

**Exercise & Cystic Fibrosis:
A Physiotherapist's Perspective**

By Peter Anderson, MCSP

In Edition 2 of the CFW Newsletter, I wrote an article entitled "Chest Physiotherapy: Who Needs It?" In that article I mentioned the importance of regular exercise in managing CF. I was contacted by a number of people asking about specific advice on this topic. So in this article I will go a bit deeper into why exercise is particularly important to people with cystic fibrosis, what types of exercise you should do, how your physiotherapist can help and how you can help yourself. Since writing the previous article, I have moved from working with adults with CF to working with children with CF, so I will try and outline the different approaches to promoting exercise in both children and adults.

It was not too long ago (up to the 1970s) that people with cystic fibrosis (PWCF) were actively discouraged from exercise, the thought being that the strain of it and the breathlessness it caused would be too much for them; that their lungs just couldn't cope with it and possibly somehow cause more damage. We now recognise the exact opposite to be the case, and exercise is actively encouraged in PWCF, even during infections.

We know that PWCF who keep fitter cope better with the impact of CF, have fewer infections and generally have longer, healthier lives. You may think that being fitter is simply an indication that you suffer from less severe CF in the first place, but as I mentioned in my last article, breathlessness can develop in PWCF independent of whether your lungs are in good condition or not.

It would seem obvious that the more damaged your lungs are, the more difficulty you will have with everyday tasks and the more breathless you will become. However it is not as simple as that. A life of inactivity can be the primary cause of breathlessness during daily activities and this process can in fact be the precursor to infection. Damage to the lungs caused by repeated infections will cause increased breathlessness that in turn leads to anxieties about your ability to exercise. The progressing inactivity this causes can in turn can lead to more infection. It can be the fear of

exercise and breathlessness that drives this process. If you think you could be more active, your physiotherapist will be delighted to offer help, advice and monitoring to make sure you are getting the best you can from your efforts.

In children with CF, it is not too difficult to keep them exercising. They should be encouraged to participate in all the activities that any child would do as they grow. Soccer; swimming; hockey; basketball and any sport that is aerobic based (e.g. makes you breathless) are to be particularly encouraged. Other activities such as martial arts and dancing also have the same effect. More and more, physiotherapists are incorporating physical activity into the chest clearance regime. Vigorous activities that change how you breathe (like the trampoline for children) can be very effective at helping to clear mucus from the lungs, especially when some chest clearance techniques like Positive Expiratory Pressure (PEP) Therapy or Autogenic Drainage (AD) is performed for a short time afterwards. This is true for children and adults; (your physiotherapist can give you more information on these techniques). I tell the young children I see that their parents are not allowed to give them trouble for bouncing on the bed at home! Of course they think this is great, but I'm not so sure their parents do!

As we get older and into teenage years, exercise levels tend to drop off. Time spent with friends, for example, tends to move away from playful activities to more sedentary pastimes. As you move through school there may be less emphasis placed on physical education and more on academic studies. When you leave school regular exercise may stop all together. As you become more independent your parents are less likely to be taking you to soccer training or swimming practice, for example. This is true for PWCF as well as the general population. So it is at this time in particular where specific advice and help from your physiotherapist is especially helpful.

All treatment centres will try to carry out annual exercise tests; certainly in the United Kingdom it is part of our physiotherapy clinical guidelines. (There are many factors that may make this difficult to carry out in particular centres however). Over time, exercise testing will give us a clear idea of how CF is affecting your ability to cope with everyday activities. Annual exercise testing help the physiotherapists' identify those people who may require

specific advice on how to improve exercise tolerance and lessen the impact that CF has on their quality of life.

Regular vigorous physical activity, however, will provide the maximum potential benefits to you in terms of general health and managing cystic fibrosis. I will go on to outline how you can go about this.

What types of exercise should I do as I get older?

It is a general rule of thumb that if your lung function is about 55% of normal or above, you should be able to exercise much the same as the rest of the population without the need for specific advice, although of course your physiotherapist will be only too happy to help you if you wish.

Most research on exercise tells us that a combination of aerobic exercise (cycling, running, swimming etc.) and muscle conditioning (e.g. light weights) produce the best results. Most physiotherapists will concentrate on advising and helping with aerobic exercise, as this can be the most difficult to motivate yourself to do regularly. An exercise regime that does not include regular aerobic training is going to have limited benefits for the vast majority of PWCF. I have outlined below the general advice on how to carry out regular aerobic activities.

How long should I exercise for?

Physiotherapists call this exercise *duration*. The advice given for exercise duration is not any different from anyone else. Aerobic exercise should last for at least 20-30 minutes at a time.

How often should I exercise?

Physiotherapists call this exercise *frequency*. Again the advice is not any different from anyone else. Three sessions per week has been shown to produce optimum results.

How hard should I exercise?

Physiotherapists call this exercise *intensity*. You may see people taking their pulse to see how fast their heart is beating during exercise. What you should be looking for is for your heart rate to be within a certain target. Your physiotherapist can tell

you what this target should be for you. If you want to work it out for yourself, it is a simple calculation;

Working out target range;

- This target is usually between 60% to 80% of how hard your heart can work, (or your **maximal heart rate**).
- You find out a rough guide to your maximal heart rate by subtracting your age from 220. (e.g. a 20 year old will have a maximal heart rate of 200)
 - 60% of 200 is 120
 - 80% of 200 is 160
- So target pulse range for a twenty year old is 120-160 beats per minute
- It is very simple to learn how to check your pulse. Ask your physiotherapist to show you.

*This formula does not suit all patients, as some are not able to increase their heart rate to these levels. CF patients should discuss their individual target with their CF physiotherapist.

Adjusting exercise for more severe disease

If you suffer from more severe or more advanced lung disease don't think for a minute that regular exercise is not for you, even if you require oxygen. Your physiotherapist will adjust exercise **duration; frequency** and **intensity** in order to meet your particular needs. If your lung function is less than 55% of what it should be, it is advisable that you discuss it first with your physiotherapist before starting, but I will give you some examples of how we adjust exercise to fit individual requirements. Physiotherapists call this process **exercise prescription**.

First of all you can decrease **exercise duration** and increase **frequency** if you find it hard to exercise for too long at one time. For example, instead of exercising for 30 minutes at one time, you can do three 10-minute sessions spread across the day. One of the things I sometimes suggest to get people started is to do 2 sessions per week, then increase this to 3 when you have established a routine.

You can also adjust how you monitor **exercise intensity**. You

can do this by using how breathless you get with exercise instead of your target pulse range. Your physiotherapist will teach you how. As a guide you should only work until you feel *moderately* breathless. That is, any exercise should make you breathless enough that you can still speak and that you feel in control of your breathing at all times. If you become more breathless than this during exercise you should slow down or stop and only restart when you have recovered. It is important to give yourself enough time to recover, so you don't need to stop again too quickly.

Your physiotherapist can also teach you breathing techniques to help you recover your breathing, but the best advice is not to become too breathless in the first place. Some of this might seem quite complicated, but your physiotherapist will obviously only give you the advice that is specific for you and make it much simpler.

One of the main reasons I have found that people with more advanced disease avoid exercise is because of their fear of breathlessness – the fear that somehow they won't get their breath back again. Often they may feel they do not want to discuss these fears, but if you can talk through these feelings with your physiotherapist and get started on a regular exercise programme you will find that your breathlessness should start to improve and you'll be gradually able to do more. The less breathless you become, the less anxious you will be and you can start to build your confidence. Your physiotherapist will prescribe an exercise programme that will be targeted at your ability and needs. If you are in hospital, the physiotherapist will likely be supervising these sessions, which often helps you get started and gives you the confidence to carry on at home.

I have also found that some people who become very breathless when they exercise can be quite selfconscious. This can be one of the reasons they avoid going out shopping or socialising – not necessarily the fear of becoming breathless. Again your physiotherapist can give you advice on controlling your breathlessness so you feel more in control in these situations.

Should I avoid exercise if I'm having trouble putting on weight?

The answer to this is no. Obviously over exercising in order to lose weight is a very bad idea, but following a sensible programme can actually help you put on weight.

Exercise can produce a sense of well-being and help stimulate your appetite. The key is to get proper advice, which may include discussing the possibility of diet supplements.

What about replacement of salt, electrolytes and fluids on hot days in summer?

People with CF lose excessive salt and electrolytes in sweat. Therefore, if you are exercising in the heat of summer, you need to replace them while drinking extra water. Replacement can occur in different forms for example salt tablets and some sports drinks. Ask your nutritionist and physiotherapist about the best way for you to avoid dehydration and heat exhaustion. Sometimes excessive lethargy and fatigue can be the result of dehydration and salt and electrolyte depletion.

Summary

We know that a sedentary lifestyle has a significant negative impact on quality of life and health issues for the general population, but it can also have a significant impact on the disease path of CF as you get older. As the majority of PWCF now go on to lead productive lives well into adulthood, planning for further education and careers beyond schooling is something that is now very important. This is for reasons of self esteem, but also because it is the first step in leading an active lifestyle.

You will find that increasingly, more and more emphasis is placed on exercise and activity. Your physiotherapist will be delighted to give you the necessary advice on this and monitor progress, both in the hospital and in the community. It will no doubt take some time for resources to become available to meet these aspirations. Hopefully the information I have provided here will give you an idea of how physiotherapists think when prescribing exercise for PWCF and what you can do for yourself to provide some guidance to those who may not have easy access to a physiotherapist. Also keep in mind that there may be issues other than CF infringing on your ability to exercise regularly that you may need specific advice on, for example if you are also asthmatic you will need advice on controlling this during exercise. Whenever possible seek the advice of your doctor, nurse or physiotherapist when thinking about exercise.

Nobody is suggesting that taking up regular exercise is particularly easy, especially if you suffer from a chronic

condition like CF, but the potential benefits of doing so make it important to consider. As physiotherapists, we are here to help and advise you (as well as to provide therapy when needed of course). It is your decision as an individual what to do with that advice, but your physiotherapist will support you in any way they can to help you lead as normal and active a lifestyle as possible. Regular exercise is crucial in achieving this.

Peter Anderson graduated from Queens College in Glasgow, Scotland and specialized quite quickly in Respiratory Care. He developed Pulmonary Rehabilitation Programs in Glasgow and began working with adults suffering from CF. For several years he was the Senior Physiotherapist in the West of Scotland Adult CF Unit. After several years working away from CF, he is now clinical specialist physiotherapist in the Paediatric CF Unit in Yorkhill, Glasgow.