

BODY IMAGE

A CYSTIC
AND FIBROSIS

PORTS, PEGS
AND SCARRING

TATTOOS

WEIGHT

POSTURAL
CHANGES

**Cystic
Fibrosis Trust**

Cystic Fibrosis Trust

This booklet was originally written by Jacqueline Didsbury and Emily Thackray in 2010 and was updated in 2019 by Jacqueline and the Cystic Fibrosis Trust. This booklet contains quotes from people with CF from the original booklet, and these are marked with the individual's gender and age. Recent quotes are marked with initials.

The Trust is grateful to all the people who have shared their stories and given up their time to review this booklet. Sincere thanks must also go to the CF professionals who contributed their expertise and time to its development - we would not be able to produce resources like this without your help. Thank you.

Disclaimer:

This booklet contains quotes from people with cystic fibrosis about how they have dealt with body image issues, based on their own individual experiences. These quotes, and the overall contents of this booklet, are not intended to replace any advice you may receive from your doctor or CF multidisciplinary team. If you have any questions or concerns about the issues raised in this booklet, or about your own CF care and treatment, you should always speak to your specialist CF team.

“I would like to dedicate this updated booklet to my co-author and dear friend Emily Thackray. Emily sadly passed away in 2014 but she would have been delighted that her original ideas have been given a new lease of life. She continues to inspire me each and every day.”

- Jacqueline Didsbury



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INTROD

Body image is about how you view your physical self, and how you feel others see you. Body image may be influenced by many factors: individual thoughts, beliefs, feelings and behaviours about our bodies, what we believe counts as the ‘ideal body’ (which we learn from our families, culture, society and the media), and external factors like illness, accidents and disability that can change how our bodies look or what they can do.

There are many things that may concern us about our bodies: hair, lack of hair, face and body shape, height, weight, teeth, physical disability, size of breasts, scarring, body odour and countless other things. But it’s not just about the way we look in the mirror. People, with and without cystic fibrosis (CF), often view their reflection through their own personal lens that is made up of lots of other expectations and beliefs. Ideas of beauty vary across the world and through different times in history, and some people may view their body through the lens of current ideas of beauty, rather than just seeing their own reflection.

“I AM A HUMAN BEING WHO HAS HER MOMENTS OF INSECURITY, I THINK WE CAN ALL AGREE THAT WE ALL HAVE THOSE MOMENTS.” (LD)



UCTION

Society bombards us with images of 'beautiful people'. TV shows, social media, adverts and magazines focus relentlessly on images of tanned, muscular, slim, toned people with perfect skin and hair (and often ridiculously white teeth). We know that these images have been airbrushed and heavily altered to create the 'perfect' impression. We know that people just don't look like that. But what's also important to think about, is why we would want to replicate these looks. What is it about these images that makes us believe that they constitute 'beauty'?

It can be a bit of a battle to push against this societal pressure to look a certain way. Having a positive body image is a good start, but it's often easier said than done.

Being positive about your body isn't just about liking the way it looks. It's more than that. It's about appreciating and celebrating all that our bodies do for us; their strength and achievement even in the face of adversity. It's also about finding ways to accept aspects of our bodies that perhaps aren't to our liking but can't be changed. It's probably not realistic to be completely satisfied with your body throughout your life;

it's unlikely that many people achieve that. But learning to accept it and see your body as beautiful in its own way can be very powerful and liberating.

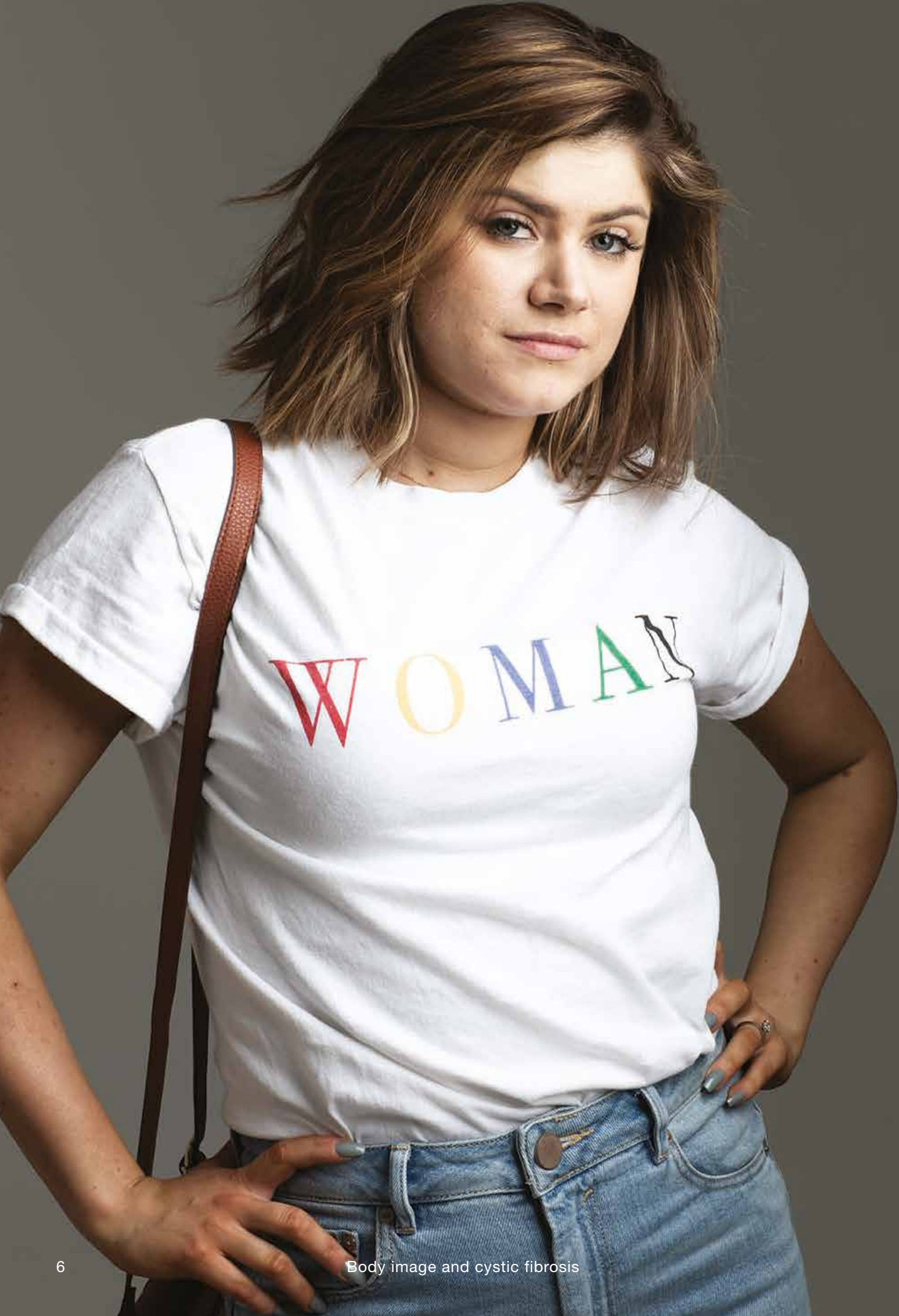
“IT MIGHT NOT BE POSSIBLE TO UNDO A LIFETIME OF SOCIETY AND MEDIA MESSAGES ABOUT WHY OUR BODIES ARE NOT OKAY... BUT WE CAN START TO SEE THE BIGGER PICTURE, TO UNDERSTAND HOW TO CHALLENGE MYTHS ABOUT BEAUTY AND DIETING AND SEE HOW REJECTING SOCIETY'S IDEALS COULD MAKE US STRONGER AND MORE CONTENT.”

(CF Psychologist)

The way we feel about our bodies can change over time, in different situations and contexts and, even if we are not always satisfied with our bodies, they may not cause us too many problems. Body image can become a problem if the way you feel about your body is consistently negative and you, or someone close to you, notices it affecting your mood, health, work, study or relationships. If the way you feel about your body is having a negative impact on any of these areas of your life, you should speak to your GP or CF team for help. If you are losing weight, lying about eating, eating a lot

very fast or over-exercising you should also seek professional help, as these are signs of an eating disorder.

This booklet will highlight some of the body image challenges and solutions that people with CF have told us about, as well as offering suggestions for further support and information.



CYSTIC FIBROSIS AND BODY IMAGE

Cystic fibrosis can present specific challenges to body image through the way the body develops, looks and functions, and the impact of treatments. But it's really important to remember that CF is also an extremely variable condition. It's wonderful that with improving treatment and care, some people with CF are able to undertake great physical challenges, maintain ideal weight and muscle tone and may look really quite untouched by the condition. But this isn't the case for everyone at all, with many people experiencing a range of physical and psychological difficulties associated with CF, which can then have a significant impact on their body image and self-esteem.

“There is a huge external pressure to be ‘bigger’ as a guy in the 21st century! This is because of social media expectations of ‘beauty’ and that men need to be ‘big and manly’. For me personally it has always been more about my own body image and feeling healthy with myself whilst coping with the challenges CF has created. My advice to anyone else is to do the same; remember that societal expectations are a false mirror of beauty and you do not need to compete with the impossible challenge of looking beautiful to everyone. Just try and be comfortable with yourself. Health comes first!” (JH)

Some people with CF have said that they have been made to feel that their focus should be only on the function of their body and that, in some ways, wanting to look their best rather than just wanting to be alive might be seen as shallow. Positive body image and body confidence for many people are important factors in their quality of life and shouldn't be undermined. Positive body image helps us to appreciate our bodies as a whole and to feel more positive about ourselves generally.

“Think about the last time you put effort into your hair, clothes, or style. How did this make you feel? Was this for a special occasion, or would you do this every time you leave the house? Paying attention to how you present yourself can be very empowering and have a positive effect on mood. It is also important that some of your positive body image comes from considering your body's strengths as well.

“Working on having a healthy body image when you have CF is an essential part of staying well. Treating your body with respect and kindness might include beauty treatments and paying attention to style, as a daily routine. However, feeling comfortable with and accepting how you look will also help you to maintain a healthy weight, by eating well and managing treatments that affect weight like Creon™ and insulin.” (CF Psychologist)

“One of my main concerns is my hair and skin. My hair is really fragile, I think because of vitamin deficiencies, and my skin can be really dry. I also feel that sometimes my face looks very pale, or if I've had any liver issues, a bit yellow. I spend a lot on cosmetics, moisturisers and exfoliators to make my outside look 'less ill'. I sometimes feel that people might think I'm a bit superficial, like somehow I should just be grateful to be alive, but it matters to me and I want to look nice.” (FC)

“People hear you have CF and expect a certain person with certain characteristics, which I can't stand. I want to be recognised for who I am and not be defined by my cystic fibrosis. So I do make a real effort not to look ill – because although I do have a disability I don't want people to see that and make judgements.” (GEV)



**“ MY
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(OR)

BODY SHAPE

Cystic fibrosis is often considered an ‘invisible disability’ because visually it’s almost impossible to tell that someone has the condition. However, as you will know, CF can have an impact on how you look, particularly in relation to body shape.

Body shape can be very influential on body image. Lots of factors influence body shape, including genetics, weight, posture, muscle mass and bloating, and CF can affect many of these.



WEIGHT

Although weight isn't the only factor in your body shape, it often gets the most attention if you have CF because, as you know, a higher body mass index (BMI) is associated with better health for people with cystic fibrosis. Achieving and maintaining an ideal weight can be challenging for some people with CF for several reasons. Loss of appetite and pressure to maintain or gain weight can make eating more of a chore than a pleasure, and the added issues of feeling breathless when eating, or the loss of taste through sinus problems, can further increase the sense of effort involved. Weight can also be heavily associated with how people feel about their body shape, and this applies to people with and without cystic fibrosis. The need to have a healthy BMI can be challenging for some people with CF, who may feel comfortable with a body with a low BMI.



PERCEPTIONS OF WEIGHT

There is a difference between actual weight and perceptions of weight. Weight and BMI are simply numbers, though they are, of course, very important indicators of health in cystic fibrosis. However, the way that people feel about their weight is quite different and what someone is comfortable with may not relate to what the numbers say is 'healthy'. It's likely that other influences, such as social media, advertising and other external sources, influence our perceptions of weight.

“I’ve been thin for my whole life. At college, I got lots of compliments on how ‘skinny’ I looked. People would say things like ‘I’m so jealous, I wish I was as skinny as you’. It felt really good and I got a real confidence boost; I felt like a normal girl in college, not someone with a life-limiting condition. I started to gain weight because my team wanted my BMI to be higher to support better lung function. My team were delighted when I started to increase my weight, but when I looked in the mirror I hated what I saw. My clothes didn’t fit and I felt like I had a noticeable tummy, but when I mentioned it people would just say ‘You are not fat!’ or ‘Shut up, you’re still skinny’. To me, though, I didn’t see what everyone else saw. My teenage years and young adult life I always looked a certain way and I liked the way I looked, so it was difficult to come to terms with a new body shape. I’m still not quite there yet.” (ID)

“I do think I’m bigger than I am, and I no longer look like the media perception of the ideal figure. However, whenever I’m unhappy about it I remind myself that my weight has kept me out of hospital, enabling me to enjoy life a lot more.” (Female, 26)

“I achieved a BMI of around 20 for the first time. I felt enormous, although in reality this is just bordering on a normal weight.” (Female, 31)

“I probably do have an altered body image; I know I’ve thought I’ve been a size 10 before and it was a shock when size 6 jeans were too big. When I went into hospital about a week later, seeing myself in the full length mirror was a shock!” (Female, 23)

Generally, it is thought that women with CF are more likely to think they’re overweight, even when their BMI is normal, and men with CF are more likely to identify as being underweight, even when their BMI is normal.

This gender difference may represent the cultural stereotypes, reinforced by the media, that females should be slim and males should be big and muscly. Studies have found that thin females with CF were happier with their shape and weight than females without CF, yet males with CF reported being unhappy and desired to be heavier. These altered perceptions may not be unique to CF but are important when considering how we assess our own body image.

It is very difficult to change how we think, feel or behave if we are constantly unkind to ourselves. In addition, sometimes feeling ‘fat’ or ‘too skinny’ can be used to label feelings or emotions that are otherwise difficult to describe, such as sadness, frustration, fatigue or, in CF, discomfort after eating. It can be helpful to explore what might underpin feeling ‘fat’ or ‘skinny’ and work on ways to cope with these feelings.

Psychologists may use various talking therapies to help you. See the story below for an example of talking therapy, or ‘narrative therapy’, a particular way of talking about problems that helps to separate the problem from the person, thereby allowing the space and perspective to make changes.

“I felt narrative therapy really helped. I externalised my problems with eating and learned to shut them out behind walls. For example, at first I saw having insulin through my pump as a scary-looking creature, a bit like a dementor from Harry Potter, draining the life from me. I also created ED, who was a cheeky, mischievous elf – he was the personification of my fear of eating, and was light-hearted, unlike the dementor. These personifications really helped me; I find when a problem becomes something you can imagine outside of you, it’s easier to tackle, easier to shut out. I also found being honest with my team helpful. Their support and understanding made the situation less stressful; having people to be open with and not being judged. The people closest to you aren’t always so understanding.” (AM)

LOW BMI

Some people with CF have a low BMI despite really trying to get their weight up, while others have a low BMI for a variety of other reasons including a lack of appetite, not taking Creon™ or insulin or because of challenges with their relationship with food.

“As a young girl I never really concentrated too much on my appearance and I always had a little bit of meat on me as a teenager. But as an adult, I’ve found it difficult to put on weight. It gets trickier when you’re running around working and looking after a family, so you don’t have as much time to focus on what you’re eating day to day. Cystic fibrosis has impacted on my body image negatively and has affected me in small ways such as me opting to wear a swimming costume rather than a bikini so people can’t see my ribs. It sounds silly but I actually enjoy it when I get bloated from the side effects of Creon or eating a lot of food. But I’m learning to appreciate my body for what it is and learning to love myself regardless of how my body looks, because at the end of the day it’s getting me through this thing called CF!” (BP)

“Around age 16 I really started to resent the constant pressure to eat and constant monitoring at hospital visits. I think at that point some of the pleasure of eating disappeared.” (Female, 31)

“My struggle to gain weight has always been an issue and apart from anything else it’s expensive! I spend most of my income on fatty food just to maintain my little physique. It’s not all negative though, I have a six pack from coughing so much!” (OR)

“I was a lot smaller than my peers at school and that was difficult, especially as a teenager. I worked harder than anyone else at PE but I still wasn’t getting the desired results. I was also teased and all of that really impacted on my body image and self-esteem. I’m 33 now and although I’m much less concerned about what other people think about how I look, I still don’t wear shorts and instead choose baggy clothes that hide my body shape.” (DC)

“Keeping weight on has been a HUGE issue to me and a problem I have dealt with through all my life. I was taller than nearly all children in my class at school which led to a lot of remarks about being ‘tall and skinny’. I hated being called skinny and even to this day, I still get really upset if I’m called skinny. On an average day, I am eating around 4,000–5,000 calories to keep my weight up.” (JH)



“I was on the very-skinny side until my mid-20s. I went through a period where I really wasn’t comfortable with myself, or the way I looked, and even now there are things I’d like to change, like the size of my arms, which I feel stem from being so skinny when I was younger. I try to avoid taking my shirt off in public too, if I head to the beach or go on holiday, because I still see myself as incredibly skinny sometimes. I feel like the only reason I’ve got past these issues is because I’ve gotten older and realised it’s just who I am. It’s how I look. This is me. Which is incredibly cliché, but it’s true.” (MT)

The inability to gain weight can be frustrating and disheartening. Some people also report finding it difficult to cope with people’s reactions, especially the idea that they are ‘lucky’ to be thin, or paradoxically, the way people circumvent social norms by commenting when they do gain weight.

“I find it hard to explain to people who say things like ‘Oh you are lucky to be so thin’ exactly how difficult it is sometimes. I wish that maintaining a good weight was not such a huge component of my life. I hate getting weighed at clinic for this reason.” (Female, 31)

Balancing the multiple factors associated with maintaining an optimum BMI, like Creon™, insulin use and good nutrition can feel like a full-time job for people with cystic fibrosis. It might be helpful to work with your dietitian to set realistic goals and tackle one thing you’re struggling with at a time. It might also be helpful to have regular check-ins to help you stay on track.

EATING BEHAVIOUR

There have been studies looking at eating disorders amongst people with CF, and although most have not found an increased incidence of anorexia and bulimia, there has been an increased incidence in abnormal eating behaviour with similar features to these conditions.

“Concerns about body, weight and eating may lead to people with CF doing things that may be harmful, like restricting food, bingeing and then missing Creon™, not taking insulin and misusing laxatives. Often, people also feel guilty or ashamed about this and work hard to hide these behaviours from their CF team. You are not alone, and finding someone you trust and can speak to is an important step to making a change.”
(CF Psychologist)

People with CF probably have more means available with which to control their weight, although paradoxically they may be prevented from developing eating disorders due to close medical scrutiny of their weight.

“I have on occasions skipped insulin and steroids to prevent putting on weight. I have always been extremely involved with my care and am aware of the dangers of skipping medication, so along with the weight issues I am always riddled with guilt about it.” (Female, 26)

“I was bulimic in past years. I think without the CF I would have issues with body weight anyway, but I do think having CF makes it so much harder.”
(Female, 18)

“When I was a child, my dietitian at the clinic in Europe where I was treated had a real emphasis on just getting the calories in. She was happy, in fact she encouraged me to eat McDonalds regularly and as a result I put on ‘bad weight’. I was overweight at school and as a result I struggled with my self-esteem and developed a bad relationship with food. When I went to university, I then had a time when I just really wanted to be ‘skinny’ and I was also just done with the stomach aches and hassle. So I did lose a lot of weight, partly from just not eating but also not taking Creon™. Having CF made it much easier to hide my eating behaviours.” (FC)

Although most people with CF would not be classified as having a diagnosis of an eating disorder, any abnormal behaviours such as restricting food and missing treatments in order to control weight can be very damaging to long-term health. It is important to confide in a member of your CF team if this affects you, to prevent harm being done and to help improve negative body image.



OURS

SUPPORT FOR SETTING GOALS

- Agree a target weight that you are happy with. This might have to be a compromise between you and your team, but it is important you are in agreement, so you can work towards this goal together.
- Set lots of small goals, such as 'increase weight by 1kg,' and then assess how you feel. This can make the prospect of reaching your target less daunting.
- Psychology services will be available through your team and you might find it useful to talk over any fears you might have about gaining weight.
- Many people worry about the health effects of a high-fat diet. Healthy eating choices can still be incorporated into your diet, even if your calorie requirements are increased.
- Contact your dietitian to discuss how to meet your individual dietary needs. You can use healthier monounsaturated oils for cooking (eg olive, rapeseed, peanut), olive oil spread and still include fruit and vegetables in your diet.
- Try to focus on the longer-term benefits that weight gain could have on your health, and the positive effects this could have on your life. People often find once they have actually gained weight, they feel better and can view themselves in a different light.
- Muscle mass weighs more than fat and has been shown to have a beneficial impact on lung function. Consider working with your dietitian and physiotherapist on exercise and the correct nutrition to increase your muscle mass.



HIGH BMI

Although some people with CF are underweight, this is not always the case. There are many reasons that contribute to people with CF being overweight and those who are may have different body image issues and require personalised advice.

Many people find that they gain weight following a lung transplant. This can be due to many different reasons such as increased appetite with steroid treatment, or just enjoying food more. Depending on your BMI before transplant this can either be a positive or negative experience.

WHAT CAN I DO ABOUT MY WEIGHT?

Whether you need to gain weight or your team have suggested you lose weight, you should liaise with your CF dietitian for tailored information and support. The Cystic Fibrosis Trust has been working with CF specialist dietitians to develop leaflets on nutrition, including on achieving a healthy weight. You can download these leaflets here: cysticfibrosis.org.uk/nutritionleaflets.

“

I HAVE SUFFERED FROM FEELING OVERWEIGHT FOR A FEW YEARS NOW. ALTHOUGH I'M GLAD I DON'T LOOK 'ILL,' I OFTEN FEEL OVERLOOKED BECAUSE OF THIS. MY LUNG FUNCTION IS ONLY 38% AT BEST AND I DON'T THINK PEOPLE (DOCTORS AND NURSES, AS WELL AS FRIENDS) NOTICE HOW HARD LIFE CAN BE BECAUSE I DON'T LOOK LIKE I'M STRUGGLING. ”

(Female, 17)

POSTURAL CHANGES

“

I'VE ALWAYS FELT LIKE MY RIB CAGE WAS A LITTLE LARGE AND IT WASN'T UNTIL I SPOKE TO SOMEONE ELSE WITH CF THAT I FOUND OUT THAT 'BARREL CHESTS' ARE QUITE COMMON IN PEOPLE WITH CYSTIC FIBROSIS. I'VE STARTED DOING WEIGHT TRAINING ON MY BACK AT THE GYM TO TRY AND HELP STRENGTHEN MY MUSCLES IN MY BACK.” (IR)



Postural changes are common for people with cystic fibrosis. The muscles in the trunk (torso) of the body are needed for both posture and breathing, so when the body has to use these muscles excessively for breathing and coughing (often in a bent-over position), posture may start to be compromised. Changes also result from the effects of increased pressure in the chest, due to lung disease and excessive coughing, pushing outwards on the skeleton. These changes tend to start near puberty with the most common abnormalities being thoracic kyphosis (curvature in spine), barrel-shaping of the chest and forward rotation of the shoulders, giving a hunched and rounded-shoulder appearance. As well as the adverse effects on body image, these changes can also result in back pain and joint problems, and have a detrimental effect on the lungs.

Hyperinflation (barrel chest) refers to the expansion of the rib cage occurring as a consequence of air trapping due to airway obstruction. This results in a wider rib cage than normal and there is some evidence that the problem is greater in females with CF than males. The obstruction can be caused by sputum or structural changes in the airway walls. Improving airway clearance may therefore reduce hyperinflation, with autogenic drainage and positive pressure devices (eg PEP valve or mask) limiting the amount of air trapping, helping you breathe out more effectively. Hyperinflation can also increase the work of breathing, cause shortness of breath, impair respiratory muscle function and increase oxygen consumption. Ask your physiotherapist if any additional techniques would be helpful to you.

“One of my main issues is my rib cage – I am barrel-chested and this has gotten more prominent as I have gotten older. It affects what I want to wear and what I can wear quite a lot and it can be difficult to find clothes that I feel comfortable in. I have always been conscious of this and have tried to hide it a lot in the past by wearing really baggy clothes.” (LB)

“My shoulders are rounded because of the years of coughing – I don’t like it but I have to accept it. I wear baggy clothing anyway and that helps to disguise it.” (CH)

“I’ve noticed that my posture improves with my weight, so I try to keep this at a good level.” (Male, 22)

“My shoulders are a little rounded, so I wear appropriate clothes to hide that and my arms, which I feel are a bit thin.” (SB)

“I feel my posture is different to others; my shoulders always look hunched like I’m tense and I have a slouched over look in terms of standing up straight. It may not look as much to others but I can certainly see it in myself. My posture has improved over the last few years, but I can still see the differences when I look in the mirror or when I stand next to others who do not suffer with cystic fibrosis.” (JF)

WHAT CAN I DO ABOUT IT?

Prevention is better than cure, so it is important to start being aware of postural difficulties early and get into the habit of practising a few exercises as part of your daily routine. Postural exercises can have a positive effect on pain and lung disease, as well as improving body image and self-esteem. Cystic fibrosis specialist physiotherapists have worked with the Cystic Fibrosis Trust to develop a leaflet on postural exercises, which you might find useful. You can download this leaflet here: [cysticfibrosis.org.uk/physioleaflets](https://www.cysticfibrosis.org.uk/physioleaflets). Please also talk to your physiotherapy team who will be able to offer you specialist and tailored advice.

MUSCLE MASS

It has been shown that people with CF have weaker muscles than other people of the same age. This is a result of reduced muscle mass and not abnormal functioning of the muscle, which means that the CF muscle should have the ability to generate strength if the volume of muscle is increased. This reduced muscle mass occurs for several reasons, including low body weight, chronic illness, low testosterone, low vitamin D and decreased physical activity.

“I had insecurities with my body shape as a teen. Most of my peers were bigger and better developed than me and I always looked very young for my age. Until I started exercising and going to the gym to lift weights I had skinny arms and legs and a pot belly.” (Male, 47)

“Over the past months I have lost my ability to exercise and have lost muscle mass as a result. This has seriously affected my mood.” (Female, 17)


WHAT CAN I DO ABOUT IT?

Increasing body weight

There is a direct correlation between weight and muscle mass, so improving your nutritional status can help to build muscle. It is worth consulting your dietitian regarding dietary needs and supplements.

Exercising

Loss of muscle occurs due to decreased activity, particularly a lack of resistance exercises. Weight training with progressed exercises for your arms, legs and upper chest should help build muscle, and in addition can offload the extra burden on the diaphragm and reduce feelings of breathlessness. Appropriate resistance training can help to redistribute the weight from the stomach area where it can look out of proportion to the slimmer arm, and legs. This in turn can give the appearance of a more balanced body shape.



“I go to the gym once a week to work on all major muscles for size and body strength. I also swim twice a week and aim for about 40 lengths per visit. People say I look very fit.” (Male, 47)

“Go to a gym with a mate and don’t expect immediate results. Keep plugging away as it takes time but before you know it your image will change for the better.” (Male, 25)

“I’d always struggled with my body image, mainly because I felt too small and thin. I started working out at the gym when I was a teenager and built up good muscle mass. But frequent chest infections and ill health made it increasingly difficult to keep up with that training. It was immensely frustrating to feel that all my good work was being undone. I now work out using online exercising and have found it incredibly helpful. Exercise needs to be part of your whole life, not just something you do for cystic fibrosis.” (DC)



EXERCISING WITH CYSTIC FIBROSIS

Most people with higher lung function ($FEV_1 >60\%$) can train without any particular restrictions as long as they stay within the generally accepted limitations for healthy people. There may be risks associated with some sports, so it may be worth discussing these with your physiotherapist, for example positioning of a portacath and involvement in contact sports.

People with lung function of less than 60% may have some restrictions, so it would be helpful to take advice from your physio before undertaking any exercise programme.

For those with very low lung function it is advisable to have some supervised sessions in order to monitor heart rate, oxygen levels and respiratory rate whilst being given more tailored direction on intensity of exercise.

Exercise can influence blood glucose levels and the uptake of insulin, both during and after the activity takes place. Those with diabetes should monitor blood sugars before and after sessions. Some useful advice is available from your diabetes specialist, as well as online. People with CF are also more prone to dehydration and salt loss, so must make sure they take in enough fluids. Energy drinks may be helpful in providing fluid, salts and glucose. The Cystic Fibrosis Trust's leaflet on exercise nutrition offers more information: cysticfibrosis.org.uk/nutritionleaflets.

For those prone to haemoptysis (coughing up blood), exercises for the upper limbs and chest may cause a large increase in thoracic pressure and can make haemoptysis a little worse. In these circumstances it is advisable to use light weights with more repetitions.

Vitamin D is known to be important in bone health, but there is increasing recognition of its role in inflammation, the immune system and muscle function, and vitamin D deficiency is associated with a wide variety of disorders including endocrine, gastrointestinal and neurological disorders. Correcting vitamin D deficiency with treatment doses and maintaining levels in the desired range with maintenance doses will optimise bone health but compliance with vitamin supplements may also have additional benefits, including improved muscle function.

Research has indicated that the genetic defect in CF could be directly involved in muscle wasting and weakness. Data suggests that lung infection and inflammation could be major triggers that interact with the genetic mutation; therefore, control of inflammation and infection could possibly reduce levels of muscle wasting. This is one more reason to keep on top of infections and take prescribed treatments regularly.

Varying degrees of testosterone deficiency can occur in men with cystic fibrosis. Delayed puberty can be behind lower levels of testosterone in adolescents with CF, but chronic illness can also affect levels in adult males. Testosterone is required for muscle strength so, theoretically, low levels could reduce muscle mass, although for the majority of males it appears that testosterone deficiency is not sufficient to cause major effects on muscle mass. However, it may be an important factor for certain individuals and, on this basis, testosterone levels can easily be checked by your CF team, who can advise further if prescribed replacement therapy is required.

ABDOMINAL DISTENSION

“

I THINK I SPEND ABOUT 75% OF MY TIME BLOATED, WHICH MEANS I SPEND A LOT OF MY DAY IN DISCOMFORT. HOWEVER, I THINK THAT THINGS HAVE IMPROVED SINCE I STARTED GOING TO THE GYM AND THINKING MORE ABOUT WHAT I EAT. WHEN I WAS YOUNGER THERE WAS SO MUCH EMPHASIS ON PUTTING ON WEIGHT WITHOUT ANY CONSIDERATION TO MAINTAINING A HEALTHY DIET THAT YOU GET INTO BAD AND UNHEALTHY HABITS. ”

(IR)



Abdominal distension and bloating are known to be common in CF and can affect body image.

“I actually don’t mind being bloated. Yes, I look pregnant and I’ll get some looks, but I like the feeling of having a bit of weight on me! It can at times be embarrassing when I have to undo my jeans button in the middle of a restaurant but I just cover up with a jumper or something until it’s gone down and I’m so used to it now it rarely bothers me.” (BP)

“With my bloating I just have to be clever with how I dress, I have tried to figure out which trigger foods or drinks make it worse. I have also found drinking lots of water can really help reduce the bloating.” (LF)



WHAT CAUSES IT?

There are a number of factors that contribute to distension and bloating including stress, food intolerance, fluid retention, constipation, wind/gas and diarrhoea. People with CF can be affected by any of these issues, but may also face specific problems due to their condition that contribute to these symptoms:

- **Incorrect amount of pancreatic enzymes** – too few enzymes causes malabsorption of fats and can result in symptoms of bloating, cramping and loose, foul-smelling, pale and oily stools. Excess stomach acid can also stop the enzymes working, although medication can help this.
- **Central weight distribution** – in CF low muscle mass on the arms and legs can make the stomach appear disproportionately large.
- **Constipation** – this occurs when thick, bulky stool sits in your large intestine for too long. It can be accompanied by abdominal (tummy) pain and/or bloating. Constipation is managed with a combination of laxatives, adequate fluids, salt and dietary changes.
- **DIOS (distal intestinal obstruction syndrome)** – this is when mucus and stools block where the small intestine joins the large intestine. This mass of stool (which is often on the right side of your abdomen) can often be felt when a doctor examines you or seen on an abdominal X-ray. It causes pain, nausea and bloating. DIOS is usually managed with medication and sometimes hospital treatment is required.

WHAT CAN I DO ABOUT IT?

- Talk to your dietitian about your enzyme intake; they may recommend keeping a diary detailing food, enzymes and symptoms to help determine if your enzymes need to be adjusted or if there are dietary changes that could help. You might find it beneficial to avoid fizzy drinks and try not to eat too quickly (therefore avoiding 'swallowing' air).
- Drugs to reduce stomach acid may help enzymes work better. A variety of laxatives are available from your doctor if constipation or DIOS is a problem. In recurrent DIOS some preventative medications can be helpful. Again, speak to your CF team if this is relevant to you.
- Exercise can help. Weight training can help to build muscle in the arms and legs, thus reducing the appearance of bloating around the tummy. Abdominal exercises can help with the muscle tone in your tummy, again reducing the appearance of bloating.
- Whatever you do, don't try and lose weight to minimise the stomach bloating because it won't help and in fact is likely to make the problem worse.
- Relaxation and mindfulness are increasingly popular in gastrointestinal conditions as a means to cope with abdominal discomfort like bloating, which may not be fully resolved with medical intervention.

“When my BMI was under 20 I still had a belly even though I had no boobs and was really bony everywhere else. Now my BMI is 24.3 and even though my belly is still a big problem it looks a bit more in proportion.” (Female, 24)

“Keeping an eye on enzymes, eating snacks regularly instead of huge meals and eating more slowly seems to have reduced my bloating, although I do sometimes still need laxatives.” (Female, 30)

FINGER CLUBBING

Clubbing is the word used to describe the flattened and rounded appearance of fingertips and fingernails that affects people with cystic fibrosis. First the base of the nail softens and the skin next to the nail bed looks shiny. The nails then curve more than normal when looked at from the side and there is thickening of the end part of the finger. This can also occur in the toenails. A simple test for clubbing is to hold two finger nails back to

back. You should see a diamond of light between the nails; in clubbing this gap is not there.

It's thought that specific growth factors released into the blood, which can be stimulated by low oxygen, might result in finger clubbing. However no one fully understands why clubbing happens. It is reversible when the underlying condition is treated. For example, in people undergoing lung transplant, the clubbing often improves afterwards.



“I didn’t start to feel self-conscious about how I looked until I got to high school, where I became very aware of my nail clubbing on my fingers and toes. I was meeting a lot of new people and they had no idea about my CF, so some of the first things people would comment on were my nails, asking why they were so curved and large. At the time, I wasn’t comfortable sharing with people that I had CF so I always came up with different excuses like, “My mom has nails like mine” or “I don’t know, they’ve just always been that way.” I didn’t wear bright coloured nail polish because I didn’t want to draw attention to them. It’s only quite recently that I’ve finally started to not be so self-conscious about the clubbing on my hands and feet. I even wear bright nail polish colours!” (LD)

“Growing up I always hated my clubbed nails. I bit them in high school and they looked horrendous. After leaving high school I took up a real love for nail varnish. Painting my nails was an hour out of my day that I felt pampered and was me time; it wasn’t doing treatments or taking tablets. After experimenting with different shapes and colours I fell in love with my nails. People now comment on them and that’s really built my confidence. I think also as I’ve got older and met different people, I’ve started being thankful for what I do have.” (LF)

COUGHING



It seems an obvious point to make, but coughing can be a much bigger body image problem than you might imagine. Most people with CF have a chronic cough and at the very least will have periods of excessive coughing during infections. This can often be a very loud, productive cough which can lead to embarrassment when coughing in public.

“It’s the coughing more than anything else that’s affected my body image. People constantly saying “you should get that checked out” or one guy who always says “bless you” when I cough. Coughing is so noticeable, and people who don’t understand about CF don’t know what to say or do; often they’re just trying to help by offering a drink or something but it can make me feel very self-conscious.” (CH)

“When you have a coughing fit in public and some people tut or pre-judge you for having a cough or make silly remarks, the most common being “You should give up smoking”. I’ve also experienced people moving away from me because I’m coughing or people giving me a disgusted look when I’ve unfortunately had to spit out phlegm into a tissue. I’m thick-skinned so I can handle silly remarks or dirty looks because I’m happy to explain to people why I am like I am or why I’m coughing and most people listen and are apologetic once you explain.” (JF)

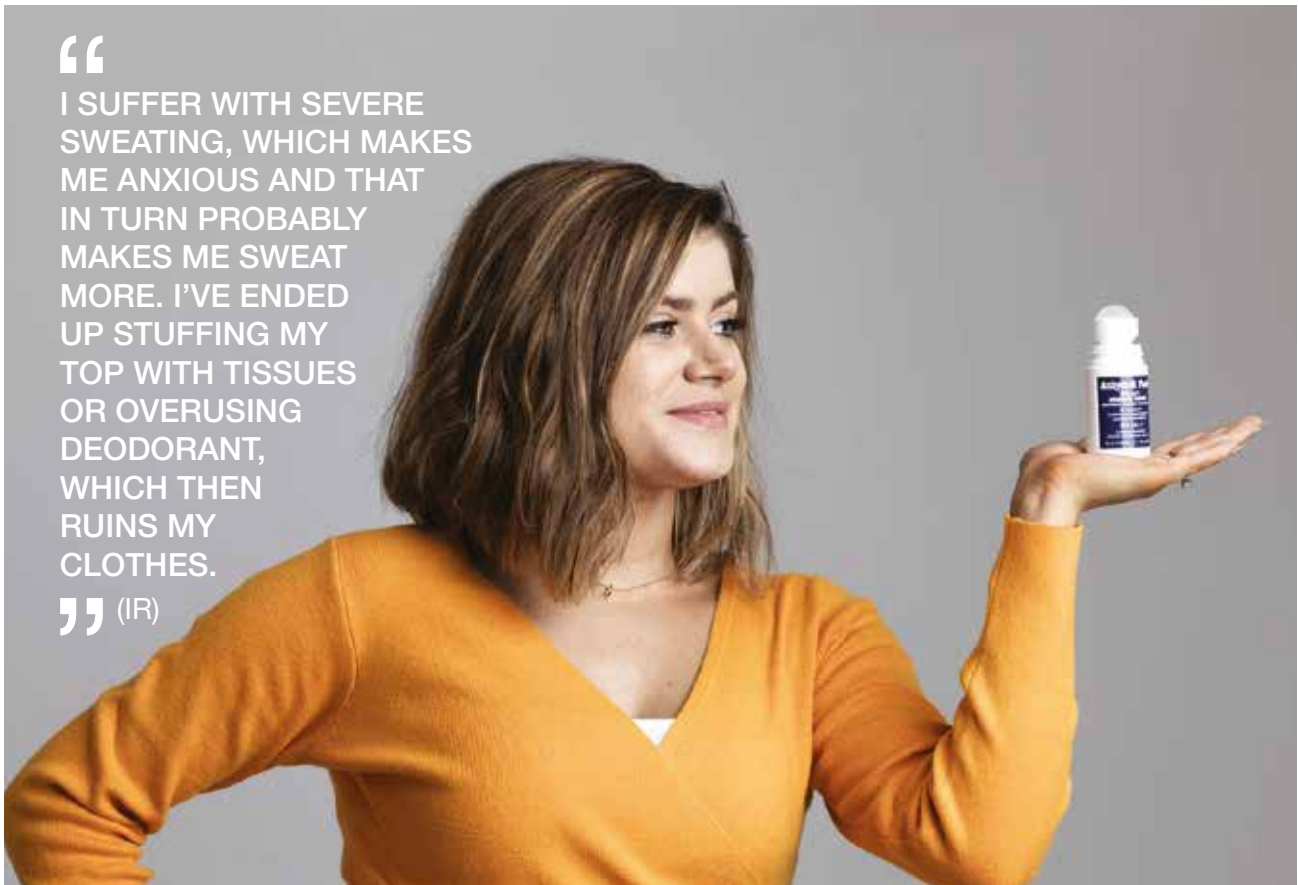
There is no simple answer to this issue other than finding a routine that helps you. Often people cough more in the morning due to mucus accumulating overnight, so extra physio in the morning may help with this, as well as short episodes of clearing your chest throughout the day, perhaps with a few huffs or autogenic drainage breaths. Having a good supply of tissues to cough up mucus more discreetly in public can help, as can having a collection of one-liners for those people who feel the need to make inappropriate comments!

SALT AND SWEATING

“

I SUFFER WITH SEVERE SWEATING, WHICH MAKES ME ANXIOUS AND THAT IN TURN PROBABLY MAKES ME SWEAT MORE. I'VE ENDED UP STUFFING MY TOP WITH TISSUES OR OVERUSING DEODORANT, WHICH THEN RUINS MY CLOTHES.

” (R)



People with CF have a much higher concentration of salt in their sweat due to the underlying genetic defect, which affects sodium and chloride transport. Some people with CF find that the salt can start to form crystals on the skin, leaving a white, powdery residue. This tends to occur after heavy sweating during exercise or in hot weather and can make those affected feel self-conscious.

Although excess sweating in itself is not known to be directly related to CF, anecdotally many people report having excessive

sweating that can lead to salt loss. Some people with CF may need salt replacement tablets; you can discuss this with your CF team. Excessive sweating or night-time sweating can be a sign of other medical conditions, so if it affects you, do raise it with your CF team.

“I GET SALTY EYEBROWS AND THEY GO WHITE WITH SMALL GRANULES OF SALT WHICH LOOKS VERY WEIRD!”
(Female, 19)

TOP TIPS ON DEALING WITH SWEATING:

- If you know you are going to be exercising, make sure you take deodorant and a change of clothing with you.
- Wearing cotton clothing helps the skin to keep cooler and reduces the amount of sweating.
- Test clothes before you buy them. Put a couple of drops of water on the hem of a piece of clothing to see if it goes really dark when wet. If it does then don't buy it!
- Carrying some wet wipes can help keep the sweating under control and you can use them to remove salt from your skin before it crystallises.
- Anhydrol Forte deodorant is available on prescription and some people with CF have found it really useful. It's applied a few times a week and it works by blocking the sweat glands, which eventually forces them to turn off. It can only be used on small areas such as armpits, hands and feet.
- NHS dermatologists can offer botox injections, which block the nerve endings and stop production of sweat in those areas. These are thought to be very effective.



INCONTINENCE

Urinary incontinence (UI) is common amongst women with cystic fibrosis. It's less common in men, but there does appear to be an increased incidence compared with the general population. There are a number of risk factors associated with UI in people with CF, which may include poor nutritional status in younger people, imbalance of the respiration, posture and continence muscles, and increased intra-abdominal pressure associated with persistent coughing and constipation.

Coughing is the most commonly reported cause of UI, and the occurrence of UI seems to increase at times when coughing is worst, such as during a chest exacerbation. It's thought that stress incontinence experienced by people with CF is due to the pelvic floor muscles not coping with increased pressure in the abdomen, for example, during coughing. Leakage can range from a few drops to, in extreme cases, emptying of the bladder. Although the main cause is thought to be chronic coughing, spirometry tests, sneezing, laughing, running, jumping and heavy lifting have all been reported as causing problems with leakage.

“This is embarrassing to say but I've wet myself more times than I'd care to admit. It's led to some very awkward situations for me. However, since I started going to the gym and doing pelvic floor exercises, it barely happens anymore.” (IR)

Naturally, some people find it embarrassing and may not wish to seek help as a result and this can then have a knock-on effect on their self-esteem and body image. There is help available and it's a common issue, so do speak to your CF team if you are affected.

WHAT CAN I DO ABOUT IT?

Specialist CF physiotherapists have worked with the Cystic Fibrosis Trust to develop a leaflet with information about pelvic floor exercises, which have been shown to improve pelvic floor strength and reduce leakage. You can download the leaflet here: cysticfibrosis.org.uk/physioleaflets. Your CF physio will be able to help you with these exercises, so do ask.

If you continue to experience problems, you can request a referral to a specialist continence service. They can offer further treatments such as surgery and medication, so you do not need to suffer in silence.

LOOKING YOUNG



People with CF are usually shorter than would be predicted based on mid-parental height (a way to predict a person's height based on the heights of their parents) and may also experience delayed puberty. The tendency to be smaller, with a lower BMI and delayed pubertal onset, are factors that contribute to the fact that some people with CF look a lot younger than their years.

“I was late to go through puberty, around the age of 16. I found this very difficult to deal with as I looked so young for a long time and felt I was lagging behind all my friends.” (Female, 31)

“I always get people thinking I'm younger than I am, many ask me ‘what school do you go to?’. I have even had people knock on my door selling things asking if my parents were home; I do still live with my parents but it annoyed me that people think I am not old enough to be a home owner. This does knock my confidence as I don't look my age but don't like to be constantly reminded about it by others.” (CM)

MEDICALISATION OF YOUR BODY: PORTS AND PEGS



Many people with CF will have some physical sign from treatments they have had for the condition, whether that's a scar from a meconium ileus operation, insertion of a port or even an intravenous (IV) line for a course of antibiotics; treatment can be invasive and can have an impact on body image.

PORTS

A port is a small device that is implanted under the skin, with a connecting tube that is fed into a large vein, and is used for giving IV antibiotics. A needle is placed into the port for the course of drugs and removed afterwards, although the port remains under the skin. Ports tend to be suggested when someone has veins that are difficult to access (sometimes called poor veins) and needs frequent courses of IV antibiotics.

Traditionally the port is implanted on the chest wall, but in recent years other sites have been used to make it more discrete, for example, on the side of the chest or upper arm. The port can be visible as a small bump under the skin but is often not noticeable in those who are heavier. It is advisable to have a

discussion with the surgeon who is fitting your port about where you would prefer it to sit, because it is important you are comfortable with the position.

“I was 14 when I consented to getting a portacath fitted, but to be honest I didn’t really feel like there was much choice because of the difficulties with my veins. It was a big deal and I couldn’t even look at it for the first few weeks. I felt like the port was a symbol of CF, a permanent reminder of my condition. My family were very supportive and encouraged me to try and see the positive. When I started to need more frequent IVs, I realised it had definitely been the right decision and most of the time now I don’t even notice it unless it’s being accessed and that can make me more aware of it.” (CM)

GASTROSTOMY TUBES

A gastrostomy tube is a tube placed into the stomach through a small incision, to allow high-calorie liquids to be fed directly into the stomach. People with CF tend to have these tubes when struggling to gain weight. You may also hear them referred to as G-tubes or PEG tubes. Most people with CF will have a long tube inserted first but this would normally be changed to a ‘button’ later on, which is more discrete and looks like a small valve.

“My PEG helped me feel confident about my weight and no matter how I felt during the day and whatever calories I managed to fit in, I always knew I would get a further 2,500 calories overnight.” (Female, 38)

“I’m just about to have a PEG, which in itself is a stigma. A PEG to me was the final sign that I was actually ill and that I couldn’t fight off my illness. The idea of having something sticking out of my stomach took some getting used to. I realise that it is needed, but it’s the final nail in the aesthetic coffin.” (Male, 26)

“I used NG feeding for many years and saw it as quite a positive thing as it took the pressure off me having to eat and also it wasn’t permanent.” (SB)

“I’ve had a PEG since I was nine, so I’ve really just grown up with it. It’s never really given me any great issues – when I was little and in the pool, people would stare but I just ignored them. More recently, my issue with it has been that I like to wear white t-shirts, that’s my thing. The PEG had been a bit leaky over recent years and so if I ate anything with a strong colour, like chorizo, it would stain my t-shirt. So I adjusted my diet. I’ve recently had a new PEG fitted and haven’t had any issues.” (CH)

An alternative to gastrostomy is to use nasogastric (NG) tubes which the person can learn to pass through the nostril each night, allowing overnight feeding. Some people prefer this as it can be removed during the day.

“I started with NG feeding at age 11 and I was soon passing it myself. I find it really easy now. I have had periods where I don’t need feeding and at least with an NG tube I can just use it when necessary and don’t need to have surgery.” (Male, 30)

“

GETTING A PORT WAS A REALLY BIG THING FOR ME. IN FACT IT TOOK ME A YEAR TO AGREE. I WAS REALLY RELUCTANT BECAUSE CF HAD ALWAYS BEEN INVISIBLE FOR ME AND I COULD CONTROL WHO KNEW ABOUT MY CONDITION. HAVING A PORT WOULD MAKE IT VISIBLE. IT WAS REALLY ABOUT ME ACCEPTING THAT CF WAS NOTHING TO BE EMBARRASSED OF AND THAT WHETHER I HAD A PORT OR NOT, IT WAS PART OF ME. I EVENTUALLY AGREED AND AM NOW IN A PLACE WHERE I EMBRACE MY SCAR AND LUMP... WHICH ISN'T ANYWHERE NEAR AS BAD AS I THOUGHT! HAVING MY PORT ENABLES ME TO STAY HEALTHY AND LIVE MY LIFE.

” (SP)



SCARRI

People with CF can have various types of surgery resulting in scarring of some description which can, understandably, affect body image. A scar forms when the normal skin is replaced by fibrous tissue after an injury. The scar tissue consists of collagen fibres that are produced as part of the repair process and continue to be remodelled over 6 to 12 months. The scar formation process can be affected by a person's age, race, genetics and general health, as well as specific wound factors such as size, depth, location, type of injury and any wound infections during healing.



CAN I IMPROVE SCARS?

- Moisturising can speed up the healing process. Products people with CF have found helpful include cocoa butter and Bio-Oil, although no moisturiser has been proven to be superior, so something as inexpensive as Vaseline could be used. Massaging the moisturiser into the scar will also help blood circulation and improve healing.
- Silicone patches or gel have been proven to help scars. They have been shown to soften, flatten and smooth scars, and to relieve the itching and discomfort associated with them. Products can be bought over the counter but are also available on prescription.
- Higher temperatures increase the activity of the enzyme that breaks down collagen in scar tissue. Paraffin wax or heat application can therefore be beneficial in scar reduction, though you should not try this on your own but should speak to a trained professional if you wish to undergo one of these treatments.
- Some people find make-up helpful in disguising scar tissue that is a different colour from surrounding tissue. The charity Changing Faces offer a free service showing how to apply products, which are then available on prescription. You can ask your doctor to refer you to this service.
- If home remedies have not helped and you remain troubled by scarring, then you can request referral to a plastic surgeon to consider more radical treatments. These can include laser therapy, steroid injections into scar tissue, radiotherapy, cryotherapy (freezing tissue) and revision surgery.

NG



TATTOOS



Some people with CF have said that their tattoos are an important part of their body image. Tattoos are sometimes used to disguise CF-related scars, or to express an emotion relating to the condition. For others, it's about taking back some control of their body and choosing their own 'scars' or pain. And of course, many people with CF have tattoos just because they like them!

"I have a half-sleeve, which I designed myself – it's basically CF as a dragon and me as a tiger, fighting the CF. I also have tattoos to cover scars." (DC)

"Across my collarbone I have a tattoo that says 'ante emoriar quam sit tibi copia nostri,' which I understood to mean 'I will die before I give you power over me.' It hit me as a powerful statement to my CF, especially with it being directly over my chest. Google translate offers a slightly different translation, which doesn't come across quite the same, but I'm happy to go with what I originally heard it as!" (MT)

"I have so many CF-related scars and I'm quite sensitive about them. For me, getting tattoos is like me taking back some control of my body – it's me choosing my own scars. It's funny because I have a needle-phobia and get very emotional when I'm having IVs, but for tattoos it's different; it's my choice and I control the where and the when." (FC)



“I’M PROUD OF MY BODY AND I’VE CELEBRATED THIS BY GETTING THREE TATTOOS. ONE IS A CF MEDICAL TATTOO BUT I’VE HAD IT STYLISED SO THAT IT’S ATTRACTIVE AND THE TWO OTHERS HAVE QUOTES RELATING TO LIVING IN THE MOMENT AND DEALING WITH THE ADVERSITY THAT LIFE CAN THROW AT YOU.” (GE)

“

IT WAS REALLY HARD FOR ME TO GO OUT FOR THE FIRST TIME WITH OXYGEN. IT JUST MADE ME FEEL REALLY SELF-CONSCIOUS. PEOPLE DO LOOK OR ASK QUESTIONS AND SOMETIMES IT'S REALLY INAPPROPRIATE, EVEN IF THEY DON'T ACTUALLY MEAN TO BE RUDE. I TRY TO REMEMBER THAT MOST PEOPLE AREN'T LOOKING AND THAT GENERALLY PEOPLE ALL MEAN WELL.

” (GE)



DETERIORATING HEALTH

For some people with CF, wheelchairs and oxygen can represent ‘giving in’ to their condition. Wheelchairs in particular can be synonymous with all sorts of thoughts and feelings: a loss of independence, a visual reminder of deterioration of health and a growing reliance on others. However, a different outlook is to consider them simply as tools. The use of a wheelchair or oxygen can improve your quality of life, and some people with CF will feel that it’s worth battling the body image issues for. Try not to think about these things as ‘giving in,’ but as fighting back to maintain independence and allowing you to continue living life to the full.

“The first time I agreed to leave the house with oxygen on, I cried; I was acutely aware of the tubing on my face. It felt like someone had drawn all over my face in marker and then asked me to just go out and act normally! I’m glad my mum forced me out (bribing me with a shopping trip!) as the experience was nowhere near as bad as I thought it would be.” (Female, 26)

“If someone asked if there were any positives about using a chair, one word: FREEDOM. Although at first I felt uncomfortable using it (I felt like everyone was staring at me, especially when I stood up to get out of the chair), I now feel free and can go for ‘walks’ and go shopping.” (Female, 35)

“I remember the first time someone mentioned that I might find a wheelchair handy. I was extremely upset and felt so defeated. I felt that my body had let me down. But I’ve had a wheelchair for a year now and even though I don’t enjoy using it, it has helped me participate and be included. I can go on family trips much more easily and I can get out of the house a lot more; if I didn’t use it I could be stuck in the house for long periods of time. Sometimes I feel anxious going out in the wheelchair but I know that overall my mental state will be improved in the long run.” (KP)

POST-TRANSPLANT

When a person with CF has very low levels of lung function, the option of a transplant will be discussed. Understandably, the focus of this conversation will be on key issues such as the risks and benefits of the surgery, the waiting process and health management following the operation.

However, many people with CF who have been through the process feel that transplant changes their body, and consequently their body image, in some very significant ways. They are often unprepared for these changes, having only been focused on the immediate health benefits of transplant.

“When I first had my transplant, I put on weight. I was still at the bottom end of normal, but everyone kept saying how healthy I looked after putting on the weight. I just thought I looked fat because I wasn’t used to being anywhere near a normal weight.”

(Female, 34)

However, for many people the fight to put on weight pre-transplant was a constant battle, and therefore the ability to gain weight post-transplant is viewed as a huge positive. Transplant can often come with an improved appetite, which allows people to enjoy food once again and rely on ‘real’ food, not supplements and overnight feeds.

Post-transplant, people with CF need to take steroids to protect their transplanted organ, and most will continue to take these indefinitely. Steroids can cause the face to appear rounder and fuller. Many people find this difficult to cope with, although many will already have experienced it during previous treatment with steroids. Other people, of

course, may feel that this simply makes them look healthier. It’s important to remember that immediately post-transplant the steroid level is much higher but as time goes on the steroid dose will be reduced and side-effects should settle.

Immunosuppressant drugs can also cause side-effects such as hair thinning or, conversely, thicker hair growing on the body. Tremor is another side-effect, although this does tend to improve with time and not everyone will be affected. Your transplant team should take your concerns into consideration and discuss side-effects and consider alternative treatments in some cases.

“I was worried about gaining weight until I realised I actually looked so much better and was still a normal BMI anyway! Any medication side-effects are trivial compared to what I coped with pre-transplant and if I could do this again, even for only a few months, I would. The difference post-transplant is hard to describe and with all my new-found energy I really have little time to worry over my body image.”

(Female, 30)

“After about a year my hair was falling out and looked very thin, but within a few months it was growing back and is as thick (if not thicker) than it was pre-transplant.” (Female, 31)



“I HAVE A CLAMSHELL SCAR FROM MY DOUBLE LUNG TRANSPLANT. I EMBRACED MY SCAR AND HAD A LOT OF FUN WITH IT WHEN I WAS YOUNGER – MOSTLY SHOWING IT TO PEOPLE I DIDN’T KNOW TOO WELL AND SEEING WHAT STORIES I COULD MAKE UP AND GET AWAY WITH. SHARK BITE, PECTORAL REDUCTION AS I WAS TOO BUFF AND A LUNG REDUCTION AS I USED TO HAVE FOUR ARE ALL STORIES THAT I HAD FUN WITH. MY ATTITUDE HAS ALWAYS BEEN THAT I MIGHT AS WELL HAVE FUN WITH IT. I’D ALWAYS TELL THE TRUTH IN THE END!” (OR)

For more information about transplant, including the impact it can have on body image, please have a look at the Cystic Fibrosis Trust’s booklets on transplant at cysticfibrosis.org.uk/transplants.

LEARNING TO LIKE YOURSELF AND HOW YOU LOOK

This booklet has illustrated the wide variety of body image concerns that can affect people with CF, and offers some practical suggestion on how to overcome these. However, for some people with CF, it just might not be possible for them to achieve the body image they desire. Some things just can't be changed – for example, if you need oxygen, then you need oxygen. This may very well be a temporary situation but it's still one that is pretty much non-negotiable. Some people with CF also find that no matter how well they adhere to the 'plan,' their weight doesn't go up to where they'd like it to be, or they put weight on in the 'wrong' places.

For everyone, regardless of whether they have CF or not, acceptance is an important part of life; trying to find contentment with our own lives and bodies. Many people who've shared their stories for this booklet have said that acceptance becomes easier with age.

“Even if you can't love your body, you need to accept it. Your scars, the way you look. Your features, your body, it's all what makes you, you. I have some AWFUL tattoos, ones that are badly done, uneven, not symmetrical where they should be, but I wouldn't change them because they're a part of me. They show who I am, what I've done, part of my life experiences. It wasn't until I accepted my body and became comfortable in myself that things started to change.” (MT)

“I try to look at the positives and think about what I can do rather than what I can't. My lower weight meant that I could be a jockey, which has been a huge part of my life.” (SB)

“I can focus more now on the function of my body rather than just the looks – I think that's just a time and maturity thing. I've also found the silver lining to my years of being too thin – a lot of my mates are starting to get the middle age spread or 'daddy belly'!” (DC)



“

WHEN WE CAN TRULY NOTICE ALL THE NEGATIVE OUTSIDE INFLUENCES WE HAVE EXPERIENCED THAT AFFECT HOW WE FEEL ABOUT OUR BODIES, WE CAN START CHOOSING TO IGNORE THEM, FOCUSING ON OUR BODIES' STRENGTHS AND ABILITIES INSTEAD, AND BEGIN FEELING MUCH MORE BODY CONFIDENT.”

(CF Psychologist)

THE FOLLOWING **IDEAS** MIGHT HELP YOU WITH **THE ACCEPTANCE** **PROCESS**

1. **Accept your genetics** – all bodies, including those with CF, are genetically wired to be a particular size and shape. Forcing your body to change could be harmful.
 2. **Consider factors that have influenced your body image**, eg weight changes or insertion of a PEG. How did your attitudes and perceptions develop? Have they changed over time? What would help you to start creating a positive image now?
 3. **Consider what you do like about your body**. Scan your body for things you like rather than dislike. If this is difficult, start with a body part that you dislike the least. Practice paying attention to it.
 4. **Think about your body function**. Consider each body part for its purpose or function and what it can do well, eg legs allow us to walk, run and dance, a scar tells a story about your life. What parts of your body are you grateful for? Think about how amazing it is that your body has adapted to the challenges of CF and can allow you to do many things.
 5. **Identify activities** that help you feel good in your body, eg playing a musical instrument, practising yoga or relaxation, having a bath, walking the dog, visiting a friend...
 6. **Evaluate your body image attitudes** as if you were a scientist or lawyer. Do you have factual evidence to support your beliefs? Do others agree with your attitude?
 7. **Try to catch yourself** continually focusing on areas of your body you're unhappy with and challenge yourself to broaden your awareness to your body as a whole.
 8. **Focus on what you can change in your life**. Sometimes things to do with our bodies feel 'bad' no matter what we do, and we must somehow learn to 'sit with' these feelings. This can be made easier by bringing your focus to things in your life that you can change or act on, eg making changes to your behaviour or doing nice things for yourself.
 9. **Expand your areas of interest**. When undue importance is placed on one aspect of life (eg appearance), other interests may be neglected. Think about an activity that matters to you. Make a plan to try something new this week.
 10. **Keep at it**. Remind yourself that improving body image takes time and practice.
- (Modified from the Centre for Clinical Interventions booklet on Body Dissatisfaction: www.cci.health.wa.gov.au)

FINALLY

Most people, including people without CF, have some concerns about body image and most have something they'd like to change if given the choice. How much this has an impact on your life is down to the individual. It's important that you talk about your concerns with your CF team because sometimes body image issues can be overlooked in the bigger picture of your physical health, but the team can't offer advice if you don't speak up.

Although some of the difficulties may not have a simple solution, we hope that this booklet has given you a sense of how common these concerns are, how other people have coped with their worries and what help is available. We also hope this booklet might give some people the courage to seek help if they are neglecting their health due to concerns related to body image. Sharing your worries and problems is an important first step in making positive changes.

Further information and support:






- www.beateatingdisorders.org.uk – the UK's eating disorders charity.
- www.changingfaces.org.uk – UK charity for people with a mark, scar or condition that makes them look different.
- www.bladderandbowel.org/help-information/just-cant-wait-card – 'Just can't wait' cards can be used to get quick access to the toilet for those with bladder or bowel problems.



All the photographs in this booklet are of people with cystic fibrosis who contributed their stories to this pack.

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BODY IMAGE

A CYSTIC AND FIBROSIS

PORTS, PEGS
AND SCARRING

TATTOOS

WEIGHT

POSTURAL
CHANGES

**Cystic
Fibrosis Trust**