

EARLY DELIVERY

Barbara Annersley and her partner left the champagne unopened when their daughter Freya was born at 27 weeks gestation. Just as their daughter entered a new world, so too did they, as parents of 'preemies' in the world of special care nurseries. It's not a normal newborn world, the one where most new parents celebrate amidst the fatigue, and are surrounded by well wishers, cards and flowers and friends and family delighting in the new arrival. Parents are cheated: in the post natal ward there are the incessant cries of other people's children but not your own. This is a different world, one of bewildering technology and incubators, a world of babies who could fit into the palm of one's hand clinging onto life. Life is on hold. Once the mother is discharged, the nursery at home remains pristine, incomplete. Friends are unsure whether congratulations are in order. There is the ache of empty arms and the countless hours in the hospital watching and waiting with the baby, helping where possible; hoping, frustration, grief, unrequited love. It's a time of highs and lows, of triumphs followed by setbacks and overshadowing it all, the uncertainty of what the future holds for this baby, and whether or not she will emerge from this place.

Premature births (that is, birth before 37 weeks gestation) are increasing in Australia. Professor Judith Lumley from La Trobe University suggests that multiple births, assisted reproductive technology and increasing maternal age are by far the most important factors associated with prematurity. As maternal age increases, so too does the risk of multiple birth, and by association, premature birth. Along with this, more and more women seek assisted reproductive technology (ART), facing their declining fertility in later years. ART increases the chance of multiple births. John McBain, from Melbourne IVF, has recently been advocating that only one embryo be implanted, due the risk of multiple pregnancy and the complications and sequelae that can result.

Allison Webb underwent four years of fertility treatment before she discovered she was pregnant with twins. Her excitement was short-lived: she spent three months in hospital with bleeding problems and went into labour at 23 weeks. Her twins were born by caesarean section at 26 weeks.

There are many reasons for preterm delivery. Smoking during pregnancy can increase the risk of premature delivery. Sometimes the membranes rupture early and contractions begin. Infection may precipitate labour. There may be placental problems or maternal disease, or an abnormality in the structure of the cervix or womb, all of which can be more common in the older mother. Obstetric intervention may increase the rate of preterm births. And sometimes the reason for the premature birth is unexplained.

It is rare for babies born before 23 weeks or under 500g to survive, although Dr Neil Roy, Director of the Neonatal Services at the Royal Women's Hospital in Melbourne, speaks of a 'miracle baby' who was born at 364g and survived. Premature babies can have breathing problems and problems maintaining their temperature. They can have feeding difficulties and low blood sugar levels, jaundice, infections and brain haemorrhage. Up to 28 weeks, survival chances in a Neonatal Intensive Care Unit (NICU) have improved steadily. Babies born at or after 28 weeks have a survival chance almost as good as term babies (Kitchen et al, 1998). Around 4% of babies

born at term will have a major disability, but the overall major disability rate for very preterm infants from 23-25 weeks is approximately 6 times higher. (Doyle, 2005). Aside from major disabilities, many of these babies will have a minor disability, often one they will outgrow with increasing age. Babies born prematurely can face many health problems, the extent and severity of these depending on their birth weight and degree of prematurity.

Victorian Infant Collaborative Study (VICS) followed a group of babies that were born under 1000g and reviewed them at 2, 5, 8, and 14 years of age. A smaller group was also reviewed at 18 and 22 years of age. Most grew normally and achieved expected average heights and weights according to their genetic potential. Most had no blood pressure problems, although some showed early hypertension. Since all were ventilated at birth, the study was also interested to assess lung function. It found that those who smoked had significant (but not irreversible) lung damage, a higher number than their smoking non-premature peers.

Allison's twins were among the 70% of babies born under 1kg which now survive (VICS, 2004). Allison comments that the feeling of helplessness of a new parent is ten fold in the NICU. They celebrated every passing week. They tried to prepare themselves for the possibility of saying good-bye to a son they had not even held. Zachary had breathing difficulties, haemorrhages, infections, and difficulty being weaned from the ventilator. Their daughter Elysse made better progress from the NICU to Special Care Nursery, and was discharged from hospital on day 78. The elation of taking home their daughter was dampened by the knowledge their son needed more time in the hospital before discharge was possible.

Keeping very premature babies alive comes at a cost to the taxpayer. It is standard to care for them in hospital until around their original due date, which in some cases can mean about three months as an in-patient. In the NICU, it can cost about \$2000 a day for each baby, which at an average stay of 90 days is \$180,000. In some other countries, the health dollar would not be available to support such advanced technology, expertise and staffing levels required.

In Australia and many other countries, Government funding has enabled research, training and support in this area. Dr Roy says that it is a huge privilege to work with premature infants. He describes the satisfaction of seeing these tiny babies develop into healthy children. This work, he says, is very rewarding, including the challenge of helping those parents who deal with their baby's death or face a future with a child with a major disability.

Deborah Davies is a psychologist who has specialised in working with parents of babies in Intensive Care. She writes of the difficulties of making decisions about whether to continue life support for very premature babies. The decision of whether to actively resuscitate a baby where the prognosis is uncertain is even more traumatic and the parents need to be armed with all the information possible so that they, along with the medical staff, can make the best decision for their baby. Some parents decide that the prospect of their tiny baby suffering with aggressive medical intervention is too much to contemplate. When describing the anguish of making the decision to withdraw life support for a disabled or premature baby, Ms Davies says it is impossible to estimate the grief and turmoil. "The urge to protect and hold onto your

baby at all costs can be so strong, and yet, your sense of ‘what is best for my child’ prevails upon you to give your child wings. This takes a lot of courage, faith and love”.

In June 2005, the Victorian Health Minister Bronwyn Pike called for a public debate on the whether sick babies born very prematurely, who are likely to be seriously disabled or unlikely to survive, should be allowed to die. (The Age, June 7th, 2005). The choice of whether to resuscitate a baby or not is extremely complex and there is the need for each baby to be assessed individually. Ms Davies suggests that doctors and nurses have their own biases and the decision on whether or not to resuscitate cannot rest solely with the health care providers without taking each particular family situation into account. Dr Neil Roy describes the decision as being collaborative, and where there is a difference in opinion regarding management, the staff and family work together to ensure the best decision is made. Other health professionals and allied health professionals are also available to assist the parents with decision making. Should a family require time to make this decision, this is respected. In the rare situation that parents wish to continue with active management in the face of a very poor prognosis, this too is respected, while staff assist the parents to come to a realisation of the situation their baby is in.

The media sometimes leaps on the ‘miracle’ babies stories, such as those born at 23 weeks, that overcome the odds and become normal healthy children with few medical issues. The other babies, the ones that don’t make it, or have cerebral palsy, mental and sensory impairments, physical dysfunction, language delays, visual-perceptual disorders, learning disability and behaviour problems are largely invisible in the press. For this doesn’t sell papers. But for some, this is the grim reality.

For Allison and her family the outcome brought relief. Her twins are now healthy two and a half year olds, who can get up to mischief as well as any other toddlers. Zachary was finally discharged from hospital on day 100. He has mild asthma and slight hearing loss requiring grommets. He had slight plagiocephaly (asymmetrical shaped head) which is now resolved. He needed to wear a helmet for several months. Elysse has mild cerebral palsy which resulted in some motor delay. She is also long sighted and has started wearing glasses. Allison can see how far they have come in their short lives and is understandably immensely proud of her two beautiful children.

One of the greatest hurdles facing the parents of premature babies is support after the baby is discharged from hospital, which could be after many weeks or months. Some families may need to wait several months to access therapy and services that their babies require, and there is a huge shortfall in funding. Some may have faced significant transport and/or accommodation costs while their baby was in hospital, and be unaware of the Carer’s Allowance from Centrelink that can help offset these expenses. After discharge, taking home a baby who may have special needs poses many challenges for the new parents. Private patients may face charges such as the \$300 per month charge for portable oxygen. Costs such as these are generally covered by Medicare for public patients. There are additional payments from Centrelink for triplets, but no extra payments for twins.

Parents may be linked into a mothers group through their Maternal and Child Health Centre. One mother’s comment, after joining such a group, was that the other mothers

came from an entirely different perspective, and had no understanding of her traumatic first few months of motherhood. Allison attended her local New Mother's Group when her babies were discharged. She found that although the mothers in this group were very supportive, the gap between her experience and theirs was enormous. "Some of them were anxious about their child liking a particular toy," she commented. "I was anxious about my changing my son's oxygen mask".

It was through this realisation that groups such as 'Life's Little Treasures' were birthed. Allison and a few other graduate mothers from their NICU found that after discharge from the hospital, there was no-where for them to go where their experiences would be understood. This group runs two playgroups in Melbourne, each of which meets every month. They are available to talk to parents of premature babies. Some of these other parents are hugely relieved when they meet Allison and others like her, at morning teas organised for parents with babies in NICU. They see healthy children who had been born premature. The sight of these children is hugely reassuring for those mothers with babies attached to life support who cannot see beyond these fragile weeks and months. Groups such as these fill a gap in services for parents of 'premmies' and their importance cannot be underestimated. The group recently received funding for \$1,000 to provide an information pack for mothers of premature infants, but this did not even pay for half of the costs of production. Funding seems to stop at the door of the hospital and parents' perception is that they are expected to fund the shortfall.

In Perth, there is a Premmie Playgroup run by the physiotherapy department of the King Edward Memorial Hospital available for parents for 12 months after their baby's birth. There are also information evenings on different topics for new parents. Like many of the other public hospitals in other states, it also offers 'generic' (ie not specifically for parents of premature babies) post-natal services for all new mothers that includes counselling and midwife home visits.

Friends and family are often at a loss when a baby is born very premature. This can have a devastating effect on the parents. Parents of new born premature babies can be still excited and delighted at the arrival of their child, as well as being petrified about the future. One mother commented on the silence that met her phone calls announcing her baby's premature arrival. Congratulatory messages were laced with sympathy and people stayed away, unsure of what to say. This reaction can add to the new parents' sense of isolation and grief in this bewildering new world of parenthood.

Having emerged from the other end of the NICU and Special Care Nursery, Allison says: "Zachary and Elysse have touched the hearts of so many people. They spent the first three months of life fighting with every bit of strength to stay alive. Since their birth our outlook on life has changed. We now have a clear understanding of what life means. Material things do not make you lucky in life, it is every breath that we take unassisted, and the time that we spend with loved ones, that makes us the luckiest people in the world".

Special thanks in particular to Dr Neil Roy for his assistance in preparing this article, and for Allison Webb for her insightful comments and courage to share her story.

Resources for parents of premature babies:

Life's Little Treasures (parent's support group) Melbourne 0437 254360.

Premature Infants Parents Association (PIPA) Support group for parents in Qld & Nth

NSW who have a prem baby. <http://www.pipa.org.au/>

Tertiary Hospitals in each state will have information about what is available in their area.

Premmie Press: Premature Baby Magazine available through
Carol Newnham, Tel: (03) 9496 4496 Fax 9496 4148