

A mother's experience of her child's time in intensive care: Part 2

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KARIN STORM INTRODUCES THE SECOND PART OF THIS ACCOUNT

In the first issue of *CONNECT*, Kate Macdonald began her story of the admission to hospital of her little daughter Mary. In the second part of this story, Kate Macdonald describes her Mary's stay in a paediatric intensive care unit (PICU), while severely ill with pertussis.

When the parents saw Mary half an hour after her arrival at the PICU, she was peacefully asleep in spite of being surrounded by technical equipment. Kate and her husband had no thought that Mary might die; they were still thinking that they would be home with her in a day or two.

After a few hours sleep, Mary's husband went home to check on the other children, and Kate went to Mary's cubicle again. Here, she spoke to a doctor who told her that Mary's heart rate had fallen during the night but had now stabilised. At the time, Kate did not realise the importance of this message; she did not realize how sick her child had been because Mary had now stabilised. She went to the visitors' hostel to have a bath. However, she did ask the staff to take some photographs of Mary, and afterwards she thinks that in some way she realized the seriousness of Mary's situation.

While Kate was in the hostel, she heard the phone ringing, but did not manage to answer it because of the locked doors; afterwards, she went to the ward with the milk-expressing machines because milk expressing had become a painful need. Here, she was told that PICU had been ringing for her. She hurried to the PICU and saw a lot of staff working with Mary; she rang her husband, David, and asked him to come immediately.

Mary's condition was getting worse and the doctors and nurses did not leave her. Kate describes in detail how intensively Mary was treated – everything that could be done was done. In these terrible hours, the ward consultant and nurses were talking to Kate and David and supporting them. Kate and David tried to rest in shifts and Kate began to make more arrangements with the hostel, and they both phoned to family and friends and tried to talk positively, but every time they returned to the unit, Mary's situation had become much worse.

At last, Mary's heart stopped. The doctor told Kate and David that there was no hope and it would be kinder to let her die. Kate's description of how they were reacting and feeling in

this situation – which is the worst situation parents can ever be involved in – is heartbreaking. I feel that intensive care nurses can learn from it and use it the next time they meet a family in a similar situation.

KATE MACDONALD CONTINUES:

My youngest daughter Mary, 8 weeks old, was admitted to hospital with pertussis. She was transferred to the regional PICU at 3am on Saturday morning, 30 hours after admittance to hospital.

We were able to see Mary after about half an hour's wait in the waiting room. She had been given the last available cubicle. She was in a cot surrounded by equipment and bleeping instruments, and looked much the same as when we had last seen her. Her head was warm, her hair still soft and downy, the ventilator was breathing for her and she was peacefully asleep, but still covered with tubes. The nurse explained the readings from all the machines on the monitor to us – seven or eight different lines and colours and bleeps. We were told that she had transferred very well, whatever that means; I wonder now if that meant that she had not died. We were given beds in the children's ward upstairs. I needed to express milk again, so while David went straight to bed, the nurse took me to another ward where there were milk-expressing machines. But I could not make them work, and the nurse on duty did not know how to use them, so I gave up, and went to sleep in the bed next to David's, lying carefully on my least-full breast.

We got about three hours of sleep, and were woken by all the sounds of the ward waking up, feeling very institutional. We went downstairs to see Mary at about 7 am. The cheerful nurse on duty reported no change, and that all was still peaceful. She told us the doctors would do their rounds at about 9 am, so David and I found the hospital café and had breakfast. We were slightly refreshed by the sleep, but still dazed, and feeling sticky from being in the same clothes for so long. We were cheered up by the report that Mary had transferred well, taking this to mean she was starting to get better. At that point, we were still thinking we would all be home in a day or so. David wanted to check on our other girls, being looked after by his mother, as well as have a shower and change his clothes, so he drove back home.

I made some phone calls, reporting to my parents and friends, and went upstairs to Mary's cubicle, to sit it out. Her nurses were friendly and kind, and very informative, but discreet. I was startled by the condition of one of the children on the ward, an emaciated boy of about 13, all ribs and arm bones, with very little movement and communication. They laughed it off, mock-shock, 'We cannot tell you that!', when I asked what was the matter with him, and so I did not ask again.

When the doctor arrived an hour or so later, he told me that Mary's heart rate had gone down to about 40 beats per minutes during the night, 'which was a bit scary', but that she had stabilised and seemed to be doing alright. I did not take this in properly: the important thing to me was that she had stabilised and that she had survived it, not that she had nearly died. It was not until much later that I thought of the event as a heart attack, and even then I was wrong: I just assumed that that was what it must have been. If David had known about it when we had gone to see Mary at 7 am he would not have gone home.

Getting ready for the next stage at the hospital

I asked again how long Mary would be on the ventilator, and was told about a week. I started thinking about who would look after Holly and Lucy. The nurses organised a bed for me in the visitors' hostel, so at last I had somewhere to put our bag of clothes, but I still needed to express milk. Mary was still peacefully asleep, and all I was doing was sitting in a corner of her room watching the nurses and doctors come and go, while Julia, her day nurse, got on with her job. Mary's new doctor, Maggie, came on shift, a very quiet-voiced woman in normal clothes, with a diffident authority.

I asked the nurses to take some photographs of Mary. I suppose I must have realised that she was going to die, or at least be in the hospital for a long time, and I wanted a record of how she looked. They had a Polaroid camera and did a couple of pictures which are blurred and overexposed, but they are our last photographs of her. She looks exactly as we saw her then: not ill, not dying, just unconscious and peaceful.

With too many things to do going through my mind and unable to do anything useful where I was, I took my bag down to the hostel, a long walk round the hospital buildings in the chilly spring air. The hostel was two houses converted into a warren of bedrooms, kitchens and sitting rooms, with interconnecting fire doors and narrow corridors, all painted magnolia-white. In private and alone at last, I could reflect on this strange, scary and barely controlled situation. Everything had happened so fast, and I still had to organise the next week for Holly and Lucy. Working out who to ask to look after them at night was a juggling decision of whom the girls would be happiest with, could get to our house fastest, and with least inconvenience to them.

After I had showered, I felt more awake and alive, and energised for the next stage. Milk expressing was becoming a painful need, and I wanted to get back to Mary. Getting out of the house became awkward, as it had locks on almost every door which had to be locked behind me as I went through, and while I was struggling with the final, back-door lock, the phone rang in the hall, a door away. I did not think about it at first, then awareness broke through and I ran to get it, but the phone went dead as I reached it. I told myself firmly that if that had been the ward I could not get there faster than walking in any case. The lock had been put into the back door upside-down so it was a struggle to get it to lock and not swing open, but I managed it, trying not to think about Mary and the phone. Then there were the back gate and yard gate locks. I walked back to the hospital fast. Getting

rid of my milk had become more important than what the phone call might have been about, but when I reached the ward with the expressing machines they told me mildly that PICU had been ringing for me.

Mary's struggle for life

This time I ran. I rang from the waiting room in case there was something really awful going on that they would not want me to see, but I was let through straight away. The sea of people parted to let me stand by her cot, and the ward consultant, a large hearty man in ordinary clothes rather than theatre scrubs, with a brisk matter-of-fact manner, told me that Mary was deteriorating. I turned on my heels and, walking out of the ward, asked for a phone. A nurse took me to the nearest office so that I could ring David. Our phone was engaged. I remembered that I had a neighbour's phone number, and I told him peremptorily to get David off the phone. When I finally got through I told David that Mary was having another cardiac arrest. He had not known about the first one, and I must have sounded terribly garbled, as I was shaking with tension.

Mary's nurse, who had stayed with me, had tears in her eyes, and I asked her hopelessly if Mary was going to die. She did not know and could not give me any hope. When I got back to Mary's cot she was still not doing well. I could see the numbers getting lower and the lines on the monitor getting more erratic. After an immeasurable time, the ward sister called out suddenly, 'I think we've lost her', and there was a rush of staff swarming into action. I got out of the cubicle and found a place to wait, watching tightly from a space out of the way by the cupboards at the door. The tension was terrible. I was watching the numbers on the monitor and willing them to increase, but it was an inexorable decrease and decline. The doctors began manual massage of Mary's heart. There were eight or nine huge adult bodies in there working on this tiny scrap of a baby – consultants, registrars and nurses flying in and out, putting up screens, wheeling in new machines. Two nurses were a constant flurry of hands at the table at the side of the cubicle, preparing syringes and fluids, checking each other's work in a methodical way among the snapped directions and remarks from around Mary's cot. A nurse appeared from nowhere and kept asking me quietly if I wanted a drink, if I wanted to telephone anyone, if I wanted to sit somewhere else. They made no fuss about me being there, and gave me water in a cup, made me sit down, left me alone but hovered out of sight. I could not have left, I had to see everything and watch Mary all the way through, even though I could not do a thing for her.

The ward consultant asked loudly where the father was, and David arrived shortly afterwards, looking as if he were about to be hit. We sat holding hands, staring at the monitors while they worked on Mary, and when the numbers began to rise I had a shuddering collapse of tears and the shakes. There was not anything in me to cry with until then, I was so wound up with tension.

After that, the doctors did not leave Mary alone. There were always one or two watching the machines, trying one thing then another. They brought in an high frequency oscillatory ventilator to try and shake loose the secretions in Mary's lungs. They said that they did not know how it worked but that it sometimes did. The 'sometimes' was as good as a full guarantee to us that it would; we clung to it pathetically. They brought in nitric oxide which also 'sometimes worked': we did not care. I was worried about Mary's right leg as it was very cold, and the hot air blower was not making any difference to it. Now, I think that she had probably lost the circulation in that leg completely.

A cardiac consultant who 'just happened to be passing' and who had helped resuscitate Mary in her second attack wheeled in an ultrasound machine, and we saw a marvellous picture of her little heart beating furiously and steadily. By then, we were able to stand by her cot again, and he explained that the problem was her right ventricle. It was very distended, big and baggy, because the oxygenated blood from her lungs was not getting through and was backing-up in her heart. The blood vessels were closing up, and the nitric oxide was intended to try and open them up more. The bacterial lung infection was preventing the vessels from functioning properly, and her blood circulation and heart were beginning to be affected. Her kidneys had also been compromised as she was not passing any urine.

David and I decided to take shifts, and as he had already had some sleep, I went back to the ward upstairs to express my milk, and get some sleep. I found some food in the hospital café, and managed two hours sleep. I had started to make more arrangements and plans, booking another room in the hostel that David and I could share, which meant that I had to go down to the hostel again, and fight my way through all the locks, hoping not to hear the phone ring, to move my things out of the first room and into the second one. I phoned my parents and spoke to my father, talking positively in the clinical terms which I had begun to memorise, something we could both concentrate on. Oddly, every time David or I rang someone to report on what was happening, we ended up passing on a positive message, but the situation had always got much worse by the time we had got back to the ward.

I took over the watch and David went to make phone calls. While he was gone his sister Sara, a haematologist, rang us in the ward, asking if she could help with diagnosing Mary's abnormal blood count. Mary's white blood cells had been measured at a count of 120–140 × 10⁹/dl. In case PICU did not have a consultant haematologist available on a Saturday morning, Sara was offering her own and her colleagues' services. The ward consultant was happy to discuss with her the haematologist's report which had discounted leukaemia. Another possibility I had been told about, but had forgotten: how could I forget leukaemia?! David was mortified by his sister's phone call, and apologised to the consultant, but the consultant was not bothered, relieving David's embarrassment by saying Sara probably knew more about the subject than he did, and that he preferred talking to members of the family who knew the area as they could explain things so much better to the parents. Quite remarkable forbearance.

Mary's death

About 10 minutes after David at last decided to go to the café for some food, Mary's heart rate started to drop again, and I stumbled out of the way as the staff flooded back in. The events of this crisis had a grim familiarity now. I got hold of a nurse from another cubicle and asked – probably told – her to ring the café to get David to come back. The memory of that disembodied voice, calling a name over the loudspeaker system, which he gradually realised was his, is still filled with fear. He came running up the stairs and straight into the ward, no stopping for the waiting-room summons, as the doctors began manual massage of Mary's heart again. I do not think this attack lasted too long, as although the numbers seemed to be stabilising, they were not high. We had already looked at each other and said that Mary was dying. Both doctors were very gentle, soft-voiced women, bending down to us to say the unspeakable – that there was no hope of Mary surviving or managing to carry on unaided, and that it would be kinder to let her die. We had already

agreed, I think, that it would be best to do this, so we told them to let her go. They checked her heart with stethoscopes, and the ward sister turned off the monitor so that we would not see the lines go flat, when they disconnected Mary's ventilator.

I have never cried so loudly in my life. When I lost my first baby in a miscarriage, I cried noisily in the lift after the scan showed that all of the fetus had gone, but not for long. It was worse with Mary's death: loud, raucous agonised sobs in David's lap, angry at any other parents listening, and hoping they could hear my grief because their babies were alive and mine was dead.

The nurses asked us if we would like to give Mary a cuddle, and I told them to take out all the tubes first. I had become very peremptory, nothing left in me to consider other people's feelings. Sitting there watching the nurses take away the bottles and tubes, at the end of things, was unbearable. We had to start telling other people, to get it over with. Walking was stiff and painful, my legs and hips had seized up with tension, and I had to concentrate on getting from the chair to the door without staggering. As we passed the other cubicles on the way out, green screens were being wheeled into position and I was dimly aware of gowned and masked surgeons beginning what must have been an emergency operation. David said he saw blood-stained instruments being dropped on the floor.

We went to the consultant's office from which I had rung before, and started to make the calls. Telling people about Mary's death was like leaving a trail of broken people crying behind us – a horrible experience. My parents were first and worst. Mary was their third grandchild. David kept trying to get through to his mother, but she was on our phone, and he could only get through to his three sisters at first, all disbelieving and left crying. We both had to say firmly to everyone that we would tell people ourselves, and they were not to ring round for us. Even then, people were trying to jump in and help, but there were some things that we needed to do for ourselves. Managing it, deciding what we wanted, and telling other people, gave us something different to consider, apart from the thought of Mary's cubicle.

A new ward consultant came into the office where we were, with Jane, having just come on shift. He must have felt so awkward, being faced with these white-faced parents of a newly dead baby, and having to explain what had happened without having been involved himself. He had been briefed about Mary's case, and he wanted to take us through what he thought was a fair reconstruction of what had happened. By this stage, half an hour after Mary had died, we wanted to know more than what had killed her, but why, and we were more or less able to comprehend the science of what he was telling us. Moving from the emotional trauma to the mental effort of understanding the processes of Mary's illness was also an effort, but not so draining as dealing with other peoples' tears.

The need for a post-mortem

We were told that a post-mortem was necessary, as Mary had not been in hospital long enough before she died for Jane to sign her death certificate, and that although it seemed fairly clear that pertussis and pneumonia had killed her, other factors might have been present to alter the final diagnosis. We were far more concerned with reasons why she had died than keeping Mary's body intact. It seemed clear to us, without asking, that her organs, damaged and infected by the bacteria, would be of no use to anyone but the medical investigation. We more or less understood the convoluted regulations for a coroner's post-mortem as opposed to a hospital one, and signed the consent form. When Matthew began to tell us, delicately, about the new regulations

governing the disposal of the organs of people who had died in hospital, we were jolted into reality again, but not with horror. The recent publicity of children's organs going missing in a British hospital had been of vague interest to us, but more in terms of how could an inadequate system like that could have continued for so long. Now we had to decide what should be done with any organs removed after Mary's post-mortem, we were part of the reverberations from that story, we were like the parents of the children we had seen on television and in the papers: parents of a dead child. Seeing ourselves reflected in the experience of others was almost more real, getting through to our emotions far more effectively, than experiencing it ourselves. Matthew was treading very carefully here, but, for me at least, it was not repellent knowing that some part of Mary might be left in the hospital after she was buried, as a layer of cells on a histology slide. The practical side of some part of her being useful for research – an example of an infant lung badly infected with pertussis – was almost secondary.

Saying goodbye to Mary

Helen, another of Mary's nurses, came to say goodbye, going off shift in tears. We were taken through to Mary's cubicle, which the nurses had arranged as sympathetically as they could. All the equipment was tidied away or screened, the lights were dimmed, the Polaroids the sister had taken of her were propped up on the window-sill, and Mary was wrapped in a new woolly blanket, lying in her cot. David lifted her up, and almost staggered because she was so heavy, filled with all the fluids they had been pumping in, trying to increase her blood pressure. She was still warm, and looked as she had been in life. Her face had two small purple marks beside her mouth where the sticking plasters had held the tubes in place, and her hair was still soft and downy. But she was not our Mary, she had already gone. We stayed with her for about 20 minutes, and then left her in her cot.

Leaving the ward was awful. We went back onto the ward to thank the staff still on shift who had worked on Mary, driven by a sense of duty and good manners, as well as a need to say goodbye properly to where Mary had died. Leaving the ward and walking down the corridors without her was our final admittance of defeat. We had lost our baby here, even though we'd not made the journey in with her. We had been separated the evening before by the ventilator and unconsciousness, never to be together again.

JOS LATOUR PROVIDES A SUMMARY OF THE STORY FROM THE NURSING POINT OF VIEW:

Coming to the end of Kate's story, a minute's silence is what any reader wants to do out of respect.

In this second part of her account, Kate has described in detail the resuscitation of her daughter, Mary. Kate has been able

to write down her emotional feelings during one of the most dramatic events parents can experience in life. This article is therefore very helpful for health care professionals. It gives insight into the psychological effects of a mother whose child is resuscitated. Something nurses and doctors hardly have time or dare to ask after resuscitation.

Although nurses and doctors are concerned and have doubts about family and parental presence during resuscitation, it is increasingly becoming daily practice. A recent study on a PICU found that the staff believed that the advantages of allowing parents to be present during their child's resuscitation appeared to outweigh any potential disadvantages (Jarvis, 1998). The same study indicates the need for educational background for this topic and continuous resuscitation training.

A disadvantage of parental presence during resuscitation mentioned by professionals is the potential for increased stress among the staff. Boyd and White (2000) have studied this statement using a questionnaire designed to elicit self-reported symptoms of acute stress reaction. Among the 114 staff members who returned the questionnaire, there was no significant difference in the incidence of adverse reactions. Although this study was performed among accident and emergency personnel, it demonstrated that the presence of family members during resuscitation did not affect stress levels in staff participating in resuscitation attempts. Whether the presence of parents at the resuscitation of a child influences stress levels among staff has never been studied. Further guidelines, training, and evaluation after paediatric resuscitation are strongly recommended.

Robinson *et al.* (1998) have followed-up family members who witnessed resuscitation. There were no reported adverse psychological effects among the relatives, and all were pleased with their decision to remain with the patient. One respondent in Jarvis (1998) stated, 'since parents have cared for their child from birth, why should they be denied access at death?'. Meanwhile, there is sufficient evidence to give a clear answer to this question. Parents should never be denied access during resuscitation of their child.

And for Kate and her husband David ... they walked out of the hospital alone. A final admittance of defeat. Was there nobody available to walk them to their car? One does not have to talk all the time, a hand on a shoulder is sometimes more than enough.

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