MY RHEUMATIC FEVER / RHEUMATIC HEART DISEASE JOURNEY



Te Whatu Ora
Health New Zealand

Information about Rheumatic Fever and Rheumatic Heart Disease

About this booklet:

This booklet is designed to help **you** and **your whaanau** navigate the journey ahead, after being diagnosed with **Rheumatic Fever / Rheumatic Heart Disease.**
You can **complete** this booklet **together** with the team of health professionals caring for you.

Contents page

- The Rheumatic Fever journey.
- What is Rheumatic Fever / Rheumatic Heart Disease?
- Why is it important to take care of my health after being diagnosed?
- Managing my Rheumatic Fever/ Rheumatic Heart Disease.
- Looking after myself.
- Returning to activities I enjoy.



Going home check list:
What you need to know before going home and leaving hospital:

My condition:

- [ ] I have a good understanding about my Rheumatic Fever/ Rheumatic Heart Disease
- [ ] I have received the Rheumatic Fever/ Rheumatic Heart Disease booklet and this has been explained to me by a health professional.
- [ ] I feel confident that I can cope well at home and have the right supports in place

Medication:

- [ ] I understand why I need to have bicillin injections, and that these will be for a number of years, until a health professional lets me know when I can stop.
- [ ] I have received my first dose of bicillin
- [ ] I understand when I need to have my next bicillin, and where this will be given.
- [ ] I know who to contact about my injections

Follow up care:

- [ ] I am enrolled with a family doctor (GP)
- [ ] I will have an outpatients clinic appointment arranged for me to attend. This will be held at _____
- [ ] I know who to contact if I have questions about my condition.

WHY IS IT IMPORTANT TO TAKE CARE OF MY HEALTH AFTER BEING DIAGNOSED WITH RHEUMATIC FEVER?

Rheumatic Fever can happen again and again. Each time it comes back the heart can get damaged.

The valves inside the heart that keep the blood moving in the right direction get especially sick and no longer work properly. This is called Rheumatic Heart Disease.

People who get rheumatic heart disease can end up very tired and short of breath because the heart has to work harder to move the blood around the body when heart valves are not working properly. They may not be able to do the things they used to do, such as play rugby, netball, tag, housework, chores, or lawn mowing.



WHAT IS RHEUMATIC FEVER?

It is a **sickness that** happens, in some people, after they have a **Streptococcal (Strep) germ.** This germ causes **sore throats** and **skin sores**. Sometimes after causing **a sore throat** the strep germ can cause the body's germ defence system to **start attacking your joints, heart, brain and skin** – this is called **Rheumatic Fever.**

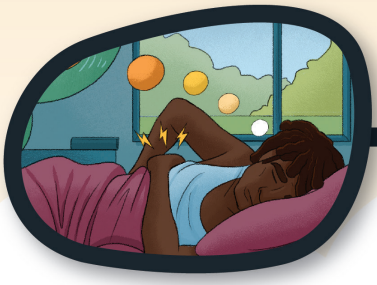


HEALTHCARE PROFESSIONALS WILL OFTEN CALL THIS ARF WHICH STANDS FOR ACUTE RHEUMATIC FEVER.

When you have ARF, this can cause fevers, pain, and swelling in your joints. Sometimes it can hurt so much that you can not move or walk. Your team of healthcare professionals will have done a number of tests on you to diagnose you with Rheumatic Fever. These include:

- Blood tests
- Swabbing your throat to see if you still have the strep germ
- A special heart scan called an echocardiogram to see if your heart has been damaged by ARF.

A YOUNG PERSONS RHEUMATIC FEVER /



Feeling unwell with sore throat, painful swollen joints



See GP/ other health provider; admitted to hospital for tests if needed.



Diagnosis c
My diagnos

_____



Returning to doing the things I enjoy e.g. school / work, sports and exercise



Bicillin injections every 21 / 28 da

(circle one)



Dental check ups every 6 months

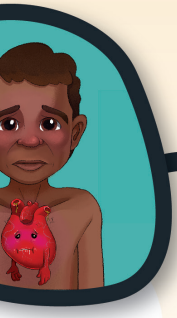


Annual flu vaccination



Follow up with Rheumatic Fever Specialist every 1-3 years. Follow up echocardiogram (if required).

RHEUMATIC HEART DISEASE JOURNEY



of Rheumatic Fever.
sis was on:
_____



Information and education on Rheumatic Fever / Rheumatic Heart Disease is provided



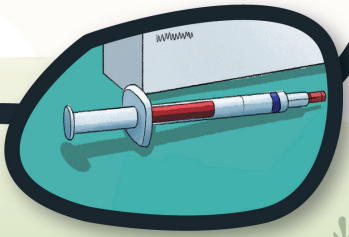
Engagement with social support services
Cultural / Social worker: _____
Healthy Homes: _____
Dental checkup: _____



ys



First outpatient appointment with Rheumatic Fever Specialist. My appointment is on:
_____



First bicillin injection. My first bicillin injection was on:
_____



Discharge from secondary prophylaxis (bicilin injections). Expected date of finishing bicillin injections:
_____

Ongoing follow up care e.g. cardiology and other services

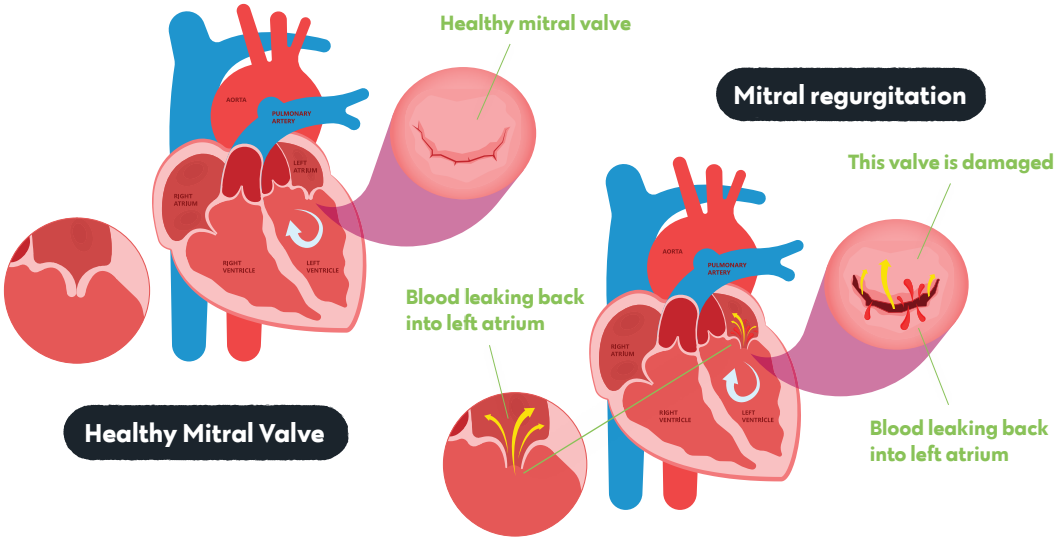
RHEUMATIC HEART DISEASE

When Rheumatic Fever affects the heart this is Rheumatic Heart Disease. Rheumatic Heart Disease is the damage to the valves that makes the heart weak.

The heart has 4 sections, they are like "rooms" also called chambers. The heart valves are the "doors" that stop the blood from flowing the wrong way. When the heart pumps, blood flows from one chamber to the next.

What happens if you have Rheumatic Heart Disease?

If Rheumatic Fever has affected your heart, you may also be under the care of a Cardiologist (Heart Doctor). They may ask for you to have an echocardiogram on your heart regularly, so that they can see how your valves are working and will follow up with you. If your valve is very damaged, you may need surgery to repair or replace the valve. Your Cardiologist and health care team will be able to provide you with more information if this is the case.



Unhealthy valves are sometimes referred to as leaky valves. This means the blood is leaking between the "rooms" (chambers) in your heart. It does not mean blood is leaking out of your heart into your body.

MANAGING MY RHEUMATIC FEVER

To stop the Strep germ from getting into the body and prevent Rheumatic Fever from happening again, you will need have an injection of benzathine penicillin, also known as **Bicillin** every 21–28 days. You may hear health care professionals call this secondary prophylaxis.

The injection is given into a big muscle in your hip / bottom area. Even though this may hurt a bit, it is important that you receive it on time. If you are late, it increases your chances of Rheumatic Fever happening again.

HOW LONG DO I NEED TO HAVE BICILLIN INJECTIONS?

Most people need to have the injections for 10 years after the last Rheumatic Fever episode, or until they are 21 years old (whichever is the longer period).

Your health worker, nurse or doctor can tell you more about the treatment.

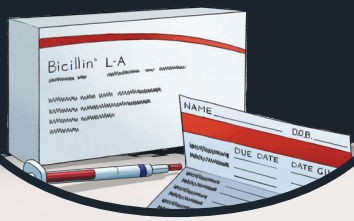
Your Rheumatic Fever Specialist will tell you when it is safe to stop having Bicillin injections.



LOOKING AFTER YOURSELF

RECEIVE YOUR BICILLIN INJECTIONS ON TIME

If you are going to be away for the next due date of your Bicillin injection, please let your nurse know. They will make sure you are covered when you are away. If you are moving don't forget to let your nurse know so they can make arrangements for you.





EXERCISE

Keep active and exercise as per healthcare professional advice.



EAT GOOD FOODS

Because rheumatic fever can affect the heart, it is IMPORTANT to protect your heart.

If you have Rheumatic Heart Disease, there may be some foods that can interfere with your medication, particularly warfarin. Please check with your Cardiologist.

QUIT SMOKING AND VAPING

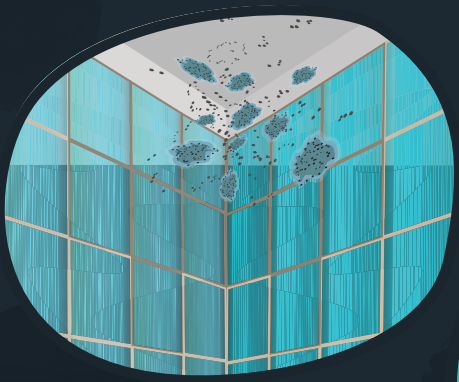


THE IMPORTANCE OF WARM, DRY, HEALTHY HOUSING

Many illnesses including acute Rheumatic Fever and respiratory tract infections are linked to cold and damp homes that are poorly ventilated.

The Healthy Housing Initiative is a free service that can discuss your housing situation and provide support, if needed, to help you create a home that is warm, safe and dry which can help to keep you well.

For more information on Healthy Homes Initiative, please see Ministry of Health website: www.health.govt.nz/your-health/healthy-living/warmer-drier-homes or talk to your nurse when you receive your Bicillin injection.





WHEN CAN I RETURN TO DOING THE THINGS I ENJOY?

When can I return to doing the things I enjoy

As you recover from Acute Rheumatic Fever, you might find that you become tired easily, or your joints are still painful. You should take it easy and pace yourself. Your Rheumatic Fever Specialist, nurse and GP will be able to give you guidance on when you can return to doing your normal everyday activities and things that you enjoy. I can return to school/ work: _____

Sports and exercise

When you have been sick and not exercising or moving around much, your body will need time to get back to your normal exercise levels.
Your healthcare professionals will be able to provide you with advice that is specific to your situation – it all depends on your severity of Rheumatic Fever/ Rheumatic Heart Disease and impact on your heart.

Some questions you can ask your Rheumatic Fever Specialist or nurse, or GP :

- When can I start light exercise? _____
- What does light exercise include? _____
- When can I do higher intensity strength/cardio exercise_____
- What higher intensity strength/ cardio exercises does this include?
- When can I return to playing sports?
- What sports can I play?



HAVE REGULAR MEDICAL CHECK-UPS

Regular medical check-ups with your doctor or other health professionals are are important.

- Have your flu vaccine every year in March/April. This can be done at your GP, or pharmacy. It is free for you as you have Rheumatic Fever / Rheumatic Heart Disease and are at risk of becoming more unwell if you get the flu.
- If you have a sore throat get it checked and always finish the antibiotics that have been prescribed for you.
- Attend your Rheumatic Fever Specialist appointments when invited. You will receive an appointment when it is time to see them (usually between 1–3 years). If unsure when you should be seeing them, ask your nurse or GP when you should be seen.

My Rheumatic Fever Care team:

- Rheumatic Fever Specialist
- Cardiologist
- Rheumatic Fever nurse specialist
- Social worker / Cultural support
- GP
- Cardiology nurse
- Community Support worker



LOOK AFTER YOUR MOUTH AND GUMS

It is important to have regular check ups with a dentist – every 6–12 months.

You will need to tell any doctor, nurse or dentist that you have Rheumatic Fever or Rheumatic Heart Disease. Before any treatment or operation you may be given antibiotic medication to stop any germs from your mouth causing problems to your heart. This is known as antibiotic prophylaxis.

If you are at primary or intermediate school, you will need to enrol so you are seen at school by a school dental nurse. Please ask the school.

If you are at high school and/ or under the age of 18, you will be able to receive free dental treatment at a a community dental practice.

If you are over the age of 18, you may be able to be referred to hospital dental for treatment (check with your specialist or nurse)



WANT TO PLAN TO HAVE A BABY?

Rheumatic Fever or Rheumatic Heart Disease does not mean you won't be able to get pregnant or have a healthy baby, you just may need more planning. Pregnancy can put stress on the heart so it's very important that you keep going to your doctor, nurse or midwife all through your pregnancy for regular check-ups. It is also important to continue your Bicillin injections, they are safe to have during pregnancy.

If you have Rheumatic Heart Disease, have had surgery and are taking warfarin it is especially important that you talk to your doctor (RF Specialist/ GP) before becoming pregnant. If you become pregnant and are taking warfarin, contact your doctor immediately for planning how to keep your baby healthy.



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Te Whatu Ora
Health New Zealand

RHD Queensland

Queensland Government