



7. How does it feel to go through infertility treatment?

A guide to help women with cystic fibrosis make informed choices

A patient's perspective - Terri

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I've always wanted children and always assumed I would. It never occurred to me this could be a problem because of my CF. I knew conceiving could be a problem, but never thought about carrying it, or looking after it. Until one day, Sarah (CF Nurse) took me to one side for one of her little chats.

I had mentioned having children in passing as something for the future.

Sarah said if I wanted children, it would have to be very soon, like immediately. Garry and I then had a chat with Sarah, and found out

how it would affect me to be pregnant, and that because of the condition of my CF I shouldn't delay. After that chat I said I wanted to start trying right away and Garry said he'd rather never have children! We weren't really in a position to have children, and Garry was very worried about my health – he said he'd rather have a wife than a baby. We spent a long time discussing the implications to my health. Garry had already been tested,

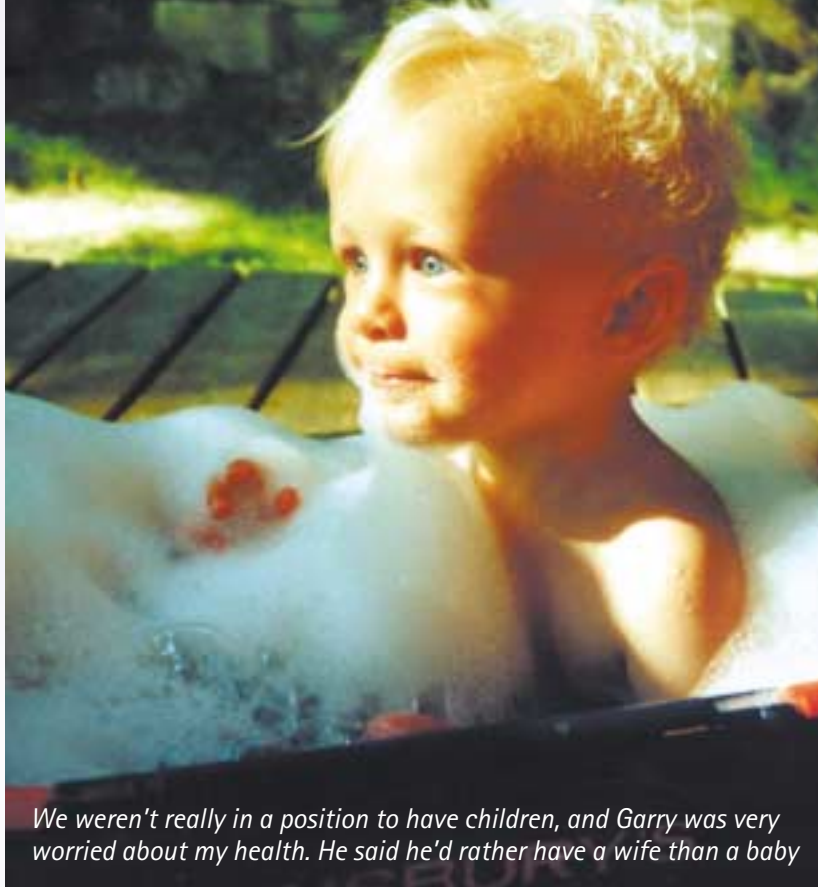
and didn't carry CF, so that wasn't an important factor, but was it fair to the baby to have an ill mother? In the end Garry said he could cope if the worst happened, and he ended up looking after a baby and a very ill mother.

So if I was prepared to take the risk he didn't feel he should tell me to do otherwise.

I also thought it would be a case of one trip to the hospital – hey bingo you're pregnant. I was very wrong

I was expecting to need treatment, but was convinced it was a just a case of intrauterine insemination (IUI). I also thought it would be a case of one trip to the

hospital – hey bingo you're pregnant. I was very wrong. The first thing they told us was IUI only works 15% of the time. However, we had our first go. We were full of hope, positive we would be within that 15%. We had to wait 2 weeks to find out. It is amazing how long 2 weeks can last. One minute I was convinced I was pregnant. Any symptom of pregnancy, no matter how common in the non-pregnant, eg. feel a bit sick/sore boobs,



We weren't really in a position to have children, and Garry was very worried about my health. He said he'd rather have a wife than a baby

only convinced me I must be pregnant. Other times I was sure it hadn't worked. We talked about what we were going to do when the baby was born and got quite excited. Then I got my period, I was very upset, far more upset than I thought I'd be, after all we could have another go. Garry was much more philosophical about it – what will be will be. Next go the same happened.

By this time my chest was deteriorating, so we decided it was probably too risky to get pregnant and decided we should give up. However, we were offered one last go. We were

too tempted, and decided to take it. We didn't really expect it to work, but thought it would be easier to cope with being childless, which I found very daunting, if we knew we have done everything possible to have a baby. This time there was no treatment. I just wanted to get the 2 weeks over with, so that I could have some IVs and start to feel better. This time, the day my period was due, it didn't arrive. I went straight out and bought a pregnancy test. I couldn't believe it when a blue line appeared, so we bought another. When that blue line appeared we told everyone we knew.

I needed to go straight into hospital for IVs, but was assured if I had ceftazidime it was safe.

Two weeks later, the day before my 6 weeks scan, I miscarried. We were both totally devastated. All I could think of was why? If I wasn't meant to have a baby, why didn't it just not work and we would have given up trying. Having the miscarriage was very painful emotionally for both of us. All our hopes and dreams were down the drain.

I found the physio-therapist very helpful at this time. She helped me come to terms with it, just by talking whilst she thumped me.

The miscarriage was, I think, one of the biggest reasons why I am now about to have this baby. I don't think I would have managed to carry that first one, my chest was too bad and the ceftazidime wasn't working. However, having been pregnant I now wanted a baby more than ever, and Garry's attitude completely changed. He now really wanted a baby, and couldn't switch his emotions off, and think practically as he had done before. I became determined that my health wasn't going to stop me having a baby, both for me and Garry. I started really working at my health, instead of just letting things happen. I doubled my physio and started swimming every day. After 6 months I was fit enough, and we were ready emotionally to try again.

Having the miscarriage was very painful emotionally for both of us. All our hopes and dreams were down the drain

This time we knew IUI could work and were very excited. When it failed 4 more times we were devastated to be told IVF was now our only option. We hadn't expected this and were very upset. It seemed like the end of the world because there was no way we could afford it. My mum worked in an infertility clinic so I knew how emotionally difficult IVF was. I also knew it could be very painful physically, and had always said that I'd

never have IVF.

However, now I knew I needed it, I wanted it more than anything, because anything was better than giving up.

Not long after, we heard great news,

Nottinghamshire were funding IVF on the NHS. We decided to go for an initial consultation to find out about what would be involved, and about funding. We couldn't really afford this, but decided to put it on Visa and worry later. After all it would be money well spent, if we could get IVF on the NHS. Funding proved more difficult than we thought, because we lived in Derbyshire and not Nottinghamshire. We were told that we could possibly get it, but it would take a long time for the paper work, and I would have to have months of tests, under a doctor who had a long waiting list. We received a lot of support from both the CF consultant and our GP, but they could do nothing to speed up the bureaucracy.

Throughout the whole of my 'trying for



a baby', I have been very aware of the time passing, and was worried about leaving things very long in case my luck

with my chest ran out and it deteriorated again. So whether to wait for the NHS funding, or whether to borrow money in order to have a go before time ran out, was the next dilemma we faced – thanks to CF.

We arranged an appointment with the counsellor at our local private fertility clinic. That being free, it was something we could afford. I was hoping that Garry would see things my way and borrow the money, and Garry thought that counselling would help me come to terms with the likelihood of giving up. So far I felt that CF was dictating everything we did, even finances – after all we couldn't just wait for our finances to improve, so when we saw the counsellor, I was determined to be an 'ordinary' IVF couple. I made it clear to Arlene that I didn't want to discuss my CF, we were there to discuss IVF.

This session of counselling was very helpful. We talked for a very long time about lots of issues – yes it did include CF and how we would cope with a baby, but I feel it helped most because Garry had to talk about how he felt. Up until now he had said very little, and was happy to just 'see what

happens'. Now he had to think about how he felt and it was good for me to hear. It was the first time he could be persuaded to really tell me, despite me constantly asking what he felt. It was also good because Garry surprised me by saying that he thought we should borrow the money. He remembered how he felt when I was pregnant, and thought he would regret not trying again much more than he would regret borrowing the money. After all in a

couple of years time the debt would be paid, but it would probably be far too late to try for a baby. In the scheme of things borrowing a bit of money was not the worst thing that could happen to us.

We decided we would only borrow up to £2000, which would give us one go at IVF and one embryo replacement, if that

didn't work I didn't want to think about what would happen if that failed.

When the IVF started I found it difficult at first, because I had to either drive to the Park, which took about an hour everyday, or learn to do the daily injections myself. I found this difficult. Having an injection is one thing, doing it yourself is a whole different ball game. Garry wasn't much help. He did try to encourage me, but when it actually came down to it, he had to leave the room. I went back into hospital to get my chest tip top in time for the embryo replacement, so that I

Throughout the whole of my 'trying for a baby', I have been very aware of the time passing, and was worried about leaving things very long in case my luck with my chest ran out

could go as long as possible without IV's when pregnant. We continued with the counselling because now we had started we were having to make some difficult decisions. Again these were mostly due to my CF. The most difficult decision was how many embryos to put back. After hours of discussion, we decided that putting only one back didn't give us enough chance of success – only 20 % to be worthwhile. However, putting two back could mean twins. I was told in no uncertain terms by the CF nurse, that this would be an impossible situation for me to cope with, both before and after birth – CF again! Garry was adamant he didn't want twins because of the risk to me, but I would have taken my chances. It was suggested that we think about putting 2 back, and selectively terminating if the result was twins. Garry thought this was a good idea, but even after counselling, I still don't know if I could have done that. After all that effort to get pregnant, I don't think I could have killed one. Garry said it's not a baby, it's just a blob at that stage. In my head I know he was right about it being our best chance, and that of all the options it was the least awful to cope with, but in my heart I honestly don't know if I could have gone through with it. I can honestly say that was one of the tougher decisions we have ever made.

Meanwhile I continued with the injections, which had to be prolonged

I got very depressed on these injections. I knew it was the hormone treatment, so I wasn't worried, but I was very miserable and couldn't shrug it off

to give my chest a chance to reach its peak. I got very depressed on these injections. I knew it was the hormone treatment, so I wasn't worried, but I was very miserable and couldn't shrug it off. I also got hot sweats, which were awful and my chest didn't pick up as well as I wanted, and I seriously

began worrying how I would cope as a mum when I felt ill, which at this point in time, seemed to be always.

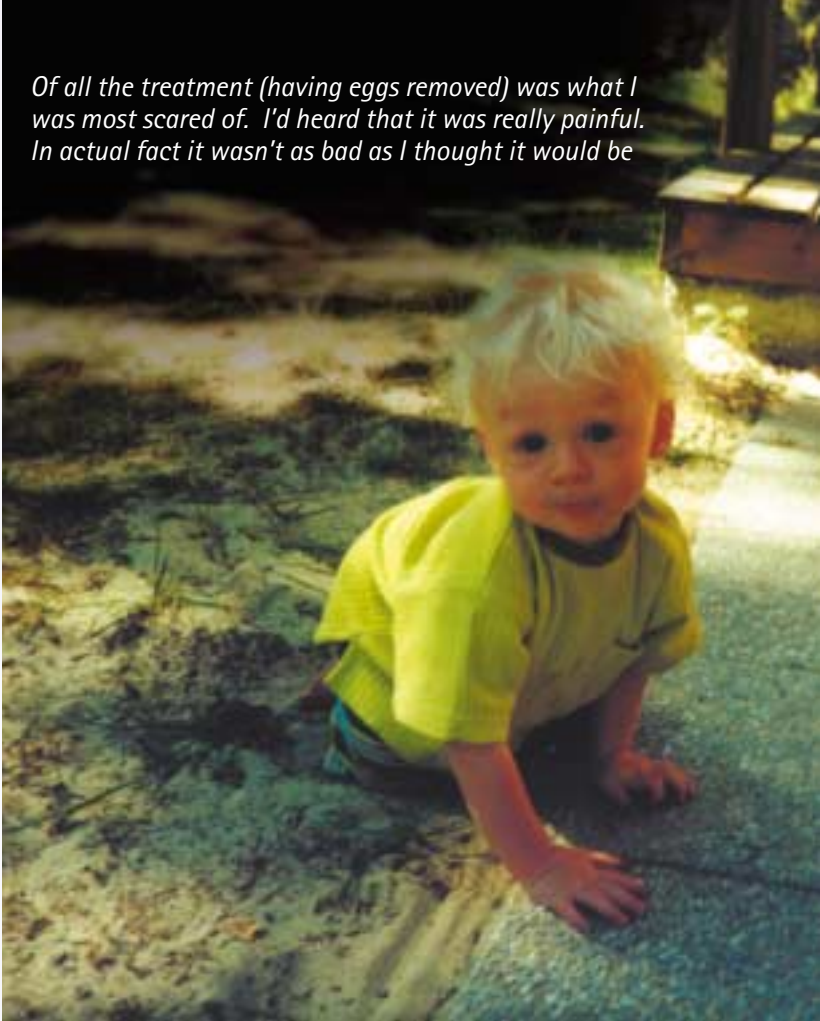
I nearly gave up because I began doubting all the things we discussed about coping with the baby. I saw Arlene on my own and came to the

conclusion that no matter how bad things get with a baby, coping with never having one was far worse.

When I started the next set of injections, apart from having two daily injections, I started feeling brighter. Then I had the eggs removed. Of all the treatment, this was what I was most scared of. I'd heard that it was really painful. In actual fact it wasn't as bad as I thought it would be, because I had gas and pethidine. Afterwards I was sore for the rest of the day, and physio was very painful for a couple of days.

Now we had the difficult bit emotionally. Once the 2 embryos were replaced we had to wait 16 days, and then do a pregnancy test at the hospital. Because of the hormones I was now on, getting a period or not didn't mean anything. These 16 days were the worst ever. Even harder than

Of all the treatment (having eggs removed) was what I was most scared of. I'd heard that it was really painful. In actual fact it wasn't as bad as I thought it would be



before. I was sure I was pregnant after a few days, but I was too scared to hope. Emotionally I was in turmoil. I talked to Arlene over the phone because Garry wouldn't talk about it. On day 16 I drove to the hospital with my bottle of pee, and then had to wait 3 hours. It felt more like 3 years. I was at a friend's house when the hospital phoned. I was so excited I burst into tears and phoned Garry, who couldn't say much because his

dad was there. We weren't tempting fate this time. We weren't telling anyone – except my friend who knew about the IVF – not until 3 months. We were adamant.

It took me half an hour to drive home. When I got there we were so excited we told his dad, then my mum, sister and Garry's mum and sister. We were so excited, but this time we were more apprehensive, and our parents and sisters were sworn to secrecy..

As the news began to sink in, we began wondering how many there were and what was I going to do if there were two. After 4 weeks of knowing I was pregnant, we went back to the hospital for our first scan. There was only one baby, and I was so relieved I burst into tears. All we could



see on the scan was a tiny blob with a little heartbeat, but that was the most amazing little blob I've ever seen. Now we could relax more because I'd passed 6 weeks, which was how far I'd gone before, and we knew there was only one baby.

A few weeks later, we had our 12 week-scan, and were told everything was perfect with the baby. From that point on we began to enjoy me being pregnant, and told everyone else we knew.

As regards my CF, I feel I have done well with my pregnancy. Chest wise I had no IV's at all for the first 12 weeks. Since then I've had lots of IVs. I still

find having IVs very difficult, because I still think of the miscarriage, but it was the first ones which were the worst, and I was really glad to make 12 weeks without any. The biggest problem I've had is dietary. For the first 10 weeks I felt too nauseous to eat, and therefore lost weight. That passed, and I put the weight back on, but then the indigestion set in. Its mostly controllable during the day, but night feeding is very difficult so by week 27 I've lost 2 kg, although the baby is growing well. I am trying to overcome this weight loss by NG feeding in the evenings and mornings.

Despite these little problems, I have really enjoyed being pregnant. It's lovely to be fat for once in my life. I do wonder sometimes, especially

when I'm tired, how I will cope without becoming a burden to Garry, but we've discussed it, and still regularly discuss it, and have made a few practical plans, so I'm sure we will cope. When the baby is born, Garry is

having time off work. Then my mum is coming to stay, followed by his mum and then his dad. After that we will pay a cleaner to do the bigger jobs. When the baby is 6 months he will go to the crèche where Garry works, to give me a chance to rest. When I'm ill I can take the baby into hospital to start with. When he is bigger he will go to the crèche all day, then Garry will cope in the evenings. My family have said they could have time off to help out when I'm in hospital, although realistically this wouldn't be

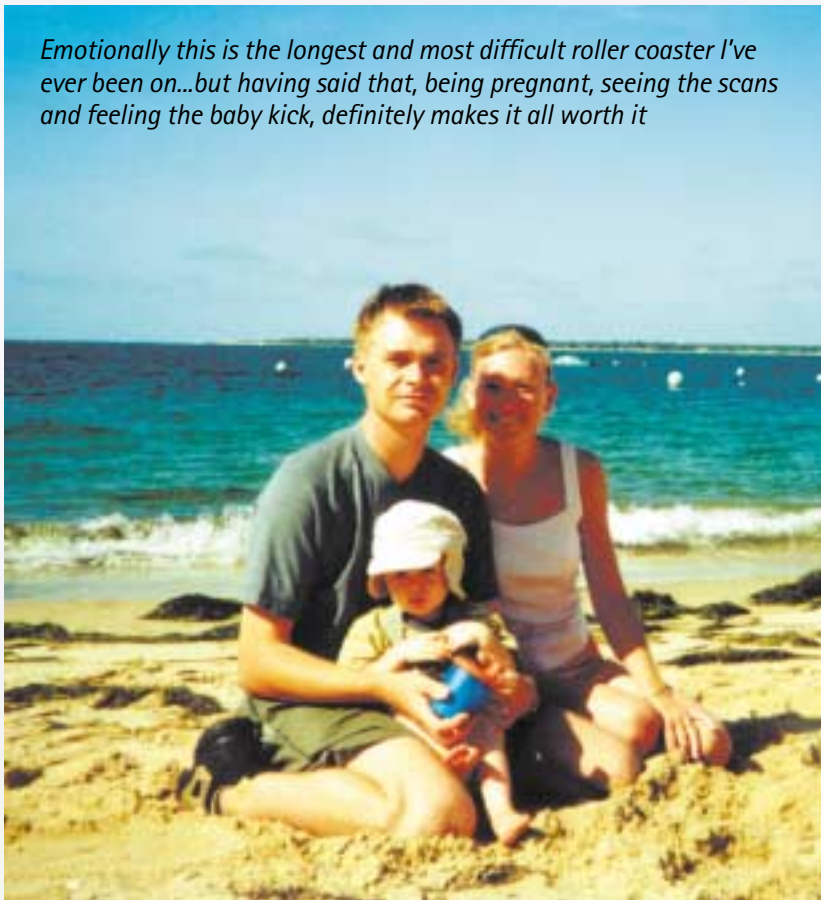
Despite these little problems, I have really enjoyed being pregnant. It's lovely to be fat for once in my life

possible very often without them losing their jobs. Garry is sure he can cope when I'm ill, and I have total confidence in him. Mainly though, we will just have to play it by ear, and adapt as and when things happen. If the worst happens I have made a video diary, which I intend to continue with. Garry will show the baby this video so he will always know his mum.

In summary, IVF is difficult both physically and mentally. Physically, egg removal is the worst, but generally

IVF isn't a patch on CF physically. Emotionally this is the longest and most difficult roller coaster I've ever been on. This constantly aggravated by the CF, despite my determination that it wouldn't be. The CF constantly made us have to make very difficult decisions that healthy couples wouldn't give a second thought to. But having said that, being pregnant, seeing the scans and feeling the baby kick, definitely makes it all worth it, and the money problems sink into total insignificance"

Emotionally this is the longest and most difficult roller coaster I've ever been on...but having said that, being pregnant, seeing the scans and feeling the baby kick, definitely makes it all worth it



Terri wrote this contribution while she was still pregnant and making her plans for becoming a mother. It seemed useful eight months on to ask her how the final part of her pregnancy, the birth and the experience of caring for her son, Cameron, had matched up to her hopes and expectations. She kindly agreed to answer the following questions:

■ *How did the final part of your pregnancy go?*

Slowly. During the last few weeks I had to just sit still. If I did that I felt fine, but if I walked even just a short distance, eg. to the loo, then I got very short of breath and even needed oxygen towards the end. Also, as is very common in pregnancy, I had terrible indigestion, which made it very uncomfortable to do my night feed so I lost weight (1 stone) during my pregnancy. This did not affect the baby but I found this very difficult to regain after the baby was born.

■ *What was the delivery like?*

Lovely. I had a planned Caesarean. Because it was planned, and 5 weeks early, I had no contractions and therefore no pain. Garry was there which I needed because I was terrified of the spinal anaesthetic. Once that was over, I could relax. The delivery was a bit impersonal in that there were about 10 strangers in the room but it was very exciting and very emotional. After Cameron was born I did not notice anyone except him and Garry. Because Cameron was early he was

taken away to Special Care a few minutes after he was born. That was really awful.

■ *Why did you have a Caesarean and how did it feel?*

I had a caesarean because my lung function was very low and the Doctor said he did not think I would manage labour, because it is very exhausting, so he said it was best to go straight for a Caesarean. I was a bit reluctant because I was very nervous about the spinal anaesthetic and worried about coping with the pain afterwards, when I would have my physiotherapy. Also antenatal classes made labour sound like a really wonderful experience and I was left with a feeling of being 'left out' of the most exciting thing that was ever going to happen to me. In reality none of my antenatal class enjoyed their labour so I did not miss anything. Several ended up having a Caesarean anyway and thought that was the best bit. The only thing I missed was the pain, it was still very exciting being handed the baby.



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■ *What was it like being in hospital after the birth?*

Immediately afterwards I had to stay in bed to have a blood transfusion. That was hard because I just wanted to get to Special Care to see Cameron. After I could get out of bed, I was free to go to him whenever I wanted to, and that was a lot better. At first I was very

nervous with this tiny bundle, but in hospital there is a lot of support so being in hospital gave me quite a gradual introduction to being a mum. I also had lots of support with physiotherapy, which I needed. I was in for 3 weeks, so by the time I went home, I was confident that I could cope with both my baby and my chest.

■ Did you have any pain?

Very little. Morphine was given before the spinal injection wore off. When that wore off, I felt okay. It was uncomfortable to change position from standing to sitting and vice versa, but that was bearable so I did not have any more pain relief. However when the physiotherapist came the first afternoon (Cameron was born in the morning) the pain was awful so we stopped and before the next thumping I had morphine and that made physiotherapy uncomfortable but not painful. I had morphine for the next session of physiotherapy and then after that I had Volterol for a few sessions of physiotherapy. By the time Cameron was 5 days old I did not need anything at all for physiotherapy because the pain was gone.

■ Did you need any extra IV treatment – How were your lungs?

Immediately after having Cameron I felt as if my lungs filled up with air, and in fact my lung volume doubled to about 50%. However I had some infection in the base of my lungs which had been squashed by the baby, and so I needed 3 weeks IVs and then went home feeling great.

The physiotherapy and nurses fitted my treatment around Cameron's feeding-times so I was there for all feeds and nappy changes, so I did all his care during the day

■ How much time did you spend with the baby?

After the transfusion I was able to spend all day in Special Care, except I had to take time out for my treatment. I got up for my morning IVs, then went to SCBU, then I went back to have my night-time IVs and stayed there for the night. I just went back to my ward for physiotherapy and IVs and food during the day. The physiotherapist and nurses fitted my treatment around

Cameron's feeding-times so I was there for all feeds and nappy changes, so I did all his care during the day. I did enjoy my unbroken nights though, until he was discharged to my ward. Then I had him 24 hours a day.

■ What is it like to have a baby in Special Care?

It was awful. I felt guilty because it was my fault he was early (my chest). But the staff were really nice and he was happy enough, so I quickly got used to it. It sounds awful, but it was actually nice to be able to sleep all night because SCBU did the 'night duty!' Having said that, it was lovely to get him back to my ward, by which time I felt quite rested, unlike the other mums.

■ Did you breast feed and how did it feel?

At first I did not breast feed because of my treatment. I was a bit disappointed, but I had not expected to breast feed because I knew I would need IVs. Antenatal classes did try to bully you into breast feeding but I felt confident it was better for the baby if I had the IVs than if I forfeited them to breast feed. But my milk did not dry up so after my antibiotics finished I did breast feed. I really enjoyed breast feeding. It was hard work for the first week, because he was constantly feeding, but after that it settled down. Breast feeding gave me time to spend time with the baby with no one interrupting it was really intimate and lovely. On the down side, it made me lose more weight so I did bottle-feed as well, usually at night because it made him sleep longer. After 6 weeks I started more IVs so I had to bottle-feed again. This time my milk did dry up. I do miss breastfeeding, but bottle-feeding is enjoyable too, and I feel happy knowing I have done my best. Anyway he has got teeth now so he would be on the bottle now even if my milk had not dried up!

■ When you came home how did you cope with a new baby?

I think I coped very well when I first came home with my new son. We had arranged for each of the grandparents to stay for a week each, after Garry's paternity leave ran out. They looked after me whilst I looked after the baby. It was easier than I thought it would be. I was tired but I felt really well and was so happy that I felt indestructible.

Things started getting harder when Cameron was about 5 months. My chest gradually deteriorated until it reached a level where I felt ill. That was when he was 5 months. He was sleeping through the night by then but I still have constant early mornings and cannot have early nights to make up for them and looking after Cameron when I really wanted to be in bed for the day, had started taking it's toll.

■ How is your health now?

Now my health is not as good as it was before I was pregnant. It is quite a bit worse. I think this is partly because being pregnant knocked the stuffing out of me, but mainly because I have not had the time to myself, to indulge in treatment and therefore allow myself to recover totally, with each set of IVs I have done. Having said that I am less well but lots happier.

■ How is the financial side of being parents?

The first cost was making him (IVF) so we started off in debt but if you do not count that, then it has not been too bad. Getting set up is very expensive because prams, cots, car seats, sterilisers, bottles etc are all expensive. But he is so special to us and our family, we have been very lucky with gifts, in fact I have only just started buying clothes for him, now he is 6 months.

Going out for a night is the most noticeable cost so far because it costs a bouquet of flowers each time (for the babysitter) because our family all live a long way from us.

My second child will not cost anywhere near as much because I have kept all his clothes and he can use Cameron's pram and cot and toys, however we have no plans to have a second baby.

■ How do you fit your care around your baby's care?

With difficulty. I have to have my treatment whilst Cameron is asleep. At first he slept a lot so that was okay, but now he sleeps less it is getting more difficult. I try to rest when he does. However, he is beginning to play, so when he can play unsupervised I hope it will become easier again.

■ How do you feel now?

Now I feel really contented with my life. I have got to where I want to be in life. I did not get there how I wanted, in that I wanted a career, then a family. I did not have a career because of CF and I did not plan on needing IVF. I always wanted to give up work for a family. Now I am at home with a beautiful baby so that is exactly what I wanted. How I got there does not matter.



Cameron is a beautiful, happy baby and he has made both our lives complete as well as all the joy he brings to all his grandparents, who always thought we would never have a family

■ Was it all worth it?

Definitely. Cameron is a beautiful, happy baby and he has made both our lives complete as well as all the joy he brings to all his grandparents, who always thought we would never have a family. The difficulties we had making him just make him more precious to us all. Every time I see him I feel very lucky. Garry said I used to wake up moaning it is too early to get up, now I wake up and smile because it is Cameron's chatter that wakes us up now.

■ What about the future?

We will play the future by ear. Health wise I have got the biggest incentive ever to keep well. We are both really enjoying Cameron and watching him change as he grows and this is what we want to continue to do.



Contributors to this leaflet:

Terri Cornell – CF patient

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