

19 December 2001

Dear Dr C

I received a complaint from Ms A and Mr B concerning health services that you provided in early September 1999. Their complaint is summarised as follows:

- *In September 1999 Dr C spoke to Ms A regarding his views on the Guthrie Heel Prick Test (the “test”) although she had previously requested that he talk to her partner, Mr B, rather than to her. Further, his manner was intimidating and he did not go through the relevant brochure with Ms A.*
- *During the conversation with Ms A, and fifteen minutes later in a conversation with Mr B, Dr C threatened them more than once. He stated that if they did not agree to proceed with the Guthrie Heel Prick test he would approach the Children Young Persons and their Family’s Service (“CYPFS”) in order to have their child removed from their care.*
- *Dr C indicated that he wanted Ms A and Mr B to make a decision immediately and would not give them time to consider all of the options before making a decision.*

I have been investigating this complaint and have formed an opinion on the matter. During the investigation I considered information from yourself, Ms A and Mr B, a District Health Board and the medical records from the public hospital.

Facts gathered during investigation

Conversation with Ms A about the test

In August 1999 Ms A gave birth to a son by Caesarean Section at a public hospital. She had been admitted as a transfer from her residence. It had been intended that she have a home birth. In September 1999 you spoke to Ms A about the test to be carried out on her son. You advised me that you had been requested by the hospital midwives to speak to both Ms A and the child’s father, Mr B, about the test as they had declined to consent to the test. You went to Ms A’s room expecting both parents to be present. However, Mr B had gone to the supermarket.

Ms A stated that at this time she asked you to speak only with Mr B about the test. She recalled repeating this request three to four times during her conversation with you, once at the very beginning. Ms A advised that she had been through a lot during her pregnancy and the birth, and she did not want to think about the test.

You stated that you did not remember Ms A asking you to speak only with Mr B. You recall Ms A suggesting that Mr B would make the decision. Nonetheless, in your view, you said it was still important that Ms A had full information about the potential consequences of not proceeding with the test.

In response to my provisional opinion Ms A said that she was quite stunned that you could make the comment that you did not remember her asking you to speak only with

Mr B about the test. She said that she made this request to you a number of times, once at the beginning of the conversation. Mr B and Ms A also said that after the difficult birth and complications Ms A had been through, she wanted to focus on recovering her health to look after her baby.

The Guthrie heel prick test brochure

It is not disputed that, in your conversation with Ms A, you did not discuss the relevant brochure with her. You stated that the midwife, Ms A's lead maternity carer, told you that Ms A and Mr B had been given the brochure produced by the National Testing Centre. In response to my provisional opinion Ms A and Mr B said that the midwife told you that she had been through the relevant brochure with Ms A but she told you this *after* your conversation with Ms A. You said you normally ask parents if they have seen the brochure and if they have any questions about it. Ms A confirmed that she had seen the brochure some months before and been through it with her midwife.

You stated that on this occasion you explained:

- What is involved in pricking the baby's heels to obtain blood;
- What conditions can be tested for;
- What the consequences of those conditions were and the effects of those conditions. For example, hypothyroidism is the largest risk to severe brain damage (of all conditions able to be detected through the test), with the risk being one in every 4000–5000 newborn babies;
- You had looked after several children who had hypothyroidism. If this condition had not been detected by the test the children would have had significant brain damage;
- The test can reveal several other conditions. The majority of these are able to be detected and can be treated by a special diet to prevent severe brain damage.

You stated that your manner was calm and matter-of-fact. You remember having a reasonable conversation with Ms A. She appeared to listen carefully and understand your explanation; she did not cry and was not overtly angry. You stated that she appeared to have internal conflict about what was the right thing to do. After your explanation you said that Ms A suggested that the test was reasonable but Mr B needed to give his approval. You stated that you informed Ms A that you needed to speak with Mr B so you would wait for him on the ward. The conversation concluded on that note and you left the room. Both Ms A and you thought that your conversation had taken approximately 10 minutes.

Ms A stated that you discussed the test with her in an intimidating manner. You were pushy, arrogant, domineering and spoke as though you had the only possible viewpoint. She stated that you asked her why she did not want the test done and she replied that she could not see any reason for it. However, Ms A said that you were not interested in her viewpoint. She found this distressing and cried while you spoke to her.

In response to my provisional opinion Ms A also reiterated her recollection of your demeanour during the conversation.

Approaching the Children, Young Persons and their Families Service

Ms A said that toward the end of the above conversation you twice threatened that if she and Mr B did not consent to the test you would approach CYPFS to have their child taken off them. Ms A said this was the “*ultimate*” intimidation. Ms A also said that after the conversation she had been unable to breastfeed. She advised me that the conversation took place in her room with a nurse present for some or all of the time. She said that you then left the room and returned when Mr B was present.

Your recollection is that you did not discuss this issue with Ms A in your initial conversation with her, but later with both parents together. However, you said that your memory of the conversation was one year old and you did not document who was present in the notes.

Mr B advised me that a nurse had told him on his return that you wished to speak to him. You met with him in Ms A’s room and recalled that he confronted you for upsetting her and told you that they had chosen not to have the test performed. Mr B said that then you seemed to back down a little. Mr B said that you explained his concern and twice said to him that he would contact CYPFS and have the child taken from them. Mr B said that you never raised your voice but your manner was very strong. He further recalled you not wanting them to leave the hospital without agreeing to the procedure. The above conversation took place approximately 15 minutes after Ms A’s conversation with you.

In response to my provisional opinion Ms A and Mr B said that they were certain you made threats to them individually and not together, as Mr B was unaware that Ms A had been threatened until a day or two after leaving hospital. They said that if he had been aware of the threats to Ms A before leaving the hospital he would have taken the complaint to hospital management immediately.

You stated that you told the parents that “... should they decide not to have a Guthrie Card Test done then I would not consider that they were acting in the child’s best interests and I would then consider discussing this with the Children and Young Persons’ Service”.

You said you believe in family centred care but, as a paediatrician, your primary obligations are to the baby. You said that in some instances families are unable to adequately care for their child and may in some instances actively harm their child and in such a situation the paediatrician has the prime obligation to look after the interests of the child, not the parents.

In this case you found yourself in a difficult situation. You thought mentioning CYPFS was appropriate because there was a significant difference in the attitude and opinion of the parents, and Mr B had an undue degree of influence on the decision. Further, if the child had a condition that could easily have been detected by the test, the child would later view his paediatric services as “totally inadequate”.

In response to my provisional opinion Ms A and Mr B said your statement that you would “consider” discussing this with CYPFS is incorrect. They said that you told Ms A twice: “I will go to CYPFS and have your child taken off you.” They said you made the same threat to Mr B.

Ms A and Mr B also stated in response to my provisional opinion that, with reference to your comment that there was a significant difference in the attitude and opinion of the parents, they had agreed not to have the test done prior to being referred to hospital.

Time to make a decision

Mr B recalled that you wanted an immediate decision. He stated that he advised you in “no uncertain terms” that they would consider their options before making a decision on the test. Mr B said the brochure stated that they had three weeks in which to make a decision. Mr B also advised me that his manner was non-threatening but firm.

You stated that you asked Mr B what decision he wanted to make after giving information about the test. You stated that he advised that they would consider the issues and inform you of their decision within one week. You gave Ms A and Mr B your business card and asked them to telephone or email you with their decision.

Your notes record that later that day you telephoned their midwife, and she agreed to further discuss the issue of the test with the parents and let you know the outcome.

Ms A and Mr B subsequently discussed the test with the midwife and decided not to proceed with the test.

In response to my provisional opinion Ms A and Mr B said that they did not discuss making a decision as there was so much emphasis on your threats to contact CYPFS.

Advice

You then sought advice from local and national colleagues. You sought advice because you were distressed as this was the first time in your practice of medicine that a parent had refused to have the test performed after the relevant information had been given them. You said that there was no clear explanation for the refusal and there appeared to be a significant difference in attitude and opinion between Ms A and Mr B.

Most of the advice you received recommended that:

- Further confrontation with the parents was not advisable as there was no legal protection for the child’s interests in this situation;
- A risk to the child of one in 1:4000 of a significant disorder needing treatment was not sufficient to take any action to preserve the child’s interests against the parents’ interests;
- You did not have a legal responsibility to discuss the issue with the parents and get them to make a decision about what was best for their baby. The responsibility lay with the lead maternity carer.

Emails

On 7 September Mr B and Ms A sent an email to you. The email stated that they were “... corresponding with the Health and Disability Commission regarding our conversations with you ...” in early September 1999. As a result of the advice you had received, you sent an email to Mr B and Ms A which stated:

“After taking advice from my colleagues, it has been clarified for me that the responsibility for ensuring that the Guthrie card is done is that of the Lead Maternity Carer, not mine. I still believe that it is in your baby’s best interest to have it done but would now agree that you can choose this or not. If not, it would be wise for the lead maternity carer to have a disclaimer in writing that this is your choice against medical advice.

Should you not take up the opportunity for the Guthrie screening test then I would advise that your baby have his growth and development monitored very carefully (certainly more frequently than the usual Tipu Ora well child scheme usually done by GP or Plunket) and I would suggest [unreadable] – 4 weekly growth measurements at least for the first 6 months.

I am sorry we got into confrontation mode so quickly on Saturday. My belief that screening for hypothyroidism and PKU is so important is based on my understanding of what would have happened to the other children I currently look after who were born without a thyroid gland who would be in a much worse state today except for this screening programme. In this situation I see my role as advocating for the child and it is rare for this to conflict with parents.

I will be happy to co-operate with the Disability Commissioner in this matter and will not be taking this forward to the Children and Young Persons’ Service.”

Opinion

Conversation with Ms A about the test

While Ms A had a right to request you to discuss the test with Mr B and not her, there is a conflict in the information about whether this request was made. In the absence of any other information and, despite the response of Ms A to my provisional opinion repeating that this request was made several times, I am unable to determine whether you failed to comply with specific requests from Ms A. Therefore in my opinion you did not breach the Code of Rights.

The Guthrie heel prick test brochure

I accept that you provided information on the test to Ms A which was consistent with the requirements of Right 6 of the Code of Health and Disability Services Consumers’ Rights, notwithstanding that you did not refer to the brochure. Ms A admitted that she saw the brochure some months before her meeting with you and discussed it with her midwife. It is not critical whether you knew this at the time of your discussion with Ms A.

However, in my opinion you did not create an environment that enabled Ms A to communicate openly, honestly and effectively with you, and therefore breached Right 5(2) of the Code, which states:

RIGHT 5

Right to Effective Communication

(2) Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.

You have provided statements to me which indicate that you felt strongly about the benefits of the test in this case. Your employers, the District Health Board, have also stated this to me. For instance, you told me that you believed that the test should be performed as all but one of the conditions that are tested for are treatable, leading to normal development and lifespan. You said that you also believed the test is in the best interests of every child born in New Zealand as there is increasing evidence that early treatment decreases the amount of brain damage.

In addition, you also said that you were concerned with the financial and social costs of not performing the test. Finally, you felt strongly enough about the test to say to the parents that you would discuss the matter with CYPFS if the parents decided not to have the test performed.

I also accept that Ms A became upset during this conversation, for the following reasons:

- Ms A has consistently stated during the course of this investigation her concerns about the conversation she had with you and how she became as a result of it “stirred up” or “pretty upset”.
- Mr B has also stated to me consistently that he subsequently found Ms A in this state and spoke to you about it. You confirmed to me that Mr B did this and this is recorded in your notes.
- You acknowledged that Ms A was in a state of “internal conflict”.
- You also said to Ms A, when you met with her alone, that if she and Mr B refused to consent to the test then you would contact CYPFS.

Therefore, in my opinion it is more probable than not that during this conversation you acted as an advocate for the test, rather than presenting the information in a balanced way and listening carefully to Ms A’s views. In my opinion the way in which you did this had the effect that Ms A felt that her views were not treated with respect; she felt intimidated and upset by this, particularly when you mentioned that you would involve CYPFS in the issue.

Thus, the manner in which you presented your views did not create an environment in which you and Ms A could both communicate openly, honestly and effectively about the test. This resulted in you breaching Right 5(2) of the Code.

Approaching the Children, Young Persons and their Families Service

In my opinion you also breached Right 2 of the Code of Health and Disability Services Consumers’ Rights, which states:

RIGHT 2

Right to Freedom from Discrimination, Coercion, Harassment, and Exploitation

Every consumer has the right to be free from discrimination, coercion, harassment, and sexual, financial or other exploitation.

I accept the comment made by the complainants in response to my provisional opinion that you said you would discuss rather than “consider” discussing the matter with CYPFS if they decided not to have the test. This version is consistent with the contemporaneous note you made of the conversations with Ms A and Mr B which states: “ I clearly said that I would see this [not consenting to the test] as not having the baby’s best interest at heart and that I would then discuss this with CYPFS.” However, I am unable to conclude on the evidence whether or not you said their child would be taken off them as a result.

In relation to the contention of Ms A and Mr B that the threats you made to them to contact CYPFS were made to them both individually rather than together, I accept that Ms A and Mr B were each seen alone by you. This is consistent with your contemporaneous note, which states: “discussion with the mother and then the father about the test”.

The parents, as the child’s legal guardians, had a right to refuse the test. The test is not mandatory under the law. Therefore, I find it difficult to characterise the statements made by you – that you would seek the involvement of CYPFS if the parents did not consent to the test – as anything but coercive. The statement was intended to place pressure on the parents to consent to the test and thus affected their exercise of their right to choose what they thought was best for their baby.

However, I acknowledge the following circumstances:

- You did agree after discussion that Mr B and Ms A would have one week to make a decision on the test. Under usual circumstances this would have been a sufficient length of time to make a decision;
- Mr B and Ms A did not have the test performed;
- You were acting in good faith and believed you were acting in the best interests of the baby of Mr B and Ms A;
- You had looked after several children in your Clinic who had been diagnosed with hypothyroidism and who, if they had not had the test, would have had significant brain damage;
- I accept a statement made by your employers that paediatricians in New Zealand “strongly support” the use of the test and that the number of babies not screened is very small. I also accept their statement that the test involves no more than minor discomfort for the baby;
- The incidents complained of happened over a relatively brief period of time;

- You withdrew your threat to contact CYPFS soon after consulting with your colleagues;
- You had not experienced a refusal by an informed parent to consent to the test in 15 years of clinical practice;
- The issue of disagreements between professionals and families about health-care for children is complex.

Nonetheless, the statements made by you were serious and implied that the decision-making rights of Ms A and Mr B as guardians of their child could be in jeopardy on the basis they were unfit parents. The threats were further strengthened by the fact that you are a senior paediatrician, the statements were made in a hospital setting, and this was the parents' first child. Ms A and Mr B were also outside their home area and Ms A had only recently had a difficult labour followed by a Caesarean section.

In addition, your statements cannot be justified on the basis that you considered the matter was urgent. As mentioned above, it was agreed that the parents would communicate their decision to you on the test within one week.

Therefore, it is not surprising that the parents felt intimidated by your statements that you would discuss their decision with CYPFS if they chose not to have the test. In my opinion this threat was a clear illustration of your strong views on the benefit of the test.

Since the overall approach you took was clearly intended to coerce Ms A and Mr B into a course of action they did not wish to take, it is my opinion you breached Right 2 of the Code.

Vicarious liability

Employers are vicariously liable under section 72(2) of the Health and Disability Commissioner Act 1994 for ensuring that employees comply with the Code of Health and Disability Services Consumers' Rights. However, under section 72(5) employing authorities have a defence if they have taken steps as were reasonably practicable to prevent their employee from breaching the Code.

While your actions breached Rights 2 and 5(2) of the Code, it is my opinion that the District Health Board could not have taken steps in this case that would have prevented this from occurring. Your actions in breaching the Code were based on your strong views on the benefits of the test.

It is unlikely that your employing authority could have taken steps to prevent such actions. Therefore, in my opinion the District Health Board is not vicariously liable for your actions in breaching the Code.

Recommendations

I recommend that you:

- Apologise to Mr B and Ms A. This apology is to be sent to my Office and will be forwarded to them;
- Review your practice in the light of this report.

In response to my provisional opinion you commented that you feel somewhat uneasy about writing an apology because throughout the whole affair you held the interests of the child as being pre-eminent and that so far during my investigation you feel that the child's interests have not been paramount. However, I remain of the opinion that an apology is warranted in all the circumstances.

I look forward to receiving a letter of apology and confirmation that you have reviewed your practice.

Yours sincerely

Ron Paterson
Health and Disability Commissioner

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