

Littlebliss

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The magazine for parents of special care babies

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Bliss
for babies born too soon,
too small, too sick

When home is a

Every expectant mum dreams of that special moment when she proudly carries her newborn baby out of the hospital ward and home. But for parents of premature or sick babies, that road home can be a long and exhausting one. **Kim Jones** speaks to three families about their different experiences.

A shortage of cots for premature babies means that some women may give birth at a local hospital, only to see their tiny newborns whisked away and transferred to specialist facilities in hospitals far away from home.

These transfers to distant units are sometimes unavoidable but can be extremely stressful for families and can cause practical and financial difficulties, too.

Emma Pugh, 34, from Hereford, gave birth to son Tom at 23 weeks, in her local hospital, but he needed special care and was transferred to Birmingham Women's Hospital, 70 miles away.

"I remember feeling terrible

that he was travelling so far without me. I'd been given a blood transfusion and couldn't follow him until the next day," recalls Emma.

"That first journey was awful for us, we didn't know how to get to the hospital and got

"These transfers are sometimes unavoidable but can be extremely stressful for families"

lost in Birmingham. We were stressed and eager to reach our sick baby, not knowing if he'd be alive by the time we got there."

Over the following 12 weeks Emma and husband Gary, along with their three-year-old daughter Nancy, regularly made the exhausting 140-mile round-trip to see their son.

"I visited Tom every day, arriving at the hospital around noon and spending the day with him. Gary would drive to the hospital after work, arriving at about 6.30pm. He'd see Tom for an hour or so then we'd drive home in separate

cars in time to put Nancy to bed, both of us physically and emotionally worn out."

As well as the stress of travelling, there was the emotional stress Emma and Gary faced as their tiny baby battled for survival.

"I hated leaving him behind every evening; often I'd drive home in tears. I felt so far away

Tom Pugh in his incubator; posing for the camera and with Mummy and Daddy on the ward in Birmingham



long way away...

from him. If traffic was bad, it could take four or five hours to reach the hospital. The journey was often really uncomfortable for me as I was supposed to be expressing my milk every three hours!"

As well as a physical drain on the couple, the situation was a financial struggle too.

"We had to eat out in the hospital canteen or spend money on takeaways. The petrol cost us about £150 a week," recalls Emma. "We used up almost £2000 of our savings."

"I wish I could have stayed in a room at the hospital, just

Yet being able to stay close to your baby can make all the difference, easing emotional and financial stress and making a difficult time a lot easier.

When hospitals are unable to provide accommodation, charities, such as the Ronald McDonald House Charity and the Sick Children's Trust, provide free 'home from home' accommodation at, or near hospitals, but demand can outstrip supply.

Mum Carole Fowler, 31, says she doesn't know how she would have coped if she hadn't been given a room to stay in. Her son Luke, born

"I hated leaving him behind every evening; often I'd drive home in tears"

to feel close to Tom or to be around more to take part in his daily care. But there was nowhere for us to stay and a hotel was out of the question financially."

It's an awful situation too many parents of premature or sick babies find themselves in.

A Bliss survey from 2008 found that accommodation for two parents with a premature or sick baby in hospital far away from home was available for less than half of the parents who requested it.

at 31 weeks, was transferred to Bristol Royal Hospital for Children from Swindon for emergency cardiac surgery to correct a congenital heart defect.

"For the first two nights, my husband Mark and I stayed in a bunk bed in a hospital room, I was grateful to be there but to be honest it was a bit like a prison cell" says Carole. "Then a cardiac liaison nurse told me there was a free room in a Ronald McDonald House five minutes up the hill from the



Top to bottom: Luke on the ward in Bristol; dressed up for his first birthday with proud parents Mark and Carole; looking very happy to be out-and-about in his buggy



Baby Jake having his first cuddle with Mummy after 5 days; and in his incubator. Now he's a happy and healthy little toddler

hospital. I'd never heard of the charity before, but it was a real godsend."

"The room was comfortable and homely with a direct dial telephone from the hospital unit to the room, which meant that if Luke suffered any setbacks during the night, I was at the end of a phone only five minutes away.

"I couldn't have imagined travelling home and leaving Luke. At times, I was too scared to leave his cot-side, so the thought of having to get in a car and to drive over 30 miles away from him to get home was impossible to contemplate."

Carole lived in the house for a total of five months until Luke was well enough to be transferred back to their local Swindon hospital.

"Having the room meant I could get rest and have somewhere private to express my milk for Luke. If I'd have been driving back and forth every day, I would have been too exhausted to keep it up.

"Staying close to Luke made a difficult time a lot easier," says Carole. "Meeting other

parents at the house in similar situations helped too – you didn't feel you were going through it alone."

When it's finally time to take your baby home, many mothers say the practice of 'rooming in' - the chance to stay for one or two nights in the same room as your baby - can be a great help in the transition from hospital to home. It's a good opportunity to learn about your child's sleeping patterns and to familiarise yourself with any medical equipment you'll need to use at home, with the knowledge that medical staff are close at hand should you need them.

"The chance to stay for one or two nights in the same room as your baby can be a great help in the transition from hospital to home."

Amanda Painter, 31, from North Yorkshire, found rooming in a great help after her son Jake was born ten weeks premature and rushed to the intensive care unit.

"Jake spent seven and a half weeks in hospital and although I spent 12 hours with him every

day, I had never cared for Jake without the nurses help so the thought of taking him home was a little nerve-wracking.

"The day before his discharge from Pontefract Hospital, my husband Dean and I were able to stay in one of the special flats in the hospital to have our first experience of looking after Jake by ourselves overnight, with the knowledge that, should he stop breathing or suffer any setbacks, the hospital staff were on hand.

"It was a really positive experience. For the first time I felt like we were a family. I changed Jake's nappy, fed him, and followed his lead in the peace and quiet of the

room – with no distractions or the bleep of medical machinery around. It gave me real confidence and time to bond with Jake, so that by the time we left for home the next day I felt more capable to look after him than I had since he was born."