Insulin Dependent Diabetes Trust

April 2009 Newsletter Supplement

The Most Special Care

By Carolyn Murray

I believe every woman who delivers a healthy baby should have the right to keep that baby by their side in hospital. A mother needs time and space to bond with their new arrival and to get breastfeeding off to the best possible start.

My baby was born with an APGAR (scoring to evaluate newborns physical condition after delivery) of 10/10 and had the same score 5 minutes later. She was very healthy and happy despite a long labour and emergency c-section. She wanted to suckle straight away in recovery and I was overcome with a rush of love and joy. What could be more perfect?

How was I then only minutes later arguing with a paediatrician to keep my baby with me? My husband had been primed and was ready to argue the case that to take our baby into Special Care without her being in immediate risk to her life or health without our consent was assault. He was also prepared to physically stop anyone from separating us, my biggest fear when paralysed from a c-section.

Why should I fear the immediate removal of my newborn baby? Am I a criminal? Do I have a history of violence? Neglect? Cruelty? Am I mentally unstable? No. I have diabetes.

Going through pregnancy and delivering your baby are for most women a bit of an emotional roller coaster from the thrill of finally realising you are going to have an actual baby, the tedium of medical appointments and the trepidation of knowing it will be making an exit soon. Having diabetes adds an extra complication to the mix and means trying to

plan well in advance of trying to get pregnant to ensure high folic acid levels (taking a 5mg supplement rather then a 400ug supplement) and tight blood glucose levels making sure you stay neither too high or too low. Pregnancy itself means many more trips to the hospital for careful monitoring by a team of experts and additional help in managing the condition for optimal health for baby and mother. Delivering your baby with diabetes can also be more problematic and it is recommended that you have the baby in hospital to ensure help is available for both the mother and newborn if it is needed.

This was my second pregnancy and so I felt more confident in many ways. Although having moved to a new area after our son was born I had planned well in advance and so knew my baby was likely to develop normally, and I found the support of the diabetes care team at Warwick Hospital exceptionally good. They were much more advanced in the use of new technologies, such as insulin pumps and were pleased with my ability to manage my condition.

At 15 weeks pregnant it was mentioned to me that Warwick hospital has a policy of placing all babies born of mothers with diabetes are routinely put into Special Care for the first 24 hours. I was bewildered and upset. My first child had been born at a different hospital and had stayed with me, which I had loved. He had been born very healthy and had continued to have good blood glucose readings and an even temperature, both of which can be risk factors if the mother's blood glucose control has been poor during pregnancy. "Why?" I asked. Made-Up Supplement:Supplement 16/3/09 09:53 Page 1 "It's just the standard care for the hospital", was the reply.

I called my husband and sobbed down the telephone. My baby was only just growing inside me and already I couldn't bear the idea of being separated from it. My husband reassured me "Whatever it takes we will make sure our baby will stay with you". Over the following weeks I took strength from him and started to work out what to do. I wrote down what I wanted to happen. I want to keep my baby with me unless there is a clinical need for them to be taken into Special Care.

With our computer out of action I felt a little lost, but decided to try contacting Diabetes UK, of which I am a member, as I knew their guidelines were to keep babies together with the mother. I wanted to find out the latest information and check the science hadn't changed. To be honest they were totally useless. Not only did the woman I spoke to not know the information, she gave me incorrect advice (all babies have to go into Special Care) and was not helpful. I was dejected and unsure where to go next. A quick check on the back of my pregnancy notes reminded me of my National ChildbirthTrust [NCT] membership so I decided to give them a call.

The person I spoke to initially was sympathetic and supportive, but felt I would probably be better off trying the pregnancy and birth helpline, so they gave me the information and wished me well. The lady I spoke to was now great. Horrified at my predicament she researched information for me, suggested ways of getting support from the NCT and made me feel like I could do it. She also reminded me I could chose to take my care elsewhere and suggested I investigate other hospitals. Renewed, I decided to contact another charity called the Insulin Dependant Diabetes Trust (IDDT). Again I hit jackpot and I was given plenty of support and information to back up my gut instinct that my baby should be with me. The latest research all pointed to the fact that babies from mothers with Diabetes should be kept with their mothers as it lowered the incidence of problems with the baby.

I contacted the hospital at Coventry and spoke to the head midwife there who assured me that they had changed their care about 5 years ago and found that the incidence of problems had dropped as a consequence. They were happy to take on my care if needed. I decided that if I had not resolved this by the time I was 20 weeks pregnant I would transfer my care (which had to include the care from my diabetes team) to University Hospitals Coventry for the duration of my pregnancy.

With all of the information I gathered and a growing sense of confidence and determination I decided to tackle the hospital again. I called and managed to speak to a midwife and argue my case. I was able to state

several sources and the latest draft guidelines from NICE backing up my viewpoint. I made it clear that this was not something I would contemplate compromise on. It was suggested that as I was still early in my pregnancy I could wait and see how I felt, but I was sure this would not be something I changed my mind on. I needed to know my baby could stay with me in the hospital or I would start making arrangements to change the hospital caring for me. Finally someone in Special Care agreed that I could keep my baby with me on the ward, under the care of the Special Care staff as a special case since I felt so strongly about it.

The paediatrician at my birth was surprised that I was expecting to keep my baby with me and I explained it had been agreed in advance. They went on to say it was standard care in the hospital to put the baby in Special Care. I was adamant my baby would stay with me. Upon saying they were only following NICE guidelines they were somewhat surprised to find a ranting mother on their hands, as I told them it was not, gave them details of the latest advice and where it was from and insisted I kept my baby. According to my husband she actually took a Made-Up Supplement:Supplement 16/3/09 09:53 Page 2 step back from me, which probably indicates the force of my feelings bearing in mind I was still paralysed on the bed and wasn't going anywhere! The paediatrician left to consult with others saying she would return (but actually she never did – very wise...)

I feel relieved and pleased that my baby did stay with me, but I am trying to get Warwick Hospital to change their policies to fit in with the latest NICE guidelines so that mothers with diabetes do not have to fear an unnecessary separation from their baby. Their latest letter indicated they are likely to put these changes in place in the next 5 years, as they feel they need higher staffing levels first, but as I feel this is too slow I will continue to campaign for all healthy babies born from mothers with diabetes to have the most special care of all – with their Mummy.

My top tips for getting the right maternity care are to FIGHT:
Figure out what you want and write it down because it's hard to put a good case together on the fly when you are a hormone driven and emotional. Be realistic about what you are after and what is really important to you. If possible try to boil it down to a single sentence. Don't take it personally that you are not being offered this however personal it feels. Hospitals are generally a large and unwieldy beast that is hard to turn around, and you are just another patient. *I want to keep my baby with me unless there is a clinical need for them to be taken into Special Care.*

Investigate the latest information – the internet is great for this, but remember to use some caution before thinking it is all accurate. Check out if there are NICE guidelines that would relate to your case. Seek out charities and institutions that may be more knowledgeable if it is a specialist area, but don't assume that whoever answers the phone will know more than you. The people like midwives implementing hospital policy may not agree with it so ask for their help as well, they might say no, but they might not. The latest research all pointed to the fact that babies from mothers with Diabetes should be kept with their mothers as it lowered the incidence of problems with the baby.

Give yourself enough time to make your case and allow it to be looked into, but keep in mind that if you want to change which hospital is providing your care, you may want to do it sooner rather then later so that it is consistent. You are working to a deadline so keep an eye on how many weeks pregnant you are and that the baby may arrive earlier then your due date. I decided I needed to have resolved this by the time I was 20 weeks pregnant.

Help – find out who can offer it and get in contact as soon as you can. The NCT pregnancy and birth helpline may be able to offer some assistance and may be able to arrange for a local member to act as an advocate (going with you for moral support). Sometimes just knowing the right information and knowing other people are willing to support you is enough to give you the strength to do it yourself after all. Don't forget your partner and family. I got help from my family, the NCT, the IDDT, others at Warwick Hospital and University Hospitals Coventry.

Take yourself elsewhere! If all else fails you may be better off travelling to a hospital further away that is able to offer more appropriate care for you. I knew I could transfer my care to University Hospitals Coventry. If you are an NCT or IDDT member thank you very much for supporting them and enabling them to provide me with the help I needed to keep my baby with me. If you would like to give your support to makingWarwick hospital change sooner, please get in contact as I'd love some help!

NICE Guidelines: Diabetes in Pregnancy

[re-issued July 2008]

Key priorities for implementation

Some of the key recommendations in the NICE guidelines on diabetes in pregnancy are as follows:

Pre-conception care

- Women who are planning to become pregnant should be informed that good glycaemic control before conception and throughout pregnancy will reduce the risk of miscarriage, malformation at birth, still birth and neonatal death.
- Women with diabetes who are planning to become pregnant should be offered preconception care and advice before discontinuing contraception.

Ante-natal care

- If it is safely achievable, women with diabetes should aim to keep fasting blood glucose of 3.9 to 5.9mmol/l and 1– hour post-prandial [after meals] blood glucose below 7.8mmol/l during pregnancy.
- Women with insulin-treated diabetes should be advised of the risks of hypoglycaemia and hypoglycaemia unawareness in pregnancy, particularly in the first trimester.
- They should be directed to take folic acid supplements, given lifestyle advice and be told of the importance of maintaining vitamin D levels during pregnancy and while breast feeding if required, they should be offered Vitamin D supplements.

Neonatal care

Babies of women with diabetes should be kept with their mother unless there is a clinical complication or there are abnormal clinical signs that warrant admission for intensive or special care.

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