Paediatrician, Dr B

Bay of Plenty District Health Board

A Report by the

Health and Disability Commissioner

(Case 07HDC10316)

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

Overview

Baby A was born on 29 March 2007 with a rare condition that had been diagnosed during pregnancy, rhesus isoimmunisation.[1] This condition requires monitoring in the postnatal stage to ensure that a baby does not become anaemic[2]. However, in Baby A's case such monitoring did not occur after she was discharged from hospital. Although she had one blood test taken two days after her discharge, no further blood test was performed. Unfortunately, Baby A's condition suddenly deteriorated and she died that day despite attempts to resuscitate her in Tauranga Hospital. It was found that she had become severely anaemic.

This report considers the responsibility of paediatrician Dr B to communicate instructions about blood testing after Baby A's discharge, and reviews the systems in place at Bay of Plenty District Health Board to provide appropriate care after discharge.

Parties involved

Baby A	Consumer
Mr A and Mrs A	Complainants/Baby A's parents
Dr B	Paediatrician/provider
Dr C	Senior House Officer
Ms D	LMC midwife
Ms E	Midwife
Ms F	Midwife
A medical practice	Baby A's GP practice
Bay of Plenty District Health Board	Provider

[1] Rhesus factor is a protein found in most people's red blood cells. Someone who does not have the factor is known as Rhesus negative. A Rhesus negative mother exposed to blood having the Rhesus factor will produce antibodies (isoimmunisation). If her baby is Rhesus positive the antibody may cross the placenta and bind to the baby's red blood cells, which will be destroyed by the baby's spleen, causing anaemia.

2 A decrease in red cell production.

Complaint

On 13 June 2007 the Health and Disability Commissioner (HDC) received a complaint from Mr and Mrs A about the services provided to their late daughter, Baby A, by Bay of Plenty District Health Board. The following issues were identified for investigation:

- *The appropriateness of care provided to Baby A by Bay of Plenty District Health Board from 3 April 2007 until her death.*
- *The appropriateness of care provided to Baby A by Dr B from 3 April 2007 until her death.*

An investigation was commenced on 22 November 2007.

Information was received from Baby A's parents, Dr B, midwives Ms F, Ms E and Ms D, a medical centre, the Accident Compensation Corporation, the Coroner, and the Bay of Plenty District Health Board. Independent expert advice was obtained from paediatrician Dr Jeff Brown (see Appendix A).

Information gathered during investigation

Antenatal period and birth
It was recognised during the antenatal phase in late 2006 and early 2007 that Mrs A's pregnancy was complicated by rhesus sensitisation. Isoimmunisation was identified, and her baby received three intrauterine blood transfusions at Auckland City Hospital (National Women's) on 13 and 26 February, and 3 March.

On 29 March 2007, in the 36th week of pregnancy, it was decided to induce Mrs A's labour. However, Baby A became distressed during labour, and a Caesarean section was performed. Nonetheless, she was born healthy, although she required a further blood transfusion on her day of birth, and a blood test showed that she had jaundice[3] (which was an expected finding because of the isoimmunisation).

Tauranga Hospital — 4 to 10 April 2007
Baby A remained in Auckland Hospital until 4 April, when she was transferred to Tauranga Hospital, Mrs A's local hospital. Baby A was admitted under the care of paediatrician Dr B. He recalls that, on her arrival at Tauranga Hospital, Baby A was

[3] A yellow discoloration of the skin, mucous membranes, and sclerae of the eyes, caused by greater than normal amounts of bilirubin in the blood.

"well and showed a normal physical examination though [she] remained jaundiced". Dr B reviewed Baby A on 5 April. He subsequently stated:

> "[Baby A's] laboratory tests were reviewed and I noted that her Bilirubin[4] had fallen from 296 on 3rd April to 233 on the 5th April.[5] Her haemoglobin had also dropped from 133 on 3rd April to 117 on the 5th April.[6] Whilst her jaundice was improving the possibility of ongoing haemolysis was considered.
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> …
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> Assuming that [Baby A's] laboratory tests were satisfactory and she continued to make good progress it was anticipated that she would be able to be discharged the following week with suitable follow up. As I was not due to work the following day, nor over the long Easter weekend, I made a written note in her records regarding her medical history, current management issues and investigative plan, as is my usual practice."

The plan recorded by Dr B on Thursday 5 April stated that Baby A's blood was to be re-tested the following morning (Good Friday), again on Saturday, then again on Easter Monday (9 April). He advised that Baby A was to stay in hospital until at least early the following week.

On 6 April, Baby A's bilirubin level had increased, and phototherapy[7] was prescribed. However, on 7 April the bilirubin level had decreased, and no further phototherapy was administered.

On 8 and 9 April, Baby A was reviewed by a paediatrician, and on both days blood tests indicated that Baby A's condition was improving. By 9 April, Baby A's bilirubin was 203µmol/L, and her haemoglobin 113g/L.

On Tuesday 10 April, Dr B returned from leave and reviewed Baby A. He stated:

> "[Baby A] was now 12 days old. Her weight had increased to 2815g. She had fully established feeding and was taking satisfactory feed volumes both by bottled expressed breast milk and directly from the breast. She was making excellent progress in this regard. I reviewed her laboratory results and identified that her Coombs test was negative,[8] her haemoglobin 113 and bilirubin 203. … [Baby A] was still jaundiced though she was pink and well perfused. Her cardiorespiratory

[4] The orange/yellow pigment of bile.

[5] Normal range for paediatric bilirubin: 2–20µmol/L.

[6] Normal range for haemoglobin: 110–210g/L.

[7] The exposure of an infant's bare skin to intense fluorescent light. The blue range of light accelerates the excretion of bilirubin in the skin.

[8] Coombs test is a blood test that identifies the presence of antibodies.

> examination was normal and no heart murmurs were heard. There was no respiratory distress evident. Her abdomen was soft with no liver or spleen palpable. She showed normal primitive reflexes. No limb abnormalities were identified."

As a result of Baby A's improvement, Dr B decided that she could be discharged home under the care of her Lead Maternity Carer (LMC),[9] with paediatric follow-up. Dr B stated:

> "Given the complicated nature of [Baby A's] ante and postnatal history and the risk of ongoing haemolytic anaemia, I arranged for follow up blood tests to be performed. These were likely to be necessary over the next two months or so, with their frequency guided by her clinical course. I did not want to perform the first test within two days as this would be too early. Nor did I want to leave the test for the following week as this would be too long. I was aware that I was not working on Friday 13 [April] and would be away on leave for the following week. I therefore considered possible options to ensure that there would be continuity of care during this period. I specifically recall deciding, together with the Senior House Officer [Dr C], that a repeat FBC[10] and Bilirubin would be checked by the LMC on Friday, 13 April 2007. I requested that the Senior House Officer would discuss these results with the LMC and if there were any concerns to notify the consultant on call for further advice and guidance regarding testing and review.
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> I specifically requested that the Senior House Officer call the LMC directly to discuss the ante and postnatal history of [Baby A] and explain the follow up arrangements. I anticipated that the midwife would need to visit twice weekly initially. I requested that the Senior House Officer update me on my return from leave to advise progress.[11] I would then continue to supervise follow up. I requested that a paediatric outpatient appointment be booked with me in six weeks' time. I also requested an audiology review, given the history of haemolytic disease and jaundice requiring phototherapy."

Dr C had no recollection of Baby A's case until he was reminded by a review of the clinical records subsequent to her death. He said that he met Baby A for the first time on the ward round of 11 April 2007, and that he "documented the encounter in the notes for [Dr B and] documented the discharge plan as directed by [Dr B]".

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[9] Mrs A's LMC was midwife Ms D.

[10] Full blood count.

[11] Dr B subsequently clarified: "I had asked to be left a message updating me of the action taken after the blood test results were received on Friday 13th April 2007. I do not wish to infer from my statement that I requested Dr C to personally follow up Baby A during the period of my absence and report to me on my return."

The entry in the clinical notes by Dr C advised that the blood tests were to be repeated on 13 April by the LMC. The LMC was also instructed to contact the paediatricians "if levels [increasing]", otherwise to have an outpatient appointment in six to eight weeks' time. This instruction was recorded by midwife Ms E, who was contacted by the hospital. (Ms E was the back-up midwife for the LMC, Ms D.)

The discharge summary described the follow-up arrangements: for an audiology outpatient appointment; to be cared for by the LMC; and for a follow-up haemoglobin and bilirubin blood test "end of the week". The discharge summary was not sent to a GP, as Mrs A had not at this stage named one. Baby A's parents were not given a copy of the discharge summary.

Care after discharge
Mrs A and Baby A were reviewed by midwife Ms F (another back-up midwife) on the day after discharge, 11 April, and all was considered well.

On 13 April, as Mrs A was not at home when Ms F visited, she telephoned Mrs A to advise her to take Baby A to have a blood test taken. The blood test was taken in the late afternoon and entered in ECLAIR (electronic information management system). Baby A's haemoglobin had fallen to 97g/L and, although this was below the acceptable range for one- to four-week-old infants (110–210), Bay of Plenty DHB advised that it was not low enough to require the laboratory to telephone Ms F. A copy of the results were sent to Ms F's Healthlink in-box on 14 April. The results were also electronically forwarded to Dr B, although he does not recall receiving the results. The results were automatically signed off by ECLAIR on 14 May, although no staff had viewed the results prior to this.

Dr B stated:

> "I was expecting [the result of 13 April] to prompt my next action and did not appreciate that this might not happen.
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> I was anticipating that if the result was satisfactory, I would arrange the next blood test for the week of my return. If the result was unsatisfactory, I expected this to be discussed with the consultant on call and further testing arranged during my absence. I would then have expected this result, any subsequent test results and information about [Baby A's] progress to be available to me on my return from leave."

Ms D attempted a further visit on 20 April, but found Baby A and her parents out. Ms D left a note asking Mrs A to contact her.

Dr B returned from leave on 23 April, but because he was "busy catching up on work", he did not take note of Baby A's blood test results of 13 April.

On 26 April, Ms D visited Baby A and her mother. Ms D recalls:

> "The parents had nothing amiss to report and I did not detect any abnormalities at this time."

Ms D advised that she made further attempts to visit on 4, 10, and 16 May, but found that Baby A and her parents were not at home. Ms D stated that she left a card saying she had called on each occasion, but Mrs A did not contact her. However, Mr A and Mrs A strongly disagree with Ms D's recollection and state that they did not receive any cards, and that Mrs A was not difficult to contact. On 17 May Ms D discharged Mrs A and Baby A from her care.

On 7 May, Baby A attended the audiology clinic and was assessed by an audiologist. The audiologist reported his findings to Dr B, who signed the letter on 9 May to acknowledge that he had read it.

Also on 7 May, Baby A was assessed by a doctor at their medical practice (the Practice), as there was some concern about reflux of her feed. The doctor noted Baby A's medical history, including prematurity, jaundice and Rhesus disease. The doctor stated that it was his understanding that Baby A was being followed up by the hospital and midwife. Following his assessment of Baby A, having noted a "well, healthy baby", he diagnosed gastro-oesophageal reflux, and prescribed Gaviscon powder to be added to Baby A's feeds.

Baby A was formally registered as a patient with the Practice on 14 May. The Tauranga Hospital discharge summary of 11 April 2007 was scanned into the Practice's clinical record system on 16 May. The Practice does not have a record of how it obtained the discharge summary, and Baby A's parents specifically deny providing a copy to the Practice — they reiterated that they did not receive any hard copies of the Bay of Plenty DHB discharge summary.

On 17 May, Baby A was assessed by another doctor at the Practice for a routine six-week immunisation and check. She noted Baby A's history and considered that Baby A was "doing well, feeding well, with good growth and normal development". The doctor added that there was "nothing in [Baby A's] history to suggest any concern". She noted that Baby A had a heart murmur, and referred her to the Paediatric Department at Tauranga Hospital.

A few days later, Baby A developed diarrhoea and her father took her to the Practice. She was reviewed by another doctor. Following her assessment, the doctor concluded that Baby A was suffering from a viral infection, but made an appointment with Baby A's father to return the following day. However, they did not attend the follow-up appointment, and Mr A explained that this was because Baby A appeared to be improving and had slept and fed reasonably well throughout the day.

Deterioration and death

Two days later, in the morning, Baby A's condition deteriorated. She was taken to the Practice and reviewed. The doctor decided within five minutes that Baby A required

transfer to hospital, and an ambulance was called. He accompanied Baby A to hospital in the ambulance because of concerns about her condition.

On arrival at Tauranga Hospital at 9.37am, an alert was put out for a paediatric emergency as Baby A's condition was critical. Emergency treatment including resuscitation was commenced, but Baby A's condition continued to deteriorate during the morning, and she died at midday.

Dr B recorded in the clinical notes a detailed description of the care provided to Baby A. He stated that her haemoglobin was "very dilute" and estimated by the laboratory to be 20–25g/L (normal being 110–210g/L). Dr B also recorded his discussion with Baby A's family, and his intention to contact the Coroner.

Dr B noted:

> "I have concerns about follow up since discharge from hospital, and given circumstances … would recommend that death is investigated and management of all is reviewed to prevent future similar event."

Subsequent events

Bay of Plenty DHB arranged for a paediatrician to carry out an independent review of the care provided to Baby A. Dr B also suggested changes following his own review of the case. An action plan was developed to incorporate the changes recommended by the paediatrician and Dr B.

Action taken or in process by Bay of Plenty DHB includes review of the quality and system of discharge summaries; two additional paediatric registrars to be appointed to support the consultant staff; further education on Rhesus iso–immunisation; and the process for following up abnormal results to be clarified.

Dr B has made the following changes in his practice as a result of this case:

> "I have taken this matter extremely seriously, and have reviewed my practice as well as discussing the events prior to [Baby A's] death with colleagues. I have as a result made a number of changes to my practice:
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> 1. I have undergone further information technology training and now always use a computerised calendar with alerts rather than a diary to specify reminders for future events. This enables me to receive electronic memos specifying the date a laboratory result is expected, or a call that I must make regarding a child to a family/midwife etc.
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> 2. I have further educated myself on rhesus isoimmunisation through literature review and discussion with secondary and tertiary colleagues.

3. I will utilise the neonatal homecare nursing service for any future follow up where neonates need regular laboratory testing for an extended period.

4. For future care of rhesus isoimmunised infants, I will now always specify to families and allied health staff that they should expect weekly blood tests unless they hear from me otherwise. I will also ask them to call me directly if they have concerns that follow up is not proceeding as advised.

5. I have reviewed my practice of notifying colleagues of laboratory results in my absence. I will now always handover details of a child where such a result is expected that may require their action. I am now able to electronically arrange for results to be forwarded to colleagues in my absence.

6. I am regularly reviewing written notes taken by the junior staff taken during ward rounds and especially at time of discharge. This has made me aware of a considerable variation in note taking by different staff. Where necessary I now annotate notes to ensure all relevant information is included.

7. All inpatients now receive a copy of the discharge letter as well as other relevant providers such as midwives.

8. A copy of the discharge letter is also sent to me for review. This enables me to identify any issues that have not been appropriately covered.

9. I have requested through my practice recommendations appendix and further discussion with management that the DHB address a number of issues including discharge documentation, continuity of care, lack of middle grade support and team structures, problems with Information Technology services and senior staff workloads that are adversely impacting on clinical risk."

Dr B stated:

"I have been in contact with [Baby A's] parents on a number of occasions and have freely spoken with them. I have answered questions that they have had of me openly and honestly, apologised to them for any shortcomings in my role in [Baby A's] care and expressed my profound sympathy to them.

…

I deeply regret [Baby A's] death and have spent much time reflecting on the events contributing to this. I have spoken openly and honestly with [Baby A's] family from the outset and have done my best to support them after [Baby A's] death, as far as I have been able. Whilst the plan I put in place should and would have been effective had it been carried out as intended, I did not anticipate this may not occur. In light of subsequent events, I do sincerely regret not utilising the

> home care neonatal service to provide an additional safeguard against [Baby A's] loss to follow up. I have therefore amended my practice accordingly."

Dr B commented:

> "When managing children with potentially life threatening conditions, it is my practice to always discuss this comprehensively with families and provide specific details of any investigations, treatment and follow-up required. I agree that if the family had been provided with such information, this would have provided the best safety net, particularly where other events did not occur as anticipated."

Dr B further advised that he had developed guidelines for the Tauranga Hospital Paediatric Department medical and nursing staff for management of infants with Rhesus isoimmunisation; and developed educational material for local general practitioners and Lead Maternity Carers for management of infants with Rhesus isoimmunisation.

Baby A's parents advised that they forgave Dr B for his part in Baby A's death, stating, "We have accepted [Dr B's] apology and he has been nothing but honest with us from the beginning ..."

With regards to Bay of Plenty DHB, Mr A and Mrs A stated: "... We will never forgive [the DHB] for the role they played right from the start, they have offered no help in any way, they sent us around in circles with a whole bunch of lies and were more interested in shifting the blame ... [Baby A's death] has destroyed our lives and trying to come to terms with this just might never happen ..."

Code of Health and Disability Services Consumers' Rights

The following Rights in the Code of Health and Disability Services Consumers' Rights are applicable to this complaint:

RIGHT 4

Right to Services of an Appropriate Standard

(1) Every consumer has the right to have services provided with reasonable care and skill.

…

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(5) Every consumer has the right to co-operation among providers to ensure quality and continuity of services.

RIGHT 6

Right to be Fully Informed

(1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive …

Opinion: Breach — Dr B

Although I am satisfied that the care provided to Baby A while she was in Tauranga Hospital was of a reasonable standard, it is clear that after her discharge she "fell through the cracks" of the system, as Dr B failed to ensure that blood tests were performed and monitored after Baby A's discharge. Dr B accepts that the family were not provided with specific details of the investigations and follow-up required. While Dr B believes that he did tell his Senior House Officer that regular blood tests were required after discharge, this is not what Dr C recorded following the ward round, and is not information that made its way into the discharge summary (written, I note, by yet another doctor). Significantly, Dr B did not check either Dr C's clinical note, or the discharge summary.

In addition, Baby A's only blood test taken after discharge (which showed a fall in her haemoglobin) was not noted by Dr B.

My independent expert, Dr Jeff Brown, criticised a number of aspects of Dr B's care of Baby A. In particular, there were no clear documented plans for Baby A's care after discharge (to include the blood testing), and Dr B did not involve the neonatal homecare team in the care of a baby with such a significant condition.

In my view, Dr B should also have made it clear to Baby A's parents before she was taken home that blood tests after discharge were of vital importance, and he should have fully explained the reason for these tests. Such a discussion would have provided the best possible safety net — concerned and committed parents — to ensure that the necessary blood tests were carried out.

For his part, Dr B accepts that he should have made his instructions more clear, and that he should have involved the neonatal homecare team. He has made a number of changes to his practice and has apologised to Baby A's parents for the lapses in his care. Baby A's parents have accepted his apology.

Although Dr B's subsequent actions are laudable (to review and alter his practice, communicate openly with the parents, and apologise for his lapses), the care he provided to Baby A fell some way short of the standard expected of a paediatrician. By failing to ensure that the instructions for Baby A's care after her discharge were communicated and carried out, and to refer her to the neonatal homecare team, Dr B breached Right 4(5) of the Code. In addition, by failing to inform Baby A's parents of the requirement for further blood tests, and the rationale for that testing, Dr B breached Right 6(1) of the Code.

Opinion: Breach — Bay of Plenty District Health Board

Bay of Plenty DHB was responsible for post-discharge management of Baby A's Rhesus disease, and the associated risk of haemoloysis[12]. This required ongoing monitoring of Baby A's condition through appropriate blood testing and clinical review. There were a number of deficiencies in the systems at Bay of Plenty DHB in relation to discharge summaries and the checking of blood test results. They set the scene for the tragedy that followed.

Discharge summary

No discharge summary was given to Baby A's parents when she left Tauranga Hospital. Providing a discharge summary to a patient is a very sensible practice, even more so where a patient's GP is not known. This was a missed opportunity. As noted above, had Baby A's parents been provided with a copy of an accurate discharge summary, I have no doubt that, as caring parents, they would have ensured that Baby A received the post-discharge care she required.

In fact, the information on Baby A's discharge summary was incorrect, and did not include details of the blood testing required. That, of course, is a separate problem but it does not excuse the failure to provide a copy of the discharge summary to Baby A's parents. I endorse my expert's criticism of the DHB's discharge system:[13]

> "The Bay of Plenty DHB electronic discharge system had no provision to automatically provide parent or patient copies of discharge summaries. There is no evidence in the information provided to me of a paper or manual system to routinely provide such information to parents. This is a significant departure from expected standard of care, and would incur severe disapproval from other DHBs."

[12] The breakdown of red blood cells and the release of haemoglobin.

[13] See also case 08HDC00248, 26 September 2008.

Bay of Plenty DHB has disputed this advice. It is apparently standard practice at most DHBs to provide discharge summaries to patients. Certainly, this simple precaution should be standard practice.

Communication of blood test result after discharge

One blood test was taken two days after discharge on 13 April, and showed that Baby A's haemoglobin[14] had fallen to 97g/L, from 113g/L three days earlier. Bay of Plenty DHB considers the haemoglobin result was not outside the normal range. However, the acceptable range for haemoglobin levels for infants between one and four weeks old is 110–210g/L, which suggests the results were outside the acceptable range for one- to four-week-old infants. In any event, Bay of Plenty DHB advised that the results were not low enough to require the laboratory to alert the requestor or flag (colour code) the results.

A copy of the results were sent to midwife Ms F's Healthlink in-box on 14 April, and electronically forwarded to Dr B, who was on leave until 23 April. At that point he did not take note of the blood tests, which were already 10 days old. Dr B's omission is perhaps understandable in the context of a busy specialist attempting to catch up on work after leave. That is all the more reason why the DHB should have an efficient system in place to ensure that blood test results are reviewed and signed off by the responsible clinician — with an alert system if results are not actioned in this way. Instead, Baby A's blood test results were automatically signed off on 14 May, without being viewed by any DHB staff.

It is clear that the blood test reporting system at Bay of Plenty DHB was inadequate. My independent expert comments that the DHB did not have a robust system to direct copies of laboratory tests, review results and action these results in the absence of the individual doctor involved in the care. Baby A's blood test appeared to show signs that required action, but the result was not followed up. Bay of Plenty DHB's blood test reporting system allowed her to slip between the cracks. As noted by Dr Brown:

> "Any paper or fax or electronic system of results needs to have embedded well understood systems of checking, sign-off and action that are robust enough to withstand transfers of care as well as absences of clinicians who may be the identified key recipients."

[14] A complex protein/iron compound in the blood that carries oxygen to the cells from the lungs and carbon dioxide away from the cells to the lungs.

Summary
By failing to have an effective system in place to ensure that a copy of the discharge summary was provided to Baby A's parents, and important blood tests reviewed by her responsible clinician, Bay of Plenty DHB did not provide care with reasonable care and skill, and breached Right 4(1) of the Code.

Recommendations

I recommend that the Bay of Plenty DHB:

- apologise to Baby A's parents for its breach of the Code; the apology letter is to be sent to HDC by **12 December 2008** for forwarding;

- advise HDC by **12 December 2008** of its progress in implementing the action plan.

Follow-up actions

- A copy of this report will be sent to the Medical Council of New Zealand, the Auckland District Health Board, the Royal Australasian College of Physicians, and the Director-General of Health. I will request that the Director-General of Health arrange for the Ministry of Health to audit Tauranga Hospital and advise me by **31 March 2009** of the steps taken to improve its procedures in relation to communicating post-discharge care to patients or guardians, and ensuring that patient test results are reviewed in a timely manner.

- A copy of this report, with details identifying the parties removed except Bay of Plenty DHB, Tauranga Hospital, Auckland DHB, Auckland City Hospital (National Women's), and the expert who advised on this case, will be sent to the Paediatric Society of New Zealand, the New Zealand College of Midwives, the Royal New Zealand College of General Practitioners, and the Quality Improvement Committee, and placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

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Appendix A

The following expert advice was obtained from paediatrician Dr Jeff Brown:

> "My name is Dr Philip Jeffrey Brown. I have been asked to provide an opinion to the Commissioner on case number 07/10316. I have read and agree to follow the Commissioner's Guidelines for Independent Advisors.
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> I qualified MBChB from University of Auckland in 1982 and FRACP (Paediatrics) in 1992. I have worked as Consultant Paediatrician at Palmerston North Hospital for 16 years since 1992 including neonatal care in a Level 2A Neonatal Unit. I have looked after several babies and infants with rhesus iso-immunisation both directly and following transfer from tertiary units.
>
> I have been asked to provide independent expert advice about whether Bay of Plenty District Health Board and [Dr B] provided an appropriate standard of care to Baby A. Specifically I have been asked to:

[At this point in his report, Dr Brown sets out the questions asked of him, which he repeats in the body of his report. He also sets out the documents sent to him, and a précis of the case, previously set out in detail, above. This information has been omitted for the purpose of brevity.]

> …
>
> I have searched textbooks of neonatal care available in the English language and reviews of rhesus iso-immunisation in published journals. I have also reviewed New Zealand and international neonatal unit guidelines available online.
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> After reaching my initial conclusions and advice to the Commissioner, I discussed some of the details of the case, keeping absolute anonymity regarding names and places, with [the Director] of Wellington Neonatal Intensive Care Unit, to seek whether he was aware of any relevant published guidelines or protocols. He was not, and nor was he aware of published research regarding follow-up for iso-immunisation.
>
> …
>
> **Advice to Commissioner**
>
> **The standard of care provided to [Baby A] by [Dr B] and Bay of Plenty District Health Board from 3 April [until Baby A's death].**
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> There is no available textbook or journal review or unit website protocol for follow-up of babies born with rhesus iso-immunisation. Statements are made regarding the increased vulnerability of those who receive in utero transfusions

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and those who require postnatal exchange transfusions, and the potential for ongoing haemolytic anaemia. But no precise protocol or guidance on the frequency of blood testing or clinical review is published. Therefore judging the standard of care provided by [Dr B] and Bay of Plenty DHB can only be against usual practice by Paediatricians in New Zealand faced with the same clinical scenario.

My practice, and that advised by [the] Director of Neonatal Intensive Care Unit Wellington Hospital, is to check full blood count at least weekly for one to two months until haemoglobin stable and then check two weekly until stable and then monthly until stable. This checking will thus continue until several months of age as the risk of ongoing haemolysis can continue for a few months and the haemoglobin can drop suddenly and without warning in the first few weeks. We would both also prescribe folic acid to help as with any ongoing haemolytic anaemia.

An example of advice in standard textbooks is that in Taeusch HW, Ballard RA. (eds), Avery's Diseases of the Newborn. 'Infants who do not become sufficiently jaundiced to require exchange transfusion are at risk of development of severe anemia associated with a low reticulocyte count at 3 to 6 weeks of age; thus it is important to closely monitor haemoglobin levels after hospital discharge. Follow up of hematocrits for at least 2 months is important.'

That there was no standard procedure for follow-up of infants with rhesus iso-immunisation at Bay of Plenty DHB is no different from other DHBs. No such standard procedures exist to my or [the Director's] knowledge.

No information was provided in the discharge documentation from Auckland Hospital to guide or recommend follow-up procedures.

[Dr B] states that the main requirement for follow-up is monitoring for potential haemolysis. He therefore knew himself that haemolysis was the main risk for [Baby A]. The crucial problem is that others left with responsibility for ongoing care did not seem to appreciate this — that haemolysis, not jaundice, was the major risk.

The failure appears to be that communication of this risk did not effectively occur from [Dr B] to his Paediatric SHO and therefore to primary health care professionals including LMC and also GPs subsequently caring for [Baby A].

If her parents had received information that the major risk was ongoing haemolysis they may have been empowered to require health professionals to treat more seriously any episodes of unwellness.

[Dr B's] arrangements for [Baby A's] care while he was on leave, including his decision to delegate her follow-up care, and contact with the midwives, to [Dr C].

The decision to delegate her follow-up care and contact with midwives to [Dr C] depended upon [Dr C] understanding the clinical risk of haemolysis at any stage over the subsequent weeks. The medical notes documented on day of discharge:

'1) DC to care of LMC 2) rpt SBR CBC Friday -> midwife to [discuss with] paeds if levels rising otherwise paeds [outpatient clinic] in 6–8 weeks' indicate that [Dr C] did not appreciate the risk was of haemolysis, not jaundice. It is not surprising, though unfortunate, that midwives and GPs were therefore also not aware of the risks of haemolysis.

Assumptions of understanding, particularly of rare and unusual diseases, are fraught with danger in terms of knowledge and judgement. Verbal and even written instructions may only be truly understood when reflective listening including 'read back' or 'say back' techniques are used to ensure that the reasons behind the instructions are understood. Only with this understanding can effective communication of the need for testing, follow-up, and actions on results of such testing and follow-up be assured. That [Dr C] had 'no recollection of being involved' prior to reviewing the notes after being asked to provide a statement shows that this case did not register highly in his medical experience.

[Dr B] states that handover regularly occurs to junior staff who then report to a consultant for further advice as necessary, and that it is not practical to hand over all patients directly to a consultant. This is standard practice but depends on effective communication and understanding especially when junior staff are working with many senior staff (and vice versa) and not in formerly traditional small medical 'teams'. The more staff involved, and the less each individual carries continuity of care, the more robust documentation, communication, and back-up systems must be to prevent 'falling through the cracks'.

In this case [Dr B] did not specify any frequency of ongoing testing, but requested outpatient appointment in six weeks. He also asked that results discussed with on call consultant 'if any concerns'. These instructions could be interpreted by others as less important and requiring less urgency than if frequent, weekly, and ongoing blood testing was prescribed. The latter would have indicated more serious concern about the risks of haemolysis.

[Dr B's] decision to discharge [Baby A] to the care of her LMC/primary health care provider.

Notes record 'midwife to discuss with Paeds if levels increasing'. This statement indicates that the only communicated concern was that the bilirubin level might rise. This reflects lack of understanding that ongoing jaundice was not the risk to

[Baby A]. The major risk was haemolysis leading to anaemia and a need for blood transfusion.

With this lack of appreciation of the risk of haemolysis the decision to discharge [Baby A] to the care of her LMC/primary health care provider is unfortunate. In rhesus iso-immunisation there is a significant likelihood of the need for a subsequent blood transfusion. With most conditions with a significant risk of need for intervention tight linkage with hospital staff is essential.

An expected standard of care (both at Tauranga and in other centres) would be for [Baby A] to be under the coordination of the neonatal or paediatric homecare nurses. If this had occurred it is likely that other Paediatricians would have been notified of any haemoglobin results in [Dr B's] absence and that these results would have been acted upon.

Did [Dr B] provide adequate information to [Baby A's] parents prior to her discharge?

The system at Bay of Plenty DHB did not allow for automatic copies of discharge summaries to be given to parents. If a copy of the discharge summary had been given (as is the standard expectation on many other DHBs) and if the summary had included the need for at least weekly ongoing haemoglobin tests, her parents would have been informed and able to request such checks if they did not occur.

It is advisable and should be standard practice for parents to receive the same copy of discharge summary and other clinical summaries such as clinic letters as are sent to health professionals. This enables parents to be informed and to be advocates for their children if other parts of the system break down.

There is no indication in the written notes from National Women's or Tauranga staff, or in the parent's letter, that anaemia from ongoing haemolysis was understood to be the most significant risk for [Baby A].

Bay of Plenty District Health Board's systems for managing patients' discharge, including provision of discharge summaries to primary care providers and family.

Along with failure of provision of discharge summaries to family, the lack of systems for provision to primary care providers is regrettable. Following birth there may be multiple care providers, and in some cases these providers may be unknown at time of discharge. It is important at a most vulnerable stage of life that all known and potential providers of care are furnished with accurate and timely clinical information. Until such time as all patient management systems from cradle to grave are interlinked, it is vital that DHB systems encourage and facilitate, rather than prevent, sending of discharge summaries, lab results, and

other clinical information to as many health providers as may be involved in ongoing care.

Bay of Plenty District Health Board's systems for managing patients' follow-up care after discharge, including checking laboratory results.

[Baby A's] parents state 'blood count result sent to [Ms F]' who they had never heard of. [Dr B] states that it is routine practice for consultants to receive copy of blood test results for patients in their care, but that this did not happen.

Laboratory and other results can be automatically sent to many recipients. This however depends on the data entry being accurate as to the expected recipient. More importantly, the systemic expectations for checking, signing off, and documenting action on results in an electronic lab results system are vital. Merely sending a result is no guarantee of action upon that result if the recipient has no idea why they have received the result or what they should do with it. The sending can provide false reassurance that 'someone will act'. Any paper or fax or electronic system of results needs to have embedded well understood systems of checking, sign-off and action that are robust enough to withstand transfers of care as well as absences of clinicians who may be the identified key recipients.

Each department or service in each DHB should have robust follow-up systems in place to ensure that results are checked and actioned independent of who ordered a test and who may be at work or on leave when the result is received.

Any aspects of the care provided by Bay of Plenty DHB or [Dr B] that warrant additional comment

The care provided to [Baby A] by [Dr B] after she was discharged depended on his expectation of systems within the Bay of Plenty DHB for the primary care of infants and mothers, and the linkages between various health professionals, including both employees of the DHB and others such as LMC/midwife and General Practitioner. His expectations were not fulfilled. She was not visited frequently at home by LMC/midwife and when seen by General Practitioners they had no information to heighten their concerns about [Baby A's] risk for severe illness. This illustrates that any discontinuity of responsibility or uncertainty around expectations for home visits, family support, health centre or hospital clinic review exposes 'at risk' infants such as [Baby A] to further risk of 'falling through the cracks' of care.

The fact that such discontinuities and uncertainties exist is a systemic problem that needs addressing, both in the Bay of Plenty DHB and others. These gaps in care are, however, well known to most Paediatricians and the usual standard of care (in cases such as [Baby A]) is to **not** rely on non-hospital health professionals unless precise and explicit instructions and plans have been communicated and agreed. Usual practice is to ensure follow-up by homecare

neonatal or paediatric nursing service working within the hospital Paediatric service.

[Dr B] makes a disturbing comment that a job sizing exercise had recently led to a 20% increase in remuneration for Paediatricians rather than employment of more staff to alleviate excess workload. Unless the Paediatricians were underworked at the time of the exercise this approach by the DHB is worrying. Rather than addressing excessive workloads by either reducing expected work (difficult in a mainly acute demand driven service such as paediatrics) or employing more staff, an approach of merely increasing remuneration does not provide an environment where audit, teaching, multidisciplinary review and non-clinical activities can routinely occur.[15]

If all the Paediatricians were working 20% more than expected, then an environment for ineffective communication, inadequate follow-up, and less than robust failsafe mechanisms was established as normal practice.

Summary

[Dr B] indicated he knew the risk of ongoing haemolysis for [Baby A]. He failed to effectively communicate this to junior staff who failed to document this risk in the clinical notes or discharge summary.

[Dr B] may have known that more than one follow-up blood test was indicated but there is no indication from the documentation that any other professional involved knew that more than a single blood test would be needed. This is a significant departure from the expected standard of care, and would incur at least moderate disapproval of his peers.

In such a rare condition if the hospital-based homecare service had been involved, and/or if prescribed weekly (initially) blood tests had been requested, then anaemia would have been detected before it became life-threatening, even if [Dr B] himself was on leave.

That [Dr B] did not involve the neonatal homecare nursing service in ongoing follow-up for [Baby A] is a significant departure from expected standard of care, and would incur moderate to severe disapproval from his peers.

[15] Bay of Plenty DHB advised that the paediatricians had elected to increase their remuneration rather than employ additional staff and that an additional Medical Officer position was established in 2007. The DHB advised that "at the time of [Baby A's] death the paediatricians' acute roster was 1 in 5 and is currently 1 in 7. Neither level could be considered onerous nor a potential contributor to poor medical care …".

If the parents had received a copy of a discharge summary describing the risk of ongoing haemolysis, along with verbal explanation of the need for weekly blood tests, they would have been able to request such follow-up if primary or secondary health professionals did not visit.

The Bay of Plenty DHB electronic discharge system had no provision to automatically provide parent or patient copies of discharge summaries. There is no evidence in the information provided to me of a paper or manual system to routinely provide such information to parents. This is a significant departure from expected standard of care, and would incur severe disapproval from other DHBs.

The Bay of Plenty DHB and the Tauranga Paediatric Department did not have a robust system to direct copies of lab tests, review results, and action these results in the absence of an individual doctor involved in the care. This is a departure from expected standard of care, and would incur at least moderate if not severe disapproval from peers.

In rare conditions such as rhesus iso-immunisation it is important that tertiary units transmit their knowledge and expectations to secondary units and that all clinicians involved share a common understanding of rare but potentially life-threatening risks which can be avoided by appropriate close monitoring and follow-up. If guidelines do not exist in published textbooks it is even more important that tertiary units document such advice and expectations.

The absence of directed and explicit advice for ongoing follow-up when [Baby A] was transferred to Tauranga from Auckland City Hospital National Women's Service is a departure from expected standard of care, and would incur at least moderate disapproval from peers.[16]

All these departures from expected standards of care combined with uncertainties over which primary health care professionals were responsible for day to day follow-up in the first weeks of life, to allow the eventual outcome of irretrievable severe haemolytic anaemia."

Further advice

On 1 November 2008, Dr Brown provided the following additional advice:

[16] Auckland DHB advised that children with rhesus disease are cared for by level two centres [such as Tauranga Hospital] and thus do not require detailed advice on follow-up from level three centres [such as Auckland City Hospital]. Nevertheless, Auckland DHB is looking at the possibility of adding a standard phrase to transfer letters suggesting the need for ongoing monitoring of full blood count in infants with haemolytic disease of the newborn.

"... [I]t is standard in MidCentral DHB to provide a copy of the discharge summary to the patient (in the case of adults) and to their parents (in the case of children). Copies are also sent to other providers e.g. LMC, well child provider, who may be involved in the ongoing care. Although not always achieved, the intent is to provide these copies when the patient leaves hospital. If that is not possible, the copy is posted to the patient or parent.

I cannot comment explicitly on what other DHBs have as their standard but in conversation with Paediatric and other Specialists I am aware that many have the same expectation as at MidCentral DHB ...".