

**Case 200703138: Greater Glasgow and Clyde NHS Board - Acute Services Division**

**Summary of Investigation**

***Category***

Health: Hospitals; paediatrics; clinical treatment/diagnosis

***Overview***

The Ombudsman received a complaint from an advice worker (Mrs C) on behalf of a member of the public (Mrs A). Mrs A's daughter, Child A, had a narrowing of the main artery from her heart which needed surgical repair. Mrs A complained that the surgery had left Child A paralysed. She also complained about what she considered was poor communication from Greater Glasgow and Clyde NHS Board.

***Specific complaints and conclusions***

The complaints which have been investigated are that there was:

- (a) alleged clinical failure during surgery to repair a coarctation of the aorta (*not upheld*); and
- (b) poor communication from the Board both before and after surgery (*not upheld*).

***Redress and recommendations***

The Ombudsman has no recommendation to make.

## **Main Investigation Report**

### **Introduction**

1. A Citizens Advice Bureau caseworker (Mrs C) complained to the Ombudsman on 11 March 2008 on behalf of a member of the public (Mrs A). The complaint was helpfully summarised by Mrs A in a letter received by the Board on 30 March 2007:

'[Child A] required to undergo heart surgery on 21 February 2007. I was advised that [Child A] required a correction of a coarctation to the aorta and that if she did not have surgery her coarctation could be fatal. Although her heart operation was a success, complications during surgery resulted in [Child A] sustaining a spinal injury, her legs could not move for five days and only then could she manage small toe movements.'

The surgery took place at The Royal Hospital for Sick Children (the Hospital) in Glasgow. Child A was two and a half years old at the time. As noted by Mrs A, the aorta repair was successful. However, Child A developed post-operative complications including bilateral lower limb paralysis, incontinence and right-sided Horner's Syndrome. Mrs A complained to Greater Glasgow and Clyde NHS Board – Acute Services Division (the Board). She was not satisfied with the Board's response and so came to the Ombudsman through Mrs C.

2. The complaints from Mrs C which I have investigated are that there was:
- (a) alleged clinical failure during surgery to repair a coarctation of the aorta; and
  - (b) poor communication from the Board both before and after surgery.

### **Investigation**

3. As part of the investigation into this complaint, I received information from Mrs C on behalf of Mrs A. I obtained medical records and related correspondence from the Board, as well as the Board's complaint correspondence. I also obtained clinical advice regarding this complaint from an adviser to the Ombudsman (the Adviser) who is a practising NHS consultant cardiac surgeon.

4. It is clear from my reading of the documents on file that this has been a very difficult and distressing time for Child A's family. I also note that the Board staff involved in Child A's case regret that Child A suffered complications and are very sorry that it happened (see paragraph 22).

5. The Adviser's opinion on this complaint is at paragraphs 24 to 29 in this report. At this point, I think it is helpful to include his explanation about the anatomy of the arteries in the chest, which is important context for understanding the complaint:

'The major artery is the aorta. It arises from the heart and the entire blood flow exits from the heart into this large tube which initially runs upwards at the front of the chest before arching backwards and to the left hand side before running down the back of the chest cavity adjacent to the left of the spine. It then leaves the chest and runs into the abdomen.

Within the chest it gives off several large branches, to the heart, the arms, the head, neck and brain and the spinal cord. Usually there are three very big branches which arise from the aortic arch as it turns from front to back. The 1<sup>st</sup> of these branches gives rise to the right subclavian artery, which mainly supplies the right arm and which also gives rise to an artery, the vertebral, which supplied the brain and spine. The 3<sup>rd</sup> of the great vessels coming off the arch of the aorta is the left subclavian, which does the same things on the left hand side as the right subclavian does on the right.

Coarctation is where there is a tight waist or narrowing in the aorta, usually just after the aortic arch, beyond the left subclavian artery. It is a congenital abnormality, that is to say people are born with it. In order to operate on this portion of the aorta, clamps have to be applied to the artery above and below this site so that it can be opened up without massive bleeding.'

6. I have not included in this report every detail investigated but I am satisfied that no matter of significance has been overlooked. Mrs C, Mrs A and the Board were given an opportunity to comment on a draft of this report.

**(a) There was alleged clinical failure during surgery to repair a coarctation of the aorta; and (b) there was poor communication from the Board both before and after surgery**

7. On 11 September 2006 Child A's Consultant Paediatrician, who had been treating her for asthma, wrote to a Consultant Paediatric Cardiologist at the Hospital noting that she had a heart murmur. An echocardiogram was arranged for 5 October 2006 and the test result led to the conclusion that Child A had a coarctation of the aorta. A cardiac conference was held which decided that surgical repair would be the preferred option and, on 8 November 2006, the

Consultant Paediatric Cardiologist wrote to the Consultants in Paediatric Cardiac Surgery at the Hospital asking if they could arrange for the surgery.

8. On 26 January 2007 the consultant paediatric cardiac surgeon (Surgeon 1) who performed the operation wrote to Child A's General Practitioner (GP) saying:

'I met with [Child A]'s parents at the surgical out-patient clinic on 19.01.07 to discuss [Child A]'s coarctation surgery. I explained the operation and the risks to them. They appear to grasp them including the very small risk of paraplegia. We plan to operate on [Child A] within the next few months. She is now on the surgical waiting list.'

9. Child A was admitted at short notice due to the cancellation of another patient's procedure. The nursing notes from 20 February 2007 recorded that her family were telephoned at home to come to the Hospital and they arrived at 16:30. The notes for the next day recorded that Child A attended cardiology for an echocardiogram and a chest x-ray at 08:45. The records also included a consent form signed by Surgeon 1 and Mrs A on 20 February 2007.

10. Child A's electronic medical record about the operation noted that it was a difficult procedure and that there were anomalies in her chest anatomy (her right subclavian artery was proximal to the coarctation and behind her oesophagus). It also noted that three clamp periods were required, as follows:

'1<sup>st</sup> Period 31 mins – Coarctation resected and anastomosis – high pressure grad therefor redo

2<sup>nd</sup> Period 20 min with subclavian flap performed but again the pressure grad remained high

3<sup>rd</sup> Period 20 min redo and good press grads again'

The record also noted:

'Monitor, assessment and rehabilitation as necessary for spinal shock'

The three cross clamping periods and times were confirmed in a detailed record of the operative procedure written by Surgeon 1. The medical notes for 22 February 2007, signed by Surgeon 1, noted:

'Situation regarding legs discussed with mother. Told [Child A] may have suffered spinal cord damage ...'

11. After a period of post-operative care, Child A was discharged home on 16 March 2007. On 13 April 2007, Surgeon 1 wrote to Child A's GP with an account of what happened during the surgery. In relation to Child A's condition after surgery, he said:

'In the immediate post operative period she was stable haemodynamically but unfortunately seemed to have suffered ischaemic damage to her spinal cord.'

12. Mrs A, assisted by Mrs C, complained to the Board. A meeting was held on 23 May 2007 attended by Mrs A and her husband (Mr A), Mrs C and two staff from the Board, the Associate Medical Director (the Associate Director) and a Complaints and Patient Liaison Officer (Officer 1). Officer 1 took notes of the meeting, which recorded that the Associate Director said that they needed to understand if anything could, or should, have been done differently. The notes also recorded:

'1 in 200 risk of procedure – risk of paraplegia, indicated to GP in letter and discussed with parents in consenting (this was acknowledged by [Mrs A]).'

In addition, the notes recorded that, based on information from Surgeon 1, the Associate Director explained the anomalies in Child A's anatomy that Surgeon 1 discovered during surgery, a right subclavian artery rising from the aorta near the coarctation, as well as a left-sided superior vena cava. The Associate Director also said that this artery seemed to create some tension on the anastomosis, and it was noted that Mr A said that this meeting was the first time they had been told of this tension. Mrs A also said that they were not warned before the operation that Child A's eye colour could change. The notes also recorded that Mr A was:

'... not keen to meet [Surgeon 1], he came to ward, looked at notes and left without speaking to them.'

13. The Associate Director wrote to Mr and Mrs A on 1 June 2007 with his record of the meeting and to follow up some points raised at the meeting. The Associate Director said that Surgeon 1 had told him that, once he was committed to the coarctation repair during surgery, it would not have been advisable to abandon the procedure. The Associate Director also explained that:

'... in order to minimise any damage to the spinal cord, [Child A] was allowed to cool during the procedure as cooling is thought to help protect

the spinal cord. This was a preventative measure which was undertaken recognising the risks inherent in further cross clamping.'

The Associate Director referred to a question from Mr A about the use of guidelines for surgery to repair a coarctation of the aorta. The Associate Director said that:

'... because of the range of anatomical variations affecting the aorta and its arterial branches, it wasn't always possible to decide exactly what to do until the operation was underway.'

Mr and Mrs A had also asked if Child A's anatomical anomalies could have been detected before surgery. The Associate Director said due to Child A's specific anatomy a simple pulse test did not indicate any problems. He said that there were risks in trying to detect such uncommon anomalies in young children using more invasive procedures, and that to do so:

'... would result in subjecting the majority of children to risk without potential gain.'

The Associate Director was aware that Mr and Mrs A still had some unanswered questions, and so offered some ways forward, including a meeting with Surgeon 1, a meeting with another surgeon from the Hospital, and getting a view from a surgeon not associated with the Hospital. In relation to a meeting with Surgeon 1, the Associate Director said:

'... I respect the fact that you may not wish to meet with [Surgeon 1], but I know having spoken to him that he would be very willing to meet with yourselves. I understood from what [Mrs A] said that she felt that [Surgeon 1] had not been very forthcoming with you. In my experience of working with [Surgeon 1] I feel confident in saying that it would certainly not have been his intention to create that impression.'

14. Mrs C informed Officer 1 that Mr and Mrs A wanted Child A's case reviewed by a surgeon not associated with the Hospital, and the Associate Director wrote to Mr and Mrs A on 10 July 2007 asking if they had specific questions to put to this surgeon. In his letter, the Associate Director said:

'Although I am comfortable with arranging a review and can completely understand your reasons for requesting it, I have to reserve the right to disagree with its findings. I hope you understand my position on this and think it is better stated now, rather than later.'

Mrs C wrote to the Associate Director on 24 August 2007 with a list of questions. In response to the Associate Director's statement on the right to disagree with the reviewer's findings, Mrs C said that Mr and Mrs A:

'... do realise that you may not agree with the findings of another consultant, but this will enable [Mr and Mrs A] to be more informed of all the procedures involved in [Child A]'s care. This is very important to them as a family.'

The Associate Director wrote to a consultant paediatric cardiothoracic surgeon (the Reviewing Surgeon) at a London hospital on 20 September 2007 enclosing Mrs C's letter of 24 August 2007 and explained that:

'The context of my request is to give [Child A]'s parents an objective assessment of how [Child A]'s care was handled in light of the complication which arose.'

15. The Reviewing Surgeon responded to the Associate Director's request in a letter of 8 October 2007. He said that, looking at the lead up to Child A's surgery, he thought:

'... it would be reasonable to expect the anomalous right subclavian artery to be identified pre-operatively.'

In his view, this would have led to an appropriate surgical strategy being devised and, therefore, Mr and Mrs A could have been better informed of the risk of paraplegia. Mr and Mrs A had asked if the surgery should have been stopped once Child A's anomalous anatomy was discovered, or if she should have been put on a bypass. The Reviewing Surgeon said:

'It would be better if we knew about the anomalous right subclavian artery prior to surgery. I don't think the operation should have stopped on discovery of the abnormal anatomy ... However, the situation one would always want to avoid is multiple cross clamping to deal with either significant bleeding or sub-optimal repair with a high pressure gradient and low distal arterial blood pressure. This becomes a harbinger for spinal cord ischaemia.'

In relation to the bypass, the Reviewing Surgeon's view was that some surgical units would be prepared to use a bypass in children with an anomalous anatomy like Child A's and that:

'... it would offer the comfort platform for the surgeon to undertake the surgical repair.'

However, he did not definitively state that Child A should have been put on a bypass or that it would have made a difference to the outcome of the surgery. In relation to the planned and actual procedures carried out by Surgeon 1, the Reviewing Surgeon said:

'It is quite unusual to use a subclavian flap arterioplasty in the repair of coarctation in children ... I still consider resection of coarctation with an end to end anastomosis was a quite reasonable option even though there was an anomalous right subclavian artery.'

Mr and Mrs A also asked why they were not informed that Child A had suffered a mediastinal haemorrhage, and if this could have contributed to paralysis. The Reviewing Surgeon answered:

'It is a very interesting question. If I take it at face value, I don't think the mediastinal haemorrhage would have contributed to the lower limb paralysis. However, in the context of multiple clamping for sub-optimal repair of the coarctation, together with blood loss and hypotension, this might create a rather unfavourable environment for the development of spinal cord ischaemia.'

The Reviewing Surgeon concluded by noting that these were his personal comments on the case.

16. As well as sending a copy of the Reviewing Surgeon's letter to Mr and Mrs A, the Associate Director sent a copy to Surgeon 1, who felt that it was a very fair comment on the case. However, he did make the point that the specific type of right subclavian anomaly in Child A's case was very unusual. Because the Reviewing Surgeon's letter contained some technical information and explanations, Mr and Mrs A asked for a meeting with the Associate Director and another Consultant Paediatric Cardiac Surgeon from the Hospital (Surgeon 2). Mrs A emailed the Associate Director on 17 December 2007 with questions for the meeting, which was scheduled for 19 December 2007.

17. The Associate Director wrote to Mrs A on 14 January 2008 with his account of the main points raised at the 19 December 2007 meeting. In addition to him and Mrs A, the meeting was attended by Mrs C and Surgeon 2. The Associate Director said that Child A's case had been discussed at a multi-disciplinary case conference involving three cardiac surgeons and four paediatric cardiologists. Surgeon 2 had explained why Child A's anomalous



right subclavian artery would not have been detected during the echocardiogram, and mentioned the risks of undertaking more invasive investigations (see paragraph 13). Surgeon 2 also gave his view that, while Child A's case was not discussed again at a multi-disciplinary conference in the days leading up to the operation due to her being brought in at short notice (see paragraph 9), he did not feel this had any significant bearing on her surgical management. Surgeon 2 went on to explain that:

'... with a surgical approach coming in from the left side of the chest, the right anomalous subclavian would not be visible to [Surgeon 1] until he had undertaken some significant dissection of the vessels. [Surgeon 2] explained that a left subclavian flap procedure was his general preference for a coarctation repair and that his colleagues and many other centres employed this technique ... As you know, [Surgeon 1] had considered doing a left subclavian flap procedure as his preferred choice of operation however, when he discovered the anomalous right subclavian artery he attempted an end to end anastomosis instead. [Surgeon 2], like [the Reviewing Surgeon], felt [Surgeon 1] was justified in employing this approach ... Unfortunately kinking of the aorta did occur with the first repair therefore two further episodes of cross clamping were required to achieve a satisfactory end result with ultimately a left subclavian flap procedure being used.'

18. Surgeon 2 also explained that a coarctation repair would usually take 15 to 20 minutes and that this length of time generally did not pose a risk of any spinal cord damage. In relation to using a bypass to prevent risks associated with cross clamping, Surgeon 2 said that he did not use this technique, nor did it appear from the Reviewing Surgeon's letter that he used it either. He also said that at that time there was no scientific evidence to prove that a bypass would produce fewer complications than cross clamping, and that a bypass would also involve complications which, in his opinion, made its use undesirable. In logistical terms, Surgeon 2 said that once Surgeon 1 commenced the operation a bypass would not have been an option as a bypass machine would not have been immediately available. Surgeon 2 also explained that:

'... in most circumstances where it's a straightforward surgical repair the operation is quick and therefore spinal damage does not occur. Unfortunately in [Child A]'s case she had both a mild coarctation (and therefore a weak collateral circulation) and a requirement for more complicated (and longer) surgery because of her anomalous right subclavian artery. This put her at greater risk of spinal cord damage.'

Surgeon 2 also explained that Horner's Syndrome was a recognised complication of coarctation surgery and that it tended to improve, and that Mrs A had said that there had been improvement in Child A's eye. The Associate Director concluded by saying:

'I hope from what you have heard through discussion you now have a better appreciation and understanding of what went on and the risks that had to be balanced up in [Child A]'s case. It is most unfortunate that [Child A] has suffered a complication that is extremely rare. As [Surgeon 2] pointed out this is the first such case he has been aware of in almost 20 years of surgical practice at [the Hospital].'

19. Mrs C wrote a letter to the Ombudsman on behalf of Mrs A on 11 March 2008. In that letter she summarised the complaint as follows:

'[Mrs A] is unhappy regarding the treatment received by [Child A] during cardiac surgery at [the Hospital]. [Child A] was paralysed due to complications during surgery. [Mrs A] feels that if different procedures had been followed then the risks to [Child A] would have been greatly reduced.'

Mrs C went on to say that the response Mrs A had from the Board to her complaint had increased her concerns about Child A's treatment and Mrs A felt that the matter had not been addressed fully by the Board.

20. I asked the Board for their response to the complaint. In relation to Child A's anomalous anatomy and the risk of paraplegia, they said that there was no evidence to suggest that there is a higher complication rate in patients with a right anomalous subclavian artery. In relation to the choice of procedure used by Surgeon 1, the Board said:

'... this is a matter of clinical judgement decided at the time of operation by weighing up the pros and cons of both possible approaches. Having prior knowledge that [Child A] had a right anomalous subclavian artery would not have changed [Surgeon 1]'s decision to undertake an end to end anastomosis as the preferred approach to repairing the coarctation.'

In terms of the Reviewing Surgeon's comment that he would have expected the anomalous right subclavian artery to be identified before the operation, the Board said that while they would accept this comment for the more common form of anomaly, Child A had 'an uncommon variant' which meant that it could

not have been detected without performing tests that could pose a risk to patients, particularly children (see paragraphs 13 to 17).

21. In relation to explaining the operation and possible complications, the Board confirmed that Surgeon 1 met with Mr and Mrs A on 19 January 2007 to discuss the surgery, and that he referred to this in his letter of 26 January 2007 to the GP. In relation to Child A's incontinence and Horner's Syndrome, the Board said:

'Incontinence is a consequence of the spinal ischaemia and therefore was not mentioned as such.

In relation to Horner's Syndrome, as it is our standard practice that, if a complication is relatively minor and occurs infrequently, this would not be routinely discussed. I note [Mr and Mrs A] have previously stated they were not aware of this as a potential surgical complication and I can confirm this is a rare complication of coarctation surgery which tends to improve over time and generally does not affect vision. In [Child A]'s case this was caused by damage to her sympathetic nerve chain during the left subclavian flap procedure, which had to be carried out quickly in view of this being the third episode of cross clamping.'

22. I asked the Board if it was possible to determine definitively what caused Child A's paralysis and other post-operative complications. They said that:

'There is a natural tendency for people to look at the 'what ifs' and we therefore recognise and understand the need to pinpoint causation. As [Child A]'s paralysis and other complications occurred following coarctation repair, it is evident that at some point during the surgery the blood supply to the spinal cord was compromised. This is a recognised complication of coarctation surgery, albeit a rare one ... The circumstances in [Child A]'s situation were of a particularly rare complication and, because of a range of anatomical variations affecting the aorta and its arterial branches, it was not possible for [Surgeon 1] to decide exactly how to proceed until the operation itself was underway. From the review of [Child A]'s case notes and discussion with relevant medical staff, the Director is of the opinion that the clinicians concerned acted appropriately in what was a complex and evolving situation. The Director profoundly regrets that [Child A] has suffered such complications and it is difficult to express in words how sorry the clinical staff are that this has occurred.'

23. I also asked the Board if Surgeon 1 spoke to Mr and Mrs A after the surgery. They said that Surgeon 1 did speak to Mrs A after the procedure (see paragraph 10). They were also aware that:

'... on another occasion, [Surgeon 1] was present in the ward and, although he does not recall an occasion in the ward when he did not speak to [Child A]'s parents, he unfortunately left without speaking with [Mr and Mrs A]. [The Associate Director] is conscious from his discussions with [Mr and Mrs A] that this understandably caused them some distress.'

24. Given the complex nature of Child A's case, I obtained advice from the Adviser, a practising NHS consultant cardiac surgeon. His explanation of the anatomy of the arteries in the chest is at paragraph 5. In relation to Child A's case, the Adviser said:

'In my opinion the key issue in this case is the failure of the initial two attempts at repair during the operation to satisfactorily reduce any pressure gradient across the coarctation. [Child A] had complex anatomy which could not be predicted by the reasonable preoperative examination and investigation of a child with coarctation. The anatomy was such that a highly experienced and skilled surgeon was unable to satisfactorily repair her defect without necessitating prolonged aortic cross clamping and this is what led to her spinal cord injury.

The choice of method of repair and the time taken to effectively perform the repair are dependent on the decision making and technical abilities of the surgeon. A paper ... in the European Journal of Cardiothoracic Surgery in 1998 ... stated that the major determinant of outcome after repair of coarctation was the surgeon's expertise. [Surgeon 1] is one of the most experienced paediatric cardiac surgeons in Europe and has published widely on all aspects of congenital heart surgery, including coarctation.

As such, in my opinion, the resulting complications were an inevitable consequence of [Child A]'s anatomy. I note that her parents were advised by [Surgeon 1], preoperatively ... of the risk of paraplegia, and that the quoted level of risk ... was consistent with contemporary data and the lack of knowledge (reasonably) about her abnormally sited right subclavian artery.'

25. In relation to guidelines and normal procedure for coarctation surgery, including preparation for surgery, the Adviser said:

'There are no relevant contemporary guidelines to my knowledge as to the optimum investigation of children with coarctation. I am unaware of any units in the UK that routinely perform angiography or MRI scans on all children to seek out anomalous great vessel pathology unless there are specific signs on examination (which in this case there were not) to suggest they may exist. Therefore to my knowledge every unit in the UK would have currently used echocardiography as the sole method of investigation in this case, which would have led to the failure to diagnose the aberrant subclavian artery ... An echo probe on the chest would not have been able to 'see' an artery running at the back of the chest behind the gullet, as there would be too many air filled structures between it and the probe for an echo signal to pass from the probe to the artery and bounce back to the probe again ...

Surgeons in the UK currently employ both subclavian flap repair and end-to-end anastomosis for infants with coarctation and again there is no specific guideline that I am aware of advocating one approach over the other. No unit in the UK that I am aware of routinely uses cardiopulmonary bypass techniques [in] every repair of coarctation in infants.'

26. I asked the Adviser if anything 'went wrong'. His opinion was that the preparation and execution of the operation were reasonable, even though:

'At the end of the procedure the blood supply to the spinal cord had been interrupted for sufficient a period of time to cause paralysis. There was also an injury to the sympathetic nerves in the chest which caused a Horner's syndrome.'

The Adviser said that he agreed with the Board that they could not have reasonably detected Child A's anomalous artery:

'The precise position of this anomalous artery in this specific case was so rare that the risks of performing these investigations and anaesthetic on every child with coarctation would be greater than the benefits of making the diagnosis in so few children, despite the fact that it may influence the future planned operative strategy in these children with the anomaly.'

The Adviser also said that:

'There is no clinical evidence that use of bypass techniques would have reduced the possibility of spinal injury.'

27. In relation to whether the operation should have been stopped on discovery of Child A's anomalous anatomy, or if she should have been put on bypass, the Adviser said:

'... it was reasonable to proceed with attempted end-to-end repair of the coarctation once the subclavian artery anomaly had been discovered. Unfortunately, the initial result was unsatisfactory. At that stage of the procedure, the die was then cast. The only reasonable alternative was to create a subclavian flap repair. This had to be created immediately because there was now a gradient across the suture line of the initial repair. As this had been performed without bypass, the time taken to introduce, set up and implement bypass would have been prohibitively long even if it had of been thought to be justified.'

28. In relation to whether there would have been a different outcome to the operation if Surgeon 1 had initially used a subclavian flap repair with a likely reduced cross clamp time, the Adviser said:

Unfortunately, it is not possible to say, other than the shorter the cross clamp time the less chance of cord damage. Each individual, dependent on their own specific characteristics, has a finite time beyond which cord damage is inevitable, even with the anaesthetic measures taken to reduce spinal injury as was the case here.'

In relation to the mediastinal haemorrhage, the Adviser's view was that it could not have contributed to Child A's paralysis. Also, in relation to whether the risk of paraplegia would have increased if Child A's anatomical anomalies had been identified pre-operatively, the Adviser said:

'The abnormalities themselves increased the risk because clamping the aorta would have isolated right and left subclavian, and therefore also both vertebral arteries and the anterior spinal artery, from the circulation. Pre-operative identification would have therefore increased the quoted risk of paraplegia during consent. It may not have influenced the operative strategy other than making end to end, rather than subclavian flap repair the approach of choice. What would not have been possible to identify, was the influence the right subclavian artery had on creating torsion and/or tension at the site of the join in the aorta after resection of the coarctation.'

29. In relation to whether Mr and Mrs A should have been told about Horner's Syndrome being a potential complication, the Adviser said that it was:

'... a rare complication that is usually transient and few long term effects, as such the frequency is low and the impact low and it would be reasonable not to have included this in the list of possible complications during the consent process, particularly as a proportionate consent process would have dwelled on death, infection, bleeding and paraplegia.'

30. Commenting on a draft of this report, Mrs A said that Surgeon 1 spoke to her about his concern that Child A's legs were not moving 12 hours after the operation. She said that:

'During this discussion spinal injury was not mentioned, as far as both my husband and I were concerned [Child A] at this stage was being treated for spinal shock. This was reiterated when the neurological team met with us later on that day.'

She said that the full extent of Child A's injuries only became known to them at a meeting with a neurologist on 10 April 2007, and at that stage they started to realise the full impact of what had happened to Miss A. I asked the Board for their view on this. The Board told me that, in response to Mrs A's comment, Surgeon 1 had no recollection of using the term 'spinal shock' when talking to her in the post-operative period. He had also reviewed the medical records on Child A's case and saw no reference in his notes to using this term.

*(a) Conclusion*

31. As noted in paragraph 4, this has been a very difficult situation for Mr and Mrs A and their family, as well as staff at the Board involved with Child A's case.

32. Given that it was reasonable for the Hospital not to have known about Child A's anomalous anatomy before the operation, the Adviser's view that Surgeon 1's preparation for and execution of the operation were reasonable in the circumstances, and that we cannot say that a different procedure would have meant a different outcome for Child A, I do not uphold this complaint.

*(b) Conclusion*

33. There is evidence that Surgeon 1 met with Mr and Mrs A on 19 January 2007 at a surgical out-patient clinic and that the operation and the associated risk of paraplegia was explained. This information was also copied to Child A's GP, and the risks were again explained during the surgery consent process on 20 February 2007. The medical records show that Surgeon 1 spoke to Mrs A after the operation. However, Mr A did not know about the tension at

the site of the anastomosis until the meeting at the Hospital on 23 May 2007 and he said that, on a visit to the ward, Surgeon 1 looked at Child A's notes but did not speak to the family. Mrs A said that she felt Surgeon 1 had not been forthcoming with them. Surgeon 1 did not recall not speaking to Child A's family on the ward, though the Board acknowledged that this caused Mr and Mrs A some distress. Surgeon 1 did also not recall using the term 'spinal shock' when speaking to Mrs A after the operation. There is no independently corroborated evidence to prove definitively what happened and what was said during these meetings and, therefore, I cannot reach a finding on them. In terms of other risks of surgery, in addition to paralysis, the Board explained why incontinence and Horner's Syndrome would not have been referred to, and this accords with the Adviser's view of the consenting process.

34. In terms of how the Board dealt with Mrs A's complaint, I am of the view that their handling of it was reasonable and they tried to give full and transparent answers to the questions raised, as typified by the two meetings held with the family on 23 May 2007 and 19 December 2007, and the Associate Director's letters of 1 June 2007 and 14 January 2008. In particular, I have been impressed by the Board's commitment to dealing with this complaint in an even-handed manner, demonstrated by asking for an opinion from the Reviewing Surgeon.

35. In terms of personal interactions between Child A's family and Surgeon 1 and the adequacy of information given, there are two views of what happened but no definitive evidence to allow me to reach a finding. What I have seen is evidence that there was communication between Surgeon 1 and Mr and Mrs A and their GP about Child A's surgery and the associated risks, and that this was discussed, as required, during the consenting process. I have also seen evidence that the Board's handling of the complaint was reasonable. On this basis, I do not uphold this complaint.



**Explanation of abbreviations used**

|                        |  |
|------------------------|--|
| Mrs C                  | The complainant, a Citizens Advice Bureau caseworker   |
| Mrs A                  | The aggrieved, the mother of Child A   |
| Child A                | Mrs A's daughter   |
| The Hospital           | The Royal Hospital for Sick Children in Glasgow  |
| The Board              | Greater Glasgow and Clyde NHS Board – Acute Services Division  |
| The Adviser            | A clinical adviser to the Ombudsman  |
| GP                     | Child A's General Practitioner   |
| Surgeon 1              | A Consultant Paediatric Cardiac Surgeon at the Board, who operated on Child A  |
| Mr A                   | Child A's father   |
| The Associate Director | An Associate Medical Director at the Board   |
| Officer 1              | A complaints and patient liaison Officer at the Board  |
| The Reviewing Surgeon  | A consultant paediatric cardiothoracic surgeon from a London hospital, engaged by the Board to review Child A's case |

Surgeon 2

Another consultant paediatric cardiac  
Surgeon at the Board

MRI

Magnetic resonance imaging

**Glossary of terms**

|                          |  |
|--------------------------|--|
| Anastamosis              | The connection of two structures in the body, such as arteries   |
| Angiography              | Using dye to make the blood vessels or arteries visible under x-ray  |
| Arterioplasty            | Surgical reconstruction of the wall of an artery   |
| Cardiopulmonary          | Relating to the heart and the lungs  |
| Coarctation of the aorta | A narrowing (coarctation) of the largest artery in the body (the aorta)  |
| Collateral circulation   | Blood flow in the heart that follows a channel that is alternative to, or develops in substitution for, a major blood vessel pathway   |
| Distal                   | Distal is used for the point furthest from the point of attachment to the body or part of the body   |
| Echocardiogram           | Using ultrasound to produce two-dimensional pictures of parts of the heart   |
| Haemodynamically         | Blood flow   |
| Horner's Syndrome        | Upper eyelid drooping, constriction of the pupils and an absence of sweating on the affected side of the face caused by disruption of the sympathetic nerves supplying the eye |
| Hypotension              | Low blood pressure   |
| Ischaemic/Ischaemia      | A restriction in blood supply  |

|                                       |   |
|---------------------------------------|---|
| Magnetic resonance imaging (MRI) scan | Using magnetic waves to create pictures of an area of the body  |
| Mediastinal haemorrhage               | Bleeding in area between the lungs which is bounded by the spine, breastbone, and diaphragm   |
| Oesophagus                            | A muscular tube through which food passes from the neck/throat to the stomach, also known as the gullet   |
| Paraplegia                            | Impairment in motor and/or sensory function of the lower extremities. It is usually the result of spinal cord injury or a congenital condition  |
| Proximal                              | Where an appendage joins the body or a part of the body   |
| Resected                              | A surgical procedure to remove part of an organ   |
| Right and left subclavian arteries    | The subclavian artery is a major artery of the upper chest that mainly supplies blood to the head and arms. On the left side of the body, the subclavian comes directly off the arch of aorta. On the right side of the body, the subclavian arises from the brachiocephalic artery when it divides into the subclavian and the right common carotid artery |
| Superior Vena Cava                    | A short but wide vein that carries blood from the upper half of the body to the heart   |
| Suture                                | A stitch used by doctors and surgeons to hold tissue together   |
| Sympathetic nerve                     | The nervous system responsible for regulating many functions in the body  |