

25 Harrisville Road,  
Tuakau,  
SOUTH AUCKLAND 1982.

7th November, 1992.

Dear Nigel,

During a telephone call one night you mentioned that one of your personal interests was the issue of neonatal pain relief. The comment registered, but nothing further was thought. However, events this week, have brought many things to a head.

One of the other relevant factors in the equation are some remarks I made at a July ATI meeting regarding the treatment of our eldest son Ian at the hands of one Dr Mickelson. I was absolutely distraught at the callous disregard of our son's reaction to many of the tests which were performed on him on the supposition that he had some infection (which he did not have as it turned out) The second to last straw for me was when a very upset shattered nurse, who had been forced to hold our son down while 11 (eleven) insertions were performed before a lumbar puncture was completed successfully, came to us, and tearfully explained to us why our son was unresponsive, puffy eyed, and in shock. After the lumbar puncture he had screamed non stop for 3 hours, during which time no-one thought that perhaps his mother could have helped. Perhaps they thought I would have been too upset, and they may well have been right.

But I am digressing here.

This week, I had to take Ian to the doctor for an exuberant granuloma in the middle of his palm. His only prior contact with doctors following the Middlemore fiasco was at 18 months when he was diagnosed as having measles, and 6 yrs when he was diagnosed as having measles again. His whooping cough only needed a phone call to listen to a tape recording of the resultant noises.

During this time I had always taken him in with me for things like blood tests or "trivial" doctor's visits to get him acclimatised to the surroundings. However, when I made the appointment and told him, he went to his room and started to sob. I went in and asked him what the problem was, and he said he didn't know, but that he didn't want to go. During the next two days the bottom lip was regularly seen to quaver.

I became a bit apprehensive about this, and said to him that he had a choice. He could go in on his own, or if he wanted someone to come in, he only had to name them. Initially he named his younger brother, but the next day changed his mind and said he wanted me to go in.

On Wednesday, I read the attached article, and a whole lot of thoughts flooded in. To make sense, I will have to fill in some details.

After Ian's birth, his temperature seemed to rise. I realised very quickly that the problem was the five blankets that he was

4 November 1992.

## Medical Frontiers

Babies and infants can suffer pain during routine medical procedures which may have long-term effects on their development, says a British expert.

But often they are not given pain relief because of the medical profession's common, mistaken belief that babies do not feel pain, says Albert Aynsley-Green, professor of child health at the University of Newcastle-upon-Tyne.

Evidence is emerging that babies might be hypersensitive to pain, and that it could have long-term effects on their development, he says.

Recent Scandinavian research concluded that trauma in newborn babies contributes to high rates of suicide and drug addiction in teenagers, although the findings are controversial and hotly disputed.

"We can be imposing on babies patterns of behaviour by what we do to them," says Aynsley-Green. "We ought to be much more critical in looking for long-term consequences than we have been until now."

Many procedures, including circumcision and heel pricks, are wrongly performed without anaesthesia. What about

found 77 per cent were given minimal anaesthesia and 23 per cent were "horrifyingly" given none.

TAH  
Doctors and nurses need to be much more aware of babies' pain and make greater efforts to prevent and relieve it. Also, procedures and tests should be performed only if strictly necessary.

An international review of 40 studies involving 1157 newborn babies undergoing procedures

wrapped in. His temperature went down to normal. I walked a nurse who said "We believe this baby is ill, and he needs to be kept warm," and replaced all 5 blankets. His temperature went up. So I took them off, and his temperature went down. This yo-yo game happened three times, and in the end, Mickelson came up and DEMANDED that Ian be released into their care because:

- 1) He had spinal meningitis (? how could he have known that without any tests)
- 2) I was being unco-operative and my actions could result in Ian's death.

What is a first-time mother supposed to do with information like that?

I let him go of course. He looked okay to me - alert, responsive, non-complaining, feeding well.

7 hours later we were allowed our first visit to an unresponsive, swollen baby and were informed that we were not allowed to handle him other than to sit still and hold him. They placed him in my arms and I sat there for 45 minutes looking down at a rigid clenched fist little individual who would not open very swollen eyes. A nurse came in and told us what had happened, and my anger started to swell, but I showed nothing. Later I was assured that babies felt no pain. No one could give me an answer to the question "Then why does he scream whenever you give him an injection? And why has he dramatically changed, even from the baby you took away?"

Five hours later we were called down and I was handed a screaming child who had just been given two injections of antibiotics and told to feed him. After about 20 minutes of walking him to calm him down I was able to attach him only to be told that I had taken too long and to put him to bed because he needed his sleep. I told the nurse politely to mind her own business, and I wouldn't tell her how to do her job. From that point I was down there every two - three hours, and my milk was in within 24 hours for some strange reason. Mickelson informed me that I couldn't possibly feed him and that he should be bottle fed. My response was to lift my T-shirt and squirt him on his overalls. His response was to get mad at my polluting his whites. By this time, the nurses were complaining about my continual presence at night, which they maintained was unnecessary. Ian should be bottle-fed they said. I said that to do that might cause more trouble than they could cope with...I wanted to be there, and they didn't seem to see that.

We continued for three days in a state of cold war, with a child who fed, screamed, or lay rigid and unresponsive, and a mother who was near the end of her tether -until the third day. I blew up. More tests had been ordered without our being asked, and once again, Ian was unresponsive for 7 hours, except to feed, but in a very rigid way. The last straw came when my instincts told me to get down to the neonatal unit. The lift was not working so I flew down the stairs to be stopped by some doctor and worked over for not taking the lift. I pushed him out the way and went

in to find my son screaming rigid in the arms of a nurse with another one with a syringe in her hands. I said "What the hell do you think you are doing?" Ian turned his head around, planted his feet on her stomach, and launched himself out of her arms. I caught him about 18 inches from the floor. I put him on my chest, and he collapsed like a rag doll. At that point I became a raging bull, and told Mickelson and Morreau that if he was not allowed up in my room with me I was discharging myself. That and all the other things I didn't like took one and a half hours to say, and I barred the door and made them stand and listen. I put Ian back in his basinet and said "You have one hour to comply, or else we are out of here." Exactly one hour later, Ian was wheeled into my room. He got given the two injections every 8 hours in my room in between sides (breast feeding) even though I didn't like it, and they would give me no reason for doing it. But I was scared, and what can you do when you feel you are over a barrel?

Mickelson examined him on discharge and found he had significant jaundice. He said that normally they would put them under the lights for levels this high. I looked at him defiantly and asked "And what are YOU going to do about it?" and he said "Nothing". I guess he didn't want another fight.

Wisdom is wonderful - in hindsight. We were right about our son. He is a child who cannot tolerate heat. He has virtually no bedclothes (one blanket) in winter, and hot weather makes him prone to headaches. His temperature in the first few hours I am now sure is purely because he was over-wrapped.

He has not been sick very often, but once he could talk properly something happened which cut me up something terrible. Every time he gets overheated, even now at the age of 11, he has screaming sessions about 90 minutes after falling asleep. We were told that these were normal in some children, that they had no memory of them and to ignore them. That's not easy once they are mobile and jumping around the house, sweat pouring off them and screaming "Mummy, Mummy, Mummy" and not responding to anything you do or say.

When he was four, he got a high temperature. His reaction to temperatures is to crash out on the sofa. This day we had visitors, and when he started this screaming up, the lady sat down next to him and just happened to touch the area where the lumbar puncture was taken from. Ian was lying in the position he was always in when he was younger and did his screaming, which was that foetal position, head thrown back. He jerked his back away from her hand and in a high pitched voice wailed "Mummy, mummy don't let them do it, it hurts." I didn't know what to do. And I don't know what that lady thought. I wonder if she thought he was an abused child? Over the next two days, when these screaming sessions started up again, we experimented twice more, and found that when we touched that spot, we got an identical response.

A year later, the words were the same. I no longer have the courage to do it, to see if it still happens, because it cuts me up everytime. I feel that I betrayed my son out of ignorance,

and that Mickelson inflicted suffering on my son that no adult would have been made to tolerate. But the worst of it was that I didn't fight hard enough for him. My instincts screamed against everything that was happening, and I didn't have the courage to be a real mother and just walk out.

Recent events have made me realise that we must be more vocal as mothers. The new information on the vitamin K that I was assured was so safe when Ian was born - the debate on cholesterol, and now this information on pain-relief in babies.

I took Ian to the doctor this week as planned, and it nearly tore me up. Ian allowed himself to have a general check over, which I thought would reassure him and make him more responsive, but when it came to the granuloma being looked at, this boy who is nearly as big as I am, fled over, planted himself in my lap with his head under my chin and cried his eyes out. He kept saying "I don't want to be hurt."

He is 11! He hardly even sits on me, partly because he's far too heavy, but also because it's not a cool thing for 11 year olds to do - to sit on their mother's lap. "Babies do that!" according to 11 yr olds these days.

Well I have just about run out of words. This letter has been hell to write - like dragging up being at Middlemore all over again. But this is what I think:

I think this newspaper article has missed something out. I think that the way a baby is treated after birth has a profound subconscious effect on a child's basic outlook on life. I believe, after this week's events, that what was done to Ian is why he is basically insecure, and that he has an unremembered subconscious memory of what was done to him, and that this colours the way he sees things even if he doesn't realise it. I have real worries about how I could cope with him if something really serious happened to him. What I also wonder about is the effect of this in terms of child abuse. Medical people talk about child abuse done to children, and how it can result in them doing similar things later on. If Ian gets hurt, he gets very angry. His reaction is to react violently if other children hurt him. He hasn't learned this from us, so where has he learned it? Is it his reaction to being in a situation of extreme pain where he could do nothing but scream or withdraw? I don't know, but I can't help wondering if it's the same with lots of other babies treated like that.

I wonder if this sort of treatment will do more to programme people into violently reacting to situations of pain/impotence than any smack on the backside that you or I may have received as a child.

Lots of unanswered and probably unanswerable questions. But one thing I know is that the pain of this experience in my heart has been as painful this week as it was the days following his birth. And I'm sitting down writing it to you while the events of this week have brought it up, because I know that if I don't do it now, it will fade away to the point where I won't be able to

bring it up again.

And I also want to say that the present medical reviews which I read about seem to confirm that in many ways, the trend at the moment is to maintain the intervention orientated model. I view this with great concern, especially if it does not involve changes in the way pain in anyone is dealt with.

None of this influenced my getting involved in the immunisation debate. I believed at Ian's birth that if the claims of immunisation were true, and if there was no down side, I was willing to inflict that on Ian to save him the misery of being paralysed etc. I did not NOT get his DPT etc on the basis of no pain. I did refuse the BCG in hospital for that reason, but that was because of the situation at that time, which is not exactly your normal day-to-day basis for decision making. It was not until after he was three and we had that episode of screaming where his back was touched that I started to think that maybe the doctors had been wrong, and that those tests after birth do cause pain.

Even though I had queried them about the pain of procedures, for nearly three years I buried my feelings and instincts and instead I hung on to that little comment "Babies feel no pain" because I wanted to make myself feel okay about everything that happened that week in Middlemore. I wanted to believe that it wasn't my fault. But that newspaper article is the thing that really brought it all up in a way that nothing else had. I used to say -I think this is so, but, well, no-one really knows do they? Now I can't say that any more.

I don't want my child to become a drug addict or to commit suicide, and I believe that we are aware enough that hopefully it won't happen. But what if this article is true? What about all those parents who are not aware, who carry their own pain, and maybe take it out on their children who unbeknown to their parents have a pain like Ian? What about those parents who might not realise, and might not know what to look for, and who might give out inappropriate signals to their children because they don't understand?

I'm sorry to provide you with a pile of emotions, but I felt it had to be said to someone, only I didn't know who to say it to. Ms Katherine O'Reagan???!!! Our MP Bill Birch?

Finally on an impersonal note, I hope that the article on TB which I sent to Wendy Lydall to send to you what what you required. If you need any more information, it would be easier to write to me direct, rather than the society. The answer might be more concise.

Regards,

Hilary Butler.



## **Middlemore Hospital**

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MM 039

IN YOUR REPLY PLEASE QUOTE

Address reply to officer whose  
official title appears below signature.

16 December 1992

Hilary Butler  
25 Harrisville Road  
TUAKAU

Dear Hilary

I very much appreciate you writing to me. I read your letter with initially a great deal of concern and by the time I had finished I feel a great sense of humility. I am most grateful that you wrote and your letter reminds me of the responsibilities we have as medical practitioners. I enclose the photographs of your boy as I am sure you wish to have them returned.

I would emphasize that somewhat similar experience to yours as a health provider have influenced my own practice. We do try these days, albeit perhaps unsuccessfully at times, to co-operate with parents, to obtain informed consent and to reduce trauma to infants to a minimum. The leadership here at Middlemore Hospital in Maternal & Child Health is very focused on children and sees their parents as their advocates and their most important resource. We go to great lengths at times not to separate children from their families. I hope that your friends who were recently in hospital were satisfied with our efforts to modify our practices for their child.

What comes through in your letter with your own son's birth is the terrible position that we sometimes put parents in - almost a form of emotional blackmail. I imagine it is a very unpleasant experience and your letter is another reminder to me at least that this is totally unacceptable and that my own practice of sharing responsibility openly and directly with parents is appropriate.

Your boy's response to being touch in the area where he had the lumbar puncture and his distress I am unable to explain by my own limited understanding of medicine, children, memories of the birth experience and what influence this all might have for the future.

It has taken us a long time to realise that adults feel pain and it is only in the last hundred years or so that we have had effective pain relief for adults. It has taken us even longer to realise that children do indeed feel pain and need access to similar pain relief. It has taken even longer for us to accept that neonatal children feel pain and I think we still have some way to go in looking at distress in children with disabilities. However, you need to be reassured that at least myself and the doctors and nurses I work with here at Middlemore are very well aware of the need for pain relief. We try to carry out procedures expeditiously to reduce trauma to infants and these days pain relief is given to children in and around the time of major surgery and also further major procedures or procedures that are likely to be prolonged and painful. However, as you will be aware, sometimes pain relief would require an injection and what we are then going to do is carry out an injection. In our simplistic world we regard giving one injection is better than giving one injection for pain relief and then a further injection that may have diminished pain.

### **Auckland Area Health Board**

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With regard to major surgical procedures, it has been routine practice here in Auckland for a number of years, though I would accept not always elsewhere in the rest of the world, for children with surgical procedures to have proper anaesthesia. Anaesthesia includes control of the breathing and ventilation and also adequate pain relief and also the use of appropriate medications so that people are ideally amnesiac of the procedures. However, you will be aware that in some situations in which light anaesthetics have been used, adult patients can remember their operation and sometimes have even suffered pain because of inadequate pain relief.

I was not able to hear Dr Aynsley-Green talk here in New Zealand and I am unsure what sort of trauma the Scandanavian research concluded contributed to the high rates of suicide and drug addiction in teenagers. I would agree that the findings are controversial and hotly disputed. With regard to your son, Ian, it is obvious that he comes from a loving and concerned family. These are probably the greatest influences on any child and also the greatest protection against children falling into such situations. I have four children and identify with you like many parents in questions about what the future holds for our children. However I believe being part of a loving, stable family, good role models and the ability to communicate with one's parents provide the best protection for our children in the future years. I really do appreciate you sharing your thoughts with me and, as I said before, feel a degree of humbleness and humility, qualities that I need to be reminded of from time to time. I am sure your letter will help me in the care of children and I hope this reply is adequate. It does not really do justice to your own thoughts and writing.

Kindest regards.

Yours sincerely

A handwritten signature in blue ink that reads "Nigel Stewart". The signature is written in a cursive style with a large, stylized initial "N".

Nigel Stewart  
PAEDIATRICIAN