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A 24 week baby: A life changing event

Joanne Crow's daughter Hannah was born extremely prematurely at 24 weeks and is now a thriving three year old, but following the experience Joanne realised there was a lack of support for parents undergoing the trauma of premature birth. Together with two other mum's of 24 weekers, Joanne set up the charity *24 Weeks Plus* to raise awareness of parents' perspectives. This article outlines Joanne's personal experiences.

Joanne Crow
Mother of Hannah, born at 24 weeks' gestation.

Keywords

premature birth; parental support; communication; breast feeding

Key points

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1. Information and explanation, appropriate to the individual, are some of the most important things staff can offer parents.
2. The birth of a premature baby is not always a cause for celebration for parents, but may induce feelings of fear, inadequacy and uncertainty for the future.
3. Expression of breast milk is one way that mothers can really feel involved in giving their premature babies the best possible start in life.
4. Support from other parents who have undergone a similar experience is invaluable.

With a history of poly cystic ovary syndrome I was not surprised when, at 26, after trying for a baby for a little over a year I was advised to undergo fertility treatment.

After two miscarriages and three lots of intra uterine insemination (IUI), I finally became pregnant with twins after a second course of *in vitro* fertilisation (IVF), but sadly once again I lost both fetuses. We stopped trying for a baby, as I didn't think I could go through another miscarriage and come out the other side with my sanity intact and investigated the possibility of becoming foster parents. Just before we were due to attend the Foster Panel I discovered I was pregnant naturally.

My short lived pregnancy

At 12 weeks I suffered a massive haemorrhage and was told I had also lost this baby. Later that same day during a scan I was amazed to be told "Your baby is fine my dear." The bleeding was coming from behind the placenta, so for the next two months I took things very easy.

On Tuesday the 27th November 2001, I awoke with a very strange feeling (even now I'm unable to describe the feeling. I just knew that something was not quite right). Having spoken to a midwife on the telephone and explained that I was 21 weeks pregnant, she advised me to come into the hospital, to be told I was in labour and 3 centimetres dilated and that if my baby was born she would not survive. My pregnancy needed to last at least another 3 weeks. This was hard to take in as I was not in any physical pain. I was given drugs in an attempt to stop the labour. We had a very long afternoon waiting for the results of the swabs and blood test to find out if I also had an infection. "Strep B" was diagnosed but luckily my white blood cell count was not very high. At around 9pm that evening I was prepared for surgery, so that a stitch could be put in to close my cervix.

Even now looking back over everything that has happened since, I still feel that this was the lowest and loneliest time in my life. I was paralysed (due to the epidural) trying to explain that if my daughter was born, the doctors could not just leave her to die, they were to try and help her. I felt totally out of control – my legs were in stirrups although I could still feel them laying flat on the operating table. I was breathing quite hard trying to control my feelings. Although I wanted my mind to drift off to some other place, I needed to have my wits about me, as my daughter needed me to know what was going on, she was relying on me. I could feel the pressure of the Doctors pushing her back up to where she should be, and then I heard her cry, it had all gone horribly wrong. I started to panic, but was quickly reassured by the anaesthetist that it was in fact a squeaky chair and not my baby!

The stitch only lasted for 2 weeks when my cervix started to open again. My obstetrician and I discussed the possibility of me having another stitch on top of the one I had already, but I decided not to go ahead. I asked to be given steroids for my baby's lungs and would it be possible to have a chat with a paediatrician about how my baby would cope with the labour and anything else I could expect. I found this chat invaluable later while I was going through labour. I think it stopped me from panicking knowing that if I stayed calm that in turn would help my daughter to stay calm too.

Hannah's early days

Six days later, on 18th December 2001

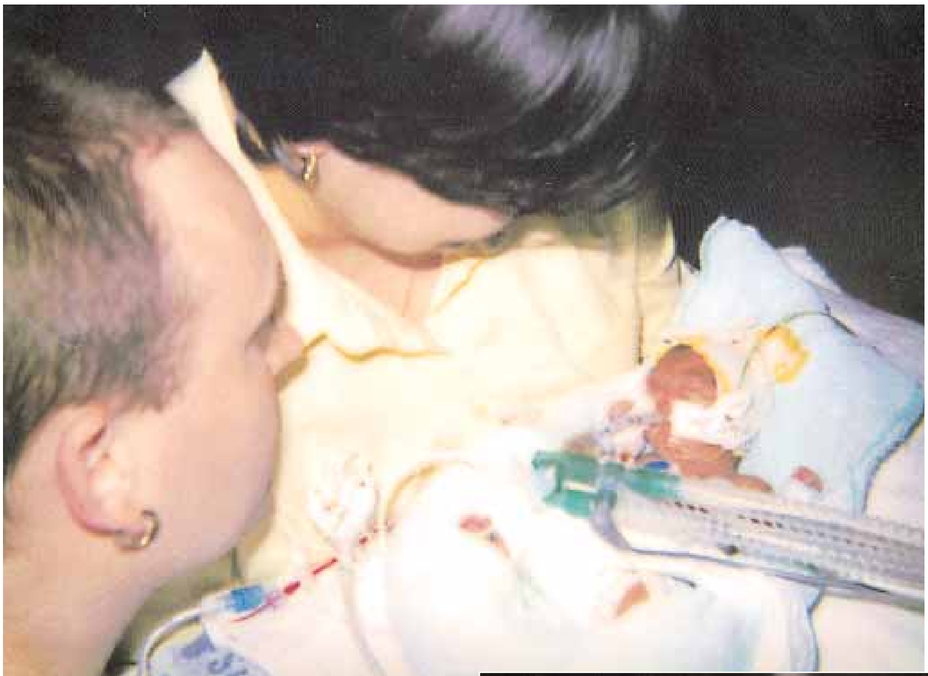

FIGURE 1. First cuddle with Mum, Christmas Day 2001 and one week old.

FIGURE 2. Hannah, surrounded by tubes keeping her alive.

exactly three weeks after I had first gone in to labour, I gave birth naturally to my daughter Hannah. She looked like a little red crumpled scrap of humanity. I didn't want to see the Doctors working on Hannah, so I turned my back. I think I was trying to prepare myself for them to come over and tell me she had died.

I didn't go to see Hannah until the following morning, because to be honest I was petrified of her, not for her but of her. Although I loved Hannah deeply somehow that famous rush of love that everyone goes on about hadn't happened for me. I didn't even think she was beautiful and felt terrible that I could think like this about my own much wanted baby.

I could only stay with her for 5-10 minutes because I was unable to get past the fact that she was going to die right there in front of me while I was watching her. At the same time I felt guilty for thinking of not being there when she would need me the most. That thought stayed with me for about a week. I would even call her incubator her "coffin" by mistake.

I had asked family members not to buy us any baby cards or presents as I felt Hannah's birth was not something I wanted to celebrate. I had also only informed close family and friends of Hannah's early arrival. It took Hannah's dad Tony, with the help of the nurses caring for Hannah, six days before they could convince me that she wasn't going to die that very second and that I would have to buy her a present for the following day, Christmas day. I was now able to visit Hannah on my own and with the fear of Hannah dying not being so intense, I was able to fall in love with her.

With the nurses nursing me as well as Hannah my confidence as a Mother grew. Being able to express milk that she was having was wonderful (although breast feeding was not something I had planned to attempt had Hannah been born full term and healthy). I got a tremendous buzz knowing I was helping to keep my little girl in this world. Drawing up her milk, tube feeding her, washing and changing her nappies may seem insignificant, but doing these things was helping me to bond with Hannah, to feel like her "Mum."

I was doing what all Mums did, even if we were in unusual surroundings. I became aware of the extra effort some of the nurses went to, to ensure that Hannah's life was made as easy and as comfortable as possible. These wonderful nurses took their very precious time to show me how to position Hannah in her nest and how important it was for her to feel boundaries which in turn would make her feel secure.

Traumatic times

One of the most difficult times I had while she was on the neonatal unit was when Hannah was three weeks old and had to have a PDA done at Great Ormond Street. Although I was frightened of the operation that she had to have, I was more worried that she would not actually make the journey. The nurse who was accompanying Hannah to GOSH explained to me that I would have to make my own way there as I couldn't go in the ambulance with them. I got myself in to such a state thinking that this was the last time I was going to see Hannah alive, that she thought it would be less stressful for Hannah if I did go with them. For that kind act I will be eternally grateful.

There was also the time we thought that Hannah could be blind or at the very least have tunnel vision. We had a very long week waiting for her next examination before we were told that her vision had improved. Thankfully Hannah's vision is now fine.

As Hannah approached her due date we made the terrible mistake of believing she was a newborn baby, ie we overstimulated her. Hannah reacted by shutting down, she didn't want to know anyone and her development had gone backward by eight weeks. After two weeks of 'time out' Hannah showed massive improvement and thankfully continued to do so.

Funny moments

There were happy and very humorous times too. Like the time, Tony was driving along the A406 and we got stuck in traffic. My milk expressing was long overdue, so I had to start it right there on the A406 in a traffic jam. The other drivers couldn't believe it, it wasn't as if I was feeding a baby or anything, there was only Tony and me in the car!!! Well I didn't care, my milk was so precious to Hannah. It did give us all a good laugh though when I told everyone else on the Unit.

Support from other parents

It was an eerie experience spending months on a neonatal unit – like living in a bubble. What really helped me to get through that period was the lifelong friends we made with two other couples who also had 24 weekers. Danny and Karen Hawkins had 24 week twins Jake and Molly, but Molly only survived for a week. Chris and Rebecca Hankins' daughter Thaila, was the smallest of all of our 24 weekers, but she too died after putting up a great and brave fight for three weeks.

Our friendship at first was based around our babies. We never would say "Morning, how are you" it was always "Morning, how's the baby" – if our babies were having a good day then we didn't need to ask if we were alright. The most shocking time of all was when Jake died 4 whole months later, on his due date. During that time the three of us formed a really intense friendship.

The support we gave to each other was invaluable and nothing that could have been offered "professionally" even came close. Rebecca and Karen knew how I felt because they were going through it too and that's what we want to offer to other parents.

Discharge

Hannah came home on 29th April 2002. On the morning of the 29th on her rounds the senior consultant stopped to have a chat with me. I had always found her to be quite aloof and a bit intimidating. "This is the baby you would have had" she proudly said to me while looking at Hannah, to which I replied "It is worth it you know". I was shocked to see she had begun to cry and with that she came over and gave me a big hug. To Tony and myself it was like leaving home for the first time, these people had become our extended family.

Tony and I really do realise how lucky we are to have Hannah. She has no developmental issues and she has higher than average intelligence for a child born full term in December 2001. She loves her Pre-school which she attends every day.

If I could change the system

Not knowing what to expect is one of the most scary things. Ideally when a premature birth is anticipated the parents should be able to visit the neonatal unit and talk to the staff about what to expect. In an emergency, when a woman in premature labour is admitted to a maternity unit or labour ward, there should be a "visit" from a paediatrician or neonatal nurse to explain to the mother what is likely to happen next. This should include information such as the size and weight of her baby, how they would expect her baby to cope with the premature labour and how they would hope to care for her baby in the first 15 minutes after the birth.

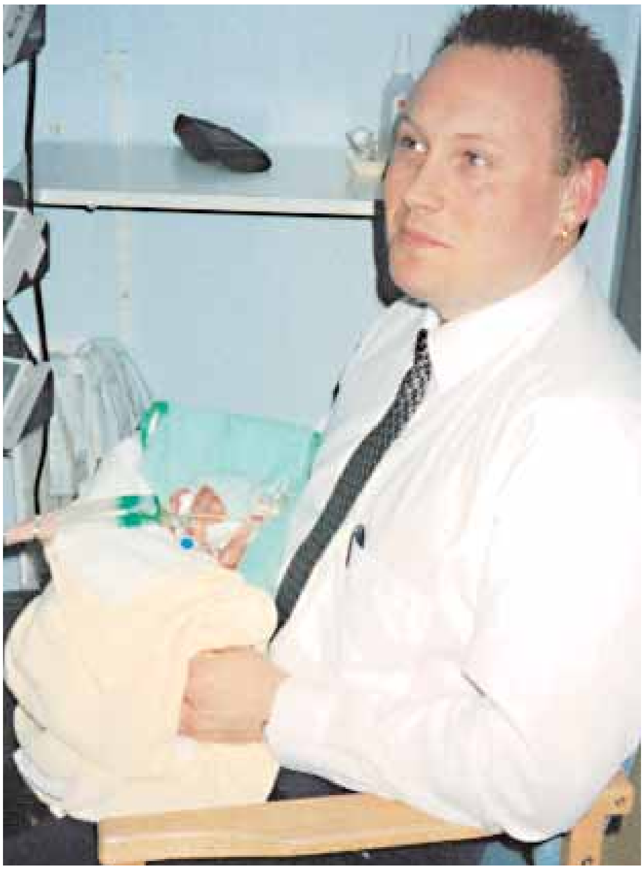

FIGURE 3. Hannah with her father Tony.

Helping parents feel more at ease on a neonatal unit

- It is important not to assume the mother will know where the neonatal unit is situated in the hospital – she may have been transferred at very short notice from her local hospital. So make sure someone is available to direct her.
- Try to remember that for most people entering a neonatal unit, it will be for the first time and it can seem a very alien place. Make sure that it has been explained to the mother and father what they should expect to see once they are in the neonatal unit i.e. breathing and feeding tubes, wires, low or no overhead lights, very little noise except for the machine alarms. These are all fairly run of the mill things for the staff but not for a parent in the first few days.
- Make it your job to explain what is going on and what the machines are for. This should be put into very simple terms, due to the fact that the mother and father may still be in shock from their baby's early arrival. The information may need to be repeated several times before the parents take it in.
- Try not to use the word "stable" without explanation. To most people if they hear the word "stable" they do not realise that their baby could still be critical.
- Parents of a premature baby can feel extremely powerless because they are forced to hand their baby over into the care of others. Never forget whose baby it is and don't make parents feel like visitors on the unit. Help parents to get involved with their baby's care even if they may seem reluctant at first.
- Providing stability and emotional support helps to counteract the stress and anxiety parents will be feeling.

What *24 Weeks Plus* does

Although there are some good charities, such as Tommy's and BLISS, involved in tackling the issues around premature birth, Rebecca, Karen and I felt there was not enough support for us during our time on the neonatal unit. So we set up *24 Weeks Plus* with the express aim of helping other parents who are going through the trauma of a premature birth. Although our name suggests we only offer support to parents and families of babies born at 24 weeks +, this couldn't be further from the truth. We offer support to anyone who is experiencing or has experienced a premature birth regardless of gestation.

Support is offered in a number of ways. We run an email service offering help, advice or a shoulder to cry on. So if a parent needs some medical jargon explained or just needs to type out all their fears and feelings, we will read the emails and give a reponse. If someone just wants to let off steam then that's what we're there for. This is our main contact with people – we don't offer a telephone service. The email service has been promoted in units by a poster campaign.

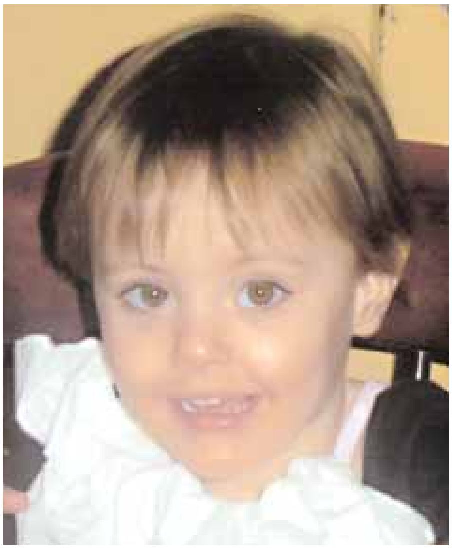

FIGURE 4. Hannah – a thriving three year old.

We have also produced leaflets listing 24 points of useful information for parents of premature babies. The leaflets include tips on how to position and touch your baby, how to bond with your baby, and advice on talking to doctors and nurses. We hope to have literature in every neonatal unit in the country by the end of 2005.

We also have a web site up and running (www.24weeksplus.com) which includes our stories for people to read. They are very different and with different outcomes. Hopefully having read our stories parents visiting the site will feel able to email us and share their experiences with us and thus feel less alone.

As well as offering advice and support we also want to change the way parents are treated on a ward and increase awareness among hospital staff of how they can help the parents of premature babies. We have given a number of talks about our experiences to professionals and what has become apparent is that staff don't necessarily realise the sorts of questions that go through parents' minds. We believe we can play a crucial role in educating doctors and nurses about how best to approach parents and how to treat their babies in ways that won't cause further anxiety or stress to the parents.

24 Weeks Plus

Helping premature babies and their families

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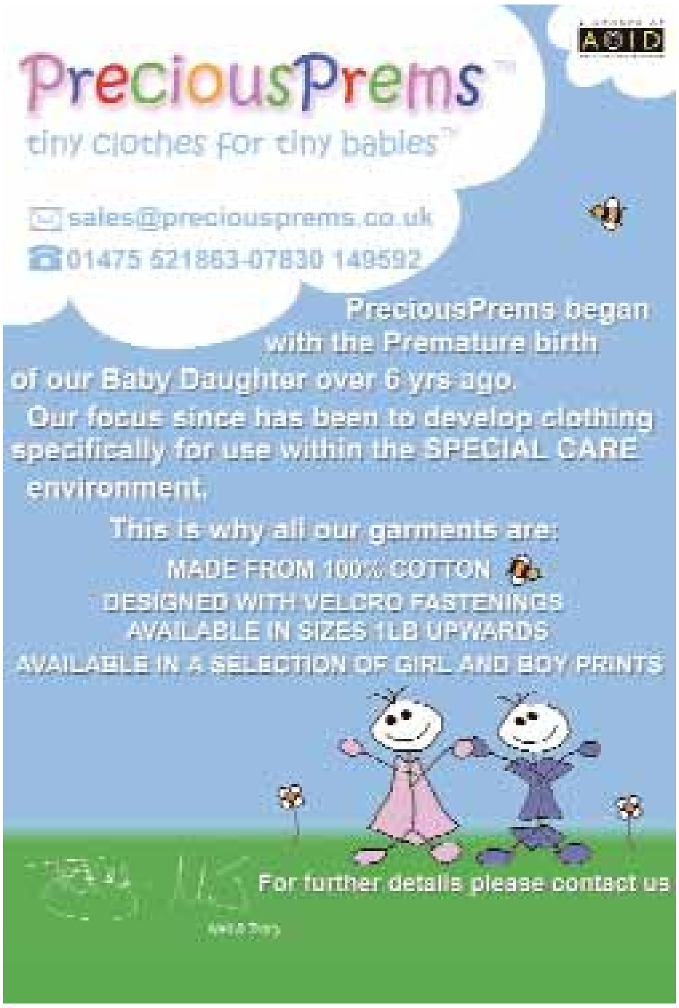

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