Scottish Parliament Region: Glasgow

Case 200801237: Greater Glasgow and Clyde NHS Board

Summary of Investigation

Category

Health: Hospital; neurosurgery; cauda equina syndrome

Overview

The complainant (Ms C), who was aged 33, was admitted to the Southern General Hospital in the area of Greater Glasgow and Clyde NHS Board (the Board) in September 2007 and October 2007 with possible cauda equina syndrome (CES). She complained that the decision not to operate near the start of the first admission seriously compromised her condition and that, despite ongoing symptoms and inability to manage her daily life, her discharge home did not include adequate follow-up support.

Specific complaint and conclusion

The complaint which has been investigated is that surgery should have been done near the start of the first hospital admission, there was inadequate communication with Ms C about the nature and outcome of her condition and the after-discharge support was inadequate (*upheld*).

Redress and recommendations

The Ombudsman recommends that the Board:

(i) apologise to Ms C for not having operated earlier;

(ii) reflect on this report's conclusions and take appropriate action in respect of each;

(iii) satisfy themselves that the consultant in question has an appropriate understanding of CES; and

(iv) update the Ombudsman's office on the main audit findings and main plans regarding after-discharge support.

Main Investigation Report

Introduction

1. The complainant (Ms C), who was aged 33 at the time, was admitted to the Southern General Hospital (the Hospital) in the area of Greater Glasgow and Clyde NHS Board (the Board) in September 2007 and October 2007 with possible cauda equina syndrome (CES - explained at paragraph 5). She complained that the decision not to operate near the start of the first admission seriously compromised her condition, that she was not adequately informed about her condition and that, despite ongoing symptoms and inability to manage her daily life, her discharge home did not include adequate follow-up support.

2. The complaint from Ms C which I have investigated is that surgery should have been done near the start of the first hospital admission, there was inadequate communication with Ms C about the nature and outcome of her condition and the after-discharge support was inadequate.

Investigation

3. I was assisted in the investigation by a clinical adviser (the Adviser). He is a consultant orthopaedic and spinal surgeon, whose role was to explain to me, and provide an unbiased comment on, aspects of the complaint. We examined the papers provided by Ms C (which included her complaint correspondence with the Board and her opinions about what had happened) and information from the Board (which included Ms C's Hospital clinical records and the Board's replies to my enquiries). In line with the practice of the Ombudsman's office, the standard by which the events were judged was whether they were reasonable. By that, I mean whether the decisions and actions taken were within a range of what would have been considered to be acceptable professional practice at the time in question. The purpose of the investigation was to use the information from Ms C and the Board to try to establish what happened (ie the relevant facts) and then to consider whether what happened fell within this range of reasonable practice. I should add that we do not judge decisions and actions by hindsight. In other words, our conclusions are not based on how things later turn out for a patient. Our approach is to consider what (for example) evidence and information were available to clinicians at the time in question and to consider whether their actions were reasonably based on that information. This is because that is the only information on which the clinicians could have based their decisions at the time.

4. I have not included in this report every detail investigated. In particular, I have not recorded details which are known to Ms C and the Board, are not in dispute or do not have any particular relevance to my conclusions. I am satisfied that no matter of significance has been overlooked. Ms C and the Board were given an opportunity to comment on a draft of this report.

Cauda equina syndrome

5. Cauda equina means horse's tail, which broadly describes the shape of the nerves as they leave the spinal cord near the bottom of the spine and fan out downwards. These nerves control the lower limbs, bowel and bladder. CES is a definition of the symptoms which may occur when these nerves are compressed within the spinal area. CES is divided into two groups – incomplete CES and complete CES. In incomplete CES, there are symptoms and signs of CES and there may be problems in, for example, urination, but some control of the bowel and bladder remains. A progressive loss of function can occur, to a point where, for example, nerves simply stop functioning. This is complete CES, where numbness in the genital area affects sexual function and loss of bowel and bladder control means incontinence of faeces and urine. The difference between incomplete and complete CES is very important in terms of the prospects for recovery. Incomplete CES needs early surgery as that can result in, for example, a good recovery of bowel and bladder function, whereas, when things get as far as a complete CES, the chances for such recovery are poor.

6. The Adviser has also made the following comments about treatment and its timing:

> 'In a patient with incomplete CES, there is no doubt that early surgery, within six to 12 hours, is an important aim.
>
> However, the position is not as clear in complete CES. The results of surgery then are so poor that it has proved very difficult to demonstrate whether or not early surgery truly has any value. A number of medical papers published within the last two years about this have produced views, which range from recommending surgery within six hours to concluding that early surgery is of no benefit. However, most clinicians would say that the aim with complete CES should be to investigate and, with the patient's consent, treat as soon as possible – taking into account the availability of suitably-trained staff and operating theatre availability. In other words, it is usually accepted that the aim with a complete CES would be surgery

within 24 to 48 hours of hospital arrival and that it is unnecessary to do, for example, an emergency operation in the middle of the night, when trained staff may not be as available. And there is no doubt that early diagnosis and urgent scan are important'.

Complaint: Surgery should have been done near the start of the first Hospital admission, there was inadequate communication with Ms C about the nature and outcome of her condition and the after-discharge support was inadequate

7. I turn now to the events of the complaint, starting with a short summary of Ms C's Hospital admissions of 19 September and 8 October 2007. Ms C, who was aged 33 at the time, was taken to Glasgow's Western Infirmary on 19 September 2007 as an ambulance emergency, accompanied by a referral letter from her general practitioner (GP), which described her symptoms and raised the possibility of CES. The accident and emergency department (A&E) of the Western Infirmary examined Ms C and made a diagnosis of possible CES. At a further examination, a doctor recorded in the clinical records that this possibility could not be excluded, that an urgent scan was needed and that Ms C was to be transferred to the Hospital. The transfer took place that same evening. Upon urgent review at the Hospital, a junior doctor's impression was of possible CES and a specialist registrar (the Registrar) reviewed the scan which had, by then, been done, noting a right-side disc prolapse. The Registrar made a plan for conservative management (ie a non-surgical approach), including physiotherapy. The records say the plan was discussed with the on-call consultant. I would assume that to have been by telephone: there is no evidence that Ms C was seen by the on-call consultant, nor would I expect her to have been as it was now after midnight. A consultant neurosurgeon (the Consultant) reviewed the scan the next day (20 September 2007), concluding that, although there were some features of CES, there was no evidence of a central disc prolapse and that, therefore, he agreed with the conservative management. The records for 27 September 2007 say that Ms C was seen by the Consultant, advised to contact him if the pain remained unchanged, and discharged home.

8. Ms C was readmitted to the Hospital's neurosurgical unit as an emergency on 8 October 2007. Another diagnosis of possible CES was made and another scan was done, the results of which prompted an operation for CES that night. Following a later referral to, and review by, a spinal injury consultant and specialist spinal injury nurses, arrangements were made for further review by

the spinal injuries out-patient clinic, the district nursing service were contacted for home support and Ms C was discharged home on 18 October 2007.

9. In her complaint letters to the Board, Ms C described the pain and the many far-reaching consequences of the disabilities caused by the CES. For example, she said that the severe pain of sitting meant she had been unable to go back to work and that she had to wear incontinence pads all the time.

10. Because of the shortcomings, this report focuses on the Adviser's criticisms and the actions the Ombudsman wants the Board to take, rather than on the detail of Ms C's situation. Here, then, are the Adviser's main criticisms:

> 'It is very difficult solely from the clinical records to decide whether Ms C had an incomplete or complete CES (see paragraph 5) when she arrived at the Western Infirmary A&E on 19 September 2007. Taking into account the GP referral letter, Ms C's account and the Western Infirmary A&E records, I consider that, on arrival in the Western Infirmary A&E, Ms C had a complete CES. While there, a proper history was taken and full examination done, a possible diagnosis of CES was appropriately made, and a correct plan for urgent scan was made. It was decided to transfer her to the Hospital, under the care of the neurosurgical unit.
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> She was examined there the same evening (19 September 2007), and, again, both the history taken and the physical signs suggested a complete CES. The Registrar reviewed the scan which had by then been done. I, too, have reviewed it and note a central right-side prolapsed disc at the spinal area of L5/S1, a considerable narrowing of the canal and marked compression. I consider that the Registrar concluded that the disc prolapse was the problem but that this was not responsible for Ms C's signs and symptoms of CES. I consider that the Registrar took undue significance from the scan and that the physical signs and symptoms made it clear that there was a CES compression. The Registrar decided on conservative management (ie not surgery). By this time, it was after midnight, and it was appropriate not to have operated on Ms C at that point as a night emergency. But a review the next day, 20 September 2007, was important. The Consultant took over Ms C's care on 20 September and reviewed the scan. There is no evidence of his reviewing Ms C herself or of her having been re-examined neurologically by anyone that day. At that stage, it is likely that she would still have had the same physical signs and symptoms as the previous day. Those

physical aspects were so overwhelming that she should have been operated on during 20 September 2007. Again, I would say that undue significance was drawn from the scan, when the patient herself was presenting physical signs and symptoms of CES.

I would repeat (see paragraph 6), in conclusion, that, despite the conflicting clinical views in the United Kingdom about early surgery in patients with complete CES, most clinicians would aim to operate within 24 to 48 hours of hospital arrival. Ms C should, therefore, have been operated on during the day of 20 September 2007. There is no place for conservative management of a CES, and it was inappropriate that she was not operated on at that point or, indeed, at all during her first admission.

Turning to the communication aspect of the complaint, there is no evidence that anyone during this first admission explained to Ms C that she had CES, nor the significance of her problems. Apart from a brief note about the discharge arrangements, the clinical records do not record any discussions with Ms C about her condition. This is a shortcoming. In a letter to the Ombudsman's Complaints Investigator, the Board said that the Consultant had discussed the option of surgery on 20 September with Ms C and that he had explained that it would mainly be aimed at relieving the pain in her leg but that, if she could tolerate the pain, a conservative approach might be suitable instead of surgery. The Board added that the Consultant said he had mentioned nerve damage to Ms C because not all patients would have been familiar with the name CES. (Incidentally, this implies that the Consultant considered that Ms C had CES, although there is no evidence that he made this diagnosis at all.) This was not enough information to enable Ms C to make an informed decision about surgery: a diagnosis of possible CES had been made all the way along, starting with the GP referral letter, and to tell Ms C that any operation would simply be a matter of pain relief was not adequate. The Board's letter also said that the decision was arrived at after 'discussing the options' with Ms C and her accepting a conservative approach, at least for the time being. There is no evidence at all of appropriate options being discussed, and I note that Ms C herself complained that, later, she felt she had been misled by the Consultant, having been advised to 'wait and see how the drugs help my pain in my lower back'. Ms C said that she was never given information about her condition during the first admission, and I have to say there is no evidence that would prompt me to disagree with her. In short, the records

inappropriately give me an inadequate level of detail to know what was or was not said to Ms C. However, that lack of evidence and the Board's account are, in fact, sufficient evidence for me to conclude that inadequate information was given to Ms C to enable her to give proper, informed consent to conservative management and that appropriate information about her condition was not given later.

Moving on to the support after the discharge of 27 September 2007, I have to conclude that the advice given to Ms C (see end of paragraph 7) was simply inadequate. She was discharged home, and to have to cope, alone, with incontinence and loss of feeling in the genital and surrounding area, without support, must have been a nightmare. (I note that nursing staff told Ms C she could not go home before she could demonstrate adequate urinary control; however, I do not consider that it was appreciated that she was having to use abdominal pressure to squeeze out urine and that she did not, therefore, have proper control.) The symptoms of CES can be absolutely devastating, requiring a great deal of support. It is not reasonable to expect the average GP to be able to do more than give very general, broad, help and advice. In this case, however, the GP does not seem even to have been asked for this as the discharge letter to the GP is very brief and raises no concerns. The letter indicates that a fuller letter would follow. However, I do not believe anything was sent until after the October 2007 discharge because the October discharge letter covers both admissions. Because of a GP's very limited role, it is, therefore, for hospital services to arrange a support package in these cases. The source of such advice is often allied to spinal injury units because many of the problems of a CES sufferer are also experienced by patients with traumatic spinal injuries. In conclusion, all units which deal with CES should have appropriate contact details available, in order to arrange hospital discharge with as much information and support as possible.

I turn now to the admission of 8 October 2007 and will simply say that, this time, Ms C's physical signs and symptoms were essentially unchanged, yet this time she was appropriately treated surgically, appropriate input from spinal injuries specialists was given, and, although I accept that Ms C was unhappy, I would say that fairly reasonable arrangements were made for after-discharge care this time'.

I should add that, in commenting on a draft of this report, Ms C did express her disagreement that the arrangements were fairly reasonable. However, the Adviser maintains his original view.

11. In paragraph 10, I summarised the Adviser's main criticisms. These were put to the Board, who responded in detail in writing to me. For example, they explained in more detail the Consultant's reasons for not operating during the first Hospital admission, as summarised here:

> '[The Consultant] would agree with the [Adviser]'s comment that there is no role for conservative treatment in the management of a CES. However, that statement is true only in the presence of a large disc prolapse causing compression to the nerves of the Cauda Equina, requiring decompression. In the case of [Ms C], with the deficits she had and a right sided L5/S1 disc it was impossible to be certain that removing the disc would give her any benefit apart from relieving the leg pain. The option of surgery was nevertheless not entirely ruled out during that admission … [The Consultant] would entirely agree with the [Adviser]'s comment that it is incorrect to believe that CES only occurs in a central disc prolapse. However, it is difficult to argue that surgery is absolutely indicated if there was no persistent and demonstrable compression of the nerve roots. There is considerable variation in the range of professional opinion about surgical management of CES. To [the Consultant's] best knowledge, there is no proven benefit of decompression alone when there is established CES, especially in the absence of a significant compression of the nerve roots forming the Cauda Equina.'

12. The Adviser reviewed the Board's letter but maintained his original view about the lack of surgery during the first admission. For example, the Registrar examined Ms C at 23:40 on 19 September 2007, noting that, on examination of the rectum, there was reduced sensation, although Ms C retained some sensation and could feel a pin-prick. The Adviser considered that this alone, without any other evidence, should have made it clear that Ms C had a CES, whether or not at that time it was complete. The Registrar reviewed the scan and noted the right-sided disc prolapse. The Adviser has said that this did not mean there was no CES and still considered that the Registrar focused too much on the scan, rather than on the physical signs and symptoms. However, the notes say that the Registrar discussed the plan for conservative management with the on-call consultant, who supported it. If that consultant was given the history and findings, the Adviser would add that the Registrar did

fulfil his or her own responsibilities. By that time, it was after midnight on the night of 19 to 20 September 2007, and the Adviser would not have expected CES surgery during the night. In other words, it was the lack of surgery on 20 September, or, indeed, at any point in the first admission, that is the real area of concern for the Adviser. The Consultant reviewed the scan on 20 September, but there is no evidence that he clinically reviewed Ms C herself at that time. The Adviser did not consider that appropriate. In summary, the Adviser has said that CES is a clinical description of a history and findings, not simply a diagnosis from a scan. It should have been clear from all the physical signs and symptoms that Ms C had CES. Early surgery was indicated – not as an emergency during the night of 19 to 20 September 2007 but at some time during the day of 20 September. The Consultant provided further, detailed, views as he continued to dispute the Adviser's advice: the Adviser considered these but has maintained his stand.

13. Regarding the after-discharge arrangements, the Board explained in detail in two letters to me that Ms C's complaint had highlighted the need to review the support arrangements for patients with CES. Discussion had revealed that the expertise available in the spinal injuries unit was not routinely available to CES patients because the unit was intended, instead, for spinal trauma patients. (See the penultimate sub-paragraph of paragraph 10 for the Adviser's general points about the involvement of spinal injuries units.) Other discussion had revealed that after-discharge support was very variable because patients with CES came from throughout the west of Scotland (ie not just from this particular Board's geographical area) - some being discharged home to GP care and some to general hospitals or community services. It became clear to the Board that a wider and more detailed approach was needed than had been envisaged when Ms C's complaint had prompted consideration of the issue. It was decided to carry out an audit to form some view of the number of patients with CES in the west of Scotland and their symptoms following discharge. This would help the Board to identify after-discharge aspects for improvement, which would be progressed through discussion with each health board in the west of Scotland.

14. The Board agreed with me that it would have been helpful to have given Ms C some of this information, given that she had complained about post-discharge support and that it was her complaint that had highlighted the need to do more. The Ombudsman has decided to make no recommendations for action regarding this omission by the Board but hopes the Board will reflect on

this in future complaint handling. That said, the Ombudsman is satisfied that the Board took the complaint about post-discharge support extremely seriously. The Adviser also has expressed 'hearty support' for the audit. It is a very welcome thought that this complaint will bring about improvements for other sufferers of this distressing condition. By way of a recommendation for further action, therefore, the Ombudsman would simply like an update on the main audit findings and on the main plans that are drawn up for support after discharge.

Conclusion

15. I accept the Adviser's advice, which means I accept that surgery should have been done near the start of the first hospital admission, that there was inadequate communication with Ms C about the nature and outcome of her condition and that the after-discharge support in relation to the first admission was inadequate. I also accept that there is no evidence that proper, informed consent to the treatment plan of conservative management was sought and that there was inadequate record-keeping about discussions with Ms C. In addition, the Ombudsman is concerned that, despite all the suspicions, no firm diagnosis of CES was made during the first admission. It is unclear why the Board said (see paragraph 10, fourth sub-paragraph) that, because the Consultant did not consider that all patients would have been familiar with the name CES, he used the term 'nerve damage' to Ms C. That implies that he had diagnosed CES, yet, as I say, there is no evidence of this. In all, the Ombudsman is concerned about the Consultant's level of understanding about CES. He recommends that the Board assure themselves about this.

Recommendations

16. The Ombudsman recommends that the Board:

(i) apologise to Ms C for not having operated earlier;

(ii) reflect on this report's conclusions and take appropriate action in respect of each;

(iii) satisfy themselves that the consultant in question has an appropriate understanding of CES; and

(iv) update the Ombudsman's office on the main audit findings and main plans regarding after-discharge support.

Annex 1

Explanation of abbreviations used

Ms C	The complainant
The Hospital	The Southern General Hospital
The Board	Greater Glasgow and Clyde NHS Board
CES	Cauda equina syndrome
The Adviser	Clinical adviser to the Ombudsman
GP	General practitioner
A&E	Accident and emergency department
The Registrar	A specialist registrar at the Hospital
The Consultant	The consultant neurosurgeon in charge of Ms C's care