



**EXERCISE AND CYSTIC FIBROSIS:** 

# A GUIDE FOR PEOPLE LIVING WITH CF





### About this guide

This booklet is designed to assist people with cystic fibrosis (CF) to exercise safely at home or within their community. It contains specific CF related exercise tips and information to help you on your journey.

The importance of an active lifestyle is becoming more evident for the CF population, with results showing better fitness levels, increased lung function and improved overall quality of life. People with CF who keep fitter are shown to cope better with the impact of CF and generally have healthier lives. Exercise can also:

- Improve daily functioning
- Slow the rate of decline in lung function
- Assist with airway clearance
- Improve the ability to perform daily activities such as cleaning and shopping
- Increase bone density
- Preserve muscle strength and function
- Increase body mass
- Improve appetite
- Improve exercise tolerance



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On the cover: Sally Edwards living with CF, working out at her gym

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### Contents

1.	GETTING STARTED	04
	<ul><li>Who to talk to</li></ul>	4
2.	MOTIVATION	05
	■ Goal setting	5
<b>5.</b>	TYPES OF EXERCISE AND	08
	THEIR BENEFITS	
	<ul> <li>Aerobic exercise</li> </ul>	8
	<ul><li>Resistance/strength</li></ul>	9
	<ul><li>Flexibility</li></ul>	10
	<ul><li>Warm up and cool down</li></ul>	11
4.	MONITORING YOUR LEVEL OF EXERTION	12
	<ul><li>Heart rate</li></ul>	12
	<ul> <li>Rate of Perceived Exertion (RPE) Scale</li> </ul>	12
5.	CONSIDERATIONS DURING EXERCISE	13
	<ul><li>Hydration</li></ul>	13
	<ul><li>Hygiene at the gym</li></ul>	14
	<ul><li>Exacerbations</li></ul>	14
	Incontinence	14
	<ul><li>Cough</li></ul>	15

Cystic Fibrosis Related Diabetes

■ PEGs, PICCs and Ports

Low Lung Function

15

15

15

<b>6.</b>	FOOD AND EXERCISE	16
	<ul><li>Carbohydrates</li></ul>	16
	■ Fat	17
	<ul><li>Protein</li></ul>	17
	<ul><li>Calcium</li></ul>	17
	Iron	18
	<ul> <li>Refuelling before and after exercise</li> </ul>	18

<b>7.</b>	USEFUL CONTACT DETAILS	19
	OSEI OE COITIACI BETAILS	



### Getting started

It is important to start slowly and only exercise at a level you are comfortable with. Choose activities that you enjoy and work up to a moderate intensity over time. You may even need to start with 5 to 10 minute sessions and build up to 30-minute sessions 3 or more days per week.

Because of reduced lung function and weakened muscles associated with having CF. you may suffer from a certain level of exercise intolerance; however people with CF can still have significant fitness and strength improvements from exercise. Remember it can take time to see results, so be patient and consistent.

#### WHO TO TALK TO?

Before you start a new exercise program it is vital to speak to the multidisciplinary team at your hospital.

Your physiotherapist will be able to develop an appropriate program for you, so that exercise frequency, duration and intensity will meet your particular needs.

Cystic Fibrosis Western Australia (CFWA) may also be of use to you as they have a range of programs to assist in supporting an active lifestyle.

### ☐ An equipment loan program offering a variety of exercise equipment.

**CFWA CAN HELP BY OFFERING:** 

- ☐ A homecare worker who can assist with exercise programs.
- ☐ Counselling and life coaching to help set exercise goals.

#### □ Subsidies

- Equipment subsidy to assist you in purchasing your own exercise equipment.
- Activity subsidy to help cover the costs of gym membership, sporting

For more information contact Cystic Fibrosis WA on (08) 9346 7333



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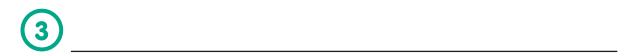
### Motivation

Starting a new exercise program may be daunting. It's important to remember that motivation doesn't just happen; it's something you make happen each and every day. If you have multiple reasons to exercise, you'll always have something to get you moving, even when motivation is lacking.

Writing down your reasons will give purpose to your workouts and make you more motivated, committed and give you something to work towards.

#### Write down 3 reasons WHY you want to begin this journey:





These could include reasons such as:

I want to be fit enough to travel overseas

I need to be able to clean my house

I want to get a job

I want to complete a fun run





# GOAL SETTING IS USEFUL TO MAKE YOUR REASONS TO EXERCISE MORE SPECIFIC AND ATTAINABLE

#### Goals should be SMART.



**Specific:** This is the who, what, when, where and how of your goal i.e. what do you want to achieve?



Measurable: How many minutes per day/days per week?



Achievable: Is your goal achievable for you?



**Realistic:** Is your goal something you are willing and able to achieve. Does your goal realistically fit into your lifestyle?



**Timely:** Your goal should have a specific timeline. When do you want to achieve your goal by?

Set both short term and long term goals and reward yourself when you reach these goals.

For example, if your reason to exercise was to travel on a holiday:

#### A short term goal may be:

I will walk for 30 minutes 3 times a week. If I do this for 4 weeks I will reward myself by researching holiday destinations.

#### Your long term goal may be:

I would like to feel comfortable walking around the local shopping centre for 2 hours. My reward will be to book my flights.

Example 2: if your reason to exercise was to be able to walk my dog around the park:

#### A short term goal may be:

'I will do 15 minutes of body weight exercises 3 times a week. If I do this for 2 weeks I will reward myself by buying a new outfit'.

#### Your long term goal may be:

'I would like to feel comfortable walking my dog around the neighbourhood for 30 minutes straight'. My reward will be to take my dog to the dog beach'.

What are your goals? Have a go at setting a long and short term goal based around your reasons to exercise:

Short	term	goa	:
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l will	(exercise)
for minutes ti	mos a wook
forti	rries a week.
If I do this forweeks	I will reward myself by
Landamanah	
Long term goal:	
I would like to	
l by	
My reward will be	

Your goals should be written down and kept somewhere you can see them every day to remind you why you started, such as on the fridge, wardrobe door or mirror in the bathroom.

#### Other tips for staying motivated include:

- Find an exercise buddy to workout with, that way you are committed to someone and are less likely to cancel. A CFWA homecare worker could help with this.
- Track your results. Use an exercise diary or chart your results to see the improvements you have made over time. CFWA has developed an exercise diary you may like to use.

# Types of exercise and their benefits

There are three basic categories of exercise: aerobic, strength and flexibility.



#### **AEROBIC EXERCISE**

These are exercises that are performed at moderate to low intensity for longer periods of time and that raise your heart rate through repetitive movement of large muscle groups. Aerobic exercise can be either weight bearing (walking or hiking) or non-weight bearing (biking or swimming).

#### CF Specific Benefits:

Aerobic training helps make everyday tasks easier by improving overall fitness. In combination with airway clearance, aerobic training can help loosen secretions. The main goal of aerobic exercise should be to increase your endurance, that is, your ability to complete activities over an extended period. This will make everyday tasks easier and improve your overall quality of life. Although aerobic exercise cannot reverse lung damage that has already occurred, it can improve lung function and help prevent further damage.

The level of aerobic exercise you can complete will depend on various factors including current physical fitness, lung function and nutrition. Don't feel bad if you can't complete high intensity exercise, as moderate or low intensity work has been proven to be just as, if not more beneficial to people with lung disease.

When you have an exacerbation you may need to decrease your intensity of exercise and have extra rest.

As aerobic exercise can burn a lot of calories, it is important to be aware of weight loss, as this is not the goal for most people with CF. Having a well-rounded exercise program and talking to your hospital physiotherapist and dietician is the best way to avoid this. See page 16 for more information on diet.

Some aerobic exercises examples are:

Jogging	Rowing	<ul><li>Aerobics</li></ul>
<ul><li>Walking</li></ul>	<ul><li>Swimming</li></ul>	<ul><li>Dancing</li></ul>
<ul> <li>Hill or stair climbing</li> </ul>	<ul><li>Cycling</li></ul>	





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#### **RESISTANCE/STRENGTH TRAINING**

These are exercises that are performed at moderate to high intensity for short periods of time and increase the power and tone of muscles and build bone density. Strength training exercises can be done using free weights (dumbells), your own body weight, known as plyometrics (push ups, squats) or with elastic resistance.

#### CF Specific Benefits:

Strength training has many benefits for people with CF, in particular, increased body strength. Improved leg strength has the ability to make everyday tasks such as walking easier, while increased upper body strength can increase chest mobility and improve posture, which may benefit your breathing.

Weight training is particularly beneficial in increasing bone strength and preventing fractures and osteoporosis. As we get older our bones become thinner and weaker, however in people with CF this can happen a lot earlier in life. About one third of adults with CF have low bone mineral density, which may predispose them to bone fractures. The causes of reduced bone mineral density in CF include low body weight and poor stores of vitamin D and calcium.

Strength training is the most beneficial type of exercise if you are looking to build muscle. People with CF often experience muscle atrophy, that is, weakened, smaller muscles. There is however, evidence to suggest that people with CF can still experience increased muscle strength through weights training. Muscle is gained through a combination of strength/resistance exercise and diet, which contains adequate energy and carbohydrate to fuel the exercise.

You may also benefit from taking a prescribed supplement drink, which will provide you with additional protein and energy to meet the demands of exercise. Ask your dietician for more details.

When first starting strength training, exercises that target the major functional muscles of the arms, legs and trunk can provide a full body workout. It is important to maintain correct technique when performing any strength training exercises, as incorrect technique can lead to injury.

Your fitness instructor or hospital physiotherapist should be able to instruct you on how to safely complete any exercises. You should stop immediately if you experience pain.

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#### **FLEXIBILITY**

Flexibility exercises help to lengthen muscles and tendons and improve or maintain the flexibility of your muscles. Good flexibility is important for posture and to keep full range of movement and to decrease chances of injury. Flexibility exercises include a mixture of stretching and core strength exercises such as yoga or pilates.

#### CF Specific Benefits:

The muscles in the trunk are needed for both posture and breathing, therefore when the body has to use these muscles excessively for breathing and coughing (often in a bent over position), the posture will start to be adversely affected. Increased pressure in the chest, due to lung disease as well as excessive coughing can push outwards on the skeleton, leading to curvature of the spine, "barrel" shaping of the chest and rotation of the shoulders forward, giving a hunched and rounded shoulder appearance. These changes can result in back pain, joint problems and have a detrimental effect on lung capacity.

Flexibility exercises can be particularly beneficial for improving posture and breathing. By keeping your spine, ribcage and shoulders flexible, you will be better able to maintain good posture and preserve full movement of the joints and muscles around this area.

Stretches or poses should be held for at least 30 seconds to get best benefits.

Core strength training uses the muscles of the abdominal walls, and can improve your posture and therefore, your breathing.



#### WARM UP AND COOL DOWN

A good exercise program should incorporate elements of aerobic, resistance/strength and flexibility training, as well as a warm up and cool down. Warm ups should last for around 5 to 10 minutes and include a mixture of low intensity aerobic work (e.g. walking) mixed with some light stretching. Warms ups are important in reducing the risk of injury, warming up the muscles and increasing the heart rate in preparation for more intense activity.

Cool downs should involve a gradual yet continuous decrease in exercise intensity (i.e. from a hard run to an easy jog to a brisk walk), stretching, and rehydration. Duration can vary for different people, but 3-7 minutes is considered adequate. Cooling down allows the heart rate to return to its resting rate.

You may choose to do your airway clearance either before or after exercise; both are beneficial to help clear secretions. You may cough initially if you haven't done your airway clearance prior to exercising, but it may make airway clearance easier and more effective. If you do your airway clearance first, you may find exercise easier as the lungs are clearer. Discuss with your hospital physiotherapist to help decide which method would be best for you.





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# Monitoring your level of exertion

#### **HEART RATE**

You can calculate your resting heart rate (HR) by feeling your pulse at rest for 30 seconds and multiplying it by 2. Your HR can be one of the things to guide you during exercise as to whether you should be working harder, slowing down or even stopping to have a rest.

Talk to your physio about what your target HR should be during exercise as it will be different for everyone.

Other things to monitor are your level of breathlessness, wheezing, increasing tight cough, excessive fatigue and chest pain. Make sure you talk to your primary care team about these symptoms if they occur.

# RATE OF PERCEIVED EXERTION (RPE) SCALE

This tool is used to measure your perceived level of exertion during exercise. Doing so can allow you to reflect on how strenuous the exercise feels to you, and whether or not you need to increase or decrease the level of intensity. The scale is based on the physical sensations you may experience during exercise, including increased heart rate, increased breathing rate, increased sweating, and muscle fatigue. This scale provides a simple way to gauge your exercise intensity, and can even be used during everyday activities such as housework.

### Check with your physio as to what your target RPE should be.

- 1: Corresponds to "very light" exercise. This is like walking slowly at your own pace for some minutes
- 4: Is "somewhat hard" exercise, but it still feels OK to continue.
- 7: "Very hard" is very strenuous. A healthy person can still go on, but they have really had to push them self. It feels very heavy, and the person is very tired.
- **9:** For most people this is the most strenuous exercise they have ever experienced. It is not recommended that someone with CF should aim for this level of exertion.

	Rating of Perceived Exertion (RPE)		
0	Nothing at all		
0.5	Very, very light		
1	Very light		
2	Fairly light		
3	Moderate		
4	Somewhat hard		
5	Hard		
6			
7	Very hard		
8			
9			
10	Very, very hard (maximal)		

# Considerations during exercise

#### **HYDRATION**

Staying hydrated during exercise is one of the most important things you can do for your body. Not only do you have more energy when you're hydrated, your performance also improves and your workouts feel better. If your body is low on fluids, performance suffers, you get tired faster and, in some circumstances, you can end up with cramps, heat exhaustion or other problems.

Sweat and salt loss during exercise can cause anybody to become dehydrated, especially in hot weather, however as people with CF lose more salt through sweat,

you are placed at a greater risk of complications from dehydration.

These symptoms may be a sign you're dehydrated:

Headache
Feeling dizzy or lightheaded
Fatigue
Diarrhea
Vomiting
Thirst
Dry mouth
Flushed skin

# REMEMBER: by the time you are thirsty you are already dehydrated!

Dehydration can cause your secretions to become thicker, making airway clearance more difficult. You may even feel too tired to eat, which means that you do not adequately refuel your body's energy stores and this could lead to unintentional weight loss.

Later symptoms include impaired mental performance, stumbling, shriveled skin, sunken eyes, muscular spasm and nausea. If you experience any symptoms of dehydration, STOP what you're doing and drink. Consider a sports drink to help balance out your electrolytes.

### TIPS TO AVOIDING DEHYDRATION DURING EXERCISE:

- ☐ Avoid extreme weather conditions. Try and exercise in the morning or later evening, or in a temperature controlled environment.
- ☐ Take additional salt supplements if you sweat a lot. This is especially important in warm weather and for prolonged periods of exercise.
- □ Discuss your exercise plan with your dietician and medical team.
- ☐ Eat salty snacks.
- ☐ Start exercise fully hydrated. Drink 500-600ml of fluid about 2 hours before exercising plus around 150-350ml right before you start.
- □ Replace the salt and electrolytes lost in your sweat by drinking extra fluids. Sports drinks such as Powerade are absorbed as fast as or faster than plain water. They contain a little salt and 5-8g carbohydrate/100ml, which will provide energy to fuel the muscles.

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#### **HYGIENE AT THE GYM**

When you are exercising at a gym, it is important to maintain good hygiene to avoid picking up germs. Try using the tips below:

**Disinfect Equipment:** Wipe equipment with disinfectant before and after you use it. There should be a supply of antibacterial wipes at various stations around the gym. If there isn't, take your own antibacterial spray or wipes.

**Bring your own mat:** If you're going to use a mat provided by the gym, sanitise it with an antibacterial spray or wipe and place a clean towel on top of it.

**Wash your hands** thoroughly with soap and water, or use an antibacterial hand gel before, during and after exercise.

**Bring Your Own Water Bottle:** Drinking fountains can harbour bacteria and viruses. If you do need to use a fountain, wash your hands before and after, don't put your mouth directly on it and let the water run for a few seconds before drinking.

**Bring your own towel:** Make sure to have a clean towel with you to wipe sweat away from your face. It should also be placed on your yoga mat and on equipment during use.

#### **EXACERBATIONS**

A pulmonary exacerbation is as an increase in severity of normal CF symptoms. It may include any or all of the following symptoms:

- Fever and/or increased cough
- Increased production of secretions
- Change in the colour of secretions
- Wheezing

- Shortness of breath (increased breathlessnees
- Sensation of tightness in the chest
- Decreased appetite
- Decreased exercise tolerance

Exercise is not likely to be the cause of an exacerbation, however if you experience an increase in such symptoms you may need to modify your exercise program, therefore you should seek medical and physiotherapy advice. Respiratory exacerbations often require antibiotic treatment and sometimes hospitalisation.

#### INCONTINENCE

Due to coughing, many people with CF have weakened pelvic floor muscles which can lead to incontinence. This may be worse during coughing and high impact exercises such as jumping, skipping and running.

Jumping on a trampoline has been shown to cause more leakage problems for adults with CF than other exercise. Jogging will actually cause less strain on the pelvic floor muscles than jumping with both feet together. Jogging instead of jumping with a skipping rope is preferable for the same reason.

Your team may routinely ask at annual review if you have any problems with leakage. The specialist team at your clinic can provide advice about managing symptoms of incontinence during exercise. Many people find it embarrassing to talk about, however it is really important to discuss this as it may get worse if untreated. Where necessary, a referral can be made to a specialist continence team who will be able to provide advice, assessment and treatment (e.g. pelvic floor exercises). It is important to be guided through using these techniques by a specialist to ensure you are performing them correctly.

#### COUGH

Exercise may cause you to cough and this is normal. You may want to keep tissues nearby while exercising if you need to clear secretions. If you are exercising at a gym, explaining CF to your trainer will allow them to understand why you may cough up secretions and may reduce any feelings of embarrassment or awkwardness for you.

#### CYSTIC FIBROSIS RELATED DIABETES

If you have cystic fibrosis-related diabetes (CFRD) you should discuss your exercise programme with your dietician and physiotherapist. They will help you to understand the effects of exercise on your diabetes and will be able to give you more specific advice.

Maintaining a healthy body weight is one of the most important steps you can take to ensure good health. People with CFRD still need to eat their usual high calorie, high protein and high fat diet to help achieve and maintain a healthy body weight.

Always carry a glucose snack when exercising in case of a drop in blood glucose levels.

If you are concerned about your blood glucose levels, you can record them pre and post exercise and discuss the results with your medical team.

#### PEGS, PICCS AND PORTS

#### PEG (Percutaneous Endoscopic Gastrostomy)

It is recommended that you avoid heavy lifting or rigorous activity for the first 2 weeks after PEG insertion to allow the wound to heal adequately. Swimming can resume once the gastrostomy tract is fully healed (2-4 weeks); consult your doctor or gastroenterology nurse.

Following this period, having a PEG should not impact on your ability to continue with your exercise program, although you may occasionally suffer side effects such as nausea, abdominal bloating or diarrhoea and may not feel up to it physically.

If any complications occur with the PEG such as infection of the wound, dislodgement, blockage/fracture or leakage of the tube, you should seek medical attention immediately. Accidental removal requires urgent action as the tract begins to close immediately and may close completely within hours.

#### PICC (Peripherally Inserted Central Catheter)

A PICC line can be used for a prolonged period of time, for antibiotic therapy. For some, lengthy hospitalisations will interrupt day to life, including your usual exercise routine. If you are discharged with a PICC line you may be able to return to exercise if you're feeling well enough.

As a general rule you should follow these guidelines:

- Do not lift heavy objects with the PICC arm.
- Do not play contact sports.

Do not swim.

 Do not do repetitive motions such as vacuuming, raking or golfing.

#### PORT (Port-a-Cath)

If you have a port you should still be able to exercise as normal. If your port is needled however, you should avoid swimming and should use lighter weights for upper body exercises. If there are signs of inflammation, swelling, tenderness, discharge or chest pain, you should seek medical advice.

#### LOW LUNG FUNCTION

If you have a lower lung function, any exercise program you engage in needs to be developed or at least approved by your primary physiotherapist and care team. It is vital that you are engaging in exercise that will not be detrimental to your health and that you are being appropriately monitored throughout the program.

### Food and Exercise

Whether you take part in recreational sport or exercise as part of a healthy lifestyle, what you eat and drink is important. We already know that most people with CF have higher energy needs than people who do not have CF. Added to this, regular exercise can increase your energy needs even further, so it is important to increase the amount you eat to avoid losing weight.

Whenever you exercise you need energy or fuel. The harder you exercise the more energy you use. It is important to replace this lost energy through appropriate nutrition.

You should speak with your hospital care team about your nutrition and also have a good understanding of your dietary needs. Eating regular meals and snacks is a good way to maintain a higher energy intake.

It is essential that you discuss your training schedule with your dietician so that a suitable diet can be planned for you to ensure that you maintain your weight, keep well hydrated and recover well after exercise.

#### **CARBOHYDRATES**

This is the most important fuel for an active individual. It is stored in the liver and muscle as glycogen and is used during exercise when energy is needed quickly. During exercise, especially high intensity exercise such as sprinting and team sports, these stores are used up rapidly. When you run out of glycogen you will start to feel tired and your performance will be affected. Therefore it is important to eat enough to replace lost carbohydrates.

Sugary foods are an important part of the CF diet and can provide additional calories to meet the needs of exercise. These should be taken in addition to your usual high energy starchy foods.

#### How much carbohydrate do I need?

This will depend on the intensity and duration of exercise. The longer you exercise the greater your energy requirements. If you are exercising more than one hour a day you may need to increase the amount of carbohydrate at mealtimes and as snacks. Generally, people are recommended to eat 250 grams of carbohydrates a day.

Starches	Fruit/fruit juices	Sugars	Snacks
<ul><li>Cereal</li></ul>	<ul><li>Bananas</li></ul>	<ul><li>Jam</li></ul>	<ul><li>Smoothie</li></ul>
<ul><li>Bread</li></ul>	<ul><li>Apples</li></ul>	<ul><li>Honey</li></ul>	Yoghurt
Rice	<ul><li>Pears</li></ul>	<ul><li>Cakes/Biscuits</li></ul>	<ul><li>Crumpets</li></ul>
<ul><li>Potato</li></ul>	<ul><li>Grapes</li></ul>	<ul><li>Muesli bars</li></ul>	
<ul><li>Pasta</li></ul>	<ul><li>Dried fruit</li></ul>	<ul><li>Muffins</li></ul>	



#### **FAT**

Fat is the richest source of energy (calories). One gram of fat contains nine calories, which is more than twice the amount found in protein or carbohydrate. Fat is converted into energy much more slowly than carbohydrate.

#### Sources of fat:

- Oils (olive, canola etc.)Fish (salmon, tuna, herring)
- Avocados
   Dairy products (butter, cream, cheese)
- Nuts (almonds, peanuts, macadamia nuts, hazelnuts, pecans, cashews)

#### **PROTEIN**

Protein rich foods are not the main source of energy for exercise. In fact most people have enough protein in their normal diet to meet the demands of exercise provided they are eating a balanced diet with sufficient energy to meet their needs.

Increased protein is helpful however in maintaining a healthy weight and if you are trying to put on muscles mass. Remember though that muscle is gained through a combination of strength training and diet. It is the exercise training, which brings about the adaptations in the muscle, not the amount of protein consumed.

#### Sources of protein:

<ul><li>Meat</li></ul>	<ul><li>Fish</li></ul>	<ul><li>Eggs</li></ul>
<ul><li>Poultry</li></ul>	<ul><li>Cheese</li></ul>	<ul><li>Pulses</li></ul>

#### **CALCIUM**

Calcium is essential for bone health. Adolescents and adults with CF may be at risk of low bone density. Although physical activity generally improves bone mass, an inadequate calcium intake can lead to an increased risk of stress fractures. It is therefore important to ensure an adequate intake of calcium.

#### Sources of calcium:

<ul><li>Milk and milk products</li></ul>	<ul><li>White bread</li></ul>
<ul><li>Tinned fish with bones</li></ul>	<ul> <li>Fortified breakfast cereals</li> </ul>

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#### **IRON**

Iron is an important trace mineral found in red blood cells and in the muscle cells. Iron deficiency can impair oxygen transport in the body and can lead to symptoms such as extreme fatigue and increased risk of infections. Iron can come from animal and vegetable sources.

#### Sources of iron:



#### REFUELLING BEFORE AND AFTER EXERCISE

It is important to remember physical activity, in any form, burns calories. Consider eating a small snack 30 to 60 minutes before exercising, especially if you haven't eaten a meal in the past 1 to 2 hours, this way the body will have some nutrients it can use for fuel. The snack or meal can be slightly higher in carbohydrates as this is the easiest form of fuel for the body to metabolize.

It is equally important to refuel after exercising to make sure that no additional weight is lost and the muscles have enough nutrients to rebuild. After exercising it is a good idea to have a mixed snack that includes some protein, fat, and carbohydrates. Your body will use the protein to repair and preserve muscle tissue, the carbohydrates to replenish its energy stores, and the fat to create a feeling of fullness and additional fuel for energy stores. Some examples of post-workout snacks would include a chocolate milk smoothie with fruit and protein powder, a cheese sandwich, yogurt and trail mix or granola, or a nutrition supplement drink (e.g. Ensure, Boost, Carnation

Instant Breakfast, etc.).
Follow with a full meal within two hours after exercising.

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### **Useful Contact Details**

If you have any questions about any information contained in this booklet please contact your health care team or Cystic Fibrosis WA.

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