# Sport, Exercise, Fitness and Cystic Fibrosis

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# Introduction

As somebody with cystic fibrosis who has also always enjoyed sport and exercise, I am writing this based upon my personal experience. I have, in my lifetime, enjoyed training at various levels in the sports of athletics, hockey, cricket, squash, martial arts, aerobics and fitness, skiing and cycling. I was always encouraged to participate in sports, even in the 1960's, when children with CF were protected and expected to avoid exertion. A lifetime of keeping fit has paid off, and at the age of 49, I am fitter than most of my peers, as well as having well-preserved lung function and an ability to do a lot of exercise. This is despite frequent episodes of ill health, hospitalisation, and intravenous antibiotics throughout my life.

I am a qualified doctor, a qualified Aerobics and Step instructor, a qualified Nordic Walking Instructor, and a qualified Advanced Fitness Instructor and Personal Trainer. I have also had a lot of experience of training and doing sport, while also trying to cope with a chronic medical condition that flares up from time to time. I have also had a lot of experience of injury, and subsequent recovery. I have also made many mistakes, and failed on occasions to follow almost all the recommendations and suggestions I have made in this document. One of the main reasons for writing this was so that others could learn from my experience and mistakes.

Another reason for writing this document was that I simply couldn't find the answers to my questions in books or on web sites, most of which deal with fit people, whose illnesses are short-term, self-limiting, infrequent and curable. Likewise, I couldn't get information from health professionals dealing with cystic fibrosis, who could only provide the most general information about taking small amounts of light exercise, and not training hard at higher levels of fitness.

Although this is written from the perspective of cystic fibrosis, it contains a lot of information that is of relevance to people with other conditions, or for that matter to anybody. I have also deliberately kept the language simple and non-technical.

I refer a lot to training and exercise, some of which is quite high level and strenuous. However this document applies to people with CF whether you have good or poor lung function – what matters is the level of effort you are putting in, not necessarily the level of performance you are getting out at the end. I am fully aware, due to the fact that I am ill quite a lot, of the fact that when your lungs are not so good, you can put in a lot of effort into walking down to the end of the garden and back. This document should help you to benefit from my experience whether or not you are running a marathon, or feel like you are running a marathon by walking to the shops. It is about making the most of your ability given the level of health and lung function that you are starting with. It is not just for sporty people, and it is not just for people with good lungs.

#### Discuss any exercise plans with your doctor and physiotherapist

If you have cystic fibrosis, you should always seek advice from your medical team before embarking on any programme of exercise to get fit, and keep fit. The physiotherapists, in particular, will be able to help you out with suggestions. If your lung function is poor, you may need to have an exercise test to see if your oxygen levels fall during exercise. You may need oxygen during exercise, and this requirement may change if you have been ill.

However my experience is that medical teams tend to be cautious in the advice that they give. It is sometimes easier to give you reasons why you should not do something than support your plans to do it. So, ask for and take the advice, but if you are told that something is inadvisable, ask for details of the reasons why this should be so. There may be very good reasons, but there may also be ways round it, so do ask whether any of the restrictions can be overcome.

# Section 1: Why do any exercise?

For anybody, even without a chronic medical condition, it is much easier to come up with excuses for not doing exercise than it is to start doing some. We have all done it. We don't exercise because of the weather, because of fitting it in to our daily lives, because we don't like being sweaty or breathless, because our relatives expect us to be invalids and have an easy life.

Exercise is not really about sport. It is about making the very best of what you have been given. By so doing, you will actually enjoy the ability to do more things and enjoy more things in your life.

Most people with CF eventually suffer some degree of lung damage – the amount varies from person to person, and the age at which a certain level of lung damage arises varies also. If your lungs are damaged, this will affect the amount of oxygen you can take in and supply to your muscles to do work. It doesn't just affect your ability to play sport, it affects your ability to do everything – to sit and read, to walk about, to dance when you go clubbing, to do your gardening, to walk about in the office, to climb the stairs.

If any person trains, it is possible to increase the amount of oxygen that can be transferred from your lungs to your muscles, regardless of the underlying lung capacity. Certain types of exercise will also increase the strength of your muscles (or specific muscles). So it follows that any kind of exercise or training will increase your ability to do work, or have fun.

Doing exercise, then, can make the difference between you being unable to do things, and being able to do things. It can make the difference between you being able to keep up with your friends, or not being able to keep up. It can make the difference between being able to carry on at work, and not being able to carry on at work. It can make the difference between you being able to do the things you like doing, and not being able to do them.

For me that is the most important thing – that at the age of 48, I can still enjoy most of the things that my contemporaries enjoy (indeed, I am actually fitter than many, and able to do MORE than many of them who were born with far fewer health problems than me).

Of course there are other benefits of exercise, particularly for people with CF:

- Exercise keeps your heart and arteries healthy and improves the balance of fats in your circulation, protecting you against heart disease, high blood pressure, stroke and some forms of cancer.
- Exercise probably protects you against getting infections unless you over-exercise.
- Exercise of the type that makes you breathless certainly helps in clearing secretions from your lungs.
- Exercise, particularly weight-bearing exercise, protects your bones from the weakness caused by osteoporosis.
- Exercise increases the proportion of your body that is composed of muscle and decreases the proportion composed of fat – fat is necessary, but too much is a burden.
- Exercise keeps your weight down not frequently a problem for people with CF. However by building up muscles, it can also help to keep your weight up, if you tend to be underweight.
- Exercise keeps you toned, and helps to improve your figure and looks.
- Exercise helps you overcome psychological stress.

• Exercise can improve your posture and so reduce pain and lung function restriction due to poor posture.

Quite a lot of studies have been carried out into the benefits of exercise in CF. Almost all of them have shown benefit. These are the main points:

- People with CF who have only mild problems with their lung function (FEV1 over 60% predicted) can exercise to the same intensity as people without respiratory disease.
- Exercise in people with CF, even over a wide range of lung function, will increase endurance, the ability of the respiratory muscles to cope with exercise (respiratory muscle endurance), strength and help you to clear your lungs of phlegm.
- Exercise in people with CF can preserve lung function.
- Weight training can also help you to build muscle and put on weight

As far as I am concerned, taking regular exercise and improving your fitness is a nobrainer.



Hiking in the Lake District

# Section 2: What is fitness?

There are a lot of published definitions of fitness. Most of them include concepts of:

- Ability to carry out daily activities
- To carry out activities with efficiency
- To do so without fatigue or by demonstration of endurance
- To have some capacity in reserve
- To make physiological adjustments appropriate to a physical task

Fitness has several elements, the number of which vary with different authors, but the most important of which include:

## Cardiovascular fitness

The ability of the heart and lungs to deliver oxygen to the muscles, and the muscles to use this oxygen as efficiently as possible in undertaking their task. It depends on several things including intake of oxygen to the lungs, transfer to the blood, transfer in the bloodstream to the muscles, and use of the oxygen by the muscles. It underpins and enhances most of the other elements of fitness, since without a degree of cardiovascular (or CV) fitness, the other elements tend to be compromised. Like all elements of fitness, this can be trained – that is progressively developed by use, until eventually something provides a limit. In the case of CF this limit is usually provided by the lungs.

This type of fitness is by definition, aerobic, that is, it relies on the continuous intake of oxygen that matches its use in the exercise or activity. It also relies on a supply of fuel in the form of carbohydrate (sugars, starch, or glycogen stored in muscle) and fat that is stored in muscle and in other parts of the body. A person who has good CV fitness will be able to turn oxygen and fuel into muscular work with great efficiency at any given level of exercise up to the point at which oxygen cannot be supplied to meet demand (the anaerobic threshold).

## Endurance

Endurance, put simply, is the ability to "keep going". That is to continue to exercise at any particular level for a long time without developing fatigue. This can be general cardiovascular endurance such as is required for long-distance walking or running, or specific endurance such as is required for repetitive use of certain muscles in certain exercises. So, for example, in rowing, the endurance will be in certain muscles, but for cycling, will be concentrated in other muscles.

In general, the time you can spend exercising *at a particular level* goes down as the intensity of exercise goes up, but by training at different levels you can increase your endurance at each level, such that you can keep going for longer. This applies even to walking – most people with CF can walk for 10 minutes, but can you keep walking for an hour? Or 2 hours? Or 9 hours? The intensity of the exercise is the same (low-intensity), but walking for longer requires greater endurance.

## Strength

This is really about the ability of your muscles to produce maximum contraction which may be static (against a non-moving resistance) or dynamic (lifting a weight). Useful strength is usually a combination of absolute maximum power you can produce, and also your ability to produce high levels of power in a repeated way (i.e. endurance at a particular level of strength).

Strength needs to be developed specifically, and usually involves developing strength in specific muscles or muscle groups, but doesn't have to involve lifting weights in the gym (although this is a common way of developing it).

So, you might want to train your legs, your arms, your back, your abdominal muscles, or even your respiratory muscles. You would normally do this by a combination of gradually increasing load, and gradually increasing endurance by increasing the length of time you use the muscles each time you apply the load.

Strength is normally developed in a slightly different way to CV fitness. You need to overload the muscle – putting a load onto it such that it consumes oxygen faster than it can be supplied to that particular muscle. When you release the load, this oxygen has to be paid back from that in circulation. So, it tends to come from exercise that makes your muscle ache almost immediately, or after a few contractions. This exercise still makes you breathe hard because you have to pay back the oxygen you have just used.

## Flexibility

Flexibility is the ability to move a joint through its full range of movement. Most people have lack of full flexibility i.e. cannot move their joints through the full range of potential movement. This is for a variety of reasons, most commonly because the muscles that control the movement around that joint are not stretched to their full extent, and become tight, limiting the movement around the joint.

Flexibility is essential for some sports, such as gymnastics and martial arts, but is also important for other sports, particularly in the prevention of injury. It is also useful in many daily activities, such as bending down to weed the garden, so something that should not be neglected.

Flexibility is usually developed by stretching of your muscles undertaken when the muscles are warm – usually after a warm-up and particularly after exercise.

## Other

You may see on some other sports web sites or in books that there are other elements of fitness included, such as speed and sports-specific technique. These are elements of fitness, but they are more relevant to specific sports, rather than to general fitness. You may wish to bring them into your training if you take up specific sports, but the basics of cardiovascular fitness, endurance, strength and flexibility form a great basis for general fitness, and on which to build speed and sports-specific technique.

# Section 3: Levels of exercise

It is obvious that some types of exercise or exertion are harder than others. For example, something like walking round the shops is relatively easy, and doesn't usually make you breathe hard or sweat. But make it either faster (walking faster or jogging round the shops) or harder in some other way (carrying heavy shopping bags) and you notice the difference – your breathing is heavier, your heart is beating faster and you may get sweaty if you try and sustain this level of exercise for a period of time.

So it follows that there must be different levels of exercise. But the point is that *any* exercise, even at the lowest level, will provide some benefit, and you do not have to make yourself hurt to improve your fitness.

When reading this section, it is important to remember that most fitness benefit is gained by taking exercise at lower levels. Indeed, if you are not accustomed to exercise, then you should aim to stick to the lower two levels for several weeks, and then gradually introduce a little exercise at level three. You should then wait several weeks before bringing in level four exercise. Higher levels of exercise are not essential, but if you want to do them, you need to introduce them gradually on a basis of good fitness at the lower levels.

There is good evidence to show that people who exercise very hard but infrequently are doing harm to their muscles and even their heart. So it is much better to do something frequent at a low level than something infrequent at a high level. It is also much better to build up gradually than try and do strenuous exercise straight away.

There are lots of different classifications of exercise levels available, many based upon how fast your heart is beating compared with its maximum rate. However you don't have to measure your heart rate to know roughly what level you are exercising. The examples I give here relate to somebody with relatively normal lung function (for example with an FEV1 over 60% predicted) – people with lower levels can follow generally the same principles, but may find that less intense exercise produces a similar effect in terms of heart rate and breathing. It doesn't matter what you do to produce the effect, just that you are producing it.

## Level 1 or Fitness level

Any gentle exercise will be level 1 – like my example of walking round the shops. If you measure your heart rate it will be increased above the rate when you are sitting or lying, and your breathing rate and depth will be very slightly increased. However at this level you shouldn't notice any breathlessness, and you should be able to carry out a normal conversation with other people. A lot of people wouldn't think of Level 1 exercise as exercise at all – just normal daily activity. It is the sort of exercise you can sustain for several hours.

## Level 2 or Fat-burning level

This is a higher level of exercise and you will notice changes in your breathing rate, heart rate and you will feel warmer because of the effort your muscles are putting in. However you should still be able to speak to other people in full sentences. The sort of exercise to achieve this, if your lung function is reasonably normal, would be faster walking, walking up hill, gentle swimming, gentle jogging, cycling at a moderate speed on the flat, the lower-intensity of an aerobics class, or gentle downhill skiing on a relatively easy slope. This is the sort of exercise you can sustain for quite a long time.

# Level 3 or Aerobic level

Again, another level up and you are noticeably out of breath with your lungs working much harder. You are getting warm and sweaty, and you cannot talk in full sentences, although you should still be able to say a few words to somebody you are exercising with. The point is that this is still aerobic – your muscles aren't working so hard that your lungs and heart can't keep up with the demand, but they are demanding a lot, so your heart and lungs are now working quite hard. The sort of exercise you might do to get to this sort of level would be the peak part of an aerobics workout, the higher levels on a rowing machine or cycling machine, cycling up a long hill, running faster, walking up a steep mountain or fell, heavy digging in the garden, or skiing over bumps or moguls. You can keep this going for a shorter period of time before you start to tire – maybe minutes rather than hours.

## Level 4 or Anaerobic threshold

You are really pushing towards your maximum here – you are reaching the point at which your heart and lungs can't keep up with the demands your muscles are placing upon them. Your legs or arms may start to ache because lactic acid starts to build up, and you are no longer able to speak, even one or two words. You can sustain this effort only for a few seconds or minutes at the most. The sort of exercise that typifies this level would be accelerating on the last lap of a middle-distance race, accelerating while cycling up hill, the last half minute of a bout of martial arts or boxing, or the maximum element of an aerobics class in the gym. You can't keep this going for very long – only a few minutes would be usual.

## Level 5 or Maximum level

This is your maximum effort. This exercise is completely anaerobic and sustainable for a few seconds only. It is at the extreme end of the scale and would represent, for example, the final sprint for the line in a cycling or running race, the last 5 metres of a swimming race, the last few repetitions of your weights training, your absolute maximum effort. There is pain in the muscles due to build-up of lactate.

The key points to remember with this scale are:

- Most of the benefits of exercise come from exercising at the lower levels 1 and
  This is in reality the level where most daily activities come. So exercise to get you fit doesn't mean you have to ache, get sweaty or suffer pain and discomfort. Even very fit athletes spend most of their time training at these lower levels, because that is where most of your fitness will be developed.
- 2. In order to improve at each level you have to exercise at that level so you will increase the amount you can do at level 2 (cardiovascular fitness, strength and endurance) by exercising at that level. Habitually exercising at level 2 will mean you can walk faster, or further, or for longer while keeping your heart rate and breathing at this level. It will produce tangible benefits and changes in your ability to do things and enjoy life.
- 3. So you don't *have* to exercise at the higher levels to improve your fitness, particularly if you don't actually need to or want to use these levels. On the other hand, if you want to be able to keep up with fit people with normal lungs, then some effort at the higher levels is definitely worthwhile, because you will be able to sustain your effort at that level a little bit more, and achieve a better performance at the same level.
- You may find it is helpful, particularly at first, to use a heart rate monitor so you become aware of the level of effort associated with each level of exercise. However these can be expensive and you don't have to do this, provided you are

aware of the general characteristics of each level of exercise in terms of your ability to sustain it, and your ability to speak while exercising at that level.

If you are interested in buying a heart rate monitor and using this to guide your exercise intensity, then I have included an appendix that describes levels of exercise in terms of heart rate, and gives some brief tips on how to use a heart rate monitor.

# Section 4: Excuses and mental barriers

It is much easier to come up with excuses for not doing exercise than to actually get out there and do some. Or at least that is how it seems to me. If people were only as creative in working out how they can take exercise as they are thinking of reasons why they cannot, then many more people would be much fitter.

## How will I compare to others?

"I won't be able to keep up!"

I think this is the main reason, in particular for people with CF, why they are reluctant to try out any exercise. If your lungs don't work as well as other folks' lungs, then you may genuinely worry either that you will hold them up, or that they will think you aren't trying. I know I've had both those concerns, and still do. This is matched by a tendency to try and do too much so that you are keeping up with the rest of the group. It is obviously more of a problem if you are in a club or class, but can be a problem if you are exercising alone – for example, what will other cyclists or runners think if they pass you when you are out riding or jogging?

What you have to tell yourself is that you are doing the exercise for YOU, not for them. In general I have found that by explaining that you have a health problem, people are not only supportive, but amazed that you are trying at all. If your lung function is normal, then you have less to worry about anyway, as there is no real reason for you to be unable to keep up with the rest of a class or club in a game once you become fit.

You just have to stop worrying what other people think of you. Does it really matter anyway? Whose life is it? What right do they have to stop you making the most of your life, and giving yourself the best chance of fitness and health?

You also have to develop a thick skin. I was passed by a cyclist going up a hill on one occasion when I was feeling rather ill. He was encouraging me to keep up, but I couldn't. The next day I was admitted to hospital with pneumonia. People don't always have the full story when they are making comments. The important thing is not to use your concerns about their perceptions of you as a reason not to do any exercise.

Everybody who is starting to exercise for the first time (or for that matter recovering from injury and illness, of which more later) has to start from a low level and build up. Nobody in their right mind, even if they are very fit, would condemn or laugh at somebody who is starting out and exercising at a low level, because most of them have been there.

## Embarrassment about body shape/image

"People will laugh at me!"

This can be a real issue, particularly if you have CF, and particularly if you are very thin. Slim is good, but thin isn't, and you may worry that you will look out of place in a class full of fit muscular young men and women, or look very weedy down at the gym.

You may also have things like gastrostomies, or vascular ports, or even venflons if you are on IV antibiotics, to explain to other people, and you may not like doing this.

But should this really stop you exercising? You don't HAVE to go to a class. You could start out doing exercise on your own, although motivating yourself may be harder than in a class. Then when you feel a bit more confident in your ability, try going to a class or a club.

You also don't have to wear lycra, and there are plenty of creative ways to cover up bits you don't want seen in public, be it thin legs (wear <sup>3</sup>/<sub>4</sub> Capri pants if you are a girl, baggy track bottoms for the lads), or a port.

The main thing to remember is that almost everybody, whether or not they have CF, has some insecurity about the way they look. Even the very pumped guy lifting prodigious weights in the corner of the gym, or the very fit looking aerobics instructor will have some insecurities. In fact they are probably so worried about they way they look they haven't got time to worry about you.

## Expense

#### "I can't afford to join a gym!"

I have been in the fortunate position of having a well-paid job, but have also been in the unfortunate position of having a high level of debt and having to trim my expenditure. There is a general feeling that to do exercise you must join a gym and this is expensive. Then you must have a lot of expensive kit. If you have a low income then it can seem daunting to find the money to do this.

But there are cheap alternatives. It costs nothing other than a bit of boot-leather to walk. You don't *have* to walk in the Lake District or Scotland, although this is very nice. You can walk to the next bus stop, or the station or the park. You can take the dog for a walk, and both of you will benefit. Running is also pretty cheap – most people own running clothes and shoes as fashion items anyway, so you just have to get out there and do it. Very good functional running shoes, albeit not with trendy designer labels, are available quite cheaply.

Most people also have a bicycle in the shed. It may not be a fantastic expensive bicycle, and it may be old, but they are easy and relatively cheap pieces of kit to make functional – you can often pull bicycles out of a rubbish skip that require minimal expenditure to fix, or from which you can get parts to make yours work again. Some Local Authorities have schemes whereby you can get your bicycle serviced cheaply, or for nothing, in order to encourage people to cycle – find out if you have one locally and get your bicycle fit for action. Inline skates or skateboards are also great fun, and inline skating is a great exercise to do between ski seasons if you like skiing. Inline skates are not expensive, and you can do it almost anywhere.

Local authority exercise facilities may not be as glamorous as the upmarket commercial fitness centres, but they have machines, swimming pools, exercise classes and so forth that you can attend very cheaply, and may make concessions if you are unwaged. Local authorities also often offer evening classes for aerobics, aqua-aerobics, Tai-Chi, Yoga and so on that are much less expensive than committing to a gym membership. If you are a student you will get concessions, and most universities and colleges have excellent exercise facilities – make the most of them. Some of them allow the public to join too, and this may be cheaper than a brand-name gym chain.

There are benefits of being a gym member, not the least being the motivation you get from seeing people there and taking part in classes, but there are other things you can do that don't cost a lot of money, so lack of money is not an excuse.

## Time

"I just don't have the time!"

Having CF and coping with a normal life, including a full-time job, is tricky, because in addition to everything else, you also have to do your treatment, and this takes up even more time.

How do you make time to take exercise, given that your time is already limited?

I think the first thing is to re-set your priorities. Your life is not just about your job or career, or the demands of your family. It is also about keeping yourself as fit as possible so you can have as much fun as possible, and stay healthy. The problem is that this gets pushed to the side – but particularly for somebody with CF it needs to be right in the middle of things. If you don't stay fit and healthy then other things fall by the wayside too. And you need to see keeping fit as part of your treatment.

The next thing to do is remember the levels of exercise – you don't have to be hot and sweaty and hurt to get benefit, all you need to do is make sure you do something regularly and in a structured way.

It is also surprising how little time is required to accomplish a great deal. If, for example, you were to walk 2 miles to work instead of take the car, it would only take you 35 to 40 minutes. How long does it take you to drive? Including the time taken to get the car out of the garage, find a parking space at the other end, and walk from that to your office? My train station is about 2.5 miles away, and I can walk there in 40 minutes (fast walk). I can drive there in about 10 minutes, but add on the time to get out the car and find a parking space and pay for parking, and this goes up to 20 minutes. So I get a whole lot of benefit for only 20 minutes' extra time AND save the 3 quid parking fee.

I have to take a slightly longer route to cycle to my train station – about 3.5 miles – and it takes me 15 minutes – it is quicker to go by bicycle than drive. That is the truth. Most short town journeys to work can be accomplished as quickly or quicker by walking or cycling. When walking or cycling to the station, I carry stuff in a rucksack, so having to carry a bag isn't an excuse. Nor is having to wear smart clothes an excuse – you can keep your smart shoes at work, and change from walking shoes once you get there. And you don't have to start out walking the whole distance – you could walk part of the way and get the bus for the rest of the way, or organise a lift part of the way, or even get a taxi part of the way and walk the rest.

And if the journey is a long one, for example from a small town to a city, then what is wrong with walking from the station once you get there, or getting off one or two stops before yours and walking on to work?

I have always taken the opportunity to walk whenever I can – I used to walk several miles to the station when I lived in London, and then from the tube station to work at the other end, as well as walking many miles during the course of my work. I walked up to 50 miles a week. This is low level exercise (levels 1 and 2) but builds up endurance superbly.

As well as fitting in exercise to your general daily life, it is also important to have some kind of routine for fitting in other types of exercise or sport – such as regular classes, so that you get into the habit of doing something specific on a particular day. Otherwise it is very easy to tell yourself you don't feel like it today, and thus leave out your walk, run, jog, cycle or whatever. You don't *have* to do it this way, but the discipline can help. So, for example, we have got into the habit of either going for a cycle ride on a Saturday morning (often having lunch at a pub and then riding back), or in the Winter, when the weather is bad, going to the gym and doing a double class of weights and aerobics.

People know we are doing stuff on Saturday morning, and we know we are doing it too. Either way, our families know that Saturday morning is exercise time.

You do also need to get others in your life to acknowledge how important exercise is to you, but this should be quite easy. If they want to enjoy doing activities with you, then they must realise that you need to put in extra effort to be fit enough to *do* these activities. So they will benefit from you doing exercise too.

The examples I have given apply to people with moderate or good lung function, but the same *principles* apply to people without such good lung function – you may not be able to walk as far or as fast, but doing *something* will be of benefit. And remember, if you persist your speed and endurance will improve, so you will gradually be able to walk further and faster for the same level of effort. That is what training is all about.

To actually train at a sport can take a lot of time, but you don't have to go to this next level if you don't want to, only if you enjoy it and are prepared to commit time and effort to it. Again, it is about making space, organising your life priorities, and having a disciplined programme and a regular schedule.

## Weather

"The weather is bad, so I can't get out!"

There is a saying that there is no bad weather, only inadequate clothing. I agree with this up to a point, but there is no doubt that the weather can be foul and unpredictable in this country and sensible shoes and clothing don't always look fashionable.

First of all, it is about priorities – if keeping fit is a priority, then you will adjust your exercise to fit around the weather, rather then using weather as an excuse not to take any exercise.

It can be hard to find indoor alternatives when it is very bad outside – thunderstorms, high winds, sleet, snow and ice - particularly if you can't afford a gym membership. Even in bad weather you can still go out walking or running or cycling, but then have to adapt your clothing. I once walked *seven miles* through snow over 30cm deep to get to work, because that is what we were expected to do, and I knew that staff were having problems getting in because of the weather. I put on snow boots, ski anorak, hat, gloves and scarf and off I went.

Anoraks are not glamorous, but they keep you dry. You have to ask yourself if it is more important to look glamorous or fashionable than be fit and able to enjoy yourself on the days when such clothing is not required. I know which option I'd choose.

It can be very difficult, particularly if your breathing is sensitive to the cold, or you have to fight against the wind, but you should be able to get out and do something. You don't have to exercise every day, just most days a week, so if you know the weather is going to be bad, treat this as your rest day.

There are also alternatives that you can do indoors. So, if you like running but the ground is too slippery or hard, you could think about getting a treadmill (second-hand treadmills can be quite cheap to buy). Likewise, if your sport is cycling, try getting a turbo-trainer and ride your bike indoors. There may be inexpensive classes at the gym, and if you are really stuck, there are videos and DVDs that allow you to bring an instructor into your own home. It is less fun than getting out, but there are in reality very few days a year when this is absolutely necessary.

## Medication and other practical issues

"I'd like to go but I have to do my physiotherapy and medication."

Fitting your medication in to the day is difficult, and it can be worse if your exercise classes or planned activities clash with your need to take medication, particularly if you need a nebuliser or lots of pills. In reality, most of us don't exercise for that long, and it should be possible to re-jig your medication to fit round your classes. So, for example, even if it isn't ideal to do your nebuliser after an exercise class in the morning, you might have to. We can't always do things in the perfect order and you have to ask yourself whether that should be used as an excuse for not doing it at all. If this applies to you, can you keep a mini-compressor at work? A lot of mini-compressors are very small, some are battery powered, and you can carry them even on hiking holidays if you need to. They are a lot better than the foot-pump powered compressors of old, and have become so light you can put them in your handbag.

Carrying pills and even injections is a nuisance, but you can get a lot of pancreatic enzyme pills into a small cycle saddle bag or runners' accessory belt (that usually has a pouch for money, mobile phone, a drink, a sports nutrition bar as well as room for quite a lot of Creon).

Not wanting to explain your need for medication isn't confined to the people you exercise with. So you might want to tell one or two people that you trust to start with, and as you get more familiar with your companions, you can then explain to more of them.

#### *"It makes me cough".*

Coughing is usually good unless it is excessive or exhausting. If you cough then it is clearing your chest. The problem, then, is not that it makes you cough, but how you explain this to other people, particularly if they laugh at you. I've had plenty of comments from passers-by along the lines of "I thought cycling was meant to make you fit" when seized by the need to cough out on the road. Likewise, I have been exhorted to give up smoking, or to see a doctor. If only they knew!

Again, it is about priorities. You are exercising for YOUR benefit, not theirs. You don't have to explain it to them. It is usually a good idea to explain the problem to a fitness instructor when you are in a class, because they will then understand that it is a known problem, under control, you are exercising with the blessing of the medical team, and that they don't have to take any special action.

One thing you are likely to find is that as you do more exercise it makes you cough less, because your lungs get clearer and less irritated by the increased level of breathing brought about by exercise. You may need to find somewhere to hide a tissue if you produce a lot of phlegm during exercise, but you may also find that if you don't produce a huge amount, you'll be able to swallow it during your exercise period. Again, it is about finding a practical solution rather than using coughing as an excuse.

## Tiredness

#### "I'm too tired!"

It is so very easy to use this as an excuse, even if you don't have CF, and I have done so many times. Having CF and having to fight infection all day every day takes its toll and tends to make you more tired than other people.

The problem is that tiredness can be exacerbated by lack of exercise, and made better by taking exercise, so long as you don't overdo it.

A lot of tiredness is mental as well as physical, and exercise is extremely effective at helping you overcome stress and mental tiredness. If it makes you physically tired, then those mental stresses are less likely to worry you and keep you from sleeping.

Exercise regularly, and the buzz you get from exercise will last a day or two, giving you a boost in energy, rather than draining your energy further.

Taking exercise CAN make you tired too, particularly if you do too much. So, you may also have to find time to rest, or to add in something relaxing to your exercise like yoga or Tai-Chi. You need to find the right balance between exercise and rest, as both extremes are not good for you.

The principle is that if you do something regularly, you will gradually improve the amount you can do, and length of time over which you can do it, for the same amount of effort. So taking exercise will actually help you overcome tiredness, because you will be able to do more without getting so fatigued. It is just taking that step into the unknown, when perhaps you don't feel fantastic to start with, that is difficult.

One way to overcome this is to try and take exercise when you aren't tired – say in the morning, but not in the evening. So you could walk TO the Station but get the bus back in the evening when you are tired. Or if you are a night owl, then do something in the evenings after you get back from work.

Ultimately it is about seeing the long-term benefit – you may feel tired today, but if you don't exercise, you'll feel worse tomorrow, and gradually your ability to do things without getting tired and fatigued will decrease.

## I don't like getting hot and sweaty

Remember the Levels of Exercise – you don't have to work so hard that you get hot and sweaty to benefit, although if you spend some time exercising at these levels, then you will improve the amount you can do at these levels too.

And what is wrong with getting hot and sweaty, exactly? To my mind this means that you are working hard, and usually breathing quite hard, and this is good. Is it just the inconvenience of having to change clothes and have a shower? If so, can you do your exercise when you first get up, then take a shower afterwards? I sometimes go out for a run immediately after I get up – then have a shower. That way you can spend the day with smart hair and make-up, having already exercised and taken your shower.

Even at other times of day, why should taking a shower be a problem? It only takes a few minutes. Is the problem really with having to do your hair and make-up afterwards? If so, can you compromise on this in any way? Do you really have to spend an hour applying war-paint and torturing your hair with heated stylers? Can you not adopt a more practical approach? Are your friends really so shallow that they wouldn't like you any more if you adopted a more practical hair style and spent a little less time on your make-up? If so, do you really want people like this as friends anyway?

And there are forms of exercise you can take that allow you to work hard but not get hot and sweaty – swimming, for example, doesn't make you hot and sweaty at all.

Provided you take adequate salt and electrolyte replacement (very important with CF), there is no reason to fear getting hot and sweaty. If you are exercising in a class, everybody else there will be hot and sweaty too – learn to enjoy the feeling! It is not an excuse.

## It makes me ache

There is a great deal written about gradually building up your levels of exercise, and not doing too much, and stretching to prevent muscle soreness. But the fact is that if you start using muscles that are not used to exercise, even if you build up slowly, you will probably experience some ache.

The key is to take action to *minimise* the amount of ache you get, and to *persist* with exercise, rather than use aching as an excuse not to do any more.

You probably can't aim to completely prevent any aching, of which there are two types – the immediate aching you get after doing unfamiliar exercise, and that terrible ache that comes on the next day and makes you think you can't get out of bed.

What you can do is follow good practice for any exercise that you take.

- 1. **Warm up**. This could be a specific warm-up routine, or something much simpler, like starting your walk or cycle to the station slowly and gradually building up pace. Loading your muscles before they are warm means that blood will not be flowing to them. Lack of blood flow means lack of oxygen means build-up of lactate means PAIN.
- 2. **Be incremental**. This means you shouldn't expect to do a great deal first off. If your goal is, say, doing a 3 mile bicycle ride to work, then for goodness sake practice doing some shorter ones first. And don't ride like the Tour de France on your first day. Accept that people will come past you. Don't worry, they have probably been doing it for years. Build up your distance and speed until you are able to cope.
- 3. **Stretch**. Stretch all the muscles you have used after exercise, preferably while still warm. People may look at you, but so what?
- 4. **If you are stiff, do some** *more* **gentle exercise**. This sounds mad, but absolutely the worst thing you can do if you have overdone it and have some stiff muscles is rest (unless you have a specific injury that requires rest). It will make the pain last for longer and make you want to give up even more. If your legs are stiff the next day, or two days after doing something, then take some *gentle* exercise. It need not be going so far, or so fast, or doing exactly the same thing, but do something to exercise the muscles. This will improve the blood flow to the muscles, clear the lactate, and get them habituated to taking regular exercise. You don't have to exercise every day, but you should do *something* if you are stiff.

You will be amazed at how quickly you can do the same thing without getting any aching, and then even more. You do have to go through a certain amount of discomfort, but provided you warm up, are incremental and stretch, this can be minimised.

## I wasn't good at sport at school

Exercise isn't just about sport, and the types of sports you do at school may not have been suitable for you – either because they were too strenuous, required too much strength, or required skill and co-ordination that you weren't born with. Many school sports rely on you being big and strong – such as rugby, for instance. This puts many people with CF at a disadvantage. You may actually be quite good at sport, but not have had the opportunity to find the sport you are good at!

Almost anybody can walk, and that is a start. You don't have to be "sporty" or talented at a particular sport to do exercise.

Think about the types of exercise you do or would enjoy doing. There are plenty of things you can do that don't come under the category of sport – do you like clubbing, for example? Or skateboarding? Or inline skating? Or BMX biking. Or digging the garden? These are all exercise.

Not being good at sport at school doesn't mean you can't take exercise.

## I'll only get ill and then have to start again

This is very demoralising, and one of the easiest excuses to understand. I know. I have been through this very many times, and it is truly heartbreaking to find your hard-won fitness ebbing away while you lie in hospital. It is very frustrating to know that at some point, illness will intervene and your hard-earned fitness will suffer during an exacerbation of your CF.

However there are a few things that can counter this excuse.

First of all, *if you take exercise you are less likely to get ill*, and the illness is less likely to affect you so badly. This is because you are fit, and because your lungs are used to supplying oxygen to your body under some degree of stress. You should therefore be able to tolerate illness better and recover quicker. Surely something you would want to be able to do?

Also, illness is generally short-term – you may have to take a week or two away from doing exercise, but the base level of fitness you have built up, particularly endurance for lower levels of exercise, will not be affected. Certainly if you do competitive sport, then illness will take the edge off your performance, but in my experience this can actually be regained much quicker than if you are trying to develop it for the first time.

You don't have to completely stop taking any exercise if you are ill. It is unwise to exercise when you have a temperature, but as soon as the IV antibiotics are working, or your viral illness has settled, you can start doing something gentle that you can cope with – it may not be what you are used to, but it will stop your fitness sliding downwards and allow you to build up gradually once you have finished your treatment. I have ridden long distances on my bicycle (over 30 miles) with IV lines in my arm.

There is a section on recovering after illness or injury later in this document. Don't let the thought that you will become ill put you off taking exercise – it is beneficial, and will help you recover from illness.

# Section 5: What sort of exercise?

Most sports books and web sites will tell you there are two types of exercise, but I actually think that there are three types of exercise.

# Types of exercise

**Aerobic** exercise is the type of exercise that trains your cardiovascular system. With this type of exercise your muscles are working sufficiently gently that the heart can supply oxygen at a faster rate than the muscles are using it up. It can still be hard work, the crucial thing is that the heart and lungs can keep the muscles supplied with the oxygen that they need.

Lots of different activities are aerobic – things like walking, cycling, longer distance running (not sprinting), most team sports such as football, netball, hockey and so on. Also gym activities such as aerobics, swimming, using an exercise bike or rowing machine, and fun activities such as skateboarding, BMXing, dancing, inline skating and many, many others. You may breathe heavily, but your lungs are keeping up with your muscles, so you can sustain the activities for quite a long period of time.

A lot of aerobic activities include periods or intervals where you are working harder and temporarily the oxygen needs of the muscles cannot be met. These are called anaerobic intervals. This type of activity can only be sustained for a few seconds before the muscles start to hurt, and you have to back off to a lower level of activity to let your muscles recover. Many activities and sports include such intervals too – particularly things like boxing and martial arts, sports that include sprints as well as lower level activities (running, cycling, football), and activities like downhill skiing, where you can work anaerobically for part of the downhill run. Sometimes such intervals are built in to aerobics classes in the gym, always followed by time to recover.

**Resistance** exercise is the type of exercise that builds up your muscles and increases strength and promotes muscle growth, definition and development. This type of exercise can be quite popular with young men in particular, who want to develop their physique. This includes things like weight training in the gym, where you lift weights for a small number of repetitions, such that at the end of the exercise your muscles are burning and working anaerobically.

However it also includes things that aren't quite so obviously resistance or strength exercises. For example, you may do sit-ups at the end of an aerobics class – the resistance used is your own weight, and you are building up strength and defining your abdominal muscles by doing this type of exercise.

Pilates and yoga also include exercises that build up strength and define muscles, but do not usually involve the use of weights or multiple repetitions of exercises.

Aerobic exercise can also include elements of resistance training using bands or lighter weights used for a longer period of time, or simple exercises without equipment designed to build strength, such as squats or press-ups.

**Stretching/flexibility** exercise is the type of exercise that improves your flexibility and reduces your likelihood of injury. This type of exercise is classically associated with yoga, but stretching is an important part of warm-up and cool-down for all other types of exercise, and is a very important part of certain sports such as martial arts and gymnastics, and other activities such as dancing. You should not normally stretch cold, and so should only do this after undertaking other types of exercise that make you warm.

It is important, if you do yoga or other exercises aimed at improving stretch and flexibility, that you also do some other types of exercise, particularly aerobic exercise.

Lots of books miss out the third type of exercise, but I think it is important. Of course some sports or forms of exercise combine all these types of exercise so you can do all three types of training in one go.

## How to choose a sort of exercise

First of all the important thing is to do *something*. So, if you can't for any reason do the exercise combinations that are the best in theory, then don't worry – doing something is better than doing nothing.

There are some other things to consider:-

- 1. **If possible it is good to combine all three types of exercise**. If you can't combine them in a single activity, don't worry. You could, for example, do an aerobics class followed by some exercise on weights machines and stretching. This would deal with all three types of exercise. Or you can combine them in one sport or activity, such as dancing, cycling, walking, running or martial arts.
- 2. You are much more likely to stick with something if you like it and enjoy doing it than if you don't. If you hate going to the gym, then you are very unlikely to stick with it. Find something you like and adapt it so that you are doing some elements of aerobic and strength exercise, and then stretch at the end of it.
- 3. Select exercises that will give you the right level of activity. If your aim is fitness, then choose exercises that mainly work at Levels 1 and 2. If your aim is to get fit for competitive sport, or you find you need to push yourself in order to keep up with colleagues who have normal lungs, then you need something that will push you (or can push you) to higher levels of exercise.
- 4. **Do discuss your exercise plans with the physiotherapists at the hospital**. They will have some suggestions, but will generally be biased in favour of aerobic exercise. You should do some of this, but if you prefer to do weight training that is OK too, so long as you mix and match a bit. Some forms of exercise may be inappropriate e.g. kick boxing if you have an IV port in a vulnerable location.
- 5. Do some weight-bearing exercise. Some exercises are not weight-bearing (cycling is partially weight-bearing it depends how often you get out of the saddle, swimming is non weight-bearing, some other forms of exercise have limited weight-bearing e.g. horse riding, and yoga and pilates done mainly on a mat). These exercises will not give as much benefit in terms of bone strength as weight-bearing ones. So if you cycle or swim a lot, remember also to walk, do aerobics, skiing, weight training, running or something else from time to time as well.
- 6. **Do something that is practical**. You may really like something but if you can't afford it, or you don't have transport to get to the activity selected, then in reality you aren't going to be able to do it regularly enough.
- 7. **Don't just focus on formal sports**. You can get plenty of good exercise by doing the garden, walking part of the way to work, or clubbing. If you think about what you are doing while you are participating in these activities, they can provide

an excellent work-out without the need for lycra, equipment, gym fees and so on.

8. **Have a goal**. Having a goal, for example completing a sponsored walk, can motivate you and give you something to aim for. It will also make it much easier to select the right kind of exercise to reach that goal.

Here's an example: I had the goal to complete a 100 kilometre cycle ride within a certain time limit. I couldn't just take my time and do it slowly with lots of rests, I had to complete it within an 8 hour time limit. When I started cycling I could do only 7 miles in an hour (that's 11.2 km per hour) - not fast enough and not nearly far enough. I spent months gradually building up the distance I rode (endurance training) and the speed at which I could ride each distance (strength/speed training and aerobic exercise at higher levels with anaerobic intervals). You can't avoid hills on a bicycle, so I had to train at higher levels, and to keep up the minimum average speed with my lungs, I had to make sure I could sustain higher levels for a long period of time (what I would call strength endurance training). Eventually I found I could ride 40km at a speed of over 23 km per hour. I did a 50km ride at 22 km per hour, and finally managed a 100km ride at 20 km per hour - plenty of time to take a meal and two snack breaks during the 8 hour period and still finish well within the time limit. The goal dictated the type of training I would do - if I had selected a different goal e.g. to do a 10 mile time trial under 30 minutes, then my training would have been completely different. But both types of training would have been beneficial to my fitness.

9. **Have fun**! This is supposed to be fun. Sometimes it isn't that much fun riding your bicycle through sleet, but most of the time you can find something to enjoy about taking exercise.



Ready to go cycling – note the IV line in my right arm

# Section 6: How much exercise?

The range of exercise that suits an individual is very variable, and the range between too much and too little is very wide indeed.

## Total amount per day/week

The total amount of exercise or activity you can do in a day, or week, will vary with your level of fitness, the intensity of the exercise, and how well you are at the time. It also varies with the purpose of your exercise/activity – clearly if you are training for a marathon, or 100 mile bicycle ride, you will need to do more to prepare than somebody exercising to maintain fitness, or somebody whose sport involves short-lived power effort rather than endurance.

There is no hard and fast rule about how much exercise you should take, although the suggestion is at present that you should take at least 30 minutes exercise a day for general fitness, which can be split into periods of 10 minutes each. However this amount of exercise is not going to be sufficient to prepare you to take part in either more strenuous activity or more prolonged activity.

You have to set a sensible amount, and then stick with it, gradually increasing as your fitness allows. You need to start with a modest amount of relatively low level exercise (Levels 1 and 2), and then build up the quantity and level when you become fitter. You should not start out by taking several hours of strenuous high level exercise (Level 3 or 4) a week. A good starting point would be to take 3 or 4 30 minute sessions of gentle exercise, and then build up duration and intensity. If you are going to exercise classes that last an hour, then I would start with 2 a week and increase the intensity and amount gradually. My current level of exercise is 8 to 10 hours of fairly strenuous activity per week, but this is balanced by not exercising every day to allow some recovery time – so it is spread out between 4 or 5 days a week. This does not include general fitness. However, this would be too much if you haven't been taking exercise before – you will need to be less ambitious and build up gradually.

It is also worth noting that there is a difference in the fitness gain between exercise taken regularly (every day or every other day), and taking all your exercise at the weekend. You will in general get a better gain in fitness by spreading exercise out through the week than by spending 8 hours mountain biking every weekend but doing nothing the rest of the week. Indeed, there is some evidence that doing very strenuous activity infrequently (i.e. at weekends only) may be harmful to the cardiovascular system. This doesn't mean you can't do longer spells, or special things, at the weekend, but if you are planning to do this, you should also do something during the week if you can.

## Amount at each level

Some sports or activities require you to make higher level efforts, either for a prolonged period (e.g. a long climb on a bicycle) or for short spells (e.g. short sprints on a bicycle, bowling an over in cricket, throwing the javelin). Others allow you to maintain a comfortable or low level of activity throughout, e.g. walking or jogging (unless it is fell-walking which can be harder work!).

Whether you choose to do some of your exercise at a higher level or not depends on what you are training for, but in general it is good to do some higher level efforts.

The general rule is that, unless you are training specifically for an explosive sport that doesn't require any endurance at all, you should do the vast majority (80% or even more) of your exercise at the lower levels (I to 2). Indeed, when you are starting out,

and for the first few weeks, you should confine yourself to Level 1 and 2 exercise only. As your fitness increases, you can start introducing higher level efforts, but most of your exercise should still be at the lower levels. You can intersperse Level 1 and 2 exercise with higher effort levels, starting wit Level 3 and eventually increasing efforts to Level 4, the anaerobic threshold, where your breathing can only just keep up with the demands of the exercise. You should not be pushing to the anaerobic threshold until you have spent several weeks working at lower levels.

How much actual exercise it takes to do this will depend on you, how well you are, your lung function and your level of fitness, but in general the higher the level of exercise, the lower the amount of time you can spend doing it. It is also true to say that the more time you spend exercising at a particular level below the threshold, the better you are able to initiate and sustain such efforts when they are required of you.

The important message here is that you can get a good level of fitness and useful health benefit by doing almost all your exercise at a lower level – **you don't have to get very sweaty or exhaust yourself to gain fitness**. However if you need to do activities where you know that, periodically, you are going to have to make a higher level effort, then it is worth doing some of your training (no more than 10- 20%) at these higher levels.

Putting in harder efforts onto a baseline of lighter level effort is called *interval training*. You can use the natural characteristics of the activity you are doing to provide the intervals (e.g. a hilly bicycle ride or walk), or you can do them deliberately (e.g. running gently and then putting in some sprints every so often, then allowing your legs to recover and doing it again).

### Avoiding over-exercise

It is easy to get carried away and so do too much exercise. A little is good, so more/harder must be better, right? Not necessarily so.

Over-exercise is not good. It can make you tired, lose weight, and impair your ability to fight infection. Over-exercise can take the form of doing too much total exercise, or doing too much hard exercise without building the base level of fitness at lower levels.

The most important ways of avoiding over-exercise are:-

- 1. Learn to feel how your body is. If you are feeling fatigued, or aching, or when you go out to train you simply haven't got any zip in your legs, then either stop, or make your training or activity session a gentle one. If you do this, you will be surprised that you can still enjoy just having a gentle run, or spin on the bicycle, or gentle swim. Nothing is to be gained from fighting hard when you don't feel good. There will be another day when you feel better and then you can let rip.
- Have non-exercise days. Don't train hard every day. You could do some gentle walking or so on every day, but actually doing sport every day is something nobody does, even professional athletes. You may sometimes need more than one day off to recover from a particularly strenuous event, and don't feel guilty – you won't lose fitness in two or three days, or even a week.
- Don't exercise when you have a virus infection such as a cold this will simply make things much worse and you will take longer to recover from the cold as a result.
- 4. **Keep a diary of the exercise you are doing** it is useful to note when you weren't feeling so good in the diary. You might be able to pick out patterns of

activity that seem to be too much and other times when you felt really good.

5. Get the opinion of somebody who knows about training, such as a fitness coach. Don't rely on your mates, because their opinions will not be reliable – they'll either say you are doing way too much (if they don't do any) or not enough (if they are very fit people doing a lot of exercise), and are judging it against their own experience and not a professional background. Your family are similarly likely to want to wrap you in cotton-wool, and are more likely to have an old-fashioned attitude towards taking exercise when you have a medical condition ("You should take it easy, it can't be good for you to get all breathless!"). The physiotherapists at the hospital will also help you to ensure your ambitions and activity levels are realistic – they can still be challenging, but you may need help to ensure they aren't unrealistic. However it is worth remembering that the physiotherapists who treat CF aren't necessarily sports and exercise specialists – take some advice from both types of professionals if you are at all concerned.



Skiing in the French Alps

# Section 7: Nutrition

If you exercise you will burn more calories than usual and so you need to eat more. This might seem daunting if you already have to eat a lot, but in fact exercise often stimulates your appetite, and so you may not have much difficulty in eating the required amount. Indeed, exercise might make eating your normal amount of food easier, if you are actually hungry and want to eat.

Apart from quantity, there are issues of quality of nutrition and in particular eating the right kind of food and drink for the kind of activity you are doing and the goals you want to achieve. Sure, you will have to eat enough or you will lose weight, but aside from that, eating vast quantities of junk food will not help you make the most of your new-found fitness, and eating the wrong kind of food will actually impair your ability to be active and exercise, because you will be lacking in energy at critical times.

# Carbohydrate

Carbohydrates come in two forms – simple (sugars) and complex (starch). Both are important for exercise. **Sugars** provide an **immediate energy boost**, perfect for explosive sports or activities, and also for short bursts of intense activity within a longer more endurance-based activity (e.g. climbing hills on a bicycle, sprinting during a football match, bowling an over at cricket). **Complex carbohydrates** are found in a wide range of foods, including flour (found in bread, cakes, pasta, pastry), vegetables (particularly potatoes), and other grains (e.g. rice, oats, rye). These are broken down in the digestive system and turned into sugars which can be used for immediate fuel. This occurs at a different rate for different types of complex carbohydrate. So, you can get quite a rapid and high rise in your blood sugar after some types of carbohydrate meals, and a slow and more sustained rise after other types. This is measured by the *glycaemic index* (GI) and high GI foods will provide more immediate energy, with low GI foods providing **more sustained energy**. Both are important in exercise.

Understanding this can be important, because if you have eaten before exercise, then you will need some carbohydrate to be released quickly to provide immediate energy and some to be released more slowly to provide energy over a longer period. If you don't take enough carbohydrate to cover the whole duration of the activity (you can't always), then you will need to eat or drink some extra carbohydrate during your activity.

If your blood sugar rises above a certain level, your body produces insulin, to allow the sugar to be stored in the liver and muscles as glycogen. A particular problem with endurance exercise is that if you have a high sugar load (either by eating sugary food, drinking a sugary drink, or eating a high GI food), a rapid rise in blood sugar leads to production of insulin. Unfortunately, if you have also started exercising and burning up sugar, this production of insulin leads to a rebound rapid lowering of blood sugar. This is one mechanism by which you can get a phenomenon called "the bonk" where you simply run out of energy and have to stop. Paula Radcliffe experienced this in the Olympic Marathon in 2004, showing that it can affect even the best prepared people. If you have ever experienced it, you will never forget it!

This emphasises the value of taking some food with a low GI to ensure there is fuel available over a sustained period. You **must** eat something prior to any exercise that is likely to last more than an hour, or is likely to involve some explosive effort that means your muscles need sugar as fuel.

Although you can, and will need to, burn fat as a fuel too, you need some carbohydrate to do this. Therefore paying attention to your carbohydrate intake is important for any prolonged activity. Remember that some low GI foods don't contain a lot of carbohydrate – you need to eat *enough* carbohydrate, as well as the right type.

Eating **enough** carbohydrate can be difficult, because the foods that contain it tend to be rather bulky, and therefore rather filling. This may mean you don't eat enough total calories, so you need to be choosy, and ensure that you mix up carbohydrate with fat so that your total calorie intake doesn't suffer. Mixing fat with carbohydrate will also delay the speed at which your stomach empties and prolong the period over which carbohydrate is available (effectively increasing the GI of carbohydrate food).

Foods that contain both carbohydrate and fat, and therefore a lot of calories, and may be useful prior to exercise, or at lunchtime include pasta dishes, pastry (pies), chips or sauté potatoes, sandwiches, jacket potatoes with filling, nuts, pulses and beans and pizza. Flapjacks, chocolate and cakes can also contain quite a lot of fat, as well as carbohydrate. Bananas contain fat as well as sugars and starch, and are a good food to eat during exercise.

### Fat

Fat is an *extremely important source of calories for somebody with CF*, who has a high requirement for calories. It becomes even more important if you are taking a lot of exercise and thus your calorie requirement goes up even further. Although the general public are exhorted to eat a low fat diet, people with CF, and particularly people with CF who take a lot of exercise, will need the calories. It is hard to take enough calories just by eating other types of food alone, because the diet would be too bulky.

So, you have to eat (quite a lot of) fat, but there are also some things you should think about.

#### All fats are not the same

Fats all have a similar structure, with large molecules called fatty acids attached to a simple backbone. The characteristic of the fat is determined by these fatty acids – their length and their chemical type.

#### Saturated versus unsaturated fats

Saturated fat is usually derived from animal or dairy sources, and is present in high quantities in fatty meat, eggs, butter, hard cheese, lard, suet and milk *and foods made from these things*, like cake, chocolate, pastry and pies. Unsaturated fats tend to derive from plant sources and are present in vegetable oils, nuts, and certain fruits like avocadoes and bananas. Unsaturated fats are also present in fish and fish oils. Saturated fats are present in some vegetable oils, notably coconut and palm oil, so you need to be careful which type of vegetable oil you use.

Margarine is made from unsaturated vegetable oil, but this is "hardened" by making a proportion of it saturated, and therefore it still contains saturated fat. The hardening also produces trans-fats, which are more harmful to your heart than naturally occurring cis-fats. In addition, oils used for cooking and heated to a high temperature, particularly if kept hot or re-heated as in fry-ups, fish and chips and takeaways, can also contain a high proportion of trans-fats. So, fried food *in excess* is not a good idea, because it contains a high proportion of trans-fats.

In general, *saturated fat intake should be limited*, because it is associated with a rise in the bloodstream of the type of fat (low density lipoprotein) that is in turn associated with problems with circulation in the heart, brain and leg muscles. It is also associated with a high level of cholesterol in the blood. So, when eating fat, it is best to choose, where possible, an option that contains unsaturated fats. People with CF now live long enough to make heart attacks and strokes a concern, and eating a high fat diet means you have to be extra careful not to eat too much saturated fat, although in CF the overwhelming priority is to eat enough calories.

An example is when you have a salad – a dressing is good because it adds calories, but an olive-oil and vinegar dressing contains unsaturated fat, whereas mayonnaise (made from eggs) contains a lot of saturated fat. This doesn't mean you can't eat meat, or cheese, with your salad, but you *can* add calories *without* adding saturated fat if you choose in addition, an olive oil dressing instead of mayonnaise

#### Essential fatty acids

Although the body can re-process most types of fat to produce the fatty acids it needs, there are two that it can't make and must be taken in from outside – Linoleic acid (LA) (also known as Omega 6) and Alpha Linolenic Acid (ALA) (also known as Omega 3). You need to ensure that you include these, or the things that they are used to make, in your diet, and in particular that you eat a relatively high proportion of Omega 3 fatty acids in your diet. In general, people with CF tend to have a relatively high level of Omega 6 and low level of Omega 3, and within the Omega 3 family, a relatively high level of one acid called arachidonic acid (AA), and a lower than expected level of docosahexaenoic acid (DHA).

While there is no evidence that taking Omega 3 and in particular DHA can make CF better in the long term, it is still worth trying to balance your diet in favour of Omega 3 and DHA-containing foods.

Fish oil and oily fish, such as mackerel, salmon, tuna, herring, sardines are useful sources of calories, and they are also high in both Omega 3 unsaturated fat and DHA.

#### Fat burning exercise

During any kind of exercise that lasts a prolonged period, you will need to burn fat as a fuel, because the body doesn't store enough carbohydrate to produce enough energy for your activity. Instead, the body is using the carbohydrate stores (glycogen in the muscles and liver, plus any sugars or carbohydrate you have recently eaten) to burn up fat.

Fat isn't a good fuel source for high levels of exercise, or effort, and you will use a higher proportion of fat as fuel at lower levels of exercise. Nevertheless you will burn a greater amount of fat in total if you include higher levels of exercise in your training.

The main importance of understanding this is that it is crucial to take in carbohydrate throughout prolonged exercise, particularly if you are going to make higher level efforts later on in your activity e.g. climbing a hill late in the day, making a sprint for the line when running. This is because you need carbohydrate to help you burn fat as fuel during the lower level parts of your activity, and you need the carbohydrate as fuel itself during the periods of higher effort. If you are seeking to reduce your percentage of body fat (most people with CF aren't but some may be, to improve athletic performance), then you should:

- a) Ensure a relatively high proportion of your exercise is at lower levels
- b) Ensure you take carbohydrate throughout your exercise
- c) Include some higher level efforts during your exercise so you will burn a larger total amount of fat.

Running out of carbohydrate, either because your intrinsic stores (in your muscles and liver) are exhausted, or because you haven't taken in enough, or usually both, will mean that you can't burn any type of fuel, including fat, efficiently. This results in "the bonk" that I referred to earlier – so you will need to take in carbohydrate, even during prolonged exercise where you are predominantly burning up your fat stores.

One final myth to be addressed: A lot of people think that to burn fat you have to restrict yourself to Level 1 and 2 exercise. This is not true. Although at lower levels of

exercise, a higher proportion of the calories you burn will come from fat, you won't actually burn very many calories. You will burn more fat by burning more calories at higher levels of exercise, even though at these levels you will also be burning more carbohydrate.

## Protein

Protein is the substance from which the body is built – muscles, bones, blood vessels – everything important contains protein. It is therefore essential to take in protein in your diet, and in particular to ensure that you take in all the essential amino acids, the building blocks of protein, that your body will need. This is harder, but not impossible, if you eat a vegetarian or vegan diet, but you must mix up your sources of protein to ensure that you get a mix of amino acids.

Protein is found in most foods, but some foods are richer in protein than others – meat, fish, eggs, cheese, milk, pulses, soya and other types of beans, and nuts are all relatively rich in protein, whereas green vegetables contain relatively little.

In terms of exercise there are two important functions that protein has:

- a) It aids recovery and repair following exercise, particularly hard or prolonged exercise.
- b) It is required when you are trying to build up muscle (body building, weight training) to provide the building blocks for the muscles you will be enlarging.

Therefore it is helpful if, soon after taking prolonged or vigorous exercise, you take some food that contains carbohydrate (to replace the muscle glycogen that you have just burned up) and protein (to aid repair and muscle building). There are commercial drinks that contain this, but a balanced meal or even a sandwich will also do the trick. It is of greatest benefit if taken soon after exercise.

## Fluid and electrolytes

When you exercise, you will use more fluid than if you are resting. This is the case whether or not you are noticeably sweating, because you will also be breathing more heavily and losing more water in your breath as you exhale. So, you must pay attention to taking enough fluid when you are doing any activity.

**How much is enough?** This is difficult, but you should be aiming to take a drink if your exercise lasts more than 20-30 minutes, and to take more fluid if you are sweating heavily, if you are exercising indoors or in a high temperature environment, and if you are exercising harder than usual. You will need more fluid (much more) if cycling or running in 30 degree heat than walking on a cold winter day, but even on the cold day you will still need some. Broadly, when cycling, I would aim to take in between 500ml and 2 litres an hour, depending on how hard I am working and how hot it is.

Even more important for people with CF is replacement of salt. This is because we lose much more salt in our sweat than people without CF, and they lose quite a lot to begin with, particularly in hot conditions and with vigorous exercise. This can be serious, leading to cramps, sickness, and collapse, so you must take heed of this, because it is very important. It is important even if you are not doing conventional sport – for example, you can get salt depleted quickly in a hot night-club if you are dancing.

**How to do this?** Again there is no hard and fast rule, because requirements will vary with the duration and intensity of exercise and with how hot the weather is. There are essentially three ways of getting salt:

- a) **Through the diet** either added to food in cooking, at the table, or by eating salty foods like crisps or convenience food with a lot of salt added. This can tend to be unreliable if you are doing a lot of exercise in hot weather, because the dose isn't terribly controllable.
- b) Salt tablets sustained release salt tablets will release salt slowly over the course of the day, and ensure that you have a reservoir of salt available. However this may not be enough to cover you for periods of more intense exercise.
- c) Electrolyte drinks drinks that contain water, plus electrolytes including salt, and some sugar that acts as fuel and also helps the absorption of the electrolytes are widely available as commercial solutions, or as DIY concoctions (water, fruit juice, a little sugar and salt). Commercial solutions have the advantage of containing other electrolytes, such as potassium, that can also get lowered during prolonged exercise, but the disadvantage of being relatively expensive.

In reality, you probably need to do all three – add a bit of salt to your food, take salt tablets in hot weather or when exercising vigorously, and make sure that at least one of the drinks you carry with you is an electrolyte drink. If you are going to spend all day exercising in hot weather e.g. a long walk, or bicycle ride, then you might need to carry some powder with you to mix up another drink on the move. Alternatively you could buy an orange juice to mix with water at the pub – this is better than using water alone.

One final point is that you should avoid alcohol, which dehydrates you due to its diuretic effect (makes you want to wee). There is no harm in having a small drink at lunchtime if you are doing some relatively light exercise and it isn't too hot outside, but don't get wasted and then expect to be able to exercise normally – it doesn't work. This becomes particularly important if you are planning to spend an evening clubbing in Ibiza – hot weather, booze and CF don't mix. If you do have a few alcoholic drinks, make sure you take salt tablets beforehand, and drink some water and juice drinks too.

## Problems of endurance exercise and CF

Most of the time when taking exercise or doing an activity, we are probably doing it for an hour or less, and at a relatively low level – it is rare for exercise classes at the gym to last more than an hour. Under these circumstances, you really don't need to do anything above eating a normal diet with added calories to cover the needs of your exercise, perhaps taking salt tablets as part of your normal CF treatment, and making sure you have enough to drink.

However some types of activity can last longer, be more vigorous, and need additional attention, particularly when you have CF, to ensure that you can take part in them without coming to harm. This would include things like long distance running (e.g. half-marathons, or marathons), long hikes, particularly over hilly terrain, adventure travelling, long bicycle rides (over 1 hour duration), a long day back-country skiing or snowboarding and so on.

### Before you start

- a) **Make sure you have something to eat**, preferably a mixture of sugar and complex carbohydrate, and possibly some fat too, to provide additional calories and reduce the speed at which you process the complex carbohydrate.
- b) **Also make sure you have taken salt tablets**, sufficient to get you through the day's activity. This provides a baseline upon which you can supplement fluid and electrolytes effectively.

c) Make sure you have everything with you that you need. This should include water and/or electrolyte drinks and refills, something to provide instant energy, and something to provide more prolonged carbohydrate energy. I would always ensure that I have a mobile phone or walkie-talkie radio, some money (for a taxi or to buy emergency supplies of food while out), enzymes, and a map and/or GPS so I can always tell people where I am if I need help. Obviously you can leave some of this out if you are going over familiar territory or a pre-planned race course, but if venturing out on your own or in a small group, over unfamiliar territory, the list above is sensible. There will be additional things you need to take for specific sports e.g. a puncture repair kit, inner tube, pump and chain tool on a bicycle ride, a shovel and avalanche transceiver when skiing or whatever is appropriate for the particular activity.

### Eating and Drinking During exercise

If you are doing any prolonged exercise, you will need to eat and drink during it. This presents some practical problems associated with CF. The things I've found to be difficult are:

- a) Eating and drinking when you are already breathing heavily sometimes you can stop but sometimes you can't, for example in a race. So you'll need to learn strategies to reduce the amount you are breathing and thus be able to eat and drink while you are on the move. For example, unless a hill is very long, I will wait until I am freewheeling on the bicycle down the other side before taking a drink, so my breathing has settled down a bit. Another thing you could try is a Camelbak, so you can take sips from a drinking tube rather than large gulps from a bottle.
- b) Pancreatic enzyme supplements it is particularly difficult to eat and drink on the move if you also have to take supplements with anything you eat. If you can't stop to take a snack, it is quite important to find things that you can eat without having to take enzymes but that will still give you benefit in terms of carbohydrate intake. I use various types of sweets such as fruit pastilles for immediate intake of sugar when required, and some commercial energy bars for complex carbohydrate that contain no protein or fat, and so can be tolerated without enzymes. A lot of athletes use bananas, but I find these too fatty. Others take flapjacks – again, much too fatty for me. But if you aren't taking in the calories in bananas or flapjacks on the move, you must make sure you take them during rest periods, or at the end!

It is also useful to have a plan for when you are going to eat and drink during your activity. People without CF don't always have to be so careful, relying on finding a suitable pub or shop, but I don't think it is so easy if you have CF and run out of energy quickly. Here are my general tips.

- a) **Drink regularly and not just when you are thirsty** if you are thirsty you have already let yourself get too dehydrated. So start to drink early on, within 20 minutes of starting, and take sips all the way round, rather than stopping to take gulps here and there.
- b) If you know a large effort is coming up, take in some carbohydrate so, if you have just walked along the valley floor and the only way is up for 3000 feet, then eat something first! This should be a mixture of immediate energy and slower release carbohydrate. Some of the quickly available carbohydrate can be in a drink.

- c) **Make the most of meal stops** even if you don't actually feel that hungry. Eat a mixed meal, with protein, fats, and some complex carbohydrate. And make sure there are enough calories in your meal.
- d) **Carry plenty of food with you** as well as something you can eat without enzymes. Carry high calorie energy-dense food that you can eat with enzymes during stops. Nuts are excellent for this, if you aren't allergic to them, as are flapjacks. I tend to choose pasta or sandwiches in the pub, if we stop there, as there is complex carbohydrate in these meals to fuel the afternoon's activity.
- e) Avoid "the bonk". By this I mean try not to exercise to the point where your energy has run out and you have to stop. If you start feeling light-headed, finding an effort that is usually OK for you too difficult, then STOP and EAT. You can experience this either if your blood sugar gets rather low quite quickly, or if you have just overdone it and depleted the supply of glycogen in your muscles such that it can't keep up with the exercise you are doing. You have to stop, and eat if this happens. Again, eat a mixture of immediate energy food and something that will give you carbohydrate over a longer period or it will just happen again if you re-start.

## Supplements and non-therapeutic drugs

There are an awful lot of products on the market that are reputable, and very helpful to people taking a lot of exercise, and which have been properly tested. But there are also a lot of people out there making extreme claims for magical results from supplements that have not been properly tested, or at least the claims being made are misleading.

You may also come across people offering you non-therapeutic drugs (by which I mean performance-enhancing drugs you have not been prescribed by a doctor). Some sports are more prone to this than others (e.g. weightlifting, bodybuilding, cross-country skiing, cycling).

- a) **Only use products from a reputable company** how do you know who these are? In general, these are products available in mainstream sports stores, or even pharmacists, either over the counter or online. I use Science-in-Sport and TorQ products, but there are others, including Maxim, Isostar, PowerBar, Lucozade Sport, EAS and so on. On web sites, there will be a variety of products available for which extreme claims are not made (they will claim to be effective in a fairly specific and limited way, e.g. making a modest improvement in recovery time after exercise). There may be testimonials, usually from high profile sports people, but these are relatively modest, praising the product in general terms. These products are also usually relatively inexpensive up to £1 for an energy bar, or bottle of drink.
- b) Avoid any product that makes extreme claims, or relies on rather excessive testimonials e.g. "I put on four stone of muscle in a month" or "I doubled my exercise capacity in a week". This is a particular problem with protein supplements associated with body building and weight lifting. Anything that makes an extreme claim will prove a disappointment. They are also likely to be extremely expensive over £20 for a relatively small tub of supplement, or pot of pills.
- c) **Discuss any non-therapeutic drugs or supplements you may be considering with your doctor**. You must do this. There can be interactions with drugs you take for CF, or with the effects of CF itself, and these can be very serious. For example, both CF and anabolic steroids are associated with damage to the liver and produce similar changes in liver function to CF. Anabolic steroids

can also interact with the antibiotics used to treat infections in CF. Be aware that all kinds of doping are likely to be found out eventually in competitive sport. However, even if you aren't a competitor yourself, but are tempted, because they will help you build big muscles and look cool you must consider why certain drugs are banned from competitive sport. They are banned because they have serious side-effects, that can kill. You need to think very carefully about whether the short-term gains outweigh the long-term consequences of taking such drugs. Do you really want to go through all the pain of treating your CF, and of trying to get fit, only to lose it all because you got impatient and wanted to get a quick and easy route to looking good, or being fit? There is no such thing as a free lunch, and no quick and easy way to achieve a good physique. If somebody offered me these things, I know what my answer would be!



One of the main reasons for cycling – the pub stop!

# Section 8: Exercising with others

One of the great things about taking exercise and getting fit is the opportunity to get out and meet people, and to take part in group activities, exercises, rides, competitions and all manner of other great things. Exercising with others is motivating if you are flagging, and makes the whole thing a social experience, rather than a lone slog.

The problem is that when you have CF it isn't quite as easy. There are a number of things that may put you off exercising with other people. Here is my list of some of the things I've encountered and of the ways in which I think they can be overcome:

## **Body image**

You may be very worried what you look like compared with fit people of your own age. This might be particularly true if you are underweight, have a curved spine, clubbing of the fingernails, or spindly legs. It can be made worse if the normal "uniform" of the sport is revealing or tight clothing.

The thing to remember is that most of the other people there will be feeling exactly the same way – they will be worried that they are too fat, too thin, too weedy, their legs are too short, their trousers make their bum look big. Worrying about body image is not confined to CF, and so you can forget about it, because it just means you are normal. In general I have found that, at least in gym classes, most people are far too worried about what they look like to be paying any attention to you! A lot of people will be frankly jealous if you are skinny particularly if you are a woman.

There are alternatives if this is really preventing you from going – you don't have to wear lycra in the gym, you could wear baggy pants and t-shirt instead. Likewise, you can wear baggy shorts on your bicycle rather than racer style skin tight lycra, or a full body swimsuit or baggy shorts instead of trunks or a bikini.

Mates can also be cruel and joke about your appearance – they may not be aware how sensitive you are. You could try going to a gym or class without your mates – it is very unlikely that a complete stranger will comment on you, or make a joke! You could also try exercising in a more protected environment e.g. a session with a personal trainer, who will not make jokes but will be genuinely trying to ensure that you achieve your goals. Once your confidence builds up, you can then try exercising with your mates too, expecting the odd joke, and giving as good as you get!

Sometimes people may ask questions, for example about a port, or gastrostomy button, or a Venflon if you are exercising while taking IV antibiotics. I see this as an opportunity to educate them about CF. Most of them are totally amazed that I am attempting the class, or bicycle ride, or sponsored walk, or whatever. I don't think I've ever had a negative reaction from anybody. People are genuinely curious, and they are usually extremely supportive once you explain things to them, as were my aerobics class when I taught them while on IV.

You should not let concerns about body image put you off exercising with other people.

## Coughing

Exercise sometimes makes you cough. How much will depend on how well you are in general, and how well you are at the time, as well as on the type of exercise, the weather conditions and so on. It is very easy to feel self-conscious about coughing, particularly when you are participating in exercise with people who don't know you. You may also feel self-conscious about expectorating in front of other people, and you will have to come up with practical ways to deal with this, such as swallowing, or discreet use of a handkerchief.

The question is, should coughing prevent you joining in group activities? I can't answer that for every situation, but what I will say is that unless the coughing is so bad that it produces a distraction for other competitors (e.g. in an archery or snooker competition), or that it means others can't hear the instructions in a group exercise class, then you shouldn't let it become a barrier.

My experience is that most people are concerned about coughing because

- a) They think you might have a cold that they could catch
- b) It is relatively unusual for somebody with a cough to do exercise, particularly if they look pretty fit. The reaction is one of curiosity
- c) People are genuinely concerned for your well-being. This really is the main reason that people might comment on your coughing.

How much you explain to other participants depends on whether you are likely to meet them again. In general I find it is always better to explain a cough to an organiser of an exercise or group activity so that they are immediately aware of your needs, and that you don't pose a danger to other participants. So, for example, we went on a ski race training course in November 2006. I didn't expect to tell everybody in the class about my condition, but the dry mountain air made me cough a bit more than usual. So, we told the organiser of the course that I have CF, and made him aware of the main requirements, and the fact that I might get breathless and cough a bit. Then he didn't worry, and the other instructors didn't worry, and I could deal with other participants one at a time.

Likewise, in an aerobics class, I would usually tell the instructor, but unless I know the other participants well, I would only joke with them about a cough, rather than launch into a full explanation about CF. Likewise, when instructing, I wouldn't usually tell the class unless I have a problem.

On the other hand, in a small club, such as a hiking or cycling club, where you meet people regularly and maybe socialise with them too, and where the activities can last all day or more, it is definitely worth explaining your condition to them.

It is easy to be self-conscious about coughing, but remember – if it helps to clear your lungs then coughing can be good. I've found that the more exercise I do and the fitter I get, the less I cough anyway. In fact I can't remember coughing at all on some activities lasting several hours.

## I can't keep up!

You may worry that you won't be able to keep up with "normal" people when taking part in a group activity. This can be a reasonable concern, and you need to make sure that you choose a suitable group activity to start with. I'd go for something where the participants can go at their own pace but meet up at suitable stops, such as a bicycle ride or hike. Alternatively, there may be a group activity that is split into subgroups going at different paces. Or if it is a group of friends, check that they don't mind waiting for you and allowing you a rest when you catch up before heading off again. They need to remember that by the time you arrive, they will already have had a rest, so they shouldn't set off again the moment you arrive. Most of them won't mind at all – they will just be impressed that you are having a go.

When I started cycling, for example, my husband used to ride with me, but I was rather slow up hills. So while I was slogging my way up in a low gear, he would ride back down and ride up again. This solved the problem of him having to wait for me at the top and getting cold, and also gave him the higher level of workout that he needed. Now, of course, I cans sometimes ride up the hill in his wheel and even go past him – no need for

him to do the hills twice any more! However his tolerance and this strategy gave me the chance to ride with him, and later in groups, without worrying about keeping up, and allowed me to get fit enough that keeping up is no longer an issue. It also meant I didn't feel I was impairing his workout.

There are also many group activities that you can take part in where there is no element of keeping up – like aerobics and fitness classes. Everybody here chooses their own level and sticks to it. If you are worried that the instructor thinks you aren't trying, then tell the instructor that you have CF, and that you are setting your own, appropriate level.

Having spent years and years participating in group activities, one thing I have learned is that the concept of "normal" is flawed. In any class, and any group, there are always people who are exercising at higher levels/going faster, and people who are exercising slower or at lower levels. The reasons for the latter vary enormously. "Normal" people can have injuries that prevent them exercising at higher levels, there may be unfit or overweight people starting out exercising for the first time, and who are deliberately keeping the level down, or people who just like to take gentle exercise. Even fit "normal" people can feel under the weather if they are starting a mild cold, or just had too much booze the night before! Everyone needs to listen to their own body and exercise appropriately each day, regardless of what other people might think.

Worrying about being able to keep up is something I do a lot, but in general that worry is without foundation. Most people are extremely impressed that you are having a go. A few people are miserable about it, but I'm afraid I see that as their problem. Most people are prepared to wait, and encourage you, and support you, and give you a chance. Most people can empathise – they started out less fit and unable to do the same activity too, so can put themselves in your place quite easily.

Therefore, provided you choose an activity that lends itself to people taking part at different levels and different speeds, keeping up isn't likely to be a problem. Of course as you get fitter, and your performance improves, you may find some "normal" people have problems in keeping up with you!

## **Competitive spirit**

This can be a good thing, particularly if you are taking part in competitive sport, but it can also be counter-productive if you are trying to train gently and incrementally.

Exercising in groups can bring out the competitive spirit in all of us, even if the sport isn't competitive, or you aren't in a competition. I suffer from a big dose of competitive spirit, and find it extremely hard to temper my enthusiasm and keep training within my own limits.

So, for example, if I've set out to have a gentle cycle ride because I did a hard/long ride the day before, and I see a cyclist up ahead, I have a huge urge to try and catch and pass them. Or if a cyclist passes me, I want to try and hang onto their wheel, even if they are obviously going much faster than I want to go. Likewise in an aerobics class I want to be seen to be trying very hard, so I might bounce up and down a bit more than my poor old injured knee can stand. I've done all these things and regretted them!

It is very difficult, if you have an inbuilt competitive instinct, to temper it and keep exercising at a sustainable, sensible rate that will meet your needs, not those of all the others around you. A group ride, or run, can so easily turn into an unofficial race, and this may not serve you well if you are trying to take it easy and come back from injury. It may also be depressing if your brain tells you to compete but on that day your lungs or body say "No". Likewise, it can be demoralising when you have kept up all day, to be left

behind in the sprint for the pub ("Last one to the bar buys the drinks!"). You just have to let it go.

So, exercising in groups can be a very good, social thing, but you must also remember to set your own limits and stick to them. If people want to ride an extra loop, or walk an extra few miles, or do some weights after an aerobics class, and your brain says you shouldn't do this, then you have to be strong and stick to your plan and resist the temptation to go on with them.

## Too much encouragement may not be a good thing

Following on from the competitive spirit comments above, you can find that you are getting a lot of encouragement from your peers in the group, or from the instructors. Again, this can be a two-edged sword – good if it gets a little bit more from you than you thought possible, but not good if it leads you to over-reach yourself, or stray into levels of exercise or endurance for which you were not prepared.

Again, you have to agree your goals with yourself, your group, or your instructor, or all three before you participate and be strong and stick to them. The aerobics instructor might shout at you to "really give it your all", but if your plan was to exercise at a lower level, then don't do what he or she says – just keep to your plan and ignore all the bouncing and shouting going on in front of you.

This doesn't mean that you shouldn't listen to encouragement or try hard, but once you have learned to listen to your own body and exercise to a plan, then you also have to learn to ignore "encouragement" that is counter-productive.

## People don't understand that you're trying hard

Following on from the points above, sometimes people will try to "encourage" you thinking you aren't trying. They may find the exercise level, or length of the activity quite astonishingly easy, and they can't understand why you appear to be flagging and interpret this as being lazy or not trying. I suffered this repeatedly when I was at school, because the teachers didn't think I was trying – we didn't know I had CF until I was 10.

It is very hard for somebody who is naturally very fit and active to put themselves in the place of somebody to whom fitness comes as a much harder-won prize. So they can genuinely think that you are taking it easy, whereas in reality you are working very hard, and that by encouraging you, and joking about your lack of effort, they will be helping you to try harder.

You need to have strategies for dealing with these people, and this includes being assertive. By assertive I don't mean aggressive, I mean that you have a right to exercise at your own level within the group, and you need to make it clear that you are exercising as hard as you want to or as hard as you can. I've had this problem with fitness instructors, on one occasion, trying to encourage me to lift weights that were too heavy for my shoulder when recovering from an injury.

So, you have to explain things to them. Most people then react with amazement and genuine admiration that you are trying to participate at all. Some can't relate to ill health, and you just have to accept that you can't get through to everybody.

## Needing to take pills

This can make you very self-conscious if you have to take pills in order to eat during an activity. It isn't so bad if there is a group of people who you already know taking part, such as a group of friends going hiking, or skiing. They will already know you need to take pills with your crêpes in the café next to the piste. But it can be a perceived

problem if you are taking part in a public mass-participation event, such as a sponsored walk or fun-run, where you don't know many people or indeed anybody at all.

It can be even worse in a competitive environment, where you need to eat during the activity, and where people are very conscious of the issues of doping in sport. For example, in cycling, there are endurance events called Audax rides which vary from 50km to 600km or more, and which take from 3 or 4 hours to several days and nights to complete. All have to be completed within a particular time frame, so you can't rest for very long, although you need to schedule in meal stops. However there are likely to be a lot of strangers eating in the same café or at the same food-stop as you, and they may see you taking pills with your meal.

I get over this to some extent by taking food along with me that doesn't require enzyme supplements. At the café stops, I keep my pills in those little plastic bags you put change in when paying it into the Bank. This can be tucked discreetly into a pocket and accessed when you need them without looking like a drug addict! Almost everybody is familiar with the need for diabetics to have insulin injections, so this isn't an issue either. Neither is taking asthma inhalers – almost everybody seems to have one! If you are very self-conscious, there is always the loo, but I prefer to be relatively open and explain if asked what it is all about.

Taking pills should not prevent you participating in group exercise activities. In most instances you wouldn't need to take pills anyway – this would only apply if you were taking part in a longer duration activity.



With some of our cycling friends - we really did cycle up that hill!

## Getting annoyed with "normal" people for whom it is all so easy!

This can be extremely frustrating, I've experienced it on many occasions. It is very hard to come to terms with the fact that you've just trained for months for a particular longdistance cycling event, and completed it in a reasonable time, only to find that somebody else who just completed it alongside you first started cycling a week ago, never does any exercise at all, and had only ever ridden 2 miles in a day before (and you've just ridden 60 or more miles). It is hard to accept because it appears to negate the effort you've just put in. It is also very frustrating to start out exercising with somebody who appears to be just as unfit as you, and find they move streets ahead of you in weeks, while you are left progressing more slowly because for you, the task is more difficult.

It sometimes makes you want to give up in frustration! But you have to remember why you are exercising and who is benefiting. The exercise is for *you*, and it is *your personal goals* that matter, *not what everybody else does*. You know how hard the goals are that you set, and you know the degree to which you have had benefit from the work you've put in. You need to be realistic, and also remember that the people who participate without training will generally be unable to walk the next day, whereas you will be fine!

It can sometimes help to keep a diary, or **make a note of achievements** over a period of time. Then when something frustrating like this happens, you can review your achievements against your own realistic plan.

# Section 9: Coping with recurrent illness and uncertainty

One of the major issues with CF is the unpredictability of illness. You may be training hard, have a training schedule, or be aiming at a particular event. However your ability to become and remain fit, and get to a peak at a particular time, is subject to much greater uncertainty about your health than for many other people. It can be extremely frustrating to train for months only to find yourself ill and on IV antibiotics when you should be participating in the event that you've worked hard for all year.

One of the consequences of this is that you might be tempted either to give up, or not to aim at particular events in the first place – in other words, you are using uncertainty as an excuse not to do something, or as an excuse not to set any goals.

This can rule you out of an awful lot of fun and benefit from exercise, so here are my experiences and tips for dealing with these little frustrating episodes that are part of life with CF.

## Illness will happen

This is the first thing you simply have to accept – if you have CF, from time to time, you will get ill, will have to have treatment, and therefore won't be able to do all the activities you want to do. Of course, this can happen at any time to anybody, with or without CF, and people with CF can also get the kind of injuries and illnesses that are unrelated to CF. However on the balance of probabilities, you will get ill and have interruptions to your activities more frequently than people who don't have a similar long-term condition.

But should this stop you actually planning, and getting involved in, activities? It is very easy to get hung up on activities that have been disrupted by injury or illness, but just take a moment to think of all the things you have been able to do that weren't disrupted. I can think of many activities I've done that weren't disrupted by CF, and only a few that were. The successful ones were in the majority. So, if I hadn't bothered, and hadn't trained, I would have missed out on a whole lot of fun in my life, and I had all the health benefits of the training.

I try and focus on the things that I can control, like my level of fitness, nutrition, endurance, strength and so on, and try not to worry about the things I can't control. Certainly you can take steps to avoid illness – so I won't travel on public transport if I can help it, or go to crowded places where sick people congregate just before a holiday or major event, to avoid catching a cold and ending up on IV. I make sure I have my flu jab every year. I make sure I warm up, stretch, cool down appropriately. But sometimes you just can't control whether you catch a cold, or pull a muscle, or whatever. There is no point in worrying about things outside your control.

## Plans can and will get messed up

You can be sure that you will sometimes get ill when you don't want to, and when it will interfere with your plans. So, it follows that some plans will get messed up and not everything will go right. To some extent this affects everybody – whether it is illness or a puncture during a cycling time trial, or an unfortunate injury just before a major event, or a problem with the weather meaning a hiking trip is cancelled. CF is just one of the other disruptions you need to face when planning.

This can lead to an unwillingness to plan any activities in case CF gets in the way. Again, how much fun will you miss out on? How many of your planned activities has CF really disrupted? It has got in the way of some things for me over the years, but I've also managed to take part in a whole lot more planned activities without disruption from CF (of course non-CF related injuries and other things have disrupted activities too).

So, it is still worth making plans, and sticking to schedules, even if you know there is a possibility that they will be disrupted. It is also worth making alternatives, so that if you have worked hard only to be defeated by a temporary illness, then having a secondary goal means that you will still be able to enjoy the fruits of all your hard work in a different way. But it shouldn't stop you from planning things, and enjoying it when it all comes together.

Also, you will reap the benefits of exercise, training and fitness if you want to take part in spontaneous activities, which you can do knowing that your health is OK, even though they are arranged at the last minute. So, for example, you may have trained all year mainly for a particular event, like a 100km bicycle ride, but then somebody suggests a 10 mile sponsored walk the next weekend – that's OK, because all the training you've done means you can be spontaneous and take part in it because you are already fit enough. Having plans disrupted isn't the end of the World, because you can still enjoy the fruits of your hard work in spontaneous activities.

## **Unwillingness to commit**

If you are frightened that illness will get in the way, you might be unwilling to commit to something. For example, if you are usually ill during the Winter, you may be unwilling to book a ski holiday, particularly if the insurance won't cover you for CF (it usually won't), in case you need to cancel at the last minute.

But again, this shouldn't be a problem if the people you are committing to understand that you have CF and may have to withdraw. Indeed, you don't always need to explain CF – just telling somebody you are ill will usually be enough. I've had to withdraw two years running from the same scheduled event due to illness, and the organiser has been pleased I let him know, because many people don't, even if they have a far weaker excuse for not turning up!

Activity holidays can be a problem, and losing your money if you can't get cancellation insurance is a worry. The way I look at it is this: I've had many, many successful activity holidays that haven't been disrupted by CF, or at least haven't been cancelled because of it (I've got ill afterwards a couple of times).

I have participated in many weeks' skiing, several weeks of walking holidays, cycling activities and motorcycling weekends, bird-watching tours, painting and drawing holidays and motorcycle track days. So, eventually one of these booked activities will be cancelled and we will lose the money, but the cost of this is a relatively low proportion of the cost of all the activity holidays we have enjoyed over the years. Most holidays or activities won't be disrupted. And some activities you can still do, even on IV, once you start to feel better – for example we rode 25 miles to watch the Tour of Britain cycle race this year on our bicycles, even though I was on IV, because I could fit this in between injections and I was already feeling much better than when I started IV. Being fit, I was still able to keep up with my husband and ride quite fast, even though I was a little under par.

## Worried about letting people down

Along with a reluctance to plan anything and commit, you might be worried about letting people down. This can be a particular problem if you are actually organising the activity yourself – what would happen if you got ill and couldn't go through with it? It can also be a problem with team activities, particularly if your place in the team is not secure – dropping out could prejudice your chance of being chosen in future.

This doesn't just affect organisation of exercise activities, but also social activities and anything else. So, do you really want to go through life not organising anything or not

taking part in things because you might let people down on a minority of occasions? How many people let you down? I'll guess it is quite a few, and with much less of an excuse than a flare-up of CF.

People will generally be impressed that you bothered to organise anything, and that you are doing these things with CF. Team sports always rely on having a squad, so your absence shouldn't cause a problem to a properly-organised team, and neither should it be permanent – you are always likely to be called upon again, when somebody else gets injured, or has a hangover or whatever. I have had to pull out of cricket matches due to injury in the past, but have also been called on to play when I turned up to do the scorebook, because somebody else didn't turn up – and I played well, and kept my place in the team!

If you feel you have to let people down frequently, or the chances are high, then you can try and have a back-up plan – for example you might be the leader of a bicycle ride, but if you ride it a week beforehand with another participant then they can be the leader if you get ill in the intervening few days. Alternatively, organise things together with a group of mates – again, if you have to drop out, it isn't a disaster, because several people can help cover for you.

Worry about letting others down shouldn't prevent you participating in group activities, nor should it prevent you taking part in exercise activities – people let people down all the time. Don't be blasé about it, plan as much as you can, have a contingency plan, and keep people informed, and they will usually be sympathetic if things go wrong.

## Disruption to training and exercise schedules

One other problem is disruption to exercise and training schedules, particularly if you are aiming for a special event or competition. Being ill can put your schedule back for weeks or at least days. Also, your health and ability may vary from day to day, and tiredness affect you on days when you are supposed to be working hard or doing a type of training that you find hard.

So, it can be very difficult to aim for scheduled activities, especially when you get to higher levels of exercise, when you need to increase and then reduce training in a set pattern for particular events. It can even be a problem if you are just seeking to be as fit as possible for a holiday or special day.

A lot of coaches, or coaching manuals, for certain sports, lay down specific levels of activity for particular lengths of time on particular days. CF means you can't always follow these plans, either because of spells of illness and IV, or because of fluctuations in how well you are, or how you can juggle CF, work and training. This can be a minor problem, resulting in rescheduling activities in a particular week, or a major problem if you are ill for a while and therefore your fitness levels drop and you have to pick up at a lower level than you were before. It can mean you're not ready, or at least not at your best, for a particular event.

Again, you have to accept that this will happen. Reading the news, disrupted training seems to affect a lot of sportspeople, so you won't be alone. You can try and minimise disruption by trying to avoid the other things that interrupt training, like injuries, and by trying to avoid catching colds.

The important thing is not to let disruption either stop you doing exercise, or stop you working out a plan – but you have to allow your plans to be flexible and realistic. Disruption to your exercise routine may mean that you genuinely aren't able to do some things, or it might just mean that you participate a little below par, but nevertheless can

still have fun. The point is that you are exercising, and fit, so you are better off than if you hadn't done anything, or hadn't been structured about what you are doing.

You do need to be careful when recovering from injury or illness though, and must not overdo things trying to catch up – you won't be able to catch up, you just have to start where you find yourself, and work out a new plan. It can be extremely frustrating to have to do this repeatedly, but what is the alternative? Doing nothing? Being modest in your goals and therefore not getting fit and not being able to enjoy taking part in activities? You have to let it go, let the disruption and frustration wash over you, and then start again, and enjoy climbing back up the fitness ladder.



Riding my Yamaha R1 motorbike on a track day

# Section 10: Coming back after injury or illness

Everybody, with or without CF, will at some time in their life get ill or injured and have to come back from a lower level of fitness than they had before it happened.

This can be extremely frustrating – people who were behind you when you got sick are now breezing along ahead of you with ease. It can also be frustrating when you have to do it repeatedly. Sometimes you feel like giving up, and not bothering, because it seems like such a hard task.

I've had a huge amount of disruption to my activities over the years, due to illness and due to some pretty serious injuries (including a major road traffic accident). Some of these have led to months of relative inactivity, others just a few days.

The most important thing to keep in your mind is why you are doing exercise – you are doing it so you can become and remain fit, and take part in activities you enjoy for as long as possible, at the same kind of level as your friends. *You are doing it to keep well*. You are doing it to prevent your CF being in control of you and your life, and what you can do. So, even if you have had injuries or illness, this remains an important goal, and is the main reason you shouldn't give up, even if at times it is understandable to feel like you can't be bothered to go through it all again.

My point is that it is normal to feel like this, and you need to tell yourself why it is important that you don't give up. What is the alternative? To accept that you will remain unfit, with deteriorating health, and reduced ability to take part in the things that you enjoy with your friends? Do you really want your illness to take control of your life? Or do you want to do everything you can to reduce the impact it has on your ability to participate in and enjoy life to the full? When it is put this way, giving up is not an option.

Another very important thing to remember is that *you won't be starting again from scratch* unless you have been out for a very long time. You will retain a lot of your fitness for weeks or even months of relatively low levels of activity. You will also not forget your sports-specific technique, and that can get you out of a lot of trouble! Indeed, I've found that due to deficiencies in my strength or aerobic capacity because I have CF, I've often had to develop better technique than people who rely on brute force, or sheer lung-power alone. You will need to build up certain aspects of your fitness, strength, stamina and technique, but fundamentally this should not take you as long as if you'd never become fit in the first place.

Here are my general tips for coming back after injury or illness:

### Don't try to come back too soon!

You really shouldn't try to exercise when you are acutely unwell, and particularly if you have a virus infection or a temperature. It will simply prolong the illness, and may lay you open to post viral fatigue. Let the temperature settle first, even if this takes a while, before you try to do anything more strenuous than a gentle walk. It might be frustrating, but trying too early will delay your recovery in the long run.

If you are injured, listen to the physiotherapist or doctor who is treating you – if they say don't bear weight for four weeks, then don't do it! If it helps to satisfy your curiosity, you can certainly ask them *why* you shouldn't do certain things. You can still do some exercises to keep your muscles in trim – ask them what you can do. But don't do things they say you shouldn't.

This applies to minor injuries as much as to major illness or injury. A lot of people try to train with minor injuries and niggles that in the longer-term actually hold them back, and it would be much better to rest up for a week and let a soft tissue injury settle than to try and battle on. This isn't confined to people with CF! If it isn't getting better then get some advice and take some rest. A little break will not harm you!

## How long to get back to full fitness?

I would say, in general, it will usually take you as long to get back to your best as you have been away from training. You can mitigate this to some extent if you are still able to do something while you are ill or injured. And sometimes it will take longer, if your illness has been particularly severe, or the injury has affected a particular muscle group.

So, for example, I broke my collar bone a few years ago. It would be tempting to do nothing, but in fact I spent a lot of time doing weight training with my legs and other arm, and doing some aerobic stepping and walking, so that when I started to come back I was starting from a higher level than if I'd done nothing while it was healing.

Likewise, if you are on IV, it doesn't mean you can't do anything once the immediate episode has started to resolve, and in particular once your temperature has come down and stayed down for a day or two (don't try and exercise with a temperature!).

Even a walk, or a spin on an exercise bike, or a bit of weeding in the garden will help reduce the time it takes you to return to full fitness once you are able to resume your normal level of activity or training.

## How much can you expect to do?

Don't expect to just go out there and do what you did before - it will be different, unless your illness was limited to a few days. You will not be able to go out full blast and sustain it as long as you used to, at least not straight away, and you really should not try. Just as it was when you were first building up your fitness, so you should be incremental now – start low and build up gradually.

The books will tell you that the first thing to go is your strength, then your cardiovascular fitness, particularly for higher effort levels, and finally your endurance. However I haven't found this to be completely true. Although your endurance for lower level efforts will be relatively unaffected, even after months out of training, your ability to sustain higher level efforts, and to put in bursts of strength at the end of a long activity (like a sprint at the end of the race, a hill climb, or a spell of bowling in cricket at the end of a long day in the field) will be the first things to suffer. The best term I have found to describe this is "strength endurance", but a colloquial term for it is "stamina". In my experience, this is definitely the first thing to go.

So, for example, a hill that I would be able to climb relatively comfortably at the end of a 35 mile bicycle ride becomes really difficult if I've been ill – but I still find it relatively comfortable if I reduce my ride to 20 miles. Thus my maximum strength and cardiovascular fitness is relatively intact (this particular hill requires an almost maximum effort) but I can't produce it when I've had to sustain exercise for a long time. This is what I mean by "strength endurance".

Of course there will be a bit of a drop in your cardiovascular fitness, or anaerobic threshold, by which I mean the point at which your lungs and heart can't keep the muscles supplied with oxygen at the same rate as they are consuming it. You will notice this more in some sports than others, particularly those where you have to put in frequent efforts close to this threshold – for example football, where you have to sprint repeatedly from one end of the field to the other. That is why players coming back from injury are often substituted before the end of the match. If you are out for a very long

time, endurance will also suffer, and the length of time you can sustain lower levels of effort will drop.

Because of this, you might think you are making reasonable progress at the start of your first session, and think you are doing as well as you were before – you may be, but it won't last as long, and you won't be able to put in stronger efforts near the end of your training session like you did before you were ill.

So, you will have to reduce either your speed/level of effort, or the duration of your exercise, or both, depending on how long you have been out and therefore how much this "strength endurance" has fallen.

### Start off low and build up

Just as when you are first building up fitness, you have to be incremental. You must start off with gentle sessions to build up at lower levels of exercise, and don't be tempted to put in sessions or intervals of a higher level of effort. If you're like me, you might need to tape up the speedometer on your bicycle, or take other action to avoid working too hard.

A heart rate monitor might help you here, as it will quickly tell you when you are going out of your required zone, allowing you to back off and keep at the level you need. Some exercises, like cycling, present you with involuntary interval training (known as hills), but don't add to this by putting in intervals that you don't need, at least to start with. I'd wait until you are comfortably up to your normal base speed before putting in intervals at higher levels of work. This applies to other sports where the level of effort isn't completely under your control, such as team games requiring intermittent sprints. You could consider cross-training at another sport to do some lower level exercise and build up your "strength endurance" before going back to your team sport, and you certainly shouldn't make things harder than you need to.

You will also need to work on your "strength endurance". What I find best for this is to start off doing something a bit shorter than usual and possibly a bit slower than usual too. Then I gradually build up speed, and add in intervals at higher levels of effort. Then I increase the distance/duration, but drop the speed or level down a bit. Then I add in speed and intervals of higher levels of effort, and finally get up to my normal distance and speed, with some higher levels of punishment thrown in! This works for cycling, but it also works for other sports to some extent – you could take a riser away from your step in aerobics, or do a shorter, slower run, or drop out of a training session earlier, or do a bit less sparring in martial arts, or bowl some of your spin as well as quicker bowling in the cricket nets. The point is you need to set a level, stick to it, and have a plan as to how you will build up.

I would also say you shouldn't try to build up speed/intensity and endurance/duration at the same time – do either one or the other but not both. So, in cycling, you shouldn't increase both the distance and your target speed at the same time – increase the distance, but drop the target speed slightly. You can always increase it again next time out.

If your exercise forms part of your daily routine, like cycling or running to work, then for the first week or two back, you may want to allow more time, or alternatively not run, cycle or walk every day. Take the bus some days, or take the train part of the way and run or walk the rest. Even a routine activity like this may need to be built up again gradually. So, for example, my cycle commute home from the station is all uphill. When I'm fit, it is a breeze. But when I'm not so fit, it isn't – 3  $\frac{1}{2}$  miles of solid uphill gradient is not easy even for a fit person without CF. So I might do it less frequently to start with, or slower, or ride down to the station but get a taxi or a lift back up, or walk back some days, when I can take it easier. It doesn't take long and I'm back to overtaking buses

### again!

## Training alone or in company?

When recovering from injury, I'd be very wary of training with my friends. Don't be tempted to train with your mates unless you can trust THEM not to encourage you to do things that you shouldn't be doing (e.g. sprinting to the cake stop) or YOURSELF not to try and race/keep up when you can't. I don't want to do this and it won't help my recovery. I won't cycle with my husband when trying to come back, because I know I can't trust MYSELF not to try and keep up with him, or respond when he "attacks". If you are the slightest bit competitive, then the first few sessions after your return to training should be solo.

This can be an issue with team games, where the training session is set and you have to follow a pattern. However the coach will know you've been ill and unless he or she has no sense and wants one of their players out even longer than need be, then he or she should help you to adjust your training within the context of the group, in order to get back to fitness and be able to play a full match again. Again, you could start by devising with your coach some exercise you can take on your own, away from team coaching sessions, so that your fitness is already on the way up when you return.

On the other hand, company can be encouraging, and if you choose your activity wisely, then you should be able to benefit from encouragement, rather than find it counterproductive. Your absence from team activities will only need to be temporary and brief, provided you build up sensibly to the level where you can join in again.

## Eat properly

If you've been ill and off your food, and particularly if you have lost weight because you haven't been eating, your strength will be down, and glycogen stores in your muscles will be low. This is one of the reasons why your total peak strength and also your "strength endurance" will be below par. This can occur quickly and with only modest weight losses of 1-2kg.

So, it is important to eat well, and appropriately. You might want to concentrate on replenishing carbohydrate and protein stores after each session more carefully than when you are well, and concentrate on building strength through resistance activities such as weight training in order to build up strength and gain weight faster.

Also, in some sports, like distance running, or gymnastics, where a low weight can be an advantage, there is a temptation not to put weight back on after illness. But you will have lost the wrong kind of weight – you will have lost predominantly muscle bulk and only a relatively small amount of fat. So you still need to eat properly and aim to put on some more weight even if you subsequently train to lose fat and level your weight off. Remember, in most sports it is strength over body-weight that counts, rather than weight or strength alone – so low weight isn't the only thing that matters!

## Avoid making unhelpful comparisons

Don't compare what you are doing now with what you did before your illness or injury, or you'll get depressed, particularly after a long lay-off. It can be agonising watching people you previously beat with ease blasting away from you as if you are standing still. You must not let that get to you. You will have to accept where you are and just set achievable goals, then watch the improvement. Keep writing it down, and then you will get great encouragement when you see yourself improve. It is fine to compare your performance with yesterday, but not with several weeks ago.

So, if you could previously cycle for 35 miles at 14 mph average speed, and you now find that the same level of effort gets you an average of 10 mph over 15 miles, then accept

that as your level, and work on improving your speed and distance (not both at the same time!). Also, don't set an unrealistic improvement for your next session – this will just lead to frustration and lead to you trying too hard and setting yourself back. No point in saying next time out you will improve by 20% (speed or distance) because you won't - the best you can expect is 5-10% improvement. This applies to other sports – for example in weight training, you must be incremental, and build up small percentages at a time – and either increase the weight or the number of repetitions or sets, but not both together.

However, if you do this each time you train, you'll be back to full speed, or full weights, or your top level of performance in a few sessions. Likewise, increase duration by a small amount and you will be amazed how quickly the duration mounts up and gets back to normal levels.

You certainly won't take as long to come back as you did to get there for the first time. If you keep a diary you can see this, and it will encourage you the next time illness or injury strikes.

## Don't try and compensate for lost time

One thing you must not do is try and compensate for time out from a training schedule by trying to do more to make up for it. If you missed 5 sessions because of illness, then don't try and do these in addition to the other scheduled sessions you are supposed to do over the next few weeks – it won't work, and you will just go backwards. Indeed, don't try and stick to the original schedule at all, unless your absence was extremely brief (less than a week).

You will have to go back to a point in the schedule that you can cope with, and then move forward again from there. When recovering from illness the last thing you need to do is try and train more or harder than before. Your training will have to be lighter, at least at first, or you will end up getting demoralised, and tired, and prone to infections, and even getting ill or injured again.

## Concentrate on technique

Good technique can help you get the very best out of your existing fitness. Then when your fitness returns, you may end up faster, stronger, or better than you were before.

# Section 11: Final thoughts

I simply cannot envisage where I would be now if I had not maintained a high level of physical fitness and exercise throughout my life. I can imagine I would not be nearly so well and quite possibly wouldn't be here at all.

Fitness and exercise is so ingrained in me, I cannot see myself ever giving up enjoying activities and training.

CF is a condition that is in control of your life in so many ways and taking exercise is a way of taking some of that control back again, and



Skiing at Courchevel

making a real difference to your ability to enjoy life to the full. Ultimately, it may make your life longer too.

Exercise isn't just about sport, or about athletes, or about competition. It is about being active, and not being afraid to be breathless or of making an effort. You can do this in many ways without doing sports or taking part in competitions – clubbing can be incredibly energetic and you can get surprisingly fit by dancing, provided you don't drink too much alcohol at the same time.

A healthy lifestyle is very important for everybody, but more so for people with CF, who weren't born with the advantage of healthy lungs and digestion. People with CF were, in the past, discouraged from taking part in exercise and sport, and even today, there is surprise when people with CF set themselves challenges and achieve things that many healthy people would find hard.

I have found it extremely beneficial to keep a diary of my activities. There will always be days when you don't feel well, and find it extremely difficult to motivate yourself to get out and do something. That is completely normal, and not confined to people with CF, although de-motivating experiences and recurrent illness may happen more often if you have CF. On those days, looking at the diary can give me enormous encouragement – I can see how I recovered from the last spell of illness, and so I can be confident that I will recover again if I put in a little effort.

Exercise and training is about putting in a little effort to reap huge rewards. Many people with my level of lung function find it hard to walk up a couple of flights of stairs. Indeed, a lot of people with normal lungs who do no exercise also find this difficult. Exercise has allowed me to remain active and fit at the age of 49, and thus to participate in activities that even fit normal people find challenging. Even when I'm ill, I don't suffer so much, and am able to participate in things that, without the benefits of training, I would have to miss.

To me, taking exercise if you have CF is a no-brainer. It is something you simply have to do. It is possible to fit exercise into your life, even if you need IV antibiotics, if you have to do nebulisers, if you have to take enzymes with everything you eat, and if at times your ability to exercise is compromised by illness or injury. It is also possible to stay fit

through a long lifetime with CF – all the pictures in this document were taken after I turned 45 years of age.

You have everything to gain and nothing to lose if you become more active and take up some type of exercise.

Go on, have a go!

# Section 12: Useful Resources

These are some useful, free, web-based resources for sports and exercise, both general and related to CF. Some of these are commercial web sites that also sell information, coaching services, supplements or other products. I can't recommend or endorse any of the commercial content of any of these web sites.

## **Exercise and cystic fibrosis**

The Cystic Fibrosis Trust factsheet about exercise and CF. This is non-technical and relatively non-specific.

www.cftrust.org.uk/scope/documentlibrary/Publications/fs\_Exercise\_March2005.pdf

An excellent review of exercise and cystic fibrosis from the CF team in Manchester. This is technical because it is aimed at professionals, but contains some very interesting and useful information and further references. <u>http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1295056&blobtype=pdf</u>

Another excellent article by the Manchester team describing a trial of exercise training in CF and demonstrating the benefits

http://thorax.bmjjournals.com/cgi/reprint/59/12/1074

The evidence for effectiveness of exercise in treatment of cystic fibrosis is reviewed in the Cochrane Library. This library considers randomised controlled trials only – these are trials in which people are randomly allocated to receive either the study intervention or a control intervention. It does not consider evidence from other kinds of studies. http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD002768/frame.html

## General sports and fitness training information

#### **Peak Performance**

This is a commercial web site, and products are offered for sale. However there is a great deal of free information also available on this site, including a lot of information about general and sport-specific fitness and training. Click on the specific links to access the information that you require. http://www.pponline.co.uk/

#### **Sports Coach**

A very similar site to Peak Performance, with commercial and free information available on a variety of sports and fitness topics <a href="http://www.brianmac.demon.co.uk/">http://www.brianmac.demon.co.uk/</a>

#### **Surgery Door**

Has some useful free general information about sports and fitness in a question and answer format. Some items on this site are sponsored or you have to pay for them. <u>http://www.surgerydoor.co.uk/sportfitness/detail1.asp?level1=Introduction</u>

#### **Physio Room**

Sports injuries site with some sports specific advice around injuries and recovery. They also sell Maxim sports drinks and energy bars and a lot of other products besides. http://physioroom.com/index.php

#### **Sports Injury Bulletin**

Another site with free information mixed with commercial products, but quite a lot of useful advice about avoiding injury, and some sports specific guidance too <a href="http://www.sportsinjurybulletin.com/">http://www.sportsinjurybulletin.com/</a>

## **Personal accounts**

A fantastic and moving story of Faye Goodwin, a young woman with CF who continues to swim, taking her oxygen tank with her. A demonstration that being ill, and requiring oxygen to take exercise, is not an excuse to do nothing. http://news.bbc.co.uk/1/hi/health/5241252.stm

Lisa Bentley's account of being a professional triathlete with CF <a href="http://www.ccff.ca/page.asp?id=237">http://www.ccff.ca/page.asp?id=237</a>

## Energy bars and electrolyte drinks

**Science in Sport** – this is what I use. I have no commercial interest in this company whatsoever, I have just used the products and found them to be helpful. <u>http://www.scienceinsport.com/</u>

# Appendix: Heart Rate Monitoring

In section 3, I described five different levels of exercise in terms of the general effect that they have on the way you feel, and your ability to breathe and speak during the exercise. This is a reasonably good way of telling how hard you are exercising, and you don't have to buy a heart rate monitor in order to benefit from training, or to structure your training according to different levels of exertion.

However, if you have difficulty knowing how hard you are working, or if you want to be more scientific about how you train, then a heart rate monitor can be helpful.

Heart rate monitors consist of two parts – a watch-sized device that you wear on your wrist, and a sensor that you place round your chest near your heart, that can detect the heart rate. This sensor then transmits that information to the watch, giving information about the current heart rate, average heart rate, which zone you are in, and so on. Different monitors have different and more sophisticated features, but a simple heart rate monitor that just shows your current heart rate can still be helpful, and need not be expensive. Entry-level monitors cost under £30.

## Calculating your maximum heart rate

The first thing you need to do in order to use a heart rate monitor is to calculate your maximum heart rate. There are essentially two ways of doing this:

- a) Use a mathematical formula
- b) Take a maximum exercise test

A lot of exercise and sports web sites give information about how to conduct a maximum exercise test. However, I would definitely not advise that you do this without professional supervision if you have CF. A maximum exercise test is very hard work, as anybody who has ever done one will attest! More importantly, if your lung function is moderately or severely affected, such a test can cause the oxygen levels in your blood to fall to very low levels, and also the carbon dioxide levels to build up. Therefore this is not something you should try at home. Therefore you should start off by calculating your maximum heart rate using a formula.

There are several formulae available, the commonest and simplest being that your maximum heart rate will be

- a) 220 minus your age if you are male or
- b) 226 minus your age if you are female

As with all formulae, this is based on knowledge of what the average person of your age can achieve, and you may find that you fall to one side or other of the average. In terms of setting limits for lower levels of exercise, however, it is a good place to start.

### **Exercise levels**

The next step is to work out the heart rate associated with different levels of exercise. You can work out the range of heart rates associated with the different levels of exercise by calculating the heart rate associated with different percentages of your maximum heart rate. This is personal to you, so you must work out your own zones, although there are a lot of online calculators available to help you with this.

#### Level 1: Fitness Level

This is associated with 50-60% of your maximum heart rate. This is relatively easy exercise, and although your heart rate will be raised from its resting level, it will not be raised very far, and your breathing will not be noticeably hard. You will not be getting sweaty and hot, and you should be able to talk in normal sentences without difficulty.

### Level 2: Fat-burning Level

This is associated with 60-70% of your maximum heart rate. You will notice that your breathing is heavier than normal, and you may get warm, but you should still be able to carry out a conversation.

#### Level 3: Aerobic Level

This is associated with 70-80% of your maximum heart rate. Here you will really be working hard, and should only be able to say a few words. You will definitely be getting hot and sweaty.

#### Level 4: Anaerobic Threshold

This is associated with 80-90% of your maximum heart rate. You will not be able to speak, and will be working very hard. You can only sustain this for a minute or two at the most before you have to back off.

### Level 5: Anaerobic or Maximum

This is associated with a heart rate over 90% maximum. You can only sustain this for a very short time because at this level your muscles are consuming oxygen faster than it can be supplied by heart and lungs, and eventually will accumulate lactate and you will have to stop because of the pain.

This is a summary of my heart rate zones, based on the above. My resting heart rate is 64 beats per minute, and my maximum calculated by the formula is 176 beats per minute. **Remember that you will need to calculate these levels for yourself** based upon your own maximum heart rate. Don't use mine!

| Zone                                      | Lower Limit | Upper Limit |
|---|-------------|-------------|
| Level 1: Fitness (50-60% max)             | 88          | 106         |
| Level 2: Fat-burning (60-70% max)         | 107         | 123         |
| Level 3: Aerobic (70-80% max)             | 124         | 141         |
| Level 4: Anaerobic Threshold (80-90% max) | 141         | 158         |
| Level 5: Maximum (>90% max)               | 158         | 176         |

## Check that these zones correspond with perceived effort

Some people find that the description of the heart rate zone doesn't match with how they are feeling at a particular heart rate. This will vary to some extent from day to day, and also with how you are feeling. It will also vary from sport to sport – you will be able to sustain higher heart rates when doing a familiar exercise than with an unfamiliar one. Very fit people, who have been exercising all their life, will usually find that they can sustain a higher than expected maximum heart rate for their age, so the zones will need to be adjusted upwards, or they will seem too easy.

You should test this out by using an exercise bicycle or treadmill. Start cycling or walking until you are just below the threshold for Levels 1, 2 and 3 – for me, I would need to take my heart rate just over 100 beats per minute to get near the top of Level 1. Then see whether your perception of the effort matches the description. If it does, then the zones are about right. If it seems too easy, or alternatively, too hard, then you may need to adjust them a little. You should not extend this test beyond Level 3 without professional supervision, particularly if you aren't used to doing exercise.

Different formulae exist such as the Karvonen forumla, that give slightly different results, particularly for higher levels, and you may find these correspond better to your perceived effort. If that is the case, then use them. I have used the simple formula because it gives more conservative results, and is likely to be better for somebody who is just starting out.

## Use your heart rate monitor in training

Now you know the limits for Levels 1 and 2, you can make sure that you keep most of your training in these zones. If you are starting out, all your training should be in these two zones. You can gradually introduce some Level 3 work once you have a base of fitness, a few weeks after you have started training. You should wait a few more weeks before attempting Level 4 exercise. Remember that you should spend most of your time exercising at Levels 1 or 2, even if you are already fit.

# Useful web sites

## Heart rate zone calculators

A simple calculator based on the simple 220 minus age formula <a href="http://www.heartmonitors.com/zone\_calc.htm">http://www.heartmonitors.com/zone\_calc.htm</a>

Another calculator, this time using a different formula that takes into account your resting heart rate. This will usually give higher upper limits for the zones, and is therefore better for people who are quite fit, and have been training for a while. http://www.fitzones.com/heartratecalc.htm

A calculator that provides estimates based upon both the simple and the more complicated formula, allowing you to see how they differ. If in doubt, use the simple formula, at least to start with

http://www.ottawarun.com/heartrate.htm