

# Cystic Fibrosis and Relationships



**A collection of real life experiences**

*Written by people with CF and their partners*



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# Introduction

Being in a relationship can be a wonderful experience; those first few months of getting to know each other, perhaps moving in together and making plans for the future. These stages are exactly the same for someone with Cystic Fibrosis (CF), however, having CF or being a partner to someone with CF can create some additional concerns.

Around 60 people with CF, and partners of people with CF, volunteered to help with this project, sharing personal experiences of their relationship and the impact CF has had on this.

This booklet does not aim to give advice but instead its purpose is to share with you the experiences of other people with CF, to illustrate how other people have coped, and more importantly to remind you that whatever the situation, you are not alone.

*Please note: All quotes used in this booklet are genuine, however ALL names have been changed to protect anonymity.*

## About the Authors

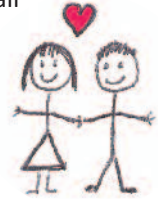
*Emily Thackray* - has CF and received a double lung transplant in January 2007. Emily co-founded, and is the vice chair of, the transplant charity Live Life Then Give Life and is also an ambassador for the Cystic Fibrosis Trust.

*Jacqueline Didsbury* - also has CF and received a double lung transplant in April 2008. She works as a doctor, specialising in the field of psychiatry.

*This booklet is in memory of Robyn Tainty,  
who founded this project, but sadly lost her battle with CF in  
September 2007*

# The Start of a Relationship

Meeting a new partner is always a mixture of excitement and apprehension. Excitement as you start to get close to someone new and learn all about them, apprehension as you worry about what they think of you and whether everything is going well.



CF should not get in the way of starting a relationship but it can add to the list of worries you have. Do they already know I have CF? How much do they know? Should I tell them all the details? There are no right or wrong answers to any of these questions and it depends on the individual and how they like to deal with their CF, as well as what seems right for that particular relationship.

## When do I tell them?

Some people like to be as open and upfront as possible, telling their partner about CF very early on in the relationship.

90%  
had told their  
partner about CF  
within 3 months

*"I disclosed the key facts on our second date – I have had 2 serious relationships in the past, both of which have failed as a result of CF, so I gave him the chance to run away immediately rather than waste time getting to know each other and being hurt again."*

*Michelle, 32*

*"I just said to him I've got cystic fibrosis. This was a huge thing to tell him as with past boyfriends I'd never felt the need to. I was always worried they'd run a mile but I guess as you get older you overcome that and learn that this person will love you for you."*

*Joanne*

*"We talked about everything, and told each other just how ill we were. I knew my partner needed a transplant and it didn't affect my feelings for her one bit. It was love at first sight for me and nothing would change that."*

*Martin (partner also has CF)*

*“My man had been a family friend for a while so knew I had CF. When we got together I had this overwhelming compulsion that he must know exactly what he was letting himself in for so told him everything I could about CF. Looking back this was a slightly hysterical way of dealing with it but he stuck with me and even married me, so I guess people can take more than you think.”*

*Cheryl, 23*

Others often prefer to wait until they get to know someone better, in the hope that it will help their partner see beyond the CF. Sometimes people wait because they feel embarrassed about disclosing CF, or are fearful that by telling their partner it will change, or even end, the relationship. Some people struggle to broach the subject at all, and will even conceal or miss out treatments. It is important in this situation to try and see your health as the priority.

*“I started with telling her that I have asthma, as that’s easier to explain. I used to hide taking Creon from her, but somehow she worked out that I had more than asthma so I told her, but specifically asked her not to start reading things about it as I wanted her to learn about the condition through me and how it affected me personally.”*

*Karen*

*“I had left it three months but at this time we were still only dating and I hadn’t seen the need to indulge my little secret. As far as he was concerned I had chronic asthma, it gave me a cough like an old horse and made me sound like I smoked 40 a day but he never asked any more.”*

*Anna, 24*

46%  
thought twice  
about starting a  
relationship  
because of CF

*“He never knew I had CF, but to be fair neither did many of my friends. I was relatively healthy then and whilst people knew I occasionally went into hospital, they never knew why. I even went so far as to not take Creon when I was with him.”*

*Stephanie, 24*

*“I worry about what people think of me generally and how people accept me, so I have always found it very difficult to tell boyfriends about CF.”*

*Paula*

It is normal to be apprehensive about that first conversation about CF and it can be difficult to find the ‘right time’ to bring it up. Some people have found it helpful to use natural triggers, for example, explaining why you are taking tablets with your meal, or bringing it up when someone comments on your cough.

*"I generally let all my friends know I have CF indirectly, for example by mentioning Creon in passing and then letting them ask questions. I don't hide my CF from anyone."*

*Richard, 20*

*"He commented on my cough. He actually said 'You're not long for this world' so it seemed a good time to tell him about CF."*

*Gail, 37*

*"I was discussing my annual fundraiser for Cystic Fibrosis when I decided to tell him I raised money for that charity because I have the condition."*

*Donna, 24*

*"I don't think I did disclose anything until a question occurred. I remember going out for dinner and having to explain my tablets and my insulin."*

*Elaine*

*"He didn't know I had CF and because we started a long-distance relationship I could never find the right time to tell him. First time I was going to I chickened out and was acting weirdly all weekend – he must have wondered what I was on! On the train home, I wrote him a massive letter and posted it when I got home, but I did play it down a bit so as not to shock him."*

*Paula*

## How much do I tell them?

So, you have decided to tell your partner you have CF but the next big question is how much to tell them during that first conversation and how will they react? You may want to tell them as much as possible to start with, or you might prefer to just stick with the basic facts and let them slowly discover more as the relationship progresses.

This process is often influenced by your partner and how much they want to know in the initial stages. They might ask you lots of questions, they might look it up on the internet, or they might simply prefer to go with the flow. Just like there is no right way to tell someone, there is no right reaction to being told.

Although you are in control of how much information to divulge, it's important to also remain sensitive to how much, or how little, information your partner can take on board at one time. Remember that you have lived with the condition all your life but for most partners it will be a completely new experience.



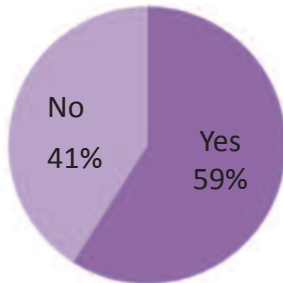
*“She didn’t voluntarily go into too much detail (about CF) but I pushed and made her open up about it. She eventually did open up and told me all about it and what she had to go through.”*  
Colin, partner

*“I knew a little about CF but I trawled the internet looking for info so he didn’t have to tell me, I didn’t want him to feel uncomfortable if he had to explain it to me.”*

Laura, partner

*“I googled it. Scary stuff. If I’m honest I will admit I did think.. gosh can I do this? Am I strong enough for everything that this relationship might bring? Twenty or thirty years into the future was an odd thing to be worrying about when we’d only just had our first kiss, but I decided it was a decision I needed to make very early on. Well, I decided that I’d met someone who made me truly happy and that for the time being at least, the ‘what ifs’ were no big deal.”*

Diane, partner



**Have you ever worried that telling your partner about CF would change the relationship?**

*“I did a lot of research at home to find out what I could about it. I didn’t ask him much about it because I wanted to learn for myself.”*

Gillian, partner

*“I was scared of him confirming he knew about the average life expectancy. I don’t like to think about it myself, so to discuss it with my boyfriend seemed very strange. After a few months however, I did start talking to him more about my CF and told him he could ask me questions. He then started to ask questions specific to my CF.”*

Sarah, 20

# Getting Serious

So, you have made it through those first few weeks and months, and the relationship has started to get more serious. You have probably already told your partner you have CF at this stage, but as the relationship progresses many more questions and worries can begin to surface.

What will their family and friends think? What happens when I go into hospital? How involved in my treatments should they be? Can I keep up with their level of socialising?

## Meeting the parents

It can be hard enough to tell your partner you have CF, but as things get more serious and it's time to meet the parents you may also wonder how they will react. Have they read stories in the newspaper about people with CF? Do they have pre-conceived ideas about the illness? Are they wondering if CF means that grandchildren are off the agenda?



You might feel that this is personal information you would rather not share, or you might feel able to be quite open about things. This is something you can discuss with your partner. They might have already told their parents, and if not, you might want them to do this in advance.

However, some people would rather share that information themselves so that they can control what is being said and can answer any questions that might come up. It might be enough to start with basic facts, and then gradually address more issues as and when they arise.

*“ My partner’s parents don’t really ask me much about CF and I am not sure they really understand it. I am quite well just now so it easy for them to see me as just ‘normal’ but I do worry about the future and how they would feel if they saw me getting more unwell and needing more support from my partner. I guess I am just hoping they see me for who I am by then and not feel that I am a burden to their son”*

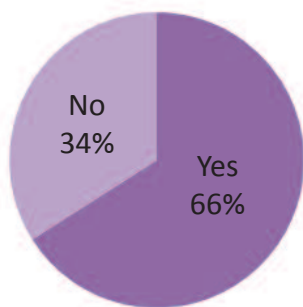
*Paula*

*“The way we give out information to family and friends differs – I shut it all in, tell on a need to know basis; he thinks I shut people out, should be more open. I’m working on this one and maybe we can reach some middle ground so he doesn’t have to make up for my reticence to share. A case in hand is the in-laws – should they know more, when I don’t want them to? Is it their right?”*

Sophie

*“I was worried that his parents would think he was making a mistake by dating someone with a serious illness. Luckily they saw beyond that, and have welcomed me into their family, showing a genuine interest in my CF whilst still respecting my privacy.”*

Paula, 28



**Did you worry how your partner’s parents would react when they found out you had CF?**

*My partner is a very private person and so am I so I think it has probably been quite difficult for him to let his friends and family know about my CF because he rarely talks about personal stuff anyway and he was also worried about whether I would mind them knowing.”*

Denise

*“I was worried his parents would not accept me because I had CF and they would want their son to have a healthy girlfriend. This created a few problems as everything they did I interpreted as them not liking me. Also my boyfriend didn't tell his other relatives about my CF so when I met them and was coughing they were asking me if I had a cold and when I had my tablets with my food they questioned this. This put me in an awkward situation as I didn't want to disclose my CF in the middle of a family get together and embarrass them for asking!”*

Karen, 23

## What happens when I go into hospital?

It is likely that at some point you will need to go into hospital for treatment, and this can cause some added stress. Partners might find it hard to see you in hospital, especially if you are particularly unwell. They may not feel entirely comfortable with hospitals and might be unsure how to cope with the situation. You could also find yourself worrying about how your partner is coping which can be an added stress on the relationship.

*"It has caused some tension as he sometimes found it difficult when I have been in hospital, as it can make him feel useless and helpless."*

Tanya, 20

*"He has never visited me in hospital - fortunately I've only had one admission for a week in the four years that we've been together but I do worry about it in the future as I would really like him to visit me!"*

Alice, 26

70% of partners visit you in hospital, 16% sometimes and 14% never visit

*"She has just visited me in hospital for the first time last week and that was a big step for me, because I don't want her to worry about me being in here anymore than she has to. I want her to be comfortable about coming into hospital, so I know I'm not stressing her out too much when I need to be in here. Anyway when she visited me, I realised that it was perhaps easier than I felt it would be."*

Danny

*"It was very difficult when my partner went into hospital as I found it very hard juggling the dog, the house, visiting and work, but we just managed and again didn't let it affect us too much. I used to hide a lot of my stress from my partner just so that she didn't worry when she was unwell."*

Colin, partner

*"When I was taken into hospital he would often avoid visiting like I had a dose of the plague."*

Donna, 24

*"Last week I went into hospital for routine IVs and he travelled the 400 miles or so to come see me for the weekend. He asks questions and is willing to learn about it which is important to me."*

Evelyn

## How do I keep up with a social life?

CF is an unpredictable illness and energy levels can change on a day to day basis. This unpredictability can make it difficult to plan ahead. The changing of plans last minute can put added stress on your relationship and it can be difficult for partners to accept that your health might have to take precedent to a night of partying. However most people try not to let CF get in the way of a 'normal' life and the compromise is often to make the best of the times when you are well, whilst being kind to yourself when you aren't.



*"Sometimes when I'm tired because I'm not so well I still try to carry on with stuff because I want to have a normal relationship. However important it is to rest and do things to help stay well, I also want to live my life".*

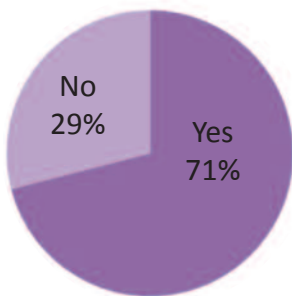
Neal

*"I walk much slower and can't do much physical activity. I find my lungs much more sensitive to smoke, so I have to avoid smoky environments."*

Felicity

*"We have often cancelled nights out with friends because I am not feeling well and this makes me feel really guilty. My partner is very understanding however, and he would rather I looked after myself properly than made myself worse by forcing myself to go out."*

Lindsay, 20



Does having CF ever affect your social life?

*"We had to stay in some nights so I could rest instead of going out and doing something. Weekends could only be spent with one day of doing a lot. We didn't have the usual dynamics of a couple our age."*

Marie, 18

# Moving in Together

As the relationship develops you may start to consider the possibility of moving in together. Although this is an exciting stage in any relationship it also brings up another set of questions you might want to consider before taking this next step. How will we cope financially? How will we manage running a household? Will I need my partner to help with treatments?



## How will we manage financially?

Renting or buying a house is an expensive business and it can cause even more stress when you are unable to work, or work part time, due to CF, or your partner has to give up work to care for you. It is important to note that means tested benefits such as Income Support may be reviewed based on your partner's income if you decide to live together, so you must take this into consideration.

For further advice contact your CF social worker, citizens advice or your local Department for Work and Pensions (DWP).

*“My husband had to cover a manager’s job for a year and he was away over 14 hours a day, 3 hours of which were commuting. This, coupled with becoming the sole earner and trying to help me, put a great strain upon him.”*  
Klirsty

*“When my partner gave up work to care for me, the hardest thing to come to terms with was the loss of income and all the security that brings with it. He had been in a well-paid job for the previous few years which had enabled us to buy a house and enjoy going on nice holidays etc. However after discussing all the options we decided that quality of life was more important than money and that somehow we would find a way through this.”*

Hannah

*“Living together has affected us financially, as I am now unable to claim some of the benefits I was entitled to as a single person because they had to take my partner’s wages into account.”*

Ruth, 36

*"We rent privately, which is a struggle financially, as my partner does not work due to his illness."*

*Rhianne, 20, partner*

*"I am still able to work so I can contribute to the finances but I worry that if I have to stop work in future that I will be reliant on my partner."*

*Cara*

68% of couples living together reported having financial worries

*"As I live alone and don't work I get the appropriate benefits from the DWP. I often worry about what I would do if I lived with someone as I would lose various entitlements, which I can't afford to do. It does put me off quite a bit."*

*Kelly*

*"I would say our perception of money and material things has changed. We no longer aspire to keep up with the "Jones's" but take stock of what we have got and are are grateful for that."*

*Thomas, partner*

Although CF does not stop you securing a mortgage, you are likely to have problems obtaining life assurance. Life assurance is a means of providing a sum of money to be paid in the event of an individual's death, and would provide financial security for your partner.

Although some people with CF have been able to get life assurance, the payments are usually very expensive, the policy may be for a shorter term, or it will exclude death relating to any existing health problems. Although it can be hard to look too far into the future, it is important to try and consider how your partner would manage financially without you. This can be a difficult conversation to have but in the longer term can help reduce worry and stress.

*"On a practical note we did have to consider finances very carefully. We have bought the house between us but were unable to get life assurance cover for him and have had to bear in mind that his health may continue to deteriorate over time and he may not always be able to continue to work in the long term. However, after considering all the factors carefully we are confident that we have found an affordable solution."*

*Sharon, partner*

*“Now that I have the CF label, I cannot get life insurance. Not only does my husband have the responsibility of being the sole earner and therefore we have less money, but he also faces the possibility of losing his wife earlier than expected. When this happens he won’t have the comfort of having the mortgage cleared through life insurance, allowing him to pursue something else in life on his own. He’ll just have to plod on as if – financially – he’d never had a wife.”*

Nicola

*“When we decided to apply for a mortgage we based the amount borrowed on my husband’s wages alone. This way, even without life assurance, I know he will be financially secure in the future.”*

Rose

## How will we manage running a home?

It can be exhausting keeping up with the running of a household and even more so when you have CF. You may not be feeling very well or are sometimes just too tired to help around the home. This imbalance can cause tension and strain in a relationship, and can be an added stress for your partner.

It can also be difficult for the person with CF, who may feel guilty at not being able to contribute equally around the home. Hopefully with some honest discussion you can work out a compromise, where you can perhaps take care of some lighter chores and are willing to take on more responsibility when you are feeling well.

*“Do I have the strength or motivation to entertain or visit friends, cook a nice meal, go out with my dog or do the housework? All of these things can be disrupted by my health on any given day.”*

Megan

*“He takes care of me, but doesn’t let me get away with things and we try to be equal in terms of housework and that kind of thing. He certainly tries not to pamper me too much, but there are times when I just can’t do things.”*

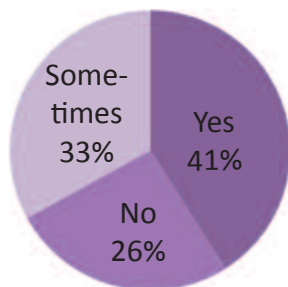
Kathryn

*“I have also had to be prepared to do that little bit extra around the house as he gets very tired and cannot do much in the way of housework.”*

Jennifer, partner

*“Since we have been living together, it seems easier to cope as Alex is always there and will always care for me. Sometimes I think he gets a little frustrated with the lack of housework I can manage but as I am getting better I can do more around the house.”*

*Julia, 20*



For those living together, do you struggle to do your share of household chores?

## Should my partner help with my treatment?

When you are living together your partner will gradually learn more about your treatments and with time they might want, or need, to become more involved. Some people find this support helpful, where as others still prefer to keep their treatments more private.

*“He knows when I need to cough but I’m just holding it in, he makes me do my nebs when I can’t be bothered. And the best thing of all, he makes me exercise. I’ve started climbing because of him and going for long walks.”*

*Jillian, 24*

*“He is very supportive and I do most of my IV antibiotics at home. He also needles my port for me and flushes it so I don’t have the stress of going to hospital.”*

*Alison, 24*

*“He takes everything new in his stride and encourages me to do all my treatment and take my pills.”*

*Lynne*

*“He had a go at helping me with physio but to be honest I still don’t like coughing stuff up in front of him – not very sexy is it!”*

*Caroline*

*“There was once when my chest was quite bad and he offered to do my physio for me but I declined because I didn't want him to feel like my carer. I thought that it was maybe crossing a line that I didn't want to cross.”*

Lorraine, 20

70% of partners help with treatments some or all of the time

*“I'm so much happier with life now since my partner gave up work [to help care for me]. I'm no longer dependent on my parents, I have more freedom and independence, my health has really improved and I don't have to be spending weeks at a time in hospital. Yes we struggle financially and it can be hard to have to go without meals out, weekends away and treats, but the benefits have definitely outweighed the costs. And on top of that I get to spend every day with my best friend – and when you have CF time is precious so this means a lot to both of us.”*

Lisa

It can also be difficult for partners to know how involved they should become in treatments, and some might prefer to stay very much on the periphery. Others might want to offer as much help as possible, or may start to worry about whether you are keeping up with treatments effectively. There is no right or wrong; only what is best for your personal relationship.

*“It's really important to me that I've always been his friend/girlfriend and never wanted to cross the line into nurse/carers. When he was really poorly I'd cook, clean, get IVs and meds ready, put his clothes away and get the pj's ready – all kinds of things. When he was well however, he did as much as could do around the house and for himself – it was hard for him and I could clearly see that but I knew him and I knew when to step in and when to step back. We make a good team.”*

Lucie, partner

*“He will never be able to take over my treatments and we've already got an arrangement with my mum and dad that if I am ever ill I can go back and live with them for the duration of my illness.”*

Angela, 26

*“I think the biggest issue that CF causes in our relationship is that I worry when he is not eating enough or he hasn't done his medicines. He is far more laid back about it than I am and I sometimes find it quite stressful because it is not something I can do for him! He has to do it for himself and he hates me nagging him about it.”*

Kathleen, partner

# Sex

Everyone knows that having CF lungs affects our ability to cope with exertion. What is one of the standard forms of exercise for partners but also a huge taboo? Sex. It's normal, we all do it. However the idea of chatting to your consultant about bedroom-induced breathlessness can make you feel uncomfortable to say the least!



*"I'm always too embarrassed to ask. In hospital the physio always asks 'do you do any regular exercise?' And I always think to say SEX but can never pluck up the courage!!"*

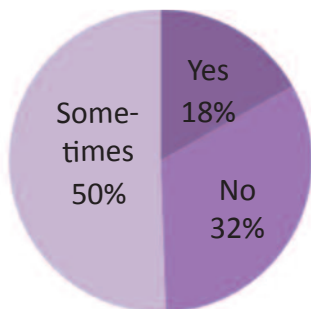
Lauren, 17

*"When I have had sex in the past I noticed I used to be ok for about 15 minutes but now I'm lucky to keep going for 5 minutes, my lungs just wont allow me to continue. The physio aspect is great though but coughing or having to go on oxygen really kills the moment for me."*

Neil

*"If I start getting breathless he will ask if I need to stop, if not then we change position and slow things down... my partner is very understanding."*

Patricia



Does breathlessness ever affect your sex life?

Sex should be enjoyable, fun and most of all romantic. Unfortunately sometimes CF throws a spanner in the works. Breathlessness, however, isn't the only issue caused by CF which can interfere with sex. Other aspects such as tiredness, thrush infections, coughing and feeling unwell can also cause problems at some point in your relationship. Please be reassured however that these problems can be overcome, and indeed many people report having no problems at all.

*“Breathlessness does cause issues during sex, but to be honest my main issue is chronic problems with thrush, which makes sex very painful at times. Although I ask for treatment, it is a recurring problem which therefore creates an ongoing problem.”*

*Eloise, 28*

89%  
have problems with  
sex at some point  
due to ‘other’  
CF-related  
problems

*“I’m fine at first but as the pace ‘increases’ I need to cough, I do that thing where you just let a little bit out and try and hold the rest in!! When I can’t hold it in anymore I have to stop and do an enormous cough and I go all red, then I have to try to find something nearby to cough into, finally have a drink and catch my breath. Bit of a passion killer...ain’t it?”*

*Trisha*

*“Let’s face it, when you feel ill, exhausted, in pain or breathless, a night of sexual acrobatics isn’t usually the first thing on your mind. It’s important not to feel a failure though if you do lose your libido as a result of CF – after all, it’s nature’s way of preserving the energy you do have to fight infections and make you rest, which is hard to do if you’re swinging from the chandeliers! Loss of libido isn’t easy for either person in a partnership, but in my experience, by communicating and working together you can both overcome this obstacle and maintain a great relationship despite it.”*

*Fern, 34*

## What can we do about it?

There is very little advice out there on sex and breathlessness. The British Lung Foundation does have a leaflet entitled ‘Sex and Breathlessness’ which you can send off for (address at the back of this booklet) with a few ideas and tips on how to overcome these problems.



Try to think about what the key issues are and if there’s anything you can do about it. Perhaps changing position or plucking up the courage to get some treatment for thrush could help you enjoy sex again. But whatever you choose to do, it appears you all agree communication is vital.

*"Lying back is good as there's a lot less effort involved and I don't get too breathless. On the odd occasion I feel I'm getting too breathless then I stop what I'm doing for a while before things get too bad, and change position to a less energetic one."*

*Jackson*

*"It's important firstly to talk about the issue with your partner in a calm and supportive manner so that you both understand how the other feels. I think it's also important to try to make time for sex in your relationship, even if you really don't feel much interest in it at the time. After all, sex is about love and bonding with your partner, not just about high-energy passion so even if you don't feel "in the mood" it's still worth making the effort if you can."*

*Marianne, 34*

*"It is vital to keep talking with your partner. If they can understand the difficulties you are having then you can help each other work through these. My partner has learned to understand that our sex life can be affected by CF at times, but that I do try to my best to address these problems."*

*Grace, 30*

Don't forget to keep things in perspective; sex isn't everything and you never know, difficulties may make you focus on other intimate aspects of the relationship, which can only help to make that bond stronger. The most important thing is to be able to talk openly with your partner about any problems and work together on ways to solve them.

*"Sex difficulties haven't negatively affected our relationship. It has made us more communicative and understanding of each other."*

*Annie*

*"I don't particularly care for sex, I prefer a good snuggle watching a movie and falling asleep on the sofa cuddling."*

*David, 18*

*"Sex isn't everything in a relationship. For me, it's more about caring for each other, enjoying one another's company and being there for the other person. I think in some ways having to discuss issues about sex has made us stronger as a couple and more able to communicate with one another."*

*Julie, 27*

# Contraception

Most females with CF have normal or near normal fertility, as do a small number of males with CF, therefore it is extremely important to use effective contraception at all times. It is also important to be aware that people with CF are just as likely to contract Sexually Transmitted Infections (STIs) as anyone else. The only contraceptive to offer some protection against STIs are condoms, so you can use these as well as your normal contraception if you may be at any risk. If you are worried about the possibility of having an STI you can speak to your GP about this or make an appointment at your local family planning clinic.

## Do antibiotics affect all contraceptives?

Short term courses of oral or intravenous antibiotics can affect some oral contraceptive methods by changing how well they are absorbed into your body. During these times you should use a condom throughout the course of antibiotics and for seven days after.

Long term antibiotics used in CF (e.g. azithromycin, flucloxacillin) will not affect your contraceptive if you have been on them for a prolonged period, although you will need additional protection for a short period when starting these antibiotics for the first time.

Antibiotics, such as rifampicin, used to treat TB and related bacteria (called mycobacterium) can affect most methods of contraception, including the Depo-Provera injection and Implanon, so take further advice if this applies to you.

## How do I choose which one?

There are many different contraceptive options, but not all are suited to people with CF and you need to get advice on the best option for your personal situation. The areas to think about when choosing a contraceptive method are how reliable it is, how easy it is to take (e.g. are you good at remembering to take tablets), how likely you are to want a family in the near future and how it might affect your health in the long term. Having CF-related diabetes or liver disease can also influence choice.

The following table summarises the contraceptives available, with some of the main advantages and disadvantages relevant to people with Cystic Fibrosis.

<b>Method</b>	<b>Action</b>	<b>Pros</b>	<b>Cons</b>
<b>Combined oral Pill</b>	<p>Inhibits ovulation</p> <p>96-99% effective</p>	<p>Easy to take</p> <p>12 hr window to take</p> <p>Can reduce PMT and painful periods</p>	<p>Affected by short term antibiotics</p> <p>Not suitable in severe diabetes and some people with liver disease</p>
<b>Progestogen only pill ('mini-pill')</b>	<p>Thickens cervical mucus and inhibits ovulation</p> <p>98% effective</p>	<p>Not affected by broad spectrum antibiotics</p> <p>Suitable in diabetes</p>	<p>Need to take at same time daily (cerazette more flexible)</p> <p>Not as effective in under 35's</p>
<b>Depo-Provera (progestogen injection)</b>	<p>12 weekly injection</p> <p>Prevents ovulation</p> <p>&gt;99% effective</p>	<p>Not affected by antibiotics</p> <p>No pills to remember</p>	<p>Thought to reduce bone density - therefore not often first choice in CF</p> <p>Fertility can take up to 2 yrs to return after stopping</p>
<b>Implanon (progestogen implant)</b>	<p>Prevents ovulation</p> <p>&gt;99% effective</p>	<p>Not affected by antibiotics</p> <p>Lasts about 3 yrs</p> <p>Not thought to affect bone density</p>	<p>Needs small procedure using local anaesthetic to fit and remove (placed under skin of upper arm)</p>

Method	Action	Pros	Cons
<p><b>Intra-Uterine Device (IUD)</b></p> <p>- Copper - Mirena (contains progestogen)</p>	<p>A T-shaped copper or plastic device in womb</p> <p>Prevent eggs from implanting</p> <p>&gt;99% effective</p>	<p>Not affected by antibiotics</p> <p>Can last up to 5 yrs (some copper ones up to 10 yrs)</p> <p>No pills to remember</p>	<p>Need to check threads monthly to ensure in place</p> <p>Copper devices can cause heavy, painful periods</p> <p>Can be slightly uncomfortable to place initially</p>
<p><b>Condoms</b></p> <p><b>Femidom (female condom)</b></p>	<p>Barrier to prevent sperm reaching egg</p> <p>85-98% effective</p>	<p>Some protection against STIs</p> <p>Condom offers some protection to partner if you have candida (thrush)</p>	<p>Higher failure rate than other methods</p> <p>Need high motivation to use properly</p>
<p><b>Sterilisation</b></p>	<p>Female: clipping/cutting of fallopian tubes</p> <p>Male 'vasectomy'</p>	<p>Permanent</p> <p>High success rate</p> <p>&gt;99% effective</p>	<p>Difficult and often impossible to reverse - may regret</p> <p>Anaesthetic risk</p>

# Starting a Family

As your relationship progresses, you may consider starting a family together. In fact 34% of those asked want to start a family, and 21% have not decided yet. 17% already had children. This is clearly an important topic, so for those who do wish to start a family, there are some important considerations for both males and females with cystic fibrosis.

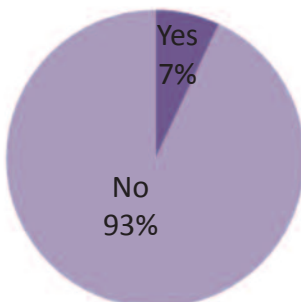


## Male fertility

Men with cystic fibrosis are usually infertile but their sexual function is otherwise normal. The infertility is due to an abnormality of the vas deferens. These are the tubes by which sperm normally leaves the body, therefore, in CF males there is no sperm in the ejaculate. Sperm are still produced however and CF males can therefore father children using the process of in-vitro fertilisation (IVF).

In-vitro fertilisation is where a woman's egg is fertilised by a sperm in the laboratory. The woman has to take medication to make the eggs mature, which are then collected. The CF male will need to have a small surgical procedure to collect sperm, which are then injected into the eggs using a technique called Intracytoplasmic Sperm Injection (ICSI). The resulting fertilised eggs are transferred back into the womb in the form of an embryo.

The process is not always successful on the first attempt, so may have to be repeated several times.



Would the issue of infertility ever stop you pursuing a relationship?

It can be difficult for men to deal with the issue of infertility, however the new techniques available do now make having children a possibility.

Although IVF can be a long and difficult process, it can also be a wonderful and exciting opportunity for those men with CF who wish to start a family of their own, and indeed around half the men we asked felt it was something they would consider.

*"We have spoken about children and know that we want them in the next few years because we're happy together. We've spoken about IVF and it's going to be a hard and scary process but it's just something that we have to deal with."*

Craig

93%  
said that infertility  
issues have *never*  
adversely affected  
a relationship

*"We had two attempts at ICSI, which in total took about 6 months; however the whole process took about 3 years, with investigative stages for both my partner and myself."*

Peter

*"Sadly the first thing on the agenda with anyone is 'I can't have kids'. That can seem a bit forward, but it has to be said. Some people have expectations."*

Tony, 29

*"I am confident in the medical techniques that are used to help male people with CF to conceive, so if and when the timing is right for us this is something we will definitely consider."*

Suzie, partner

*"I feel that there should be more information for males with CF and the opportunity to conceive. When I was 16 I was told by the doctors that I would not father children. However, we had IVF and our second attempt was successful. Fatherhood is the best thing in my world; it gave me a new purpose/goal, which is so important in life."*

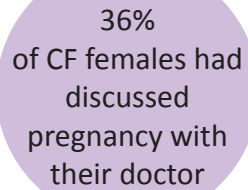
Simon

*"I would certainly consider IVF in the future if I met the right person and was ready to settle down. At least I feel there are options out there which might help me become a father."*

David

## Pregnancy

Females with cystic fibrosis tend to have thicker cervical mucus, which can make conception more difficult. Woman with low body weight can also have problems with erratic menstrual cycles, which can impact on fertility. However, in general, the majority of CF women who are in overall good health will be able to conceive naturally and have fertility levels approaching that of a non- CF female.



36%  
of CF females had  
discussed  
pregnancy with  
their doctor

If you are considering pregnancy it is vital that you receive pre-pregnancy counselling, which can be arranged by your CF team. This will allow the obstetric team to advise you on how to optimise your health to allow the greatest chance of a successful pregnancy. This would include looking at improving lung function and nutritional status before you try to become pregnant. Based on such factors they would be able to give you more detailed information on any risks or problems that are particular to your personal situation.

Throughout the pregnancy you will need to be closely monitored by your CF and obstetric team, so that they can give you the best advice, keep you as healthy as possible and make sure any drug treatments you require are safe for your baby.

There are several factors which need to be taken into consideration when planning a pregnancy:

**Lung function** - it is thought that the lower your lung function, the more likely it is for you to suffer a decline in health during pregnancy. All females with CF are at greater risk of having a premature birth and complications surrounding this, but this risk is greater in those with FEV1 less than 50%<sup>1</sup>. Mothers with an FEV1 >80% have less decline in lung function during pregnancy, better outcomes, easier deliveries, fewer preterm infants and fewer neonatal complications<sup>2</sup>.

Generally the advice given is that a lung function (FEV1) greater than 60% is preferable when planning a pregnancy.<sup>3</sup> Although increased ill health is more common during and immediately after pregnancy, recent studies suggest that longer term survival does not appear to be adversely affected by pregnancy<sup>4</sup>. As more severely affected individuals with CF begin to survive to child bearing age, it is however possible that these outcomes will change.

**Frequent infection** - this will increase the likelihood of needing IV antibiotics, which have to be carefully selected to avoid harming the baby. Therefore treatment options for infections are more limited during the pregnancy. CF women who are pregnant are more likely to need hospital admissions and intravenous antibiotics than non pregnant CF females<sup>5</sup>.

**Weight** - if you suffer from low weight, you are more likely to have problems with your pregnancy. In addition, females with CF will find it harder to gain adequate weight during pregnancy<sup>5</sup> so it is extremely important to get good dietary advice in order to optimise weight before and during a pregnancy.

**Diabetes** - if you have diabetes it is important to have good control of your sugars before you consider pregnancy, and close monitoring throughout. A certain type of diabetes can also develop during pregnancy and is more likely to occur in those with CF<sup>5</sup> so you will need to be carefully monitored for this.

**Liver disease** - more severe liver disease can cause complications during pregnancy, for both mother and child. Advice is needed from your liver specialist.

**Support system** - it is important to think about what kind of support you will have after the birth. Do you have a partner, friends or relatives who can help you out? Those with poor support systems are more likely to decline in health after the birth, probably because they do not have as much time to look after their own health.

**Post lung transplant**- successful pregnancies have been reported in women following lung transplant. However there is thought to be an increased risk of rejection if pregnancy is within the first three years post transplant<sup>6</sup>. It is recommended that any plans for pregnancy should be discussed with the transplant team and not be considered until a period of post transplant stability and after the risks have been explained thoroughly. Those who have had liver transplants should also seek advice from their transplant team.

**Carrier testing** - your partner can have a test to see if they carry the CF gene. If they do not carry one of the common mutations, your baby will be a carrier of the gene, but will be unlikely to have CF. However the risk can never be 0% , as the test cannot detect all possible CF mutations. If your partner does carry the CF gene, your baby will have a 50% chance of having CF. You should be offered genetic counselling to explain these risks more fully.

**Pre-implantation genetic diagnosis** - pre-implantation genetic diagnosis (PGD) involves the process of IVF to create embryos in a laboratory. Only embryos not affected by CF would then be implanted into the mother. However IVF is a slow and difficult process, which can be both physically and emotionally draining. Funding for this is considered on an individual basis because it is not always available and can depend on your local primary care trust. You should discuss with your GP or CF team to arrange appropriate referral<sup>7</sup>.

**Termination** - this is a difficult and emotive topic, but may be something you are asked to consider. If your partner is a carrier, you can have a procedure called 'amniocentesis' early in the pregnancy in order to determine whether your baby has CF. If this was positive you would be offered the option of termination at this stage. It is also important to consider that if you were to become very ill during your pregnancy, termination may be advised at a later stage in order to preserve your own health. This is a personal decision but might be something you wish to discuss with your partner in advance.

## Going ahead with pregnancy

Many women with CF are well enough to consider pregnancy, and with the support of their CF and obstetric team go on to have healthy babies. Some people suffer some deterioration in their health during pregnancy, whereas others manage to remain stable. It can largely depend on your pre-pregnancy state of health, especially lung function, however it can unfortunately be very unpredictable.



*"Yes we did talk it all through, although I don't think they generally played the "scare" factor enough of how bad it could get - they certainly didn't warn me I could end up as poorly as I was with a partial collapsed lung."*

*Josephine*

*"I was in near perfect health at the time so we had full backing from my CF team in deciding to plan for a baby..... I was lucky in that my labour went smoothly and only lasted 12 hours with no other complications."*

*Pamela*

You might also want to consider how you will be affected after the birth, both on a physical and an emotional level. It is hard work caring for a baby and looking after your own health at the same time. Some women with CF have also found it affects them emotionally, worrying about their child and how their health may affect them in the future.

*“You are well informed about the actual pregnancy, but nothing was mentioned about the after effects.... It was SUCH hard work. You may think you have all the help in the world from family and friends and you may well do... but in the middle of the night you still have to be the one who gets up and has to see to your baby and feed him/her. It is demanding and exhausting.”*

*Diane*

*“My health picked up very quickly after the baby was born and the pressure was off my lungs and the baby wasn't taking all the nutrients etc. I loved every minute of it and although tiring would never have changed it.”*

*Eleanor*

*“We have one child, who is nearly five. Having a child was my major emotional turning point. I felt so guilty at first because there was this tiny little person who needed his mum and for the first time in my life I worried about dying because I didn't want to leave him.”*

*Claire*

*“I've had a tough year so far and it has been a challenge trying to convince my son that I am ok. I guess he will not be unique in this. All it does is fill you with guilt. I'd urge anyone before they have an 'ickle baby' to remember that they (the child) have to deal with the CF as much as you do.”*

*Victoria*

## **Being advised against pregnancy**

Unfortunately, when you discuss pregnancy with your CF team, it is possible that they will advise against it, based on your health and circumstances. This can be devastating news to hear and, for some, is difficult to come to terms with. In this situation some people with CF have explored the idea of surrogacy. There is a website listed at the back of this booklet where you can find more information on this option. Many people, however, are accepting of the situation, and only around 15% of those asked felt that the decision to not have children had adversely affected their relationship.

*"Although we are both too young to think about kids, I do know that he had accepted that kids wouldn't happen for us even if we were older. He knew my health wasn't up to it. I had accepted the no kids bit earlier, I know the work they require and knew that my health wouldn't hold up."*

Nikki

33%  
of those who asked  
their doctors were  
advised against  
pregnancy

*"I took the decision some years ago not to have children (and my husband at the time left me as a direct result of that decision). My current partner knows that I would have loved to have a child but for many reasons it's not possible. I still struggle with the decision I made and get upset that I won't have children."*

Cara

*"Neither myself nor my husband had a great desire for children. However, it is not pleasant having the choice made for you."*

Irene

*"As most married couples we did discuss children and we had planned to have one, but as time got on and my wife's health deteriorated we decided that we would just enjoy our nieces and nephews, spoil them rotten and give them back when they started crying. This suited our lifestyle perfectly. But we did get our little boy - the dog."*

Calum, partner

*"I know I'd find it too stressful to cope with children and my health."*

Yvonne, 17

*"We coped remarkably well with not being able to have children, as we really had no option – it is a cut and dried case in my opinion. That doesn't prevent all regrets though; especially as we reach our mid-thirties and everyone round us have kids. I do think people feel 'sorry' for us sometimes but we rarely feel it for ourselves, and if we do, we try not to dwell on it. There are positives to not having dependants and that is what we concentrate on."*

Sophie

*"Not being able to have children is a difficult thing to come to terms with, but I would say that as a couple we are stronger because of it."*

Beth, 32

# Later Stages of Cystic Fibrosis

Cystic Fibrosis is a progressive disease. It is also a disease for which new treatments are being developed all the time, lengthening lifespan and improving quality of life. However, at some point, the question of what happens in the later stages of CF may well crop up; perhaps your partner is curious but afraid to ask, perhaps you are scared they don't understand what may lie ahead. This section is here to help, not to frighten, and it may not be relevant to some of you. Hopefully to others, it will help to know that as always, others have been there before and you are by no means alone.

## Is CF consuming your life?

Some people have said that in the latter stages of the disease, they feel that what makes them "them" is buried under all the illness and medication and treatments, which now seem to take up their whole life, and to some extent their partner's life. For many people the question is, where do you find time to have a relationship?

*"I had nasogastric feeds every night, so I was hooked up nasally to a machine, also hooked up to oxygen (again nasally), and when I was on IVs I had a needle and tubes sticking out of my chest! Not very romantic at all! Even if I did have the energy and puff even for the tiniest kiss! "*

Nicky

*"Sometimes it feels like everything in our lives revolves around CF and treatments. I don't feel like the person I used to be - I don't think I am as much fun anymore. My partner is very understanding however, and he is happy to support me and try to keep me focused on things other than CF."*

Julie, 29

## How will we cope?

Coping with the high levels of care needed for someone with very advanced stages of the disease is undeniably a strain. One vital thing is to admit when you need help. Sometimes being strong means accepting help and support to make both your lives easier. Some partners prefer to be as involved as possible, others may delegate to give them their own time too; however you handle it, do so as a couple and try to get the right balance for both of you.

*"My advice to anyone is never feel guilty for getting angry with the things you can't do because your partner has CF, or for panicking when you shouldn't have done something that has made them worse, for thinking about issues surrounding mortality when they don't want you to. You are a human being – not Florence Nightingale or Mother Teresa – and humans have feelings, things you cannot change or control because they are feelings, not actions."*

*Alice, partner*

*"When I became more unwell and needed a wheelchair for longer distances I hated having to rely on my husband to take me places. However we quickly got used to it and began to see it as more time together and as something he could do to help me."*

*Susan, 27*



*"It was very difficult when my partner went into hospital as I found it very hard juggling everything, but we just managed and again didn't let it affect us too much. I used to hide a lot of my stress from her just so that she didn't worry when she was in. Apart from not being able to go abroad it didn't really affect us too much. We just learned to live with her CF; we bought a caravan to go away in so the holiday issue was no longer a problem. You live with what you have and get on with things."*

*Jonathan, partner*

*"As far as I was concerned, the moment it became apparent that my wife would require a carer, I did not hesitate in wanting to do it. I felt that looking after the person I loved and spending as much time as possible together were the most important factors..... I found there were different issues that needed to be worked through; things like ensuring continued adherence to treatment as a husband and not lapsing into a "parent/child" relationship was the most difficult, but we managed it."*

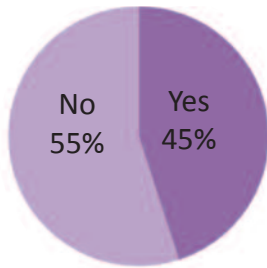
*Michael, partner*

*"I think that CF has affected my relationships in the past to the extent that it has made me want to push people away since I have always wanted to feel in control and independent. Since I have been more unwell recently, I have got used to idea of asking for help and my partner and I have made a really strong team."*

*Thomas, 26*

## How much should we talk about “it”?

There is no greater taboo than the prospect of dying. It’s actually a consideration that every single long term couple, CF or not, will some day have to contemplate - none of us are immortal. However living with a life-threatening condition may raise questions about life expectancy at an earlier stage; but is there a correct way to deal with this? How much should you say and when? How much you talk about together is up to you as a couple, however you may want to consider that certain discussions about the end stages of CF, although very difficult at the time, could make things easier later on.



Have you ever discussed end of life issues with your partner?

*“As his health deteriorated it wasn’t something we talked about as much because it was on our minds a lot anyway. When you get scared, it’s difficult to talk, especially to the person who your world revolves around.”*

*Eve, partner*

*“I found it very difficult to talk seriously about the future to Tim. I think it was just too hard for me to think that I was dying. I never really gave up hope that I would get my call for transplant, which I was lucky to get. We did try talking about the money side of things, and what he would do if I died with regards to our son.”*

*Rachel*

*“My wife and I didn’t really talk about the end of life issues and in a way I am really kicking myself now because I don’t actually know if what we gave her was what she wanted, but I think it was perfect and everyone said that it was her through and through.”*

*Leroy, partner*

35%  
thought it had helped to discuss end of life issue, 54% didn’t know and 11% didn’t think it helped

## Why would someone stay with me?

So many of us have asked this question and even more so when you are in the later stages of CF; wouldn't it be better to spare someone you love by pushing them away? Why on earth would they want CF in their lives if they have a choice? How can we bring them all the sadness of watching this decline? Do they really understand what may lie ahead?

*"I feel like she doesn't really understand the seriousness, and likes to pretend to herself it really doesn't exist. This scares me a bit, and it's one thing we haven't talked about much. I think we need to."*

Ben, 20

*"Obviously, whenever my health causes me suffering, this affects my husband's state of mind because he is concerned for me."*

Sonya, 43

*"As I became more unwell I sometimes did push my partner away, and I wondered why they stayed. I understand now though – that I was still the same person and I still had a lot to give."*

Hazel, 31

*"What I want to say is that in a way it's a sacrifice; you're sacrificing your future. When you enter into a relationship with someone who has CF you enter into a guarantee of times of emotional turmoil, and in the end, the unbearable pain of bereavement when you lose the centre of your world. I may only have my Mr. Right for 10-15 yrs, but isn't that better than "Mr. not the love of my life but doesn't have CF" for 50?"*

Kirsten, partner

*At times I wondered why he stuck around and I felt it would be easier for him to just walk away. You can't afford to think like that though. You have to just accept someone can love you as you are."*

Seonaid

People don't fall in love with someone because it's an easy option, they fall in love for someone because of the person they are and the way they make them feel.

## Waiting for transplant

When the issue of transplant is raised, it can be a scary wake up call as to just how unwell you have become. Living with CF means we learn to incorporate CF-related difficulties into life and to get on with living, but realising you are being referred for such huge surgery can be difficult to take in.

Following recommendation for transplant assessment there is a lot to think about, financially, emotionally, practically...where do you start? How do you protect your other half? Is transplant the right path for you? How will you both cope while waiting for that call? It can be a frightening time for both of you, but also a time filled with hopes and dreams for the future you can build together afterwards.

*“The realisation that I had actually been given a death sentence if I didn’t receive my transplant was horrifying. We were both so stunned - I think we both thought of me as doing OK, because that’s what you have to do to get on with life. We remained calm in the doctor’s office, but on leaving we wrapped our arms around each other and both had a little cry. That’s when I knew we’d be going through this together...and that was going to make it a lot easier for me.”*

Cat, 24

*“My partner got put on the transplant list before we got together and I remember we used to talk about things all the time. I really wanted him to know he could talk to me about anything that was going on in his head. The decision to go on the transplant list is such a huge one that I wanted to support him as much as I could.”*

Rhiannon, partner

## Life through the looking glass

Compared to before, life after a transplant is essentially impossible to imagine. Transplant can create a whole range of new possibilities and opportunities, for you to explore both on your own and together. This massive change can have a significant knock-on affect to your relationship. Some people will slip into their new roles naturally, where as others will need more time to adjust. Either way, it’s important you tackle these changes together and allow yourselves to vocalise difficulties to each other without feeling guilty.

*“After my transplant I was worried that we would find it difficult to adjust, as our roles were rapidly changing. Luckily, it was much easier than I expected and my husband was only too glad to give up the 'carer' role and have time and space to become a husband again.”*

*Linda, 28*

*“I would say that my husband has had NO post transplant support whatsoever. As an example, a year after I had my transplant I wanted to try working again, and managed to get a job quickly, and had lots of help from the job centre etc. But when he was trying to find work, although he had stopped to care for me, there was absolutely no help out there for him at all, which was a real shame. We had quite a difficult time after my transplant when I started to get better and do more and more things in the house, and also when I started to go out on my own, even to shops, or to meet friends, he really didn't cope with that well at all; the logistics were very difficult.”*

*Milly, 43*

*“It was more of a gradual thing that our roles started to change. As I became stronger and stronger I began to realise that the things that were very easy for me to do took quite some effort from him. Mike does seem to have the 'man's' role of the household though as he sorts out the bills, holidays, insurance and so on. So I don't think me now being the stronger one makes him feel inferior.”*

*Kirsten, 24, (partner also has CF)*

Whenever a key element changes in a relationship, such as one partner getting a new job, the dynamics of the relationship are bound to shift and feel strange and new. Transplant is the ultimate dynamic shift; the person who before could do nothing and needed constant care is now finding their own feet again and able to regain their independence.

This is great for both parties but can be unsettling, both for the carer who feels displaced, and for the ex-patient, who can now branch out on their own and needs to relearn what it is to be 'well'.

Be patient, move forward slowly and work together to ensure you can enjoy the incredible new opportunities transplantation can bring together.

# Losing a Partner to CF

New treatments for CF have increased the average life expectancy and children born today with CF have a much more promising future. However, at this stage, some people with CF still lose their life at a relatively young age. This has obvious implications for the partners of people with CF, as they face bereavement, coping with the loss and eventually moving on with their lives. We were deeply privileged to speak with two young men who have lost their partners to CF. We hope that by sharing some of their thoughts with you it may prove helpful to those who have experienced such a loss, or are facing this possibility.

## Did talking about end of life issues help?

*"We didn't really talk about the what ifs.... my wife was going to live forever. I didn't think anything would happen to her that soon. I wish we had talked about what she wanted for her funeral mainly. I also wish I had talked about my future with her as well; we did talk about me moving on with my life once before she died but we didn't go into great detail. I have now moved on and met someone else but I still wonder what she would think."*

David, 27

*"My partner and I never truly talked about any end of life issues as such. Whether or not it would have been helpful is something I'm not certain of. In reality, I'm not sure I would have taken it in fully. One thing that did come up not too long after her passing was a letter she began to write on the news of a (later aborted) transplant call. To this day, that letter brings up a mixture of feelings, because as much as it upsets me to think upon, it also brings with it reassurance and warmth. Had she finished the letter, it would have been a written expression of her wishes"*

## Coping with the loss

*"I coped by filling my life with as much as I could. I went out all the time. I engrossed myself in my work and I changed my job to work for the CF Trust just so that I could be around CF. It was such an important part of my life for so long I didn't want to let go of that. I then joined a group called WAY (Widowed And Young). This is a support group for young people that have found themselves in my situation. That helped me so much."*

David, 27

*“Friends and family became the main source of coping with loss, especially my partner’s family who I consider part of my own. While many of the months that followed I’ll probably never be able to truly recall, the support and help received by everyone around me helped in many ways. Naturally this wasn’t always the case and having to deal with such a thing internally is always going to be the primary coping mechanism whether you want it or not, but I found talking sometimes helped. Other times it didn’t. The duality of trying to cope vs. the pain of remembering and thinking what could have been is a very difficult thing to juggle and extremely individual.”*

Gareth, 29

## Advice for others

*“It is very individual. Everyone copes differently, what is right by one person is not right for others. Don't let people tell you the way you are coping is right or wrong. You need to find your own way of getting through the grief and rebuilding your life. The best bit of advice I could give anyone is do what is best for you and talk to someone either a friend or family member or if that isn't right an outsider like a counsellor. I found the WAY Foundation very good again because I was able to talk to people via e-mail with anonymity. Never stop talking about that person, people feel guilty talking about your partner but sometimes they are hurting too and want to talk to you about them. Finally don't take things to heart... people can easily forget what you are going through and think they are the only ones affected by it. People will occasionally forget that your partner was the most important thing in your life.”*

David, 27

*“I feel having a freedom to deal with it in your own way is important. Being given the time to go through whatever process you need to go through in its due time and being with people who can allow you that and know when to give you the space and consideration you need without straying too far for when you need them. Not being afraid to let yourself go and be emotional about it all and slowly filtering in the stuff that you experienced together or that reminds you of that person – because chances are, everything will remind you in one way or another; a song, a scent, a turn of phrase, a couple holding hands a particular way. “*

Gareth, 29

## A Final Thought

Cystic Fibrosis is not who you are, nor should it define you in any way. But it is a part of your life, and the more you share your life with someone else the more you are forced to share your CF.

As we have seen in this booklet, to what extent and when you choose to share is an individual choice, and hopefully this has shown you that there is no wrong, or indeed right, way of including CF in your relationship.



*“If things were to end tomorrow I wouldn’t cry because it’s over, I’d smile because it happened and I got the chance to experience what it’s like to love someone and have someone love me back, and that in itself is an amazing feeling and CF can’t take that away.”*

*Sam*

# Additional Resources

## Websites

*Citizens advice bureau advice guide* - [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

*Carers advice and support* - [www.carers.org](http://www.carers.org)

*Housing* - A CF Trust Publication: [www.cftrust.org.uk](http://www.cftrust.org.uk)

*Growing up with cystic fibrosis* - A CF Trust Publication: [www.cftrust.org.uk](http://www.cftrust.org.uk)

*Planning your will* - A CF Trust Publication: [www.cftrust.org.uk](http://www.cftrust.org.uk)

*Practical advice on end of life considerations* - [www.ifishoulddie.co.uk](http://www.ifishoulddie.co.uk)

*Widowed and young* - [www.wayfoundation.org.uk](http://www.wayfoundation.org.uk)

*Sex and breathlessness* - A BLF Publication. Available in pamphlet form or online - [www.lunguk.org](http://www.lunguk.org)

*Contraceptive options* - [www.contraceptivechoices.co.uk](http://www.contraceptivechoices.co.uk)

*Surrogacy information* - [www.surrogacy.org.uk](http://www.surrogacy.org.uk)

## Addresses

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## Contraception

Royal Cornwall Hospitals factsheet. *Contraception in woman with Cystic Fibrosis*. Available at [www.cornwall.nhs.uk](http://www.cornwall.nhs.uk)

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