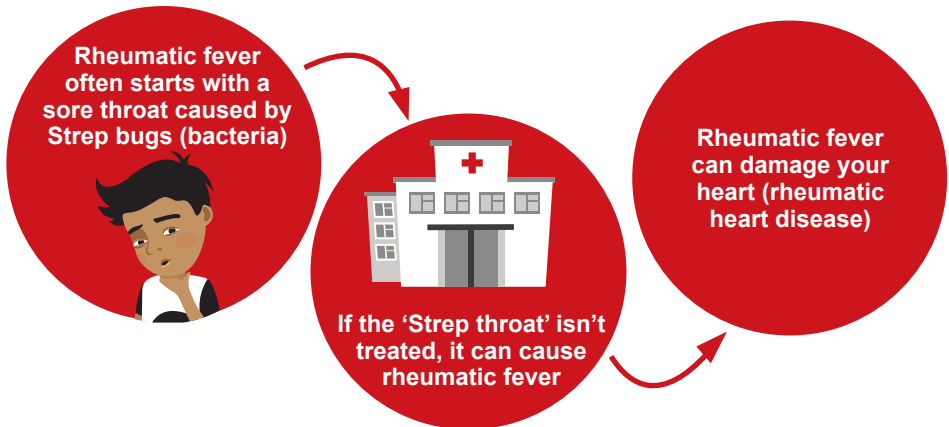
# About rheumatic fever

## 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 heart damage.**

## How can rheumatic fever affect my heart?

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

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 may be caused by blood flowing through a damaged heart valve.

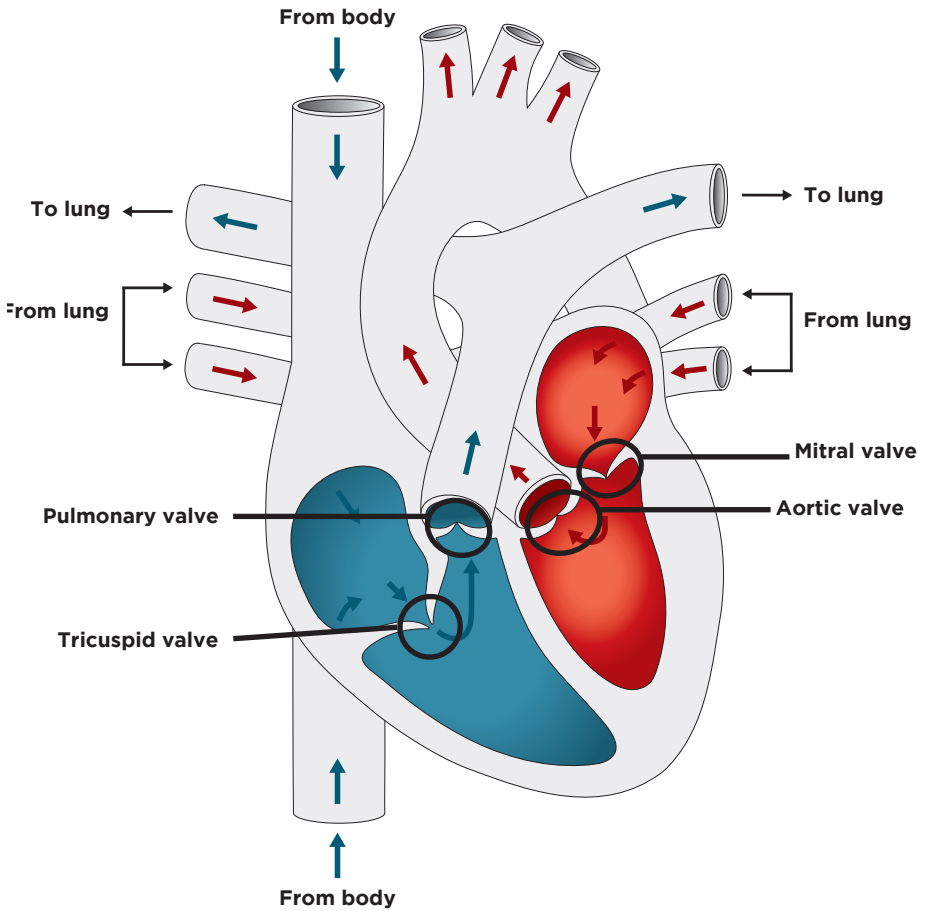
### **Leaky heart valves – rheumatic heart disease**

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.

## The heart



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

# Getting well

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## 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. You should 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 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 heart damage.



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

Talk with your nurse about how to get your Penicillin injections, so the times and places work for you.

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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

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## 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.

Regular top-ups of Penicillin kills the Strep bugs that cause rheumatic fever, stopping any further damage to your heart valves.

Penicillin injections:

- are usually given every 28 days, so that there is enough Penicillin in your body to help stop you getting rheumatic fever again
- are given in a muscle near your bottom or hip
- can be painful. Nurses have ways to make it less painful. Talk to your nurse about what works best for you
- are given by your Community Nurse, District Nurse or Public Health Nurse. The nurse may come to your home, school 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**

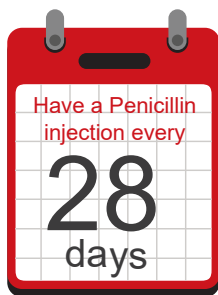
## How long will I need to have Penicillin injections?

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, such as if you have severe 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.

**What if I get a sore throat?**

**Go to your doctor and get a throat swab. You will need an extra course of antibiotics to increase your protection.**

**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 cause rheumatic fever again.**

If you forget or are late for 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 sometimes 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.

### At the dentist

Everyone has tiny bugs in their mouths. These bugs are usually harmless. 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 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.



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

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## A special note about 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 make sure 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. The aim is for you to stay as fit and active as possible.

- 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.



For advice on heart healthy eating, or to attend a Pacific Heartbeat Nutrition course, visit [www.heartfoundation.org.nz](http://www.heartfoundation.org.nz)



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/caregivers

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

Sometimes parents feel guilty and responsible for their child having rheumatic fever. Remember, it is not your fault. You may notice:

- feeling guilty
- not sleeping well
- being anxious or feeling over-protective
- you may find yourself spoiling your child.

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.

## What can I do to help with the Penicillin injections?

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

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 tell 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**

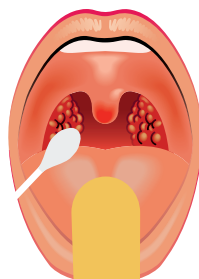


## What about the rest of my family?

### Does rheumatic fever run in the family?

There is no evidence that 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](http://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 causes 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' if a separate bed isn't available.



## 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.**

## **Before you go home from hospital, you can expect to:**

- Understand what has happened in your heart and have a labelled copy of the heart diagram on page 6.
- Know from your nurse what local support is available to help you make your home warmer and drier.
- Know from a social worker or Māori, Pacific health and cultural support worker what support is available for you and your family/whānau.
- Know what to do to get your next Penicillin injection.

## **My next Penicillin injection**

**Time and date:**

**Place:**

**Service name:**

**Service contact details:**

**My notes**

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## Hearts fit for life

The Heart Foundation is the charity that works to stop all people in New Zealand dying prematurely from heart disease and enable people with heart disease to live full lives.

Visit our website [heartfoundation.org.nz](http://heartfoundation.org.nz) to find out how to:

- join information and support sessions
- share your story
- ask questions.

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

### To donate:

Visit: [heartfoundation.org.nz/donate](http://heartfoundation.org.nz/donate)

Phone: 0800 830 100

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Printed July 2019. Information is correct at time of printing.

ISBN 978-1-927263-83-9 (print) ISBN 978-1-927263-84-6 (pdf)

The Heart Foundation of New Zealand is a registered charity (CC23052) under the Charities Act 2005



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