

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

