STAYING WELL with heart failure



Get support from your whānau/family

"Get your whānau to help you to manage your heart failure. They can support you in lots of ways. All my whānau has cut down on salt. We don't even have it on the table these days."

Acknowledgements

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Staying well with heart failure

Introduction

Many people think that heart failure sounds final and that it's too late to do anything about it. **This is not true.** There are lots of things that you, your family and your health care team can do to help you feel better and stay well for as long as possible.

This booklet has been written to help you and your family/whānau find out more about the important things you can do to stay well. Ask your doctor or nurse to go through this booklet with you and if there is anything that you do not understand, they can answer your questions. You can also find more information by visiting: www.heartfoundation.org.nz or www.healthnavigator.org.nz/health-topics/ heart-failure.

Contents

	My staying well plan	4
	Understanding my heart failure	8
	Why taking my pills is important	14
	Why eating less salt and a healthy diet are important	21
	Why doing daily checks is important	28
	My heart failure action plan	34
A.	Getting the most out of life	36
1 al	Further information	48



You are the most important person in controlling your heart failure. There are many things that you can to do to feel better and stay well. However, it really helps to have support from those around you and to work closely with your doctor, nurse or health worker.

Make a note of people who can support you to control your heart failure.

Name:	
Name:	$\langle \! \! \mathcal{C} \!$
Name:	
Name:	

Here is a list of important things to understand in order to control your heart failure. What do you want to find out about first?

- □ I want to understand my heart failure better (page 8).
- □ I want to understand why it is important to take my pills and how to manage them (page 14).
- I want to understand why it is important to eat less salt and how to do this (page 21).
- □ I want to understand why it is important to do daily checks (weight, swelling and breathing) and how to do these (page 28).
- □ I want to understand what to do when my symptoms get worse (my heart failure action plan) (page 34).
- □ I want to understand how to make changes to improve my health and get the most out of life (page 5–7/page 36).

How to make changes to improve my health

It's never too late to make changes to help you stay well with heart failure, improve your health and get the most out of life.

Making changes is difficult for most people. It can be hard to know where to start and how to go about making changes. Here are some tips to help you succeed.

Tips for making changes

- Work out what you would like to do this will be your goal e.g. cut down on salt
- Take small steps to achieve your goal
- Start with one thing you can do easily e.g. don't add salt to your food at the table
- Just change one thing at a time
- Once you get used to this change, change something else e.g. swap to a lower salt cereal
- Get support ask your family and friends to help you
- Make a plan your doctor or nurse can help you to make the "Plan for change" on the next page. This will help you to be more successful at making changes to improve your health.

5

Plan for change

If you would like more copies of this planning sheet visit: www.heartfoundation.org.nz.

1. What do you want to change first? What is your goal?

Here are some changes that you may want to make. There maybe other things that are more important to you. Decide where you want to start.



2. What small steps will you take to achieve your goal?

Week 1	Start with one thing that you think you can do easily.	This week I will:
Week 2	How did it go in week 1? Was it easy to do? Do you need more time on this step?	This week I will:
Week 3	How did it go in week 2? Are you ready to do something more?	This week I will:
Week 4	How did it go in week 3? Are you going to add something new this week?	This week I will:

3. Is there anybody who can help you to achieve your goal?

For example, your family may want to make changes with you.

4. Do you need any other support?

For example, cardiac rehabilitation programmes or community support groups.

5. What things might make it difficult for you to achieve your goal?

6. How will you overcome these things?



What is heart failure?

A healthy heart can pump blood to all parts of the body. Heart failure means that your heart can not pump blood as well as it should. When your heart doesn't pump well it can make you:

- Feel short of breath
- Have swollen feet, ankles and legs
- Feel tired and weak.

"When the doctor said I had heart failure I thought my heart had just 'packed up'. It was scary! But now I know that's wrong. Heart failure means that my heart's still pumping – it's just not pumping as strongly as it used to."

What causes heart failure?

Heart failure can affect men and women of any age. It is caused when the heart has been damaged in some way. Often this damage has been caused by a heart attack or high blood pressure. Sometimes we just don't know what has caused your heart failure.

"I was told that my heart failure was due to high blood pressure. I didn't even know my blood pressure was high – you can't feel it. I've made sure all my family have their blood pressure checked. I don't want the same thing to happen to them."

8

What caused my heart failure?

Here is a list of things that can cause heart failure. What do you think might have caused your heart failure? Tick (\checkmark) the cause (or causes) that apply to you. If you're not sure, ask your doctor or nurse.

- □ heart attack or angina
- □ high blood pressure
- Cardiomyopathy (disease of the heart muscle)
- L heart valve problems
- drinking too much alcohol
- **a** virus infection in the heart
- L thyroid disease
- other causes.

My heart failure was caused by:

What are the common symptoms of heart failure?

The most common symptoms of heart failure are:

- Shortness of breath when moving around
- Shortness of breath when you lie flat, especially at night
- Swelling of your feet, ankles and legs
- Swelling or pain in your abdomen (tummy)
- Getting tired very easily
- Unusual weight gain
- Loss of appetite.

"I felt alright when I went to bed – I couldn't understand why I woke up a few hours later – gasping for breath."

9

What causes the symptoms of heart failure?

Heart failure starts when another problem makes your heart weak or stiff, so that it doesn't pump or fill normally. This can lead to a number of things happening:

 Fluid build up. When your heart doesn't pump normally, blood flow becomes slower. This causes fluid to leak out of the blood vessels.

If the **left side** of your heart is not pumping well, fluid can leak into your lungs.

Fluid in your lungs can make you:

- Become more short of breath
- Wake up at night short of breath
- Cough or wheeze.

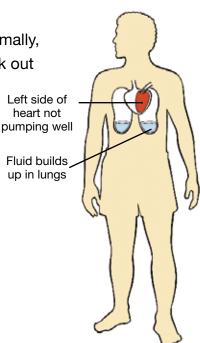
If the **right side** of your heart is not pumping well, fluid can leak into your legs and abdomen (tummy).

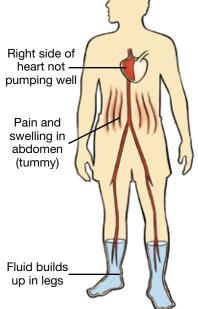
Fluid in your legs can cause:

- Swelling in your feet, ankles and legs
- Pain in your legs.

Fluid in your abdomen can cause:

- Swelling and tenderness especially over the right side of your tummy
- Loss of appetite.

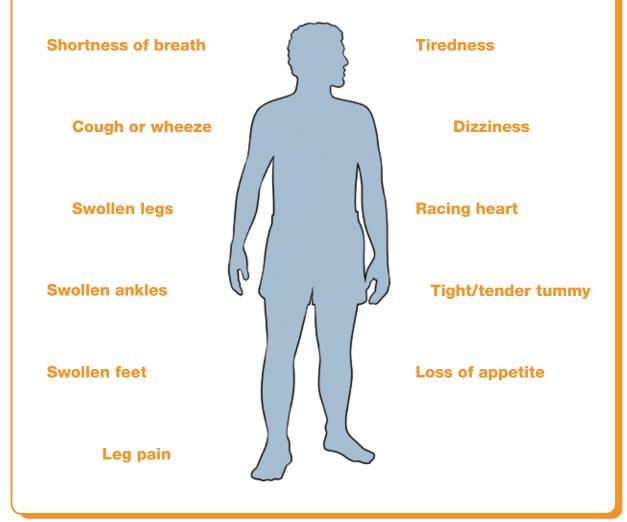




- **2. Enlarged heart.** Your heart struggles and has to work harder to pump blood around your body. Over time, this can cause your heart to become enlarged, beat faster and/or irregularly.
 - This can make you feel very tired and you may feel your heart racing.
- **3. Tiredness.** When your heart doesn't pump normally, blood does not flow well around the body. Some parts of your body, including your muscles, don't get the energy and oxygen they need.
 - This can make you feel very weak.

My heart failure symptoms

Look at the symptoms below. Which do you have? Talk to your family about these too – they may have noticed things you haven't. In this booklet you will learn more about how you can improve your symptoms.



Can my heart failure be cured?

Heart failure is a serious condition that can't usually be cured. With no treatment it will get worse – sometimes slowly, sometimes quickly.

The **good news** is that it can be controlled. When symptoms are found early, and with the right treatment and lifestyle changes, you can feel better and lead a more normal life. "It's never too late to make changes... there are many things you can do to improve your symptoms and feel better."

What is the treatment for heart failure?

Treatment for heart failure mainly involves taking the right pills, eating less salt and keeping active. You will find out more information about these treatments and why they are so important in this booklet.

There are advances being made in the treatment of heart failure nearly every year. Treatments such as pacemakers and implantable cardioverter defibrillators (ICDs) are now being used to help manage heart failure in some people. However, these are not suitable for everyone, so talk to your doctor or nurse about other treatments that might help you.

Will heart failure shorten my life?

Most people are very worried about how long they will live for with heart failure. It is difficult to say how long you will live for. We just don't know. Some people live for many years, even with severe heart failure.

Heart failure may shorten your life, but it all depends on:

- The cause of your heart failure
- · How severe your heart failure is
- Whether you have other health problems
- How you respond to treatment
- Whether you continue to take your pills.

If you are worried about your future, don't keep your worries to yourself. Ask your doctor or nurse what to expect.

Useful questions to ask your doctor or nurse

- What is my main problem?
- What do I need to do?
- Why is it important for me to do this?

www.npsf.org/askme3/for_patients.php



Why taking my pills is important

Many people say that one of the hardest things about living with heart failure is taking their pills. It helps to remember that **taking your pills correctly is the best thing you can do to stay well.** The right pills can help your heart work at its best and make you feel better!

"When I found out that I'd be on pills for the rest of my life, it was hard. But I know that being on the right pills makes me feel so much better. So now I don't have any worries about taking them."

What pills am I taking and what are they for?

The table on the next two pages lists the pills commonly used to control heart failure.

Ask your doctor or nurse:

- To help you fill in the table on pages 15 and 16
- To explain why you are on the pills you are on
- For more information on the pills you are taking.

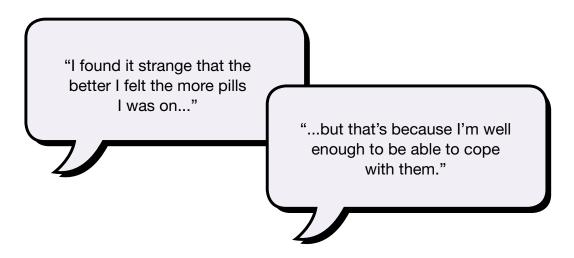
You can also find information on heart failure pills on the Heart Foundation website: **www.heartfoundation.org.nz**.

Type of pill	About my pills	What it does	I'm not on this pill because
Diuretic (water pills)	My diuretic is called:	Diuretics help the body get rid of excess fluid.	
ACE Inhibitor	My ACE Inhibitor is called: My target dose is:	ACE Inhibitors block the production of a chemical in your body called angiotensin. Angiotensin can make your blood vessels contract and tighten. So less angiotensin helps the arteries to relax. This makes it easier for your heart to pump blood through your blood vessels.	
Beta-blocker	My beta-blocker is called: My target dose is:	Beta-blockers make it easier for your heart to pump blood around your body. They limit the effect of stress hormones which can make your heart failure worse. They slow your heart rate and may lower your blood pressure.	
Aldosterone antagonist	My aldosterone antagonist is called:	Spironolactone is a mild diuretic (water pill) which helps get rid of excess fluid in your body. It also blocks the effects of a stress hormone called aldosterone, which can make heart failure worse.	
Digoxin	My dose of digoxin is:	Digoxin helps your heart to beat more strongly and helps to control your heart rate if you have an irregular heartbeat.	

Type of pill	About my pills	What it does	I'm not on this pill because
Warfarin	My warfarin is called: My dose of warfarin is:	Warfarin helps to stop blood clots from forming.	
Calcium channel blocker	My calcium channel blocker is called:	Calcium channel blockers are sometimes used to slow down the heart rate if it can't be controlled by beta-blockers and digoxin.	

Why do my pills get changed?

Your doctor or nurse specialist may change your pills regularly until you are on the best possible dose and combination of pills. Many of the pills that you will need to take to strengthen your heart have to start with a small dose and be built up gradually. You may need to see your doctor or nurse specialist every few weeks until the right dose for you is achieved. You may also need a change if you are getting more symptoms or have side effects.



Managing my pills

- Take each of your pills, everyday, at the right times. Find the right times that suit you.
- 2. Don't skip doses of your pills, even when you feel well.
- Don't stop taking pills without advice from your doctor or nurse – stopping suddenly can be dangerous.
- Plan ahead so that you don't run out of your pills. Get a new prescription a week before you need it. If you are going away on holiday, make sure you have plenty of pills.
- 5. Never take more than your prescribed dose. If you can't remember whether you have taken your pills, wait until the next time they are due. It is safer to take too few rather than too many.
- Carry a list of your pills with you at all times. Take it to your doctor or nurse appointments.

Some pills can be harmful

If you are taking non-steroidal anti-inflammatory pills (NSAIDs) such as ibuprofen (Brufen®), indomethacin, naproxen and diclofenac (Voltaren®), talk to your doctor or nurse about other pills you could use for pain relief.

If you have gout, talk to your doctor about pills to prevent gout, so that you can avoid NSAIDs.

Avoid natural remedies such as:

- Ephedra (ma huang)
- Ephedrine metabolites
- Chinese herbs
- Hawthorne (cratageus) products

because they may interfere with your heart failure pills.



Talk to your pharmacist, doctor or nurse:

- If you think you are having side effects from your pills.
- If you want to know about ways that will help you to remember when to take your pills, for example, blister packs.
- Before you use over-the-counter medicines. Some medicines including pain pills, vitamin supplements and herbal remedies can interfere with your heart failure pills and/or make your heart failure worse.
- About taking traditional medicines, for example, rongoa. These maybe okay to take but you still need to take your heart failure pills.
- If you are planning to become pregnant. Some heart failure pills should not be taken during pregnancy as they may harm your baby.



If you have a tummy upset with diarrhoea or vomiting contact your doctor or nurse. You may need to have your pills changed to stop you getting dehydrated.

What do you think about your heart failure pills?

Many people with heart failure find it hard to take their pills correctly. There are lots of reasons for this. Here is what some people think about their heart failure pills. Have a look at the thoughts below. Which ones do you agree with? When you've finished, take a look at the answers over the page.

Thought	Agree ✓	Disagree ✓
If I'm on more pills it must mean I am really ill.		
I don't like taking my pills all the time – I just take some when I am feeling bad.		
It can be dangerous to suddenly stop taking your pills.		
I get some herbal pills from the supermarket. I don't need to tell my doctor because you don't need a prescription for them.		
It doesn't make much difference if you forget to take your pills the odd time.		
If you can't remember if you took your pills, the safest thing is to take them again.		
If the side effects are bad it's better not to take them.		



Answers

If I'm on more pills it must mean I am really ill.	Not true. The more pills you are on, the more treatments there are that can help you.
I don't like taking my pills all the time – I just take some when I am feeling bad.	Not true. Your pills won't help unless you take them regularly – each day. No matter how well you feel, don't stop taking them without talking to your doctor or nurse.
It can be dangerous to suddenly stop taking your pills.	True. Stopping taking your pills without medical advice can be dangerous.
I get some herbal pills from the supermarket. I don't need to tell my doctor because you don't need a prescription for them.	Not true. Herbal pills, traditional medicines, cough remedies and vitamin supplements can cause problems. Always check with your doctor or pharmacist first.
It doesn't make much difference if you forget to take your pills the odd time.	True. It doesn't make much difference if you forget the odd time as long as you get back on them. Take your next dose when it is due.
If you can't remember if you took your pills, the safest thing is to take them again.	Not true. Wait until they are due again. It is safer to take too few rather than too many.
If the side effects are bad it's better not to take them.	Not true. Report all side effects to your doctor. They can often be overcome.

If you have questions or concerns about any of your pills (for example, about side effects or the cost of your pills), talk to your doctor, nurse or pharmacist about them.

For more information on your pills you can also visit: **www.heartfoundation.org.nz** or **www.medsafe.govt.nz**.

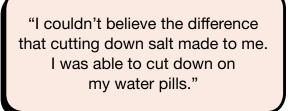
Why eating less salt and a healthy diet are important

Why eating less salt is important

Salt, or sodium, makes it harder for your body to get rid of fluid. Eating too much salt is likely to make your heart failure symptoms worse.

A healthy, balanced, low salt diet will help to:

- Improve your heart failure symptoms
- Give you more energy
- Keep you at a healthy weight
- Manage gout, high blood pressure and diabetes.





How can I eat less salt?

Making small changes in your eating can make a big difference to your salt intake.

When you eat at home

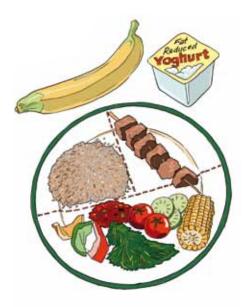
Most of the salt we eat is hidden in foods like bread, cereals, spreads, processed meats and tinned foods. Cut down on these commercially prepared, processed or instant foods. Fresh is best!

- Eat fresh or frozen fruit, vegetables, fish, meat and chicken
- Try not to add salt when you are cooking, or at the table
- Try not to use stock cubes, powders or instant soups
- Use herbs, spices, garlic, onion, chilli, lemon, vinegars, tomatoes, nuts and seeds to flavour your foods
- Salt substitutes are often too high in potassium so it is best not to use them
- If choosing processed foods, look for 'no added salt', 'reduced salt/ sodium', 'low salt/sodium' or 'unsalted'.

"It took my taste buds a few weeks to get used to less salt but using herbs and spices made my food taste better."

Small steps to eating less salt:

- Get a list of foods that are high in salt from your doctor, nurse or from the Heart Foundation website www.heartfoundation.org.nz
- Find out how to read labels to show salt levels in foods (page 23)
- Take salt off the table
- Change one food at a time such as having porridge or muesli instead of cornflakes
- Gradually swap all salty foods for foods low in salt
- Over a few months you will get used to less salt. You will know when your tastebuds are used to less salt as foods high in salt will now taste too salty.



When you eat out or take away

- Ask for food cooked with no salt and no MSG (monosodium glutamate)
- If you are unsure how much salt is in a particular food try something different
- Order food that is fresh, broiled, baked or grilled
- Ask for dressing and sauces to be put on the side you can then use a little of them or not at all.

Choosing foods at the supermarket

- Choose foods that are low in salt
- Learn to read food labels most of the salt we eat is hidden in packaged foods.

Quick label check guide

If choosing processed foods, look for 'no added salt', 'reduced salt/sodium', 'low salt/sodium' or	Nutrition I servings per pack average serving s	kage - 15 lize - 35g	% daily intake per		e quantity per 100g
'unsalted'.	ENERGY PROTEIN	480 k.J 6 g	-	680 kJ	1580 kJ 19.8 g
	FAT, TOTAL	0.1 g	0.2%	-	0.4g
	- SATURATED	< 0.19	0.1%	-	
	CARBOHYDRATE	21.4g		•	
	- SUGARS	4.1g	5%	-	15.1 g
O alt is used a summer	DIETARY FIBRE	0.9g	-		2.4.9
Salt is measured ——	– SODIUM Potassium	161 mg		217 mg	5
as sodium on	PUTASSIUM	48 mg	-	251 mg	160 mg
food labels.	THIAMIN (VIT B1)	0.20	%RDI*		0.01 ma
	RIBOFLAVIN(VITB2	0.29 mg		0.33 mg 0.8 mg	•
	NIACIN	2.5 mg		2.7 mg	
	VITAMIN B6	0.4 mg		0.4 mg	-
	FOLATE	100 µg		106 µg	
The main	CALCIUM	200 mg	-	360 mg	
ingredients come	IRON	3 mg	25%	3.1 mg	10 mg
at the start of the ingredients list. Avoid foods where salt or sodium chloride is listed near the start of the ingredients.	- Ingredient Cereals (62%)(rice flour, minerals (ce barley malt extra riboflavin, thiami	e.wheat) v alcium car ct vitamin	vheat glu bonate, ir is (niacir	iten, suga ron, zinc o n, vitamin l	r, wheat xide)salt, B6,

Compare foods and choose the brand with the lowest sodium per 100g.

Look for the words salt, sodium chloride or brine, on the ingredients list.

Eating well

Try to eat a wide variety of foods each day including:

Plenty of fruit and vegetables – half fill your plate with fruit and

vegetables first. Fruit and vegetables are full of good vitamins and minerals and are high in fibre which helps to avoid and relieve constipation. Fresh and dried varieties are also a good source of potassium. You may be advised to have extra potassium, magnesium and other minerals that you need.

Bread and cereals. Choose highfibre wholegrain varieties. Eating highfibre foods help to avoid and relieve constipation.

Milk and dairy products. These are a good source of calcium, vitamins and minerals.

Meat, fish, chicken or dried peas, beans and lentils. These are a good source of protein and other important nutrients.

Drinks. Take a look at the next page.

Eat small meals and snacks often. This is less tiring than eating big meals two or three times a day.

Small steps to eating more fruit and vegetables:

- Ask your doctor or nurse how many servings of fruit and vegetables you should eat each day
- Work out how many servings you usually eat
- Add one serving of fruit or vegetables every 2–4 weeks such as having a piece of fruit with breakfast or another serving of vegetables with dinner
- Keep adding another piece of fruit or serving of vegetables every 2–4 weeks until you are eating 5–8 servings a day
- Use the 'Plan for change' on pages 6 and 7.

Talk to your doctor or nurse if:

- You feel bloated after eating small amounts of food
- Feel too tired to prepare and cook food
- You are losing weight without intending to
- You have no appetite for food.

Do you want to learn more about how to cut down on salt and eating well? Do you have special dietary requirements e.g. diabetes or gout? Ask your doctor, nurse or dietitian for more information or take a look at these websites:

- The Heart Foundation www.heartfoundation.org.nz
- Diabetes New Zealand www.diabetes.org.nz
- Gout www.healthnavigator.org.nz/health-topics/gout
- To find a dietitian talk to your doctor or nurse or visit www.dietitians.org.nz.

Do I need to drink less?

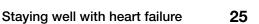
Many people need to limit the amount of fluid they drink each day to help control their heart failure symptoms. Talk to your doctor or nurse about the amount of fluid you should be drinking each day. Drink about the same amount each day.

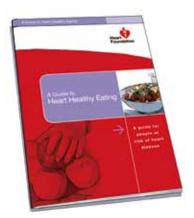
Water, diluted fruit juice, soup, tea, coffee or low fat milk are all good choices. But go easy on sugary, fizzy drinks as they can make you feel more thirsty.

Small steps to cutting down sugary, fizzy drinks:

- Decide what you can have to drink instead of sugary, fizzy drinks. Water is the best option but you may want to start by changing to diet drinks.
- Gradually swap each fizzy drink for water.







Less alcohol

Drinking too much alcohol can:

- Make your heart failure symptoms worse
- Damage your heart muscle
- Affect your heart rhythm
- Affect some of your pills
- Alter your fluid balance.

If your heart muscle has been damaged by alcohol, then you shouldn't drink any alcohol at all even when you start to feel better.

If you choose to drink alcohol:

Keep to the recommended limit – 3 standard drinks a day for men and 2 standard drinks a day for women.

A standard drink is equivalent to a:

- ½ pint of ordinary strength beer (250ml)
- Small glass of wine (100ml)
- Pub measure of spirits (30ml).



Some days don't have an alcoholic drink.

Don't binge drink.

If you are worried about the amount you are drinking, talk to your doctor or nurse or call the **Alcohol Drug Helpline** on 0800 787 797 for free and confidential advice.

Reaching a healthy weight

Being a healthy body weight will help you to feel better.

If you are overweight, you should focus on having a healthy, balanced diet (page 24) and regular exercise (page 36). If you have lost weight because of your heart failure you need to talk to your doctor or nurse so that you can avoid losing more weight and becoming too thin.

If you would like support to reach a healthy weight ask your doctor or nurse for advice. They may be able to refer you to a dietitian.

Tips for gaining weight

If you feel too tired to eat:

- Sit down when preparing food
- Rest before eating (page 39)
- Chop food up into bite sized portions to make eating less of an effort
- Eat small meals or snacks every two to three hours
- Make sure you are taking your pills correctly.

If you have a poor appetite:

- Choose a variety of foods that you enjoy the taste and smell of
- Add some foods which are higher in fat and carbohydrates ask your doctor, nurse or dietitian about these
- Include high energy drinks such as Complan, Vitaplan or Sustagen[®] into your diet
- Chew sugar free gum this can increase saliva and create a feeling of hunger
- If you can, eat with whanau/family or friends rather than by yourself.



Heart failure symptoms (swelling, being short of breath and tiredness) mainly happen because fluid builds up in your body. If you learn to recognise this you can:

- Act early to reduce this fluid build up
- Follow your action plan on page 34/35 to control your symptoms before they get worse.

"I know I'm overweight, so I've always avoided stepping on the scales. But it's not about body fat now. I need to know when I'm gaining fluid. I need to weigh myself everyday. Any sudden changes in my weight is fluid building up and I'm on to it."

There are three things that you can do to recognise when you have extra fluid in your body:



1. Weigh yourself everyday 2. Check for swelling everyday 3. Be aware of changes in your breathing

1. Weigh myself everyday

The easiest way to know if fluid is building up in your body is to **weigh yourself every day.** If you have extra fluid in your body you'll be heavier. In fact, one litre of fluid weighs one kilogram.

Weigh yourself every morning on the same scales

- Write down your weight on your record sheet (page 32) or in a diary or notebook
- 2. How does your weight compare to your target weight?
- 3. Are there any changes (increases or decreases)?
- 4. Do you need to take action? Check your action plan (page 34/35).

Know your target weight

Your **target weight** is your weight with no extra fluid. **This is the weight at which your body and heart will work the best.** Everyone's target weight is different. Your doctor or nurse will help you to work out what your weight should be.

Tips on weighing yourself

Weigh yourself every morning:

- After you have been to the toilet
- Before you eat or drink anything
- Before you put on your clothes.

Use digital scales.

Use scales on a firm surface for example, lino or tiles.

"My family help me with my daily checks. My wife reminds me to get on the scales before I've had my cup of tea in the morning. The kids check to see if I've written my weight down in my diary."

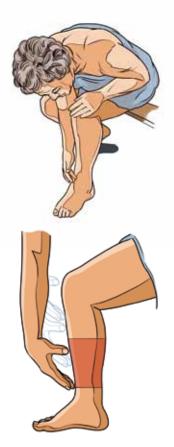
Keep scales in a visible and convenient place to remind you to weigh yourself.

2. Check for swelling everyday

Another way to know if your body is holding on to extra fluid is to check for swelling.

Check for swelling each morning:

- Check one leg
- Press firmly into the skin of your ankle, shin and knee with your finger
- If your finger makes a dent in your skin, you have swelling
- Make a note of any swelling on your record sheet (page 32)
- If there is a change follow your action plan (page 34/35).



Other signs of fluid build-up

- Does your waistband feel tighter?
- Do the rings on your fingers feel tighter?
- Do your socks or shoes feel tighter?

"Sometimes my family notice that my symptoms are getting worse before I do. They tell me to check my action plan."

3. Be aware of changes in my breathing

You can tell how well your heart is doing by how you feel. Make a note of changes in your breathing on your record sheet (page 32).

Follow your action plan on page 34/35 if you:

- Are more short of breath than usual
- Have a constant cough or wheeze
- Notice a change in your sputum colour
- Have difficulty carrying on a conversation
- Need to use more pillows at night.

"I was becoming really short of breath at night. When things were bad I used to sleep in the chair. I told my doctor and he changed my pills – now I can sleep in bed with a couple of pillows."

Do you need to use more pillows at night?

Feeling short of breath when lying flat is a common symptom of heart failure. When your symptoms are well controlled you may be able to sleep comfortably with just one or two pillows. When your symptoms are bad, you may find that you have to sleep upright or in a chair to avoid being short of breath. If you need to use more pillows that usual at night to help you breathe, it might be a sign that your symptoms are getting worse and you should follow your action plan.



One to two pillows

 able to lie flat with no shortness of breath.

2. Need to add more than two pillows to avoid shortness of breath. Take action. Follow your action plan. 3. Unable to lie down flat – have to sleep upright to avoid shortness of breath. Take action. Follow your action plan.

My record sheet

Day	Date	Weight	Any swelling?	Any change in breathing?	Notes
Mon					
Tue					
Wed					
Thu					
Fri					
Sat					
Sun					

Day	Date	Weight	Any swelling?	Any change in breathing?	Notes
Mon					
Tue					
Wed					
Thu					
Fri					
Sat					
Sun					

If you would like more copies of this record sheet visit: www.heartfoundation.org.nz

My record sheet

Day	Date	Weight	Any swelling?	Any change in breathing?	Notes
Mon					
Tue					
Wed					
Thu					
Fri					
Sat					
Sun					

Day	Date	Weight	Any swelling?	Any change in breathing?	Notes
Mon					
Tue					
Wed					
Thu					
Fri					
Sat					
Sun					

If you would like more copies of this record sheet visit: www.heartfoundation.org.nz



My heart failure action plan Understanding what to do when my symptoms get worse

If you can recognise changes in your heart failure symptoms quickly, you can take action to feel better and stay out of hospital.

Your doctor or nurse will go through your action plan with you and your whānau/family. They will fill in the shaded areas to ensure that your plan is specific to you. Remember to ask your doctor or nurse about changes to your action plan at each visit.

Name:	
Doctor/Nurse:	
Doctor/Nurse telephone number:	
Date:	
Target Weight (my weight with no extra fluid):	

To stay well with heart failure it is important that I:

- Take my pills everyday (page 14)
- Eat less salt (page 21)
- Drink about the same amount of fluid everyday (page 25)
- Limit or avoid alcohol (page 26)
- Weigh myself everyday (page 29)
- Check for swelling everyday (page 30)
- Be aware of changes in my breathing (page 31)
- Write down my daily weight and any changes in swelling and breathing on my record sheet or in a diary or notebook (page 32)
- •

Adapted with permission of Independent Health

Ifeel well	 My symptoms: Weight is on target Little or no swelling Breathing is easy. 	 What to do: Keep taking my pills (page 14) Keep eating less salt as part of a healthy, balanced diet (page 21) Keep doing my daily checks – weight, swelling and breathing (page 28) Keep making changes to improve my health (page 36).
l do not feel well	 My symptoms: Weight is up by kgs over 1–2 days Weight is down by kgs over 1–2 days Swelling in ankles, legs or tummy Hard to breath with activity or at night Need to use more pillows at night Constant cough or wheeze Very tired More frequent angina. 	What to do: Call my doctor or nurse on tel: Change my pills: Other instructions:
l need to get help now	 My symptoms: Sudden, severe shortness of breath Angina not relieved after following angina action plan Develop new chest pain/ tightness/heaviness Sweating, weakness or fainting. 	 What to do: Get help NOW Call 111 for emergency help.

Adapted with permission of Independent Health

Getting the most out of life

Taking more exercise

Exercise (physical activity) is one of the best ways to stay well with heart failure. In the past, people with heart failure were told to rest and take things easy. Now we know that exercise is healthy and safe for most people with heart failure. "I thought exercise would make me more breathless. I spoke to my nurse – she helped me make a plan to get started. She told me that it's normal to be a bit breathless when you exercise – especially when you first start."

How can I ease into exercise?

Are you new to exercise and not sure how to get started? Do you want to get back to doing something you've had to give up?

The key is to start gently with small amounts of regular exercise and build up gradually. To get started ask your doctor or nurse to help you make your 'Plan for change' on page 6.

Small steps to taking more exercise:

- Start with an activity that you can do now. It could be a 10 minute walk a day (five minutes there and five minutes back).
- On day one, do what you have planned. Don't do more, even if you feel up to it. Stop to rest if you need to.
- Do the same amount of exercise the next day. If you are too tired, do less for the next few days. If you feel okay, do the same walk each day for a week.
- Plan to increase the amount of exercise each week. Do your activity for a little longer or go a little further.
- Build up to 30 minutes a day on most days of the week.
- Talk to your doctor or nurse about suitable exercise programmes in your hospital or community.

What level of exercise is right for me?

Take the talk test – if you can't talk in sentences while you are exercising, you are working too hard and should slow down.

If you can whistle or sing, you may be going too slow and should speed up.

"The family feel more relaxed when I take my mobile with me when I go for a walk."

Don't exercise if you:

- Have just eaten a meal wait for 1–2 hours
- Are more short of breath at rest or have more symptoms than usual
- Feel exhausted
- Have a fever, infection, or feel ill
- Have chest discomfort or angina
- Have had a big change in your pills in the past week.

Why is it important not to overdo it?

Your body needs time to get used to being more active. If you build up your exercise slowly you will notice that it will get easier and you will be able to do more. However, if you overdo it when you are feeling well, you may find that you need to rest for a couple of days afterwards. This means that you will lose fitness and the next time you exercise, you won't be able to do as much. Take a look at Fred's story on the next page.

Fred's story



Saving energy for the things that I enjoy doing

You can have more energy for the things that you enjoy doing by making small changes to your daily routine. Use the 'Plan for change' on page 6 to help you make changes to your daily routine.

Here are a few energy saving tips.

- Don't wait until you are worn out to rest
- Plan rest times during the day e.g. rest for an hour after lunch
- Rest between jobs
- Don't rush too much
- Sit to do jobs such as preparing food or ironing
- Push heavy objects instead of pulling them
- Do less when it is very hot or very cold
- If you don't sleep well, talk to your doctor or nurse about what might help you to sleep.

"I used to feel exhausted after my shower. Now I put on a toweling dressing gown to dry myself and sit down to get dressed. Then I can enjoy breakfast."

Enjoying sex

For many people, having sex is an important part of their relationship. Once your heart failure symptoms are under control you can safely enjoy sex.

Sex is no different from any other form of exercise. It is good for your heart. Like other forms of exercise there are also a few important safety tips: "I was worried about having sex. I thought too much excitement would be dangerous. But it's safe and feels great."

- Pick a time for sex when you feel relaxed and comfortable
- Avoid sex within two hours of eating a big meal, or three hours after drinking alcohol
- Make sure the room is warm and relaxing
- Choose positions that feel comfortable
- Avoid positions where you have to support your weight with your arms.

What if I don't feel like having sex?

If you or your partner are feeling anxious, tired or unfit, it is natural that you won't feel like having sex. If you can, talk honestly to your partner about how you are feeling. Taking more exercise generally (page 36), will help you to get fitter and have more energy for sex.



Just like other forms of exercise you should not have sex if:

- You are feeling ill
- Are very short of breath
- You have chest pain.

What if I'm having problems?

Some people with heart failure have problems getting or keeping an erection, or having an orgasm. There are many reasons why this might be the case. It may be due to anxiety, poor blood supply, the medication you are on, or because of high blood pressure or diabetes. Pills such as Viagra, Cialis and Levitra **should not** be taken if you are taking nitrate-containing pills such as glyceryl trinitrate (GTN) or isosorbide mononitrate as it can cause a dangerous drop in blood pressure.

Talk to your doctor or nurse if you have concerns about sex. Don't feel shy to raise the topic – it is something they are used to discussing. They can talk to you about things that might help, including whether pills such as Viagra are suitable for you.

Getting back to work

When you are feeling unwell, you may not be thinking about getting back to work. But, once you start feeling a bit better, you may want to consider it. Talk to your doctor or nurse about your job and the chance of going back to your usual work. Some people will not be able to work but may be eligible for a benefit. For more information contact **Work and Income New Zealand (WINZ)** on 0800 559 009, or visit their website: **www.workandincome.govt.nz**.

What can I do to help myself get back to work?

Use the 'Plan for change' on page 6 to plan the steps you need to take to get back to work.

- Gradually increase your exercise before you go back to work (page 36). This will help you have more energy to do your job.
- Talk to your employer as soon as possible about your plans to return to work and how they might be able to help you.
- Work part-time to start with. Slowly increase the number of hours you work, so that you get used to working again.
- If your job is a heavy/manual one, you may need to change or adapt your job.
- If your job is very stressful, think of ways to lessen the stress.

Starting to drive again

Most people with heart failure can drive a car if they feel well.

However you should not drive if you:



- Have been unwell and have more shortness of breath and swelling than usual. You should wait two weeks until your symptoms are under control and you are feeling better.
- Have a history of blackouts/fainting due to an abnormal heart rhythm. You should talk to your doctor to see if it is safe for you to drive.
- Have very high blood pressure, abnormal heart rhythms or are on warfarin therapy that is not well controlled. You should talk to your doctor to see if it is safe for you to drive.

If you drive as part of your work e.g. drive a truck, taxi or bus, you will need to be assessed by a specialist before you are allowed to return to driving for work.

For further information contact the **Land Transport Safety Authority** on 0800 822 422, or visit their website: **www.landtransport.govt.nz**. Also, check with your insurance company that you are covered to drive.

Ask your doctor or nurse about getting a flu jab.

Stopping smoking

Stopping smoking is one of the most important things that you can do for your and your family's health. You may think it is too late to quit or that the odd cigarette won't make a difference to you now. But there is no safe level of smoking and quitting will:

- Improve the oxygen levels in your blood
- Improve your breathing
- Increase your energy levels
- Help you feel less tired
- Help you to sleep better
- Prevent further damage to your lungs.

If you want help to stop smoking, talk to your doctor or nurse, call **Quitline** on 0800 778 778 or visit their website: **www.quit.org.nz**.



Dealing with stress, anxiety and depression

When you have heart failure, there is a lot of focus on your physical symptoms. That's really important. But it is also really important to deal with your feelings and emotions.

Being told that you have heart failure can be a shock. Your heart failure symptoms (being short of breath and tired) can be frightening and make you feel sad, worried and depressed. For some people these low feelings improve over time. For other people they go on for longer and "When I was told I had heart failure I was frightened. I thought I would just drop dead. So, okay, it could happen but it's no use sitting waiting just in case. I've got a lot to live for. My life has changed. I've had to give up some things but there's lots to enjoy!"

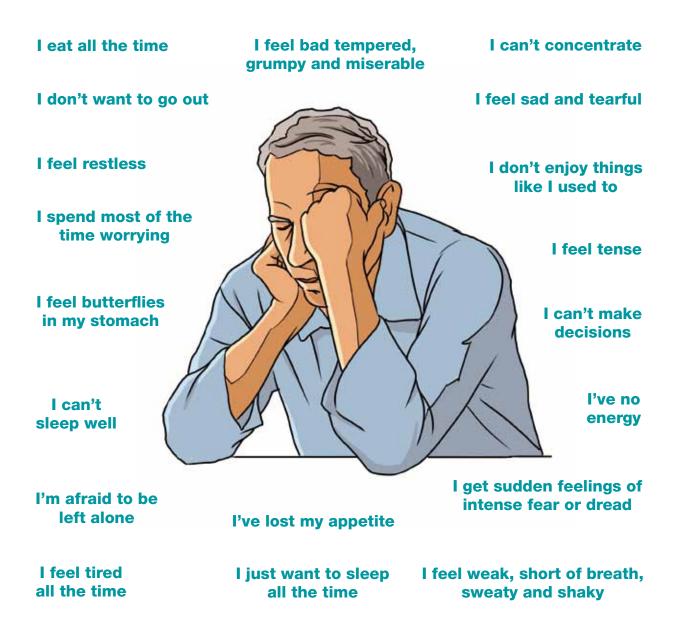
may even get worse. You don't have to put up with these emotions. There are things that you can do to deal with stress, anxiety and depression and to help you enjoy life again.

"Dad was so angry all the time. I knew that he was annoyed because he couldn't do things for himself. He hated asking for help. We tried to be there for him. It wasn't always easy."

What can I do to deal with stress, anxiety and depression?

1. Recognise your feelings

The first step in dealing with stress, anxiety and depression is to recognise how you are feeling and realise that your feelings are normal. You can then do things to help you feel better. Feeling stressed, anxious or depressed can affect people in a different ways. It's common to have signs of all three. Do you feel stressed, anxious or depressed? Look at the signs below. Which apply to you?



2. Talk to someone about how you are feeling

Talk to your partner, a close friend or family member about how you are feeling. Sometimes, just talking things through can help you feel better.

3. Take steps to tackle your feelings

Often, when you are feeling sad and low you don't feel like doing anything – even things you used to enjoy. It helps to set daily goals to make yourself do things that used to be fun, even if they aren't just now. If you keep on doing these things, you might find that you start to enjoy yourself again. "I was given all these facts about weighing myself, cutting down on salt and taking pills – I couldn't take any of it in. I felt so down. I couldn't concentrate. Thank goodness for my sister. She knew things weren't right. We talked, she listened and helped me work through things."

Activity planning

- Plan something to look forward to every day.
- Make a list of activities that you used to enjoy or made you feel good, e.g. walking on the beach or reading a book.
- Decide which of these activities you want to do each day.
- Be realistic. It is better to do something you are able to do rather than feel bad because you've tried to do too much.
- Try to write down your day's activity plan the evening before so that you have a plan of action to follow when you get up in the morning.



Do some exercise everyday

When you feel down you don't feel like taking exercise. But getting out into the fresh air and being active can really help to lift your mood. Look at page 36 to find out how you can ease into exercise.

Think about relaxation

Being relaxed is not the same as kicking your shoes off, lying on the sofa and having a beer or wine. Relaxation and breathing exercises affect certain chemicals in your body and can help you feel calm. Talk to your doctor or nurse about relaxation exercises which might help you, or visit: **www.heartfoundation.org.nz** for a copy of a simple relaxation exercise.

"I'd wake up at night and I couldn't get my breath.
The more I panicked the worse it got. Relaxation exercises have helped me to control my breathing and my anxiety – they've helped a lot."

You can often find good relaxation CDs in libraries and bookshops.

When should I get help?

If you find you are still feeling really low after a few weeks or if you or your family is worried, talk to your doctor or nurse. You may need to be referred to someone who can help you and/or you may need medication for a while.

For more information on dealing with stress, anxiety and depression or helping someone deal with these feelings contact the **Mental Health Foundation of New Zealand:** www.mentalhealth.org.nz or beyondblue: www.beyondblue.org.au





Where can I find out more about staying well with heart failure?

www.heartfoundation.org.nz – information on staying well with heart failure – including advice on cutting down salt and eating well.

www.healthnavigator.org.nz/conditions/heartfailure – information and helpful tips on staying well with heart failure.

www.besthealth.bmj.com/btuk/conditions/5871 – clear, accurate evidencebased information on managing heart failure.

www.carers.net.nz - information and support for carers.

www.medsafe.govt.nz - information on medications.

www.dietitian.org.nz – information on finding a dietitian.

www.landtransport.govt.nz - information on driving licensing.

www.workandincome.govt.nz - information on sickness and other benefits.

www.quit.org.nz - help to stop smoking.

www.mentalhealth.org.nz – information on dealing with stress, anxiety and depression.

www.beyondblue.org.au - information on depression and anxiety.

My angina action plan

If you get angina:

- Stop what you are doing. Sit down and rest.
- If the angina still persists after a few minutes, take one or two puffs of your Nitrolingual spray, or half to one Lycinate tablet.
- If the angina is relieved by rest, or by your Nitrolingual spray or Lycinate tablet, you can resume your activities gently.
- If the angina persists, you can repeat the dose safely every five minutes.
- If the angina is not relieved after three doses within 15 minutes call an ambulance. Dial 111 immediately.

My heart attack action plan

Heart attack warning signs

- Heavy pressure, tightness, crushing pain or unusual discomfort in the centre of the chest lasting more than 10–15 minutes. It may stop or get less intense and then return.
- Pain spreading to the shoulders, neck, jaw and/or arms.
- These may be accompanied by sweating, a sick feeling in the stomach. Dizziness and a shortness of breath.
- When it's a heart attack, minutes do matter.

Heart attack action plan



Dial 111, ask for the ambulance service and tell them you are having a possible heart attack.



If available chew an aspirin, unless you have been told not to in the past.



Rest until the ambulance arrives.

Summary of my heart failure action plan

The full version of your heart failure action plan is on pages 34/35. Your doctor of nurse will fill in the shaded areas to ensure that your plan is specific to you:

I feel well	 My symptoms: Weight is on target Little or no swelling Breathing is easy. 	 What to do: Keep taking my pills (page 14) Keep eating less salt as part of a healthy, balanced diet (page 21) Keep doing my daily checks – weight, swelling and breathing (page 28) Keep making changes to improve my health (page 36).
l do not feel well	 My symptoms: Weight is up by over 1–2 days Weight is down by over 1–2 days Weight is down by over 1–2 days Swelling in ankles, legs or tummy Hard to breath with activity or at night Need to use more pillows at night Constant cough or wheeze Very tired More frequent angina. 	What to do: Call my doctor or nurse on tel: Change my pills: Other instructions:
l need to get help now	 My symptoms: Sudden, severe shortness of breath Angina not relieved after following angina action plan Develop new chest pain/ tightness/heaviness Sweating, weakness or fainting 	 What to do: Get help NOW Call 111 for emergency help.

The Heart Foundation is New Zealand's heart health charity and is dependent on the generous support of the public for its life saving work. To help us continue this work and the production of resources like this please make a donation by phoning 0800 830 100 or visit: **www.heartfoundation.org.nz**

For more information about heart health resources and/or supporting the Heart Foundation, please contact:

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