Day by Day.

A day in the life of the Neonatal Clinical Care Unit at King Edward Hospital.

Tinashe is cocooned in his mother's dress, his head against her chest and his tiny fingers reaching up, all touching his mother's skin. Moira is sitting with him quietly in the hum and bustle of the special care nursery as she has done every day for nine weeks and will continue to do until she can take him home, she hopes possibly around his due date just after Christmas. He was born at 23 weeks and 5 days weighing just 635 grams.

Here in King Edward's Neonatology Clinical Care Unit every day of gestation at birth counts and every gram gained is a milestone. Birth around 22 and 23 weeks is at the extreme end of the premature spectrum. A nurse explains that previously babies born at less than 23 weeks were not resuscitated unless showing signs of life but now the unit is seeing more 22 weeks and she says even the occasional 21 plus may sneak in. Even so the challenges these babies face are enormous but each little mite, swaddled in a beanie and a tiny cotton wrap, taped with tubes and connected here and there to beeping machines has stopped the world for someone, who takes each breathe alongside their baby - hoping.

It is often one step forward and two back. Tinashe has lost 10 grams since last weigh in but is stable and generally doing well. Moira says his name means "God is with us" and she tells me about the doctor who came with her on the mercy dash from her home in Kalgoorlie who decided to take a chance on saving him. "I wish I could remember his name," she says, "but there was so much confusion."

Labour pains had began overnight and by the time she got to Kalgoorlie hospital it was thought too late to attempt a flight to the neonatal intensive care unit at King Edward - the only one in the state. A doctor decided to take the risk and accompanied her on the flight to Perth. The medical team were able to delay Tinashe's birth by three days and those days count. Often a mother will be given steroids in these circumstances which can speed the maturation of fetal lungs making a lifesaving difference.

Moira says she was prepared for the worst but was shocked to hear him cry when he was born. She didn't expect it and it gave her hope. Even so it took her some hours before she could bring herself to come down to the nursery and see her son – the thought of becoming attached and losing him was too much. He was born at 5.20p.m. in the evening on Friday and about midnight when her husband arrived from Kalgoorlie they came to the nursery together.

"He was so tiny – lying right in the middle of the cot and he was wriggling. It was amazing. He opened his eyes for the first time on the third day and hope just started to creep in," she says.

Clinical Nurse Anne Kearns is coordinating the nursery today. She allocates two babies per nurse depending on their skill mix and the acuity of the baby. She accompanies the doctors on the ward rounds and ensures that the decisions made are then acted on by the nursing staff. She also liaises with the families. “It doesn’t matter whether their baby is in nursery 3 (intensive care) or nursery 2 (special care) even for a couple of days. It is important to remember that it doesn’t matter how sick their baby is - their baby is in special care and that is a nightmare for them.”

Today she says has been beautifully quiet with no admissions so far. “We know what babies are up on the labour ward who might be potential admissions for us but there are mums who just walk in off the street and you can’t plan for that,” she says. “We had two within five minutes yesterday and it was all hands on deck. That is the world of maternity – you can’t plan but we always have lots of contingencies in place.”

She says her job is the best in the world. “There are very few people who get to see miracles every single day. I come here and look around and it puts life into perspective. If the worst thing that happens to me is that I don’t fit into my jeans well – who cares. There is so much more going on here. You learn a lot from these babies and you learn a lot from the families.”

Nurse Julie McKinley began her shift at 7 a.m. She says she will try to group all of the things she has to do for her allocated babies at the one time so that they can sleep between. She does her “cares” every four hours including taking blood and nappy changes. The noise level in the nurseries is a constant mid level hum with hushed chatter rising and falling and an array of beeps and alarms of different tones, intensities and speeds coming from all corners. “They are all different and they all mean something but you get attuned to it very quickly - hear that one,” she says, “that is saying there is something wrong with the baby – now it is speeding up and it means you’d better get there quickly.” The alarm stops. Someone has.

I expect a little panic but constant vigilance and attention is just business as usual here and the alarms err on the side of caution. They go off when a baby’s oxygen levels drop a little she tells me “They are usually o.k. because a lot of the babies just swing a little with their oxygen saturation,” she says, “you know they will come up by themselves but the alarm will keep going if you don’t silence it.”

Julie has a very personal reason for working in the neonatology ward. 17 years ago her own baby was born at 28 weeks and she knows exactly what these new parents are going through – the shock and fear have never left her. Her daughter is at high school now and doing very well. When she started school, Julie returned to secretarial work but felt drawn to a nursing career and the neonatal unit in particular. Having a premature baby was the only time she had been in hospital and even though it was an unpleasant time because of the circumstances, she knew that working here mattered.

“I’m sure mums coming in for the first time will think it is horrible just as I did,” she says. “I know exactly what they are going through but I can’t really change anything for them – they just want to be told that their baby is going to be o.k. but we can’t tell them that because we just don’t know the outcome. Every baby is different and they have their own problems in their own way. We just have to play it by ear.”

In the foyer area of the nursery an entire wall is devoted to thank you letters and pictures of children from robust looking toddlers to graduating teenagers - all sent by grateful parents who have never forgotten their child’s shaky start and the care received in these nurseries. It is a “look at me now” wall and a nurse tells me that all the new mums spend time reading through the letters because it helps.

Doctor David Bartle began his shift at 8.a.m this morning. His first task after handover from the night team is to organize the nutrition that goes into the veins of babies who can’t feed properly. He spent the morning on a ward round with a consultant doing a detailed check of each baby. He is currently supervising a doctor who is inserting a fine needle connected to a catheter into a baby’s leg. Often the babies are so small and their lungs so under-developed that they can’t cry but this one wriggles to show discomfort. The mood strangely enough is jocular and rather than being out of place, it seems comforting. The nurses are also upbeat and warm. It is a much needed psychological lift and that ambiance seems to dominate.

After working in Paediatrics for ten years in the U.K. Doctor Bartle has come to King Edward to get more experience in neonates. “It is a big unit – the biggest in the Southern Hemisphere and very, very busy but all the staff are very experienced in what they do and it is great to see how other people practice neonatology,” he says.

He admits his first experiences were not positive “When I first did it I really didn’t enjoy it at all because I just thought that we were putting lots of needles in really tiny babies but I found it really rewarding to see the babies come back to the clinic who had been born at 24 and 25 weeks,” he says. “You see these children at three and four years of age walking around who are absolutely fine and all they have got obviously left from their time here are little dots in the back of their hands where we put the drips in.”

Baby Lily is asleep at the moment oblivious to the numerous tubes taped to her. She was born at 26 weeks and one day. She weighed 520 grams at birth and now at two and a half weeks old is fighting off an infection. At one stage her weight dropped to under 400 grams. It is up and down says her mother, Joanne. “She does well – we do well.” Today is her fourth day on a five day antibiotic treatment. “The day it was picked up – you knew anyway because she was listless. She was just that little bit different,” she says.

Joanne says her cuddle count is three but one lasted over an hour when the nurses got really busy one day. “Even when she was delivered, they pulled her out, stuck her over the sheet and then a cast of thousands took her off. And then she was all intubated and everything else and by the time I had worked out where her face was…she was gone again.” It is the small things though that have made a difference she says: “the hospital is

so good that by the time I had got back to the room they had put a photo of her there. That was really appreciated."

Joanne lives quite close and she and her husband are in each morning by 7.a.m. to see Lily. This morning on the drive in she was struck by the thought that this would be her regular routine indefinitely. Today her mother-in law has come in to watch over Lily. They are reminiscing about that hour long cuddle. Both Grandmas were in that day and took turns just sitting and watching.

The neonatal nursery has become a second home to young mother, Leisha who says that you just make do. She has made the trip in to see baby Marcus every day for 6 months. "It has been hard having to come in here every day and know that his first smile was in hospital but at least he is here," she says. Today she changes his nappy and tells me about the four-day countdown. He will have a lung test then to see if he can be allowed home on supplementary oxygen. If he can pass the test by keeping up his oxygen saturation while he breathes on his own for four hours - he's home. If not it is off to Princess Margaret Hospital for a while.

"They are pretty strict and they won't let him come home until he passes this air test, just in case he pulls out his supplementary oxygen at night," she says. "That is really all that is holding him back at the moment." Baby Marcus is a good size and looks like any other healthy bub. He was born in May at 24 weeks and three days and even though he is hitting his developmental milestones it's clear that a pre term birth can mean a long journey.

For some, of course – it is not a journey that ends well. Midwife and neonatal nurse Ricki Smith says that dealing with a family's loss is the worst part of the job. I ask her if she ever gets used to it and she says that it is always difficult, particularly where the loss is unexpected but it is something that they deal with all the time. "The best thing about it is that you can make a terrible experience for a woman better. It is something that can only be devastating for anyone going through it. We have a fantastic chaplain here and together with the expertise of different members of staff we hope to make the experience the best it can possibly be, given the circumstances."

Unit Director Professor Karen Simmer, says benchmarked results confirm that the neonatal unit is working very well. "We have around 2200 admissions a year with the lowest mortality rates and the lowest rates of disability in Australia and Australia overall has very good rates internationally," she says. "If a baby is born at less than 32 weeks, they go into a long term follow up program where we can monitor any lung problems or learning problems. This also allows us to audit our outcomes and that is why I know that our survival and disability rates are really good because we benchmark them against other hospitals."

She says that the unusual thing about WA is that in intensive care – bigger is often better. "In Sydney, for example, they have about 14 or 16 small neonatal units and it is very hard to staff them and pay for the equipment and the expertise whereas with our big

centralized unit - we have research and teaching and training programs for nurses and doctors and the outcomes are very good," she says.

The special care nursery at King Edward has 80 cots for predominantly inborn preterm or sick babies and outborn babies and those requiring surgery go to the 25 cot neonatal unit at Princess Margaret Hospital. Mothers are transferred in from all over the state – some from private hospitals. Professor Simmer says that the boom time in Perth has seen the birth rate, previously 25 000 shoot up to around 31 000. "Not only has the number of births gone up in WA but the percentage coming to King Edward has also gone up," she says. "We are literally busting at the seams but we have never turned anyone away because there is nowhere else for them to go."

The approach now, she says, is to concentrate on the high risk pregnancies and facilitate a state-wide network that will allow other hospitals to increase their capacity to take more pregnant women and babies including those with some risk. They are creating joint appointments that will allow smaller hospitals to employ top medical personnel who will spend some of their time at King Edward with its attractions of a big peer group, research and teaching and training facilities. There are numerous programs aimed at increasing the pool of nurses – up skilling courses, a buddy system where nurses from other hospitals can transfer to King Edward for a few weeks to refresh skills and in 2009 for the first time UWA will run a two-year Masters of Nursing course with a prerequisite of any bachelor degree.

One thing though is a given, babies both great and small will keep on coming. The alarms in the nursery continue their irregular and strident warnings, the constant hum of chatter rises and falls and Tinashe, Lily and Marcus take one day at a time.

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