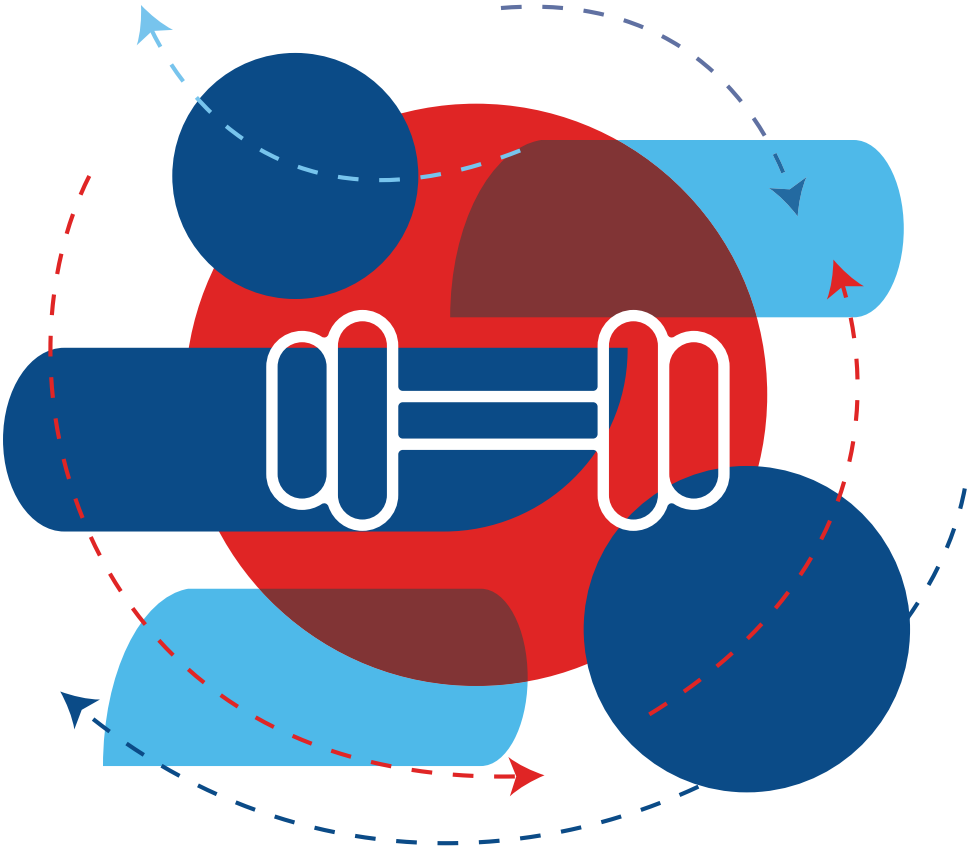
CFfit
cystic fibrosis exercise program

CYSTIC FIBROSIS

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

CYSTIC FIBROSIS

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1. Getting Started

Starting a new exercise program can be daunting and finding the motivation can be tricky. To get started, have a think about activities you enjoy, whether that be sport, gym classes, group training or other, and then work with your CF care team to develop a suitable fitness plan that you'll enjoy. They can help create an exercise program that is tailored to your level of fitness, your exercise and health goals, and the equipment you have available.

- It is important to start slowly and build up your exercise tolerance over time.
- Select a variety of activities you'll enjoy that you can do throughout the week to keep it interesting e.g. walking, gym class, sport etc.
- Exercise in a social setting so that you have more fun and can make it a catch up with friends.
- Use incidental exercise, where possible, for example, taking the stairs instead of the elevator or walking instead of driving.

WHO TO TALK TO?

As discussed, always speak with your CF care team before starting any new exercise regime. You can also contact your local state CF association to find out about any programs they may have to support your active lifestyle, such as loan exercise equipment, personal trainer programs, subsidies and home care support.

"Exercise is probably the greatest thing I feel I can do to maximise my health. It's one of the only domains in my life where I feel I can have control, which gives me a greater sense of wellbeing and accomplishment."

2. 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:

1. _____
2. _____
3. _____

These could include reasons such as:

- I want to be fit enough to travel overseas
- I want to get a job
- I want to complete a fun run
- I need to be able to clean my house

Goal Setting

Goal setting is useful and can make your reasons to exercise more specific and attainable. Goals should be SMART.

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

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

A **Achievable:** Is your goal achievable for you?

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

T **Timely:** Your goal should have a specific time line. 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.

EXAMPLE

If your reason to exercise was to **travel on a holiday:**.
Short term goal: Walk for 30 minutes 3 times a week for 4 weeks.
Reward: Researching holiday destinations.
Long term goal: To feel comfortable walking around the local shopping centre for 2 hours.
Reward: book my flights.

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

Short term goal:

I will_____(exercise)

for_____minutes_____times a week. If I do this for_____

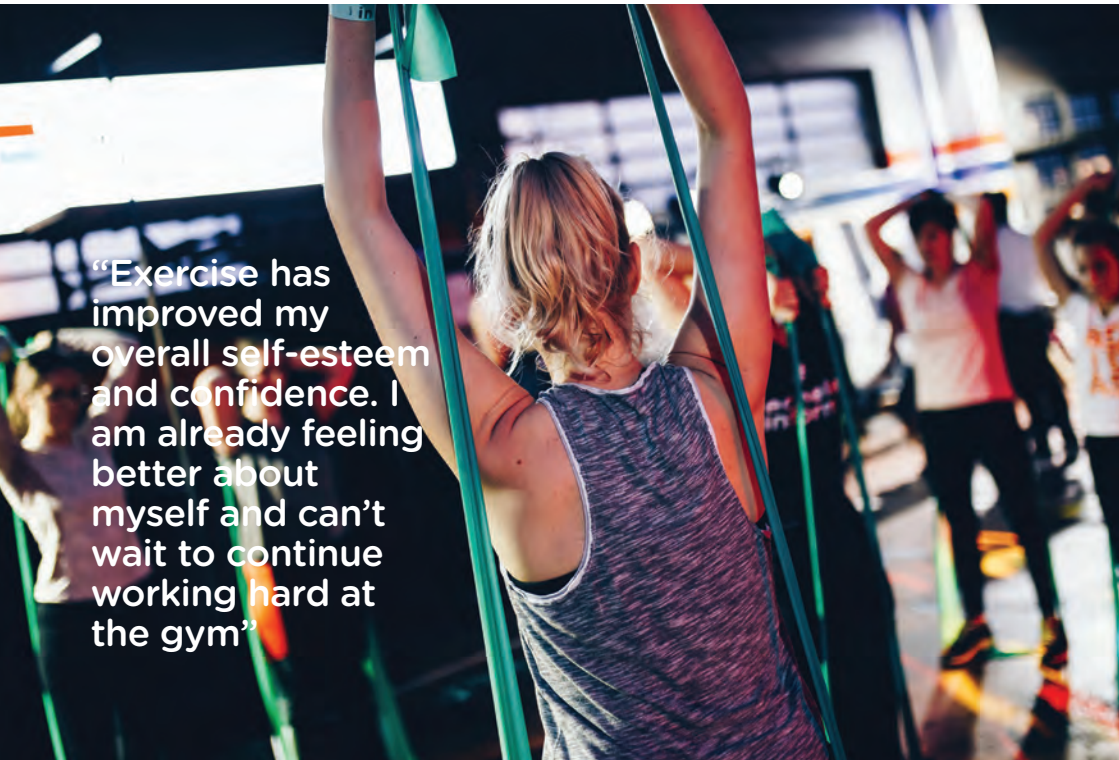
weeks I will reward myself by_____

Long term goal:

I would like to _____

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.



3. Considerations during exercise

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 harbor 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.

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.

People with CF are at greater risk of dehydration due to increased salt loss in sweat.

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

Dehydration can cause your mucus 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.

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 AVOID 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.
- 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.

EARLY SIGNS OF DEHYDRATION:

- Headaches
- Dizziness
- Poor concentration
- Feeling tired/fatigue
- Dry mouth
- Salt crystals on the skin
- Thirst
- Dark urine colour

LATE SIGNS OF DEHYDRATION:

- Loss of appetite
- Nausea/vomiting
- Muscle cramps
- Thickened mucus
- Constipation

Exacerbations

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

- Fever
- Shortness of breath
- Increased cough or mucus
- Tight sensation in the chest
- Change in the colour of mucus
- Decreased appetite
- Wheezing
- Decreased exercise tolerance

Exercise is not likely to be the cause of an exacerbation, however if you experience an increase in such symptoms you should seek medical advice. Exacerbations often require antibiotic treatment, and sometimes, hospitalisation.

Continence

Many people with CF have weakened pelvic floor muscles which can lead to incontinence of the bladder and bowel. Urinary incontinence (UI) frequently occurs with exercise. Common signs of UI include:

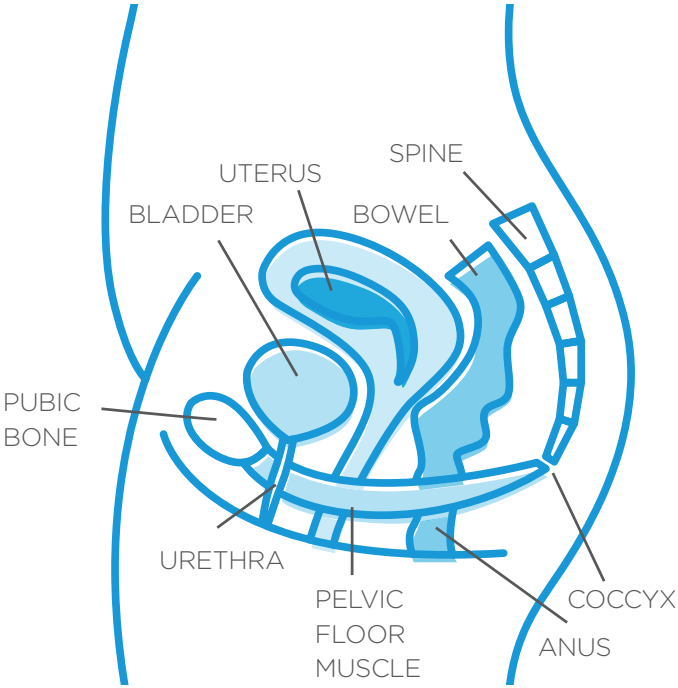
- accidentally leaking urine when you exercise, laugh, cough or sneeze
- needing to get to the toilet in a hurry or not making it there in time
- constantly needing to go to the toilet
- finding it difficult to empty your bladder
- a prolapse
- pain in your pelvic area, or
- painful sex.

Both men and women with CF are at greater risk of experiencing UI than the general population. Symptoms may be worse with high impact exercises. There are plenty of pelvic floor friendly exercises that are effective in achieving fitness goals. To protect your pelvic floor, try to avoid high impact or high intensity exercises that place downward pressure on the pelvic floor. The CFFit My Exercise Diary booklet has plenty of pelvic floor safe exercise options.

More information about pelvic floor safe exercises can be found at www.pelvicfloorfirst.org.au.

Your CF team should routinely ask if you have any problems with leakage. Many people find it embarrassing to talk about, however it is really important to discuss this as it can be improved with pelvic floor exercises, and 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 by a continence specialist to ensure you are protecting your pelvic floor while exercising.

Aerobic Exercises	Resistance/Strength Training	Core Exercises
Pelvic Floor Safe Exercises		
walking	seated resistance exercises (shoulder press, row, bicep curls, knee extensions)	plank on knees
swimming	shallow and narrow squats	arm and leg lifts on all fours
cycling	shallow lunges	
cross-trainer		
water aerobics/walking in water		
Exercises to Avoid		
running	deep lunges or side lunges	abdominal exercises such as sit ups, curl ups, crunches
jumping	wide legged or deep squats	plank position on hands and feet (eg 'hovers', full push ups)
star jumps	jump squats	medicine ball rotations
skipping	lifting or pressing heavy weights	
boxing	dead lifts	
	high bench step-up/step-down	
	exercises with both feet off the ground (e.g. chin ups)	
	full push ups	



The Pelvic Floor

Cough

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

Cystic Fibrosis Related Diabetes

Exercise is great for people with cystic fibrosis-related diabetes (CFRD) as it can help with diabetes control, however you should always discuss any exercise program with your CF and diabetes teams beforehand, as exercise can affect your Blood Glucose Level (BGL). They will help you to understand the effects of exercise on your diabetes and will be able to give you more specific advice. It is very important to let your trainer know that you have CFRD.

BEFORE EXERCISE

Always check your BGL before exercising. 5.5mmol/L to 15mmol/L is a safe range for exercise. Always carry fast-acting and slow-acting carbohydrate snacks with you when exercising, in case of a drop in your BGL.

DURING EXERCISE

If you have started a new exercise program, check your BGL after 30 minutes or earlier if you experience any signs of low BGLs (hypo).

Signs of a hypo may include:

- Feeling shaky and weak
- Hunger
- Sweating
- Lightheadedness and dizziness
- Headache
- Pins and needles around the mouth
- Mood change, confusion, irritability

If you experience these symptoms, stop exercise immediately and check your BGL. If your BGL is low (<5mmol/L), take 15g of fast acting carbohydrate, such as 6-7 jelly beans, 3 tsp of sugar or honey or 50ml of soft drink. Recheck BGL 15 minutes later and follow up with 15-20g of slow-acting carbohydrate, such as a banana or muesli bar, to prevent another hypo. Do not return to exercise until BGL has returned to a safe exercising level.

AFTER EXERCISE

Watch for signs of a delayed low BGL that can occur hours after exercising. You can reduce the risk of delayed low BGLs by doing extra BGL testing after exercise and eating extra carbohydrates.

PEGS, PICCS and PORTS

PEG (PERCUTANEOUS ENDOSCOPIC GASTROSTOMY)

Avoid heavy lifting or rigorous activity for the first 2 weeks after PEG insertion to allow the wound to heal. Swimming can resume once the gastrostomy tract is fully healed (2-4 weeks); following consultation with your doctor or gastroenterology nurse'. After 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)

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.

You should be guided by your CF care team.

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 CF care team. Exercise is very important, however 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.

4. Types of exercise and their benefits

There are three basic categories of exercise: **aerobic, resistance/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).

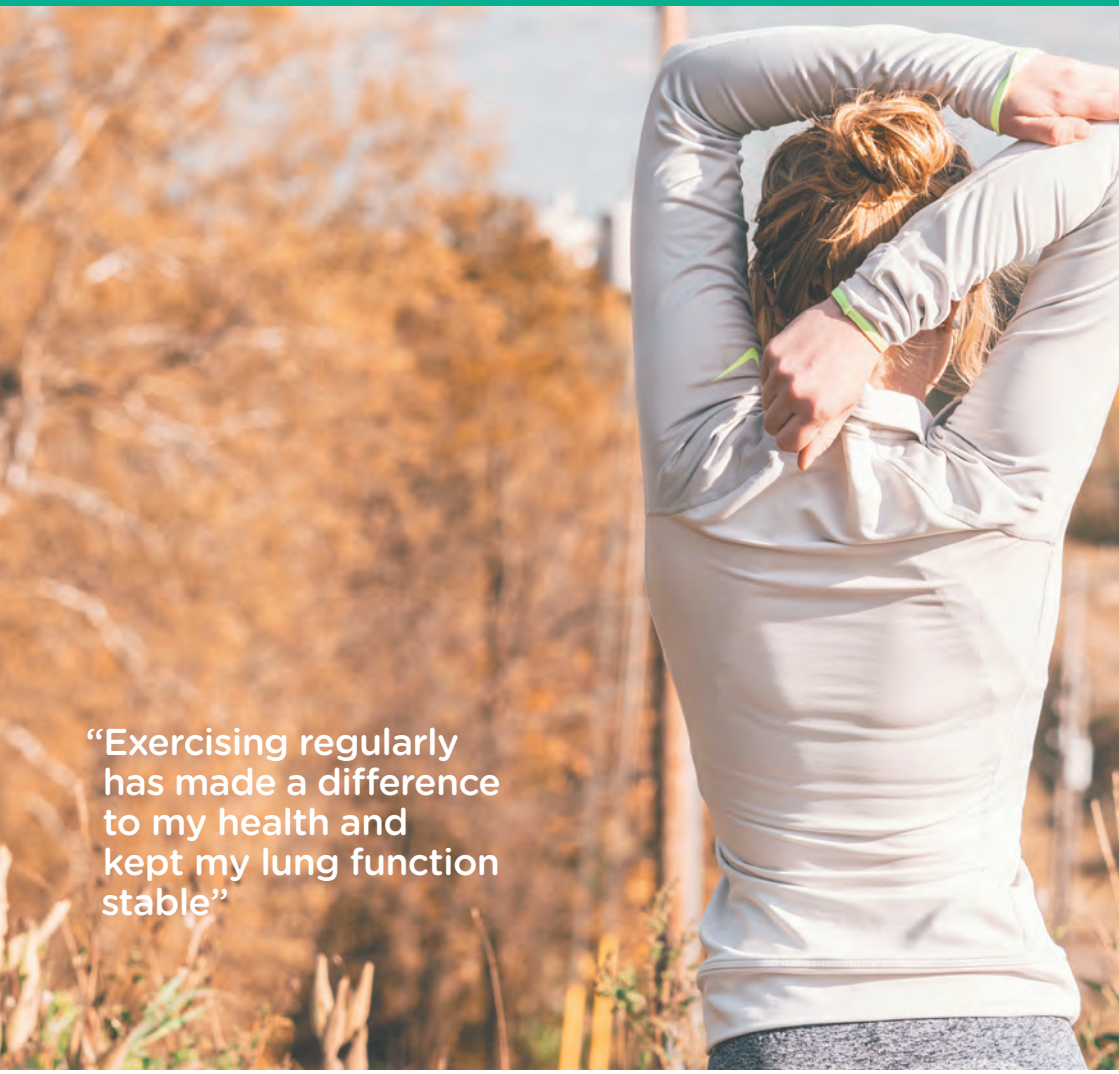
CF SPECIFIC BENEFITS:

Aerobic training helps make everyday tasks easier by improving overall fitness. In combination with airway clearance, aerobic training can help loosen mucus. 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 support airway clearance.

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 beneficial to people with lung disease.

When you have a worsening of symptoms e.g. cough, breathlessness etc (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 dietitian is the best way to avoid this. See page 19 for more information on diet.



SOME AEROBIC EXERCISE EXAMPLES ARE:

- Cross-trainer
- Rowing
- Low impact exercise classes
- Walking
- Swimming
- Dancing
- Hill or stair climbing
- Cycling
- Water aerobics/walking in water

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 (dumbbells), your own body weight, (push ups, squats) or with elastic resistance.

CF SPECIFIC BENEFITS:

Resistance 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.

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.

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.

Your dietitian may also recommend that you take a prescribed supplement drink, which will provide you with additional protein and energy to meet the demands of exercise. Ask your dietitian 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.

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:

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.

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, 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 mucus. You may cough initially if you haven't done 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.

5. Monitoring your 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)

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 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. It 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.

6. Food and Exercise

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.

It is essential that you discuss your training schedule with your dietitian 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.

Check out our CFFood resources for more information about CF and nutrition **www.cfwa.org.au**

Carbohydrates

This is the most important fuel for an active individual. During high intensity exercise, carbohydrate stores are used up rapidly. When this happens you will start to feel tired and your performance will be affected. Therefore it is important to eat enough to replace lost carbohydrates.

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 snacks. Generally, people are recommended to eat 250 grams of carbohydrates a day.

Sources of Carbohydrates

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

Fat

Fat is the easiest food group to eat to boost your calorie intake. One gram of fat contains nine calories, which is more than twice the amount found in protein or carbohydrate, however it is converted into energy much slower than carbohydrate.

Sources of fat

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

Protein

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

- Meat
- Poultry
- Fish
- Cheese
- Eggs
- Pulses
- Nuts
- Tofu
- Soya mince

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, not eating enough calcium can lead to an increased risk of stress fractures.

Sources of calcium:

- Milk and milk products
- Tinned fish with bones
- White bread
- Fortified breakfast cereals

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 metabolise.

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. Continue to rehydrate following exercise and replace salt.

Remember to always consult your CF dietitian for your specific dietary needs with exercise.

7. Useful Resources

CFFIT

Exercise and Cystic Fibrosis: My Exercise Diary
Exercise and Cystic Fibrosis: A Guide for Personal Trainers

CFFACT

A range of quick, easy to read fact sheets on various CF-related topics, including

- Airway clearance techniques
- Bone health
- Continence
- Cystic Fibrosis Related Diabetes
- Dehydration
- Germs and cross-infection
- Lung transplants
- Medications
- PEGs
- PICCs
- Ports

CFFOOD

Cystic Fibrosis Nutrition Program: A Guide for Adults
CFBites: Snacks and Meals for those with Cystic Fibrosis

CFCOOKING

A series of cooking demonstration videos for people with CF

All our resources available from our website www.cfwa.org.au

OTHER WEBSITES

Cystic Fibrosis Australia **www.cysticfibrosis.org.au**
Pelvic Floor First **www.pelvicfloorfirst.org.au**
Continence Foundation of Australia **www.continence.org.au**
PACTSTER- Online exercise for cystic fibrosis
www.pactster.com/cystic-fibrosis

8. Useful Contact Details

ACT
Cystic Fibrosis Association ACT Inc

(02) 6292 9866
info@cfact.org.au
www.cysticfibrosis.org.au

NSW
Cystic Fibrosis Community Care (NSW)

(02) 8732 5700
admin@cfnsw.org.au
www.cysticfibrosis.org.au

QUEENSLAND
Cystic Fibrosis Queensland

(07) 3359 8000
admin@cfqld.org.au
www.cysticfibrosis.org.au

SOUTH AUSTRALIA
Cystic Fibrosis SA

(08) 8221 5595
cfsa@cfsa.org.au
www.cysticfibrosis.org.au

TASMANIA
Cystic Fibrosis Tasmania

(03) 6234 6085
general@cftas.org.au
www.cysticfibrosis.org.au

VICTORIA
Cystic Fibrosis Community Care (CFV)

(03) 9686 1811
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WESTERN AUSTRALIA
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