Tuesday, 4 December 2012

(9.30 am)

(Delay in proceedings)

(9.50 am)

THE CHAIRMAN: Good morning. You'll be pleased to know that we have got a slightly shorter day than yesterday. Professor Neville has to leave by 1.15 and Dr Scott-Jupp is only available by video link from 2.30 to 4.30, so we won't be here until 6.30.

Professor Neville, you're still under oath. Thank you very much.

PROFESSOR BRIAN NEVILLE (continued)

Questions from MS ANYADIKE-DANES (continued)

MS ANYADIKE-DANES: Good morning.

Professor Neville, can I just confirm with you that you have received certain documents? Have you received two witness statements that incorporate reports from Professor Young?

A. Yes.

Q. Have you received a report from Dr MacFaul that deals with those reports?

A. Yes, I have.

Q. And did you receive the transcripts for Dr Webb on Friday and yesterday?

A. Yes, I did.

Q. Thank you. Then I wonder if I can take you first to the witness statement of Professor Young. The reference is 178/2. You can see at page 2 of that, at (b), which is a reference to a part of an earlier report of Dr MacFaul, where he is dealing with the treatment of cerebral oedema, in particular the need to act presumptively and restrict fluids in certain circumstances.

A. Yes.

Q. The criticism that's made, apart from the obvious one that he referred to an earlier edition of Forfar & Arneil, the third edition, which was 1984, although at the time of Claire's administration there was a more recent edition than that, but the criticism that's being made is that his reference to:

"In many cases, treatment of cerebral oedema is required to be presumptive. Fluid should be restricted to 60 per cent of estimated daily requirements. Low sodium-containing infusions are contraindicated."

That's one. And then if we go to page 4, then one sees the comment that Professor Young has made having gone through the report and made reference to the materials. He says:

"In reality, in 1996 there simply was not any general or widespread understanding that there was a

routine need to restrict fluid intake in encephalopathy and to use fluid with a higher sodium content than Solution No. 18."

Do you have a view as to what the practice was in terms of the treatment of encephalopathy at 1996 and the use of fluids, low-sodium fluids, and any need to restrict their use?

A. Yes. Although I see that one of the major handbooks had giving 0.18 per cent salt, it's quite clear that that required caution and that you would be watching the sodium level and making quite sure that it was not dropping further. And if it was, you should certainly increase the dose of salt so that you were giving either half normal or normal saline. So that, I think, is just giving the normal amount. That, of course, was not followed up because of the lack of doing the sodium on the next morning.

Q. But if I ask you what the knowledge and practice was in 1996. I think what you said is, in 1996, that you would be watching carefully and monitoring and so on, but what I am trying to find out is if you have reached a view that the child has an acute encephalopathy, then in 1996 what was known about how you manage fluids and administer fluids in those circumstances?

A. Well, it had been described for at least 20 years, the

problem of giving low-solute fluids to these children. So I would have, with that particular indication, been really quite careful about what should have been given and I would have given a higher amount. But in fact, if the lower amount, the 0.18 per cent solution, if given, would have been given overnight and then rapidly, I hope, corrected because of a drop in sodium. That's what I would have expected to happen.

THE CHAIRMAN: Sorry, professor, when you say it had been described for at least 20 years, where had it been described? Because the point that Professor Young is making in this paragraph is he is saying there wasn't any general or widespread understanding and he also then cites Dr Scott-Jupp as saying that, as late as 2003, textbooks and handbooks were still recommending hypotonic saline. So if Professor Young is wrong, he suggests also that Dr Scott-Jupp is wrong. So where had it been described for the previous 20 years?

A. Yes, there's a series of descriptions, which are actually quoted by himself. There's a Scott paper in 1965, there's a Worthly paper in 1986. There's another paper by Aines in 1987. And this was really saying that there was overwhelming evidence that the treatment of symptomatic hyponatraemia with hypertonic saline was associated with survival and recovery.

THE CHAIRMAN: Apart from disagreeing with Professor Young, do you disagree with Dr Scott-Jupp?
A. Could I have ...
THE CHAIRMAN: It's the next few lines beyond the bit that's in yellow. It's now being extended for you. You'll see how he finishes that paragraph. In essence, the point Professor Young is making is that there may have been units or places where your position and Dr MacFaul's position is correct, but that was far from being universal.
A. No, I think that's probably true.
THE CHAIRMAN: That's the curious change in the contents of the textbook.
A. Yes.
THE CHAIRMAN: What had been in the textbook before was then removed.
A. Yes. Well, the textbook is rather peculiarly sort of phrased in that 1992 to 1994 sort of ... By saying homoeostasis rather than saying precisely what the requirements are.
THE CHAIRMAN: But then doesn't Professor Young make the point that when it's pointed out to Dr MacFaul that he is quoting from the wrong edition of the textbook, he's quoting from the edition which came out subsequent to Claire's death, and then Dr MacFaul says, yes, but the

various doctors here would have been trained at the time when the earlier edition was out and Professor Young makes a point that if they hadn't kept up-to-date with the new edition, they'd be criticised, so it's a bit of a double standard to criticise them backwards.
A. I think his understanding, Dr MacFaul's understanding, is that that homoeostatic mechanism was what was leading the requirement and so that it would in fact be, if required, a higher amount of sodium. But of course, it isn't explicit.
MS ANYADIKE-DANES: Can I put to you that part of his report, just so that maybe that assists you to look at it as you speak to it. It's 238-004-001. This is Dr MacFaul's report. If you see under "Reasoning", if we take from the later edition under (4):
"The later edition confines its advice in the section on acute encephalopathy on fluid management to the maintenance of homoeostasis and to the use of fluid restriction in hyponatraemia. Maintenance of homoeostasis implies connection and management of hyponatraemia associated with water overload and/or SIADH by adjustment of the intravenous fluid regime and the guidance implicates inappropriate intravenous fluid management in the production of hyponatraemia by which is implied (but not stated in the later edition) change

from the use of otherwise standard volumes of low-solute/sodium intravenous fluid."
And then he goes on in (5) to say:
"The guidance provided in both editions in respect of investigation, fluid management and other aspects is otherwise essentially the same. The later edition however requires the user to refer to separate chapters: (a) on fluid, electrolyte and acid-base disturbance -- the section on low sodium and water intoxication and SIADH; (b) on endocrine disorders -- syndrome of inappropriate secretion of antidiuretic hormone; (c) on disorders of the central nervous system in the section dealing with raised intracranial pressure in focal ischaemic brain insult."
Then he finally concludes that:
"The latter edition later expands the neurology section on management of raised intracranial pressure by pressure monitoring, but removes a specific warning on usage of [Solution No. 18]."
Are you able to assist with that in whether what is being indicated in that later edition is in fact pointing to a change in practice or recommending a change in practice from that which was being advocated by the earlier edition or whether it is framing the practice in a slightly different way? That's the thing

that I think we need your guidance on.
A. I think this is reinforcing the change that was previously put forward and I think it's making it quite clear that you have to look at the individual child and look at the results that are being obtained from that child at suitable intervals in order to manage the child so that ... But that if you have a hyponatraemic damage potentially occurring and if you have that because the child is of reduced consciousness, then I think you would almost quite clearly be very careful in increasing the quantity of fluids.
Q. Can I ask it in this way: the reason for all of that, as I understand it, is because it was believed that there was a connection or there was a risk posed if, for children like that, you continued to administer them low sodium fluids.
A. Absolutely.
Q. What I want to ask you is: in between the two editions, had there been any change in the received understanding of the risk of administering low-sodium fluids to children who presented with those sort of neurological conditions?
A. Not in my view, no.
Q. Not in your view, but was that known and accepted in the paediatric neurological community, if I can put it that

way?
A. Well, I sort of thought it was well-known and that low-solute fluids were not given and was surprised that this sequence of events was being described then.
Q. When you say you thought it was well-known, is that what was being taught in your department or your hospital and being administered and practised?
A. Absolutely, yes, it was.
Q. So far as you know from your colleagues, was that what they were doing?
A. Yes.
Q. A final question in relation to the various texts. I think it goes back to the point where you were saying that a range of concerns and presentations are being addressed in detail so that you can match those to the conditions of your particular patient, if I can put it that way.
A. Yes.
Q. At 238-004-008, Dr MacFaul has produced a tabular version of -- the points going down the left-hand side are the things that would appear to be of concern or at least potential concern in Claire's case, and which are relevant for seeing whether there were changes between the editions. And then along the top he has the three Forfar & Arneil editions and there's a paper by

Professor Kirkham at 2001, which Professor Young seems to think has given some support for the way he perceived matters.
I presume the "Y" indicates "yes", ie whether those texts are recommending what is set down in the left-hand side. You've had an opportunity to look at this. Would you be in broad agreement with what is set out there?
A. Yes, I would.
Q. Then on the issue in relation to Professor Kirkham, we find it at witness statement 178/2, page 7. We're back to Professor Young's statement. He refers to this paper by Professor Kirkham in a review of non-traumatic coma in children that was published in 2001. The part that he cites from it is particularly in relation to salt wasting. You can see the quotation at the bottom of page 7 and it goes on into page 8:
"Fluid management can be very difficult and should be tailored for the individual patient's needs. There is considerable controversy over fluid restriction, which has been shown to be potentially harmful in patients with subarachnoid haemorrhage and meningitis. The syndrome of inappropriate secretion of ADH, for which fluid restriction is indicated, is relatively rare; instead, intracranial diabetes insipidus may require careful management. It is essential that the

systemic circulation is well filled and that large volumes of hypoosmolar fluids are not given."
Are you familiar with that particular paper?
A. Yes, I am. I am a close colleague of Dr Kirkham's.
Q. Ah. Does that paper provide the support for the argument, so far as you are concerned, for the argument that Professor Young is advancing, which is that there wasn't a common knowledge or appreciation that in children with neurological conditions, restriction to 60 per cent of daily requirements or that use of Solution No. 18, he says, was prohibited? It's not entirely clear that that's how Dr MacFaul was putting it. I think he was talking about a situation of acute encephalopathy. In any event, can you help by your understanding of what Professor Kirkham is addressing in that paper?
A. I think she had been particularly influenced by the study in pyogenic meningitis which was done by Dr P Singhi. That was a controlled trial in which she had found that the death rate was higher in those who had restricted fluids and thus she abandoned the trial early. So that, I think, was really quite a signal event in that. These were, of course, children who had a pyogenic infection so that they were febrile and really somewhat differently unwell, but nevertheless it

was that that pulled people away from fluid restriction.
I think that during the time that they were looking at this child, which would be in the 1980s [sic], it was relatively common practice to reduce fluids and that has somewhat --
Q. Claire is 1996.
A. No, sorry, 1996. Sorry. And I think that that has somewhat faded into being extremely careful about restriction. But that was being used at that time.
Q. Okay. So is it that in the mid-1990s the position was a fairly general approach to restrict fluids in cases where you had children who had neurological problems, if I can put it that way?
A. Yes.
Q. And since then, the more common approach now is to watch and monitor carefully and see what is actually happening to the child's serum sodium levels?
A. Yes.
Q. Would that be a --
A. Yes.
Q. And that might involve a restriction, it might involve using fluids with higher sodium content, but it's all in response to the measurement of the child's particular condition?
A. Yes. It would certainly involve the use of higher

quantities of sodium, but it would be less usually, I think, of fluid restriction.

Q. But if you're going to have that kind of regime, then it means that you are taking your blood tests more regularly.

A. Indeed.

Q. And monitoring their serum sodium levels more regularly?

A. That's right.

Q. Thank you. Just on that point, I wonder if you could help with this, because I think what Dr MacFaul went on to say was that it wasn't just because Claire had a low sodium level, it's what a low sodium level should have been understood to mean in a child of her presentation, and this is one of the things that I put to Dr Webb, and I think that there was a disagreement, I'm not sure that he accepted it. Can I pull up the transcript of Dr MacFaul's evidence of 13 November, page 75? It really starts at line 23 and perhaps we can pull up page 76 alongside it.

So as you know, Dr Webb was under a misunderstanding about when the blood tests had been taken that produced the serum sodium result of 132. He thought in his evidence that that blood test had been taken round about 8 o'clock that morning for the ward round that morning. So a lot of his -- well, we'll go into the significance

of that later, but in any event his assessment of Claire is predicated by that belief.

A. I understand that.

Q. "Let's assume that you also were in that situation, so assume for the moment that it's right and it's understood somehow that a result of 132 comes from the morning. It's low-ish, but not necessarily on its own particularly concerning."

And Dr MacFaul goes on to answer in this way, and this is where I'd like your comment:

"The view that I've expressed is that for a general paediatrician in a child without encephalopathy, it is not particularly significant [that is the level of 132]. But I have also taken the view that, for a paediatric neurologist where there is acute encephalopathy, even a measurement of 132 should have been a red flag that this common and very serious complication of hyponatraemia was evolving because it is well recognised ... So I believe his action should have been, when he saw Claire, to have taken the steps to deal with it already, even on a figure of 132."

A. Yes, I've written that in my original report and I don't use a red flag, but I do say that it is something that should be taken serious note of because it's very likely to be on the way down and it's very likely that if the

child is receiving low-solute fluids of full quantities, that it will drop really quite fast.

Q. So then the 132 is not to be seen as just a low level, slightly out of range, as you would for any other child, if you've got a child who has got acute encephalopathy 132 is significant?

A. Yes.

Q. I had asked Dr Webb -- as a result of that, I put to him what else he might have been doing at 2 o'clock. We'll go to his evidence in a minute, but while we're on this page 76, it might be helpful to have your views.

Dr MacFaul goes on to say that when Dr Webb saw Claire:

"The range of blood investigations which had been carried out was limited."

He claims that the guidance in the textbooks, both the third edition and fourth edition, and also the relevant edition of the Nelson textbook and the paediatric neurology textbooks all include a range of investigations, which he says should have been done. And it's over the page where he says what they should be:

"Further blood tests. Another blood test should have been done for liver function tests, for blood ammonia, possibly toxins. If that had been done, that

would have necessarily produced the blood sodium level even if you weren't thinking at 2 o'clock that you needed to do that because you already had a value from 8 o'clock in the morning."

Can you express a view as to whether you think that a full blood workup, I suppose that's effectively what he's saying, should have been done at 2 o'clock as part of the practice?

A. Yes, I think so. I think it could have been done earlier.

Q. And if it hadn't been done earlier?

A. Then it would have been done then.

Q. Is that just because that's out of your experience and/or because that's what the textbooks that were in current use at that time would have indicated?

A. Yes, I think so, for an encephalopathy of uncertain origin that would be the minimum.

MR SEPHTON: Sir, I don't understand the witness's answer to my learned friend's question. She put an option and the answer was yes, so which of the two options is the witness actually alighting on?

MS ANYADIKE-DANES: There were two, although they could amount to the same thing. I was asking whether you are of the view that those sorts of tests should have been carried out because that is what comes out of your

experience, and I suppose I could have said and/or is it because that's what the current textbooks would have been advocating?

A. I would have said yes to both.

Q. Thank you.

THE CHAIRMAN: Sorry, you also said, professor, that you think these tests could have been done earlier. I mean, it's self-evident that they could have been done earlier. Are you saying they should have been done earlier?

A. Yes, I would.

MS ANYADIKE-DANES: Mr Chairman, I want to refer to the transcript from yesterday, and I'm conscious I'm looking at a draft and it may be that some others are too. I'll give a page number and my junior will tell me if I've got the right page. It's page 22.

Sorry, can we try at page 55? I beg your pardon.

THE CHAIRMAN: What's the point you're looking for?

MS ANYADIKE-DANES: I'm going to put to him what Dr Webb said in response to that very question that I put to Professor Neville.

THE CHAIRMAN: Is that not it at page 55, line 12, about the lack of testing?

MS ANYADIKE-DANES: Yes. So it goes on to page 56 really. You see the bottom line, that just says "the range of

blood investigations". If we go on to page 56, I think that'll help us.

About line 10, and there I'm citing literally what I put to you. If we go to page 57, I think we will get his answer.

Then the question culminates in:

"Do you accept that you should have asked for more blood tests?"

The answer to which is:

"No, I don't."

Then his explanation starts at line 9:

"Because you are talking about the accepted practice at that time. The textbook essentially comments that these are tests that may be helpful. They're not prescriptive tests and I had no evidence that Claire had evidence of liver damage, she had a normal glucose and I had no reason to think that she had ingested toxins ... I think it's most unlikely that she would have given the supervision that she had."

I ask him:

"Why don't you simply do them as part of a broad-based approach?"

And I think he says ... This isn't quite the same as mine, so I'm trying to find ...

THE CHAIRMAN: He says:

"Some people take a broad sweep and do a lot of blood tests and others target their investigations to the most likely diagnosis."

MS ANYADIKE-DANES: No, that wasn't quite where I wanted to go. Line 11:

"Well, I think you have to think about what you're looking for when you do your investigations. So in some people with a viral infection, it's quite likely that the liver enzymes will be slightly elevated, but it doesn't help you any further really."

And then it goes on to a slightly different point, which is how persuaded he was by his own differential diagnosis. When I put that same point to you, you were of the view that a full blood workup should have been done earlier, but if not done earlier, certainly then. This is Dr Webb's response to that. Can you comment?

A. They're not complicated tests, liver function tests, and they would give a clear idea of whether this liver is seriously deranged, mildly deranged or okay.

Q. Sorry, if I pause you there. Why would you think there was anything wrong with her liver from what you'd seen at the time?

A. It's perfectly possible that this is a primarily liver start for the problem --

Q. Do you mean there's nothing --

A. -- with a hyperaemic presentation. So it is a perfectly reasonable question to ask.

Q. So does that mean there's nothing in her presentation which would exclude it?

A. No.

Q. And if she did have that, what would that lead you to start doing?

A. Well, you'd be thinking of trying to reduce the ammonia level by a number of techniques.

Q. And if you don't do that and you don't treat it because you don't presume that it's there, what is the consequence of that?

A. It's another reason for not knowing what you're doing.

Q. I appreciate that as a general point, but if it's left untreated what is the consequence of her having a liver problem, if I can put it that way, that's causing her presentation?

A. It automatically puts it into a much higher group of seriousness of problems and would indicate a need for, presumably, greater care and earlier ventilation and things of that sort.

Q. Does that mean that she was at risk in some way by, if she had that condition, that condition not being treated?

A. Yes. It's not saying that it's very easy to treat.

That's for sure.

Q. Well, he says that the liver enzymes will be slightly elevated, but then he goes on to say:

"That doesn't help you any further really."

Can you understand what that means?

A. It's a matter of whether you speculate or whether you do the test. I would do the test.

Q. In relation to toxins, he's not convinced that that would have assisted at all because he says there's no evidence that she ingested any toxins.

A. No, and I would sort of tend to agree with that in terms of the fluctuation that she had, which suggested that she wasn't going acutely into more severe coma.

Q. Can I ask you about the fluctuations because actually that was one of the things that Dr Webb used -- obviously, the presentation of the child diagnostically. He said firstly she was recorded as having seemed a little brighter at midnight. By that time, she had been on her fluids since about 8 o'clock in the evening, I think.

Then I think the nursing staff thought she was a little brighter first thing in the morning, although by the time the parents got there, they did not think she was any brighter and I think, to some extent, the nursing staff and certainly Dr Sands, although he hadn't

seen her to make a comparison, he was concerned about her presentation.

But that ability for her to seem a little brighter and then not, he took some comfort from that, that what -- not comfort, but he used it as part of his analysis of her condition to reach the view that what he was dealing with here was a non-convulsive status epilepticus.

A. Yes.

Q. Do those differences that he was informed about and would have known, therefore, when he came at 2 pm, are they relevant as part of identifying her underlying condition?

A. They're not, that she was anarthric and unsteady and then she became normal. So there's certainly not that sort of difference between the recovery after giving an anticonvulsant.

Q. Well, sorry, she hadn't actually had any anticonvulsant at all until she got the diazepam at 12.15.

A. No, sure.

Q. He does say that he was informed that she was a little better after that, or at least there was some improvement, and I'll come to that in a minute. But the point that I was asking you about, the specific thing he mentioned, was the recorded fact that she was a little

brighter at midnight, and then the nurses' view first thing in the morning -- and I think the nurses' have reflected that in their notes -- that she did seem a little better in the morning.

So she appears to fluctuate and that's the information that he had. And you're right, by the time he got there at 2 pm, he had information that diazepam had been administered rectally at 12.15 and she did seem to have some positive effect from that. And that then diminishes and recedes and she returns to her state.

A. Yes.

Q. So what I'm asking you is: is that kind of presentation relevant and was it appropriate, reasonable, for him to use that as fortifying his view that he was really dealing with non-convulsive status epilepticus?

A. My point would be that it was unlikely that it was a toxin.

Q. Sorry?

A. My point would be that it was unlikely that it was a toxin.

Q. Right.

A. I think the chances of it being non-convulsive status are quite small, but they're present.

Q. And why do you think, just so that we understand the reasoning of it, that that kind of improvement and

falling away does not reinforce a view of non-convulsive status epilepticus?

A. Because it isn't fluctuating between getting close to normal and then going severely off again; it's much less than that.

THE CHAIRMAN: So if the fluctuation was like that, that's more significant than if the fluctuation was within a narrower range?

A. It's much more significant if she's fluctuating between being fully awake and then being unconscious. That's much more like what would happen in non-convulsive status.

MS ANYADIKE-DANES: And just while we're hovering around that area, Dr Webb had the view that Claire had suffered a convulsive seizure on the Monday of her admission and that he got that information -- he says that the mother told him ... Well, he wasn't clear whether he was being given that information by the grandparents when he examined Claire at 2 pm. By the time he examined Claire in the presence of her mother at 5, her mother was describing something to him, which he interpreted as a convulsive seizure on the Monday. You've read Claire's notes. Is there anything that is at least recorded that would give you the view that she had suffered a convulsive seizure on the Monday?

A. She certainly had an episode and whether that was a seizure or a sort of dystonic attack is quite difficult. But the ones that involved one side of the body would almost certainly be a seizure.
Q. Let's be clear that we're talking about the same thing. You are quite right, there is a record of attacks that relates to the Tuesday, which does describe episodes, the first of which is recorded at 3.25.
A. Yes.
Q. What Dr Webb was talking about is her date of admission, which was on the Monday.
A. Yes.
Q. And what I'm asking you is: have you seen any evidence that, on admission, any of the history taken indicated that she had sustained a convulsive seizure?
A. I'm really not sure. Sorry.
Q. Perhaps, in fairness, I should take you to the notes. If we go to 090-011-013. That is the referral from the GP. There's a reference to her tone increasing.
A. Yes.
Q. You see that there is a difference between the right and the left side. Then there's a query from the GP, he's querying a further fit or querying an underlying infection. So that seemed to be the information from there.

Then if one looks at the record at A&E, 090-012-014, it's a bit difficult to read perhaps. Up at the top, there's the history of the epilepsy and so forth. Then:
"Speech very slurred, hardly speaking. On examination, drowsy and tired. No neck stiffness."
Then it goes on to describe left and right-hand side:
"No apparent limb weakness. Tone increased."
Then just very briefly, if we go on to 090-022-050. This is the note taken by the registrar to admit her. If you go down to the history and if we go over the page to 051, there we have what she can do and then ... Power is not assessed, but tone is and reflexes are ...
A. Yes.
Q. "Not responding to parents' voice. Intermittently responding to deep pain."
Then just to close that off, 090-022-052, that ends up with the impression of Dr O'Hare. All those details about the differential movements on left and right side may indicate things to you which obviously don't indicate it to me, but having been taken through those three records by the clinicians, do you see evidence, if you were simply drawing it from the notes, of Claire having sustained a convulsive seizure?
A. No, I can't see any evidence. That's why I sort of

asked about it because --
Q. Well, we see Dr Webb's view of it in his witness statement 138/1, page 38, and I think it's in answer to (g). He refers to focal seizures. He didn't indicate this at 2 o'clock because he wasn't quite clear on the position, but he does then describe them as focal seizures in his 5 o'clock note.
A. Yes.
Q. And he says:
"The focal seizures described included focal stiffening of Claire's right side. This clearly had been repeated on more than one occasion and, from the description, I considered it to be seizure activity. I believed that Claire was presenting with seizures that were symptomatic of an intercurrent viral infection and this infection could potentially have included involvement of Claire's meninges and brain."
He's a little more specific there than he was, I think, when he was giving his evidence. In his evidence, he relied more on the history that Mrs Roberts gave him. But there, that description of the stiffening of one side or other, does that connote to you a convulsive seizure?
A. I have thought that there were likely to be two different sorts of attacks and I agree that the ones

that involve the right side, provided they're accurately described, are likely to be seizures. They're of course highly likely to be provoked by having a low sodium level rather than --
Q. Sorry, I want to be clear on your evidence. Because when I took you through those descriptions of the difference between the left and right side, in her medical notes and records, which were taken by the GP, the description by the GP, the description in A&E, and the description by the registrar, when you looked at those you answered me to say that you didn't think that that indicated to you a convulsive seizure.
A. No. When I was --
Q. Is there a difference between that and what is described here then?
A. Well, there are, I think, probably two different sorts of attacks. One is a dystonic extension attack, which may well not be seizural, and the other is the right-sided, if it is right, stiffening. And they're in small number, and I don't know that they're of any great note, quite honestly. They are not proof of anything.
Q. They may not be to you, but they're part of what Dr Webb used, part of the general history of Claire to try and formulate a view as to what was causing her presentation --

A. Yes, I understand.
Q. -- and how he should plan her treatment.
A. Yes.
Q. But I want to make sure that I am not misunderstanding your evidence. Are you saying that the descriptions in the medical notes and records that I took you to -- forget this for the moment -- do those connote to you seizure activity? Do you want to see them again?
A. Yes, I think that one or two may be and the other one or two may not be. It's very difficult to be sure of that.
Q. Right. Well --
A. And I hope that's what I said before.
THE CHAIRMAN: It is.
MS ANYADIKE-DANES: Yes.
I think the most detailed one is taken by Dr O'Hare, 090-022-051. She starts with the tone:
"Upper limbs: cogwheel rigidity, tone elevated for the left-hand side; cogwheel rigidity for the right. Lower limbs: tone increased for the right, tone increased for the left."
Then she deals with the reflexes. Does that connote stiffening of any sort?
A. Yes, it does, but it doesn't indicate a seizure.
Q. That doesn't?
A. No.

Q. Right. Then if we go back to what Dr Webb was saying, which is at 138/1 at page 38 at (g), does this description accord -- because it may be that Dr Webb is actually getting this from Mrs Roberts and is not saying that he's getting it from the medical notes and records. But does this description accord with the medical notes and records?
A. Well, of course it does really matter where they came from. I hadn't quite realised where the potential source was.
Q. I think if we go to page 19 on this, maybe that'll help. If you look at 14(b):
"After speaking to Claire's mother [so it does appear it's coming from the mother], state whether you had a clear picture from the lead into yesterday's episodes."
That's how he described them in his clinical note at 2 o'clock:
"Describe that picture and describe where it is recorded ..."
And so on. He says:
"Following my discussion with Claire's mother, I felt more certain that Claire had experienced focal seizures affecting her right side on the day of admission. I did not record the exact timing. The

history of Claire's presentation endorsed my opinion that she had recurrence of epileptic seizures with an intercurrent viral infection."
So it may be that I have put you on the wrong lines because I don't think that Dr Webb is claiming that he got that view of Claire from the medical notes and records, but he got it from the mother.
If his conclusion from her description is correct that there was that kind of stiffening -- and "focal" means, I presume, identified to a particular place as opposed to general -- if that's the case, would that connote to you seizure activity or potential seizure activity?
A. Yes, it would.
Q. Yes. And you said that you don't think that that's particularly relevant. Why is it that you don't think that's particularly relevant?
A. Well, it would be a relatively common feature of somebody who has hyponatraemia, particularly as the sodium is dropping quite fast.
MR SEPHTON: I'm sorry to interrupt. I wonder if the doctor could help us on what evidence there was that Claire was suffering from hyponatraemia on the Monday afternoon.
THE CHAIRMAN: When she was at home?
MR SEPHTON: Yes. The story is, as I understand it, Dr Webb

sees Mrs Roberts on Tuesday afternoon at 5 o'clock. He's trying to find out from her what "yesterday's seizure activity" was. "Yesterday" must have been the Monday.
THE CHAIRMAN: Yes.
MR SEPHTON: So I want to know from the doctor why he says that seizure activity on the Monday was probably caused by hyponatraemia and that her sodium level was dropping fast.
A. Of course, the level was done at something like 9 o'clock, I think, wasn't it? So that it would have ... The problem about that is how fast it had been dropping beforehand --
THE CHAIRMAN: Yes.
A. -- and how long she had been unwell with this disorder.
THE CHAIRMAN: I think the point of the intervention is that that is an unknown --
A. Yes.
THE CHAIRMAN: -- for how long she'd been unwell. And the question Mr Sephton is asking, on behalf of Dr Webb, is what evidence there was that Claire was suffering from hyponatraemia on Monday afternoon. Is it not the case that there's no actual evidence that she was suffering from hyponatraemia? There is a possibility that --
A. Yes.

THE CHAIRMAN: -- she was suffering from hyponatraemia. Is the evidence of that possibility the fact that later in the evening she had a reading of 132?
A. I think that was partly on the agenda. She had been vomiting, so there was a considerable chance that she was dropping. But I can't be sure.
THE CHAIRMAN: If that hyponatraemia was developing, it wasn't because of excess fluid --
A. No.
THE CHAIRMAN: -- that she was receiving, and it wasn't because of the rate of fluid intake --
A. No, it wasn't.
THE CHAIRMAN: -- and it wasn't the type of fluid.
A. No.
THE CHAIRMAN: If hyponatraemia was a possibility at that time, it's from SIADH, is it?
A. Yes.
MS ANYADIKE-DANES: And if that's a possibility, you would have to do that working back, wouldn't you, Professor Neville --
A. Yes.
Q. -- because you couldn't possibly have known that at the time, for example, when Dr O'Hare was doing her slightly more detailed examination? She didn't know what the serum sodium levels were and, in fact, the first

opportunity for anybody to have really considered that would be when they came through and, in terms of any sort of consultant to take a view on that who actually might know about the implications of that neurologically, it may have been Dr Webb.
A. Yes.
Q. It could have been somebody earlier, but in any event what you would have to be thinking about was: well, if she was 132 when the bloods were taken at 8 o'clock or shortly thereafter, whenever it was, and she hadn't really received much in the way of fluids, then, as you say, do I posit the proposition that with the vomiting that she'd experienced, that she might have been slightly dropping in her serum sodium levels before she actually was admitted?
A. Yes.
Q. And if you had reached that view, that that was a possibility, so your 132 is your one point on a graph, which doesn't have any other points, if I can put it that way --
A. That's right.
Q. -- does that affect what you do when you review her fluids?
A. Well, if you were managing it as from the Monday evening, then you would have to decide between whether

you're giving low-solute sodium or you're giving normal --
Q. I'm taking it slightly later than that. I'm taking it from when you appreciate you have 132 and you're then able to engage in that sort of thinking, what that might indicate. What I'm trying to find from you is, if you had joined up the dots to think maybe she might have been on her way to having reduced serum sodium levels, would that affect any decision you made about the continuation of her fluids?
A. That would have particularly pushed you in the direction of having either half normal or normal saline.
Q. If you had made that connection?
A. Yes.
Q. But it's not necessarily a connection that might be readily made?
A. No.
Q. Thank you.
THE CHAIRMAN: And that is why the criticism of the doctors on Monday night is quite equivocal, isn't it?
A. Mm.
THE CHAIRMAN: I'm expressing this very generally, professor, but there seems to be a view that they might have thought about changing the type of fluid or they might have thought about reducing the volume of fluid,

but it would be unfair to be critical in any significant way --
A. Yes.
THE CHAIRMAN: -- on Monday night.
A. Yes.
THE CHAIRMAN: The criticism is that when Claire's condition did not improve on Tuesday morning, there should have been more tests.
A. Exactly.
THE CHAIRMAN: There seems to be a very strong view that there should have been an EEG before presuming that there was non-convulsive status epilepticus --
A. Yes.
THE CHAIRMAN: -- and that, had these tests been done, the outcome might have been very different.
A. Yes, indeed.
THE CHAIRMAN: Having said all that, Claire's condition was not easily diagnosed.
A. Well, I think a serum sodium would have made quite a difference.
THE CHAIRMAN: Sorry, let me put it this way: her condition was not straightforward; it's because it's not straightforward that you do do the tests.
A. Yes.
THE CHAIRMAN: And you do do the EEG rather than presume

that there's the rather unusual and unexpected non-convulsive status epilepticus.

A. Yes.

THE CHAIRMAN: Dr Webb made the point that you can always do more tests and I am sure he's right, but in order not to do more tests you have to have a degree of confidence in your diagnosis, which I think you and the other experts say he couldn't really have had.

A. No. Well, he didn't, at that stage, have any clear indication, I think.

THE CHAIRMAN: Thank you.

MS ANYADIKE-DANES: Thank you.

If that particular logic had not been worked out to think that her presentation -- because she did have some sort of disturbed state as she was admitted to hospital -- was as a result of her falling serum sodium levels or in part contributed to by that, if it's not that then what else could it have been in your view?

A. I think it's most likely that she had an intercurrent viral infection and that she therefore became at risk of developing hyponatraemia. So I think it's likely that she had two things, not just one.

Q. Did the two relate to each other in the sense that did the intercurrent viral infection predispose her to responding in a way that her serum sodiums would become

lower, or are they completely independent of each other?

A. They're probably independent, but of course, unless she is in a state when she is to be given intravenous fluids, you wouldn't really know.

Q. And if she was in that state, possibly with those two things happening, what is the impact of that on her having received the normal fluid regime that child would have received in those days, which is the Solution No. 18? I think her rate was 64 millilitres an hour.

A. Well, it would be likely to be a drop in the sodium level of the sort that we see occurring later.

Q. I'm just going to ask you another point that's a little bit related to that, but leading on from something the chairman asked you, which is that these things require a little bit of thought to work out what the connections are --

A. Yes.

Q. -- and to sort of test those against the presentation that you've got and the notes that you've received.

A. Yes.

Q. Dr Webb doesn't actually come into it until slightly later in the day, if I can put it that way. His view -- and I know that it's not necessarily shared by the experts -- is that the fluid management side of things is something that the general paediatric team was

covering. In the way that you've just described things now, are joining up those particular dots something that would have assisted if an experienced consultant paediatrician had been there, either earlier or at the ward round?

A. Yes. I mean, an experienced paediatrician may well know those links, but even so, they would want to know the morning level of sodium so that they could check upon that. I do think it's part of a paediatric neurologist's job to remind everybody that hypotonic solutions have hazards to them.

Q. But the process of getting in the evidence so that you could get better guidance from the neurologist might have already started if you've got an experienced paediatrician saying, "We don't seem to have our levels for this morning, we certainly need them for this child".

A. Yes.

Q. Can I ask you something else related to a query as to what else might be happening, other than what you have just described. It's something that Dr Webb dealt with. On my system, he's dealing with it at page 40. You've written your report about matters to do with raised intracranial pressure, which I am going to ask you about as well. I am citing from your report. I think it's

232-002-006:

"I would not agree that non-convulsive status epilepticus was the likely diagnosis because it is not common and epilepsy was not prominent in this child's recent history. In my opinion, non-convulsive status epilepticus needed to be proved by an urgent EEG and another more likely cause of reduced conscious level and poorly-reacting pupils would be cerebral oedema ..."

I think it might be the next page. Then:

"The reduced conscious level and poor reacting pupils would be cerebral oedema related to hyponatraemia and that should have been considered as a matter of urgency because, in its early stages, it is reversible."

And then I ask Dr Webb if he would comment on the point that you have made about the epilepsy not being prominent in Claire's recent history. What he then goes on to say is:

"I think a child, who has had epilepsy in early infancy, as I mentioned on Friday, is at very high risk of recurrence of seizures in childhood."

And then if we go over the page --

THE CHAIRMAN: Do you want to take this bit by bit? Before we go on to the next bit, do you agree with that, professor, that Dr Webb says that a child who has had epilepsy in early infancy is at a very high risk of

recurrence of seizures later in childhood?
A. Yes, there's no doubt that she's at higher risk than otherwise. And by having a low-ish IQ, she will be at higher risk as well. I just thought it was somewhat extraordinary for somebody who'd had previous infantile spasms, which is what I understood was the likely diagnosis from the previous consultant, that she should just drop into having minor status.
MS ANYADIKE-DANES: I did put that point to him. I think you see it at 43, I hope, but I'm reading from mine, which is your report, you say:
"Her epilepsy had ceased. She was at significantly higher risk of developing epilepsy again [so you do accept that], but the form of epilepsy that she had before, which as I understand it was likely to be infantile spasms, is one which tends to have an end point to it, around 2, 3, 4-ish [years], and then to either go away or persist almost continuously with a different sort of epilepsy. So I think that the chances of it just starting in the middle of something which would be 3 or 4 years away is unlikely."
And I asked Dr Webb about that in particular, and on the next page he deals with it. He does not regard her seizures in that way. He says:
"In fact, the seizures that she had had -- as an

infant, she had multiple different seizures types and she didn't have typical infantile spasms because her EEG didn't follow the pattern that was typical for that. So I'm not sure that Professor Neville is correct when he refers to infantile spasms. It's certainly not a case of infantile spasms and I'm not sure whether he is basing this opinion on his lifetime of experience of epilepsy. But certainly my understanding at the time in 1996, from my reading, would have been, in the situation, Claire had a very high risk of recurrence."
Can you respond to that?
A. Well, the diagnosis that was written down by the consultant was "infantile spasms", so I think that's clear in her writing. It isn't that everybody has to have just spasms, but they can have multiple types of attacks. But these attacks are subsumed, really, I think, within the infantile spasms group. That's where I put it for that purpose.
Q. So you could have different sorts of --
A. Yes.
Q. -- presentations which can all be grouped together as infantile spasms?
A. Sure, and you can start off with focal seizures, say, at 2 to 3 months, and then you develop spasms a little bit later. That's a relatively common thing to occur.

Q. Did you have an opportunity then to look at her earlier medical notes and records, Claire's earlier medical notes and records?
A. Yes. It was presented here.
Q. And so if she had had that kind of infantile spasm, then your view -- and is that out of just your experience or what was in the literature?
A. Yes.
Q. Your view is that that either peters out after a while or, unfortunately, increases and develops into a different kind of epilepsy?
A. No, it is -- well, there's a lot of evidence upon that with particularly the relationship between either being free of the attacks or developing a condition called Lennox-Gastaut Syndrome.
Q. And does that mean, so far as you are concerned, Claire just did not fit that pattern?
A. No.
Q. So what was the likelihood in your view -- and you may not be able to quantify it in that way -- of her actually suffering a recurrent epileptic episode?
A. Of her suffering continuous non-convulsive status, relatively small, but certainly it's --
Q. But higher than a child who had never had epilepsy before?

A. Higher than another child, yes.
Q. And "relatively small", does that mean it's sufficient to keep that in your thinking when you're trying to formulate differential diagnoses?
A. It's perfectly reasonable to put it into the group, but you have to think of other things as well. And that seems to be the difficulty.
THE CHAIRMAN: He did, didn't he? At 5 o'clock, Dr Webb revised his 2 o'clock approach --
A. Yes.
THE CHAIRMAN: -- by raising the risk level of encephalitis.
A. Yes, that's right.
MS ANYADIKE-DANES: Mr Chairman, I was going to go on to a different point and I'm conscious of the time. We started at 9.30 and bearing in mind yesterday was quite a day for the stenographer.
THE CHAIRMAN: Okay. 11.15? Thank you.
(11.05 am)
(A short break)
(11.20 am)
MS ANYADIKE-DANES: Professor Neville, just to go back to something that you had dealt with earlier --
A. Could you possibly speak up?
Q. -- but in a slightly different way, that description that Dr Webb had of his take from the history he

received from Claire's mother, and he had concluded from that that what was happening was that there were these focal seizures and that they were on the Monday, just prior to her admission or maybe on admission, but in any event they were on the Monday.

A. Yes.

Q. And he regarded those as actual seizures, so convulsive seizures that were evident, if I can put it that way. Let's say that that was correct and that the mother had described something, which could properly be interpreted in that way. In your view, what could have given rise or might have given rise to that?

A. She was in an altered state, so she had lost some skills within a somewhat reduced framework, so that she was therefore not well. That's one reason why she might have become unwell at the end and developed some seizures. That's a --

Q. Could that kind of illness, whatever was causing her altered state and so on, could that have triggered a seizure of the type that Dr Webb described?

A. Well, it depends what he's describing.

Q. Let's pull it up.

A. Because I don't think it's -- well, sorry.

Q. Let's pull it up so you can see it. 138/1, page 38, and I think it's his answer to a question at (g). There

we are. What he has described there is a focal seizure, including -- that's simply repetition. So there's "focal stiffening of Claire's right side", repeated on more than one occasion. So he interprets that as a seizure.

A. Yes.

Q. If he had correctly done that, the question I was putting to you is: what could have triggered or given rise to a focal stiffening of Claire's right side, which could be detected on more than one occasion? What could have produced that?

A. That would be a seizure disorder which involved, presumably, the left-hand side of the body and would have been because of, indeed, a triggering of that event.

Q. That's what I'm asking you. What could trigger it?

A. An infection could easily do that.

Q. An infection could do that?

A. Yes.

Q. Could an infection do that irrespective of whether the child had any previous epileptic history?

A. Much, much less likely if she hadn't had an epilepsy in the previous time, no. So that would be very surprising, but it's not impossible.

Q. So this wouldn't be a recurrence of her infantile

epilepsy?

A. No.

Q. This would be an epilepsy born out of, let's put it this way, a slightly vulnerable brain to that sort of thing?

A. Yes.

Q. She has some sort of viral infection and that is what, in conjunction with that vulnerability, produces the electrical activity that is seen as focal stiffening and seizure?

A. Yes.

Q. Would that be --

A. Yes, that would be right.

Q. And that's possible?

A. Yes.

Q. And if that's what you thought was the case and you're trying to take stock and see how you would plan the treatment and care of Claire, what would you be doing in order to do that, recognising that that's what you think has happened?

A. One aspect of that would be to try to treat the seizures. I've said, I think, that doing an ordinary -- giving a single dose or multiple doses of one drug, say diazepam, would be an entirely reasonable thing to do. But I would then be looking as to whether that really subsumed the whole illness or was really just a part of

it and perhaps a relatively minor part. So I think it would turn out to be a relatively minor part in this situation, and so I would then be looking for other reasons as to why this was occurring.

Q. If you'd thought that that kind of seizure had been triggered by some sort of viral upset, if I can put it that way, do you address the underlying viral upset or seek to --

A. You would, certainly.

Q. -- identify what it might be?

A. Surely. You would normally be giving the appropriate drugs, which were given in the end in the latter part of Tuesday.

THE CHAIRMAN: The acyclovir?

A. Acyclovir.

MS ANYADIKE-DANES: Earlier?

A. You would have thought of giving it earlier, yes. But that's ...

MR SEPHTON: I'm sorry, [inaudible] put this to the witness, what the evidence is for the proposition that it was a relatively minor part of the situation, the previous history of seizures on the Monday. Why does he say it's a relatively minor part?

MS ANYADIKE-DANES: Yes. You'd characterised it because you thought that a viral upset, given her vulnerable brain,

had triggered the seizure. If there was a seizure, that is what could have happened. So I had asked you how do you address that as your treatment plan, and you said you would treat the seizure and you thought that administering the diazepam would be a reasonable thing to do. Then you expressed the view that you would then be having to be looking at whether that was the complete picture or something else was going on. Then you went on to say that actually you would have formed the view that a seizure of that sort was a relatively minor part of her condition and so the implied statement is that it was much more important to be getting on and looking at whatever else was wrong with her.

A. Yes.

Q. And why do you characterise it as a relatively minor part and what would be the evidence that you would have to allow you to reach that view?

A. Reduced conscious level, speech being lost, and a dysarthria and an unsteadiness as well. All those things would point to something more, and the issue has been: could that possibly be having non-convulsive status?

Q. If I can ask you in this way: firstly, could any of that be the aftermath of a convulsive seizure? I think in some places in her medical records -- and the statements

of the clinicians have been -- that she might have been in a postictal state.

A. No, I think it's very unlikely that that would persist. I think it wouldn't persist.

Q. So if it's --

A. So I think when you're looking at these situations you're looking at persisting for up to half an hour or so. It isn't a more prolonged --

Q. So if it's not the aftermath of what I was putting to you as a possible seizure, if it's not that, then could it be that the vacancy and the loss of her speech and so forth, that that is all due to what Dr Webb had characterised as non-convulsive status epilepticus?

A. There are a number of reasons why it might not be characterised by that, but I can only see one way of finding out, which is to do the EEG.

Q. So --

A. And the problem is that you're either concentrating just upon this or you're taking a more comprehensive approach of, say, treating non-convulsive status, but actually also searching for yet another cause. And I think it's in that sort of area that we have the difficulty.

Q. So if I understand you, I think you would say it's a perfectly proper and reasonable thing to do, to treat the seizures, whether they be convulsive in nature or

non-convulsive in nature, as you have interpreted them to be, but you should be doing other things, certainly if you have no absolute confirmation that the entire problem is to be found in the seizure activity.

A. Exactly.

Q. Thank you. You've mentioned the possibility that Claire could have suffered both a seizure, convulsion, and at the same time also have non-convulsive status epilepticus. I know that you don't think that is particularly likely, the non-convulsive status, but is it possible --

A. Yes, it is.

Q. -- in the way that many things that have been discussed are possible for Claire?

A. Yes.

Q. I had asked Dr Webb about the differences between those two things and I think he had conceded that if you had repeated convulsive activity, so you had status epilepticus as opposed to the non-convulsive type, that was a very serious condition to have had. And I think he thought, though, that if you had non-convulsive status epilepticus, that perhaps was less serious. And I think he indicated that you had more time to deal with that. I think we find that at pages 3 and 4 of his evidence yesterday.

I'm trying to find it.

A. I know the area you're referring to.

Q. If we see there, if we look at line 10, he's saying:

"Non-convulsive status can go on for days and cause no additional damage to the brain. In that sense, it doesn't always cause the concern that you see with convulsive status."

Would you accept that as a proposition, first?

A. Yes, up to a point, I think. Convulsive status epilepticus is a medical emergency and needs to be dealt with within half an hour, and thus you start working on it after about five minutes. So that's clear. Non-convulsive is of a lesser severity. I think the only thing is that this is an acute situation --

Q. Sorry, if you pause there so that people can understand. What do you mean by "this is an acute situation"?

A. It has just happened to this child, having been previously completely her normal self. So it therefore requires attention relatively rapidly because you don't really know its significance if it's there. I don't think it's there, but --

Q. Let's assume it doesn't ever develop into a breakthrough convulsive seizure that you can actually detect and it is just continuing in the way, for example, Dr Webb thinks that that can go or to days, so you just have

this electric activity going on in the brain. Can that in and of itself cause damage?
A. It can eventually, but we have seen children and young adults who have gone on doing this for weeks on end, which they certainly would not do with convulsive status epilepticus. There is no doubt that there is a difference.
Q. What are the dangers and risks that are inherent in the non-convulsive version of status epilepticus?
A. I suppose they're partly what's the cause of it and they're partly -- probably the psychiatric risks, really, of being in this altered state for such a long time.
Q. Is part of the problem -- I think you were just beginning to say, maybe I interrupted you -- because until you actually confirm that's what you've got, you don't know that what's happening is these sort of sub-clinical seizures?
A. No.
Q. It could be anything. So until you know for sure that it's the non-convulsive type, which obviously you want to address but isn't perhaps so likely to do any brain damage, until you know that for sure you have always to be concerned about what is the real cause of it and what might it lead to?

A. Yes, and even if it were the case, you've still got the issue of hyponatraemia to think about.
Q. Yes. Can non-convulsive status epilepticus develop into convulsive status epilepticus, if I can put it that way?
A. Yes, it can, yes.
Q. Is that a known development?
A. Yes, it does, yes. Sometimes, yes.
Q. Is that a risk of itself, the fact that that can happen?
A. It is a risk, but it's ...
THE CHAIRMAN: Is it a rare phenomenon?
A. Yes, it's not that common.
MS ANYADIKE-DANES: So the more important point is because you don't know why it's happening and you don't know --
A. That's right.
Q. -- until you do one of the determining tests that that's actually what you're dealing with?
A. No, that's right.
Q. So I think perhaps it goes back to the chairman's point before, which is: if you're not doing anything further, then that is because you're pretty confident that that is what you've got.
A. Yes, it must be, mustn't it?
Q. Is there any link between status epilepticus of whatever type and development of hyponatraemia?
A. I've not seen it occurring particularly.

Q. Is there any --
A. I mean, it's ... But it's not one in which you're normally given intravenous fluids and --
Q. Is there any link between that and the development of SIADH?
A. There may be. There may be. But I think it's a relatively minor sort of link.
Q. Thank you. Then I wanted to see if you can help us with your view of the sort of factors that Dr Webb says were influencing him and he was taking into consideration when he formulated his differential diagnosis of Claire.
In my version, it starts at, I think, 37. I was putting to Dr Webb, as at 2 o'clock, the things that to him had seemed to be most important. One of the things I put to him was the fact that her serum sodium levels, as he thought them to be, were 132 at 8 o'clock that morning. So that, I think, meant that he was not so concerned about the electrolyte position, if I can put it that way.
A. Yes.
Q. And the other, which he referred to as being diagnostic, I think, is that she had rectal diazepam at 12.15 and had been seen to show some measure of improvement in relation to it. I was suggesting to him that the one had deflected him perhaps from looking further down the

electrolyte line, if I can put it that way, and the other had seemed to confirm his diagnosis of non-convulsive status epilepticus.
He agreed that those two things were important and diagnostically significant -- I think that was his term -- and then he went on to say the other things that he had taken into consideration. He said that the fluctuating course or her fluctuating course was one. It starts at about line 19, I think:
"She had been brighter at 7 o'clock than she had been at other times, which would have been very much against raised intracranial pressure as a cause."
Which was something that you had indicated that maybe people could have started to think about. His view is that there were therefore several factors that militated against raised intracranial pressure.
Then I went on to ask him about her being brighter at midnight. He seemed to think that that was also something. And in particular, that 7 o'clock in the morning, he said the significance -- this is his answer:
"If you have raised intracranial pressure, the worst time for you is first thing in the morning so, for me, that was significant."
Would you accept that, that in terms of your thinking that raised intracranial pressure was something

that the clinicians might have had in their minds or given some thought to, that the fact that she appeared brighter certainly at 7 o'clock in the morning might be a reason for them not thinking about raised intracranial pressure, at least at that stage?

A. I think that's talking about more chronic raised intracranial pressure. This is an acute situation and I don't think the rules apply. I think the other part of this is: do children with this sort of disorder fluctuate? And the idea is they do and they'll vary a bit according to all sorts of things, including if they happen to hyperventilate or something, they may well take their pressure down a bit and they may well be all right for a while.

The other thing that you asked about is about papilloedema and papilloedema really doesn't appear for the first 24 hours or so.

Q. So the fact that you didn't detect any signs of it shouldn't give you any comfort in particular because --

A. No, that's right.

Q. -- if you had, that would be a very serious situation indeed?

A. That's right, and by the time you've got that, as we said before, you are really close to the end.

Q. So what you're trying to do is you're trying to have in

mind whether you've got a developing situation that you can stop before it becomes too severe?

A. Yes.

Q. So it's a matter of bearing in mind the possibility of raised intracranial pressure so that you can do something about it?

A. Yes.

Q. And you don't particularly want to find that it's a very high level, you're trying to avoid that situation.

A. That's right. It will happen in the end, but ...

Q. And then in terms of why -- so that's why he didn't form the view that raised intracranial pressure is something he would have considered. To be fair to Dr Webb, I'm not saying that he thought about raised intracranial pressure and discounted it, but those would be the reasons why he would not have thought that that was an appropriate consideration.

He then goes on to deal with why he did think non-convulsive status epilepticus -- and why he thought that for so long, really. I think it's at 67. I asked him in relation to 2 o'clock and give him back his own statement:

"I must have felt when I saw Claire first at 2 pm on October 22nd that I would have sufficient evidence to treat Claire for non-convulsive status epilepticus."

It's going to go on to the next page. Then he recognises that you have a different view. I asked him:

"[The] evidence that allowed you to consider was sufficient ... to start treating Claire for non-convulsive status epilepticus ..."

I ask him about -- sorry, I think we've gone to the wrong place. I beg your pardon, it's a bit higher up than I want to be. I'm asking him what is the evidence. He says:

"She continues to have vacant staring and poor responsiveness."

Then that is what he was really basing his view on, that she was in the condition of non-convulsive status epilepticus.

So despite the intervention of the diazepam and her initial slight improvement or response to that, nonetheless she goes back to her previous state and it's really this vacant staring and poor responsiveness, the continuation of that is what allows him to feel that he's got the right diagnosis, it is non-convulsive status epilepticus. Can you respond to that?

A. They're very vague, aren't they? And they could mean just not being fully cognizant of what's going on around you. I can't see them as being diagnostic of any specific state.

Q. Can I ask you whether you formed the view that Claire was in any way deteriorating and, if you did, what are you basing that on?

A. Well, I think there is a change in the Glasgow coma scores so that overall, although they move around a bit, they tend to be getting more like 6 than 9 at the beginning of the Tuesday. So they've dropped down. There have been all the arguments about the Glasgow Coma Score, but --

Q. How much do you use that as a tool?

A. Yes, we do use it, yes, and I think with the sort of group that looks at the ones that ... It's not the Glasgow, it's the Adelaide score or whatever, but it's a similar score. Sorry, where was I?

Q. I was asking you if you thought there was -- I'm going to take it in two parts, the deterioration. One is the one over the day, if you like, up until, say, 5 o'clock.

A. Yes, sure.

Q. And then there's what happens in the evening when there's the slightly different evidence that one has in the evening. If you take the position over the day, the first record of her Glasgow Coma Scale is recorded at 1, no one is entirely sure when they take it, but anyway that's when it's recorded. It's 9 then and it seems to be roughly 7-ish, sometimes going down to

6-ish, and that's where it is over the course of that afternoon.
A. Yes.
Q. And having said that, though, there is what he took to be significant, the slight improvement in relation to diazepam. He also says that her level of consciousness, if that's -- I may be using that in a non-technical way -- seems to change in the sense that when he examined her at 2 o'clock he says that she sat up, she seemed to interact with him. So she's not in a constant state, if I can put it that way.
A. No.
Q. But she is having quite a significant amount of anticonvulsive medication. Apart from the diazepam, she has phenytoin, which turns out to be considerably more than he intended her to have. She has midazolam and she has a midazolam infusion.
A. Yes.
Q. So she's having quite a bit of medication, but that's her presentation, sometimes a little bit more responsive, other times not. The nurses don't seem to record that in any great detail, they just say she's pale and responding essentially only to pain. But if you take that as the description of her state over the day, then do you have a view as to whether, if she is

your patient, you consider she is deteriorating?
A. I would have said that the most obvious thing is that she's certainly not improving and that thus she is still requiring a diagnosis. Overall, I think she is probably deteriorating, but I think the most important aspect is that she's just not showing the sort of improvement which you might expect from giving an anticonvulsant.
Q. Is that diagnostic itself, the fact that you have taken a view that this is her condition, you treat her with the anticonvulsants that should have improved it, or at least in many cases would, in that case? Does that confirm your differential diagnosis or weaken it? What is the effect of it?
A. It weakens it, but it doesn't actually remove the possibility that she just doesn't respond.
Q. Yes. Does it increase the need to look for something else though?
A. Indeed, it would.
THE CHAIRMAN: And he did.
A. Pardon?
THE CHAIRMAN: And Dr Webb did because that's what prompted Dr Webb to change his view on the risk of encephalitis when he saw her at about 5 o'clock.
A. Yes, by giving drugs for that.
THE CHAIRMAN: Yes. To be fair to Dr Webb, he doesn't stick

rigidly only to non-convulsive status epilepticus as there isn't the response which he had expected or which he had hoped for. He then revisits it at 5 o'clock, doesn't he?
A. Yes. Yes, I see the situation as one in which the hyponatraemia aspect is relatively low on his ...
THE CHAIRMAN: It is.
A. So I think he has difficulty with -- or had difficulty with that subject, which he's obviously had to revise.
THE CHAIRMAN: There is certainly some, subject to whatever further evidence emerges, scope for criticism of Dr Webb, but as you said before, he came back and saw Claire more than once.
A. Indeed.
THE CHAIRMAN: He was reviewing what drugs she got and he was reviewing what her condition was.
A. Yes.
THE CHAIRMAN: Your concern is that, while it wasn't all his fault at all, there was inadequate testing of Claire earlier in the day and, if he was the gatekeeper to the EEG, that is something he should have pushed rather more than he did.
A. Yes.
THE CHAIRMAN: Then you also, I think -- correct me if I'm wrong -- take the view that he really doesn't appreciate

the risk of hyponatraemia through SIADH.
A. No, I think that's right, and should, of course, have insisted upon making exactly certain when these levels were taken and when the next one should be taken.
THE CHAIRMAN: Thank you.
MS ANYADIKE-DANES: You, I think, have expressed the view that he should have had a broader approach to the possibilities as to what was causing her presentation.
A. Yes.
Q. In fact, the approach always seems to have been threefold. They move about in terms of perhaps their relative importance. Non-convulsive status epilepticus, probably in the light of Dr Webb's evidence yesterday, remained his prime contender. But from the discussion which Dr Sands had with Dr Webb quite early on the Tuesday, it seems that encephalitis and encephalopathy were also there. Dr Sands would say, "I had thought about encephalitis myself". Dr O'Hare, to be fair to her, had thought about encephalitis also. So the three that are running are non-convulsive status epilepticus, encephalitis and encephalopathy. And encephalopathy being a kind of a broad general thing.
At 2 o'clock, Dr Webb is of the view that the encephalitis is probably less significant and he concedes that if it was there at all, maybe he could

have suggested it was treated. By 5 o'clock, although it hasn't overtaken non-convulsive status epilepticus, it's slightly more significant for him than he had previously thought it might be. But those are still the three areas. Apart from the area that would take you into electrolyte imbalance -- SIADH, hyponatraemia and so forth -- is there any other possibility that should have been in their frame of reckoning, if I can put it that way?

A. Apart from hyponatraemia? Well, I suppose the other things that could have been thought about would be the other things that might be revealed by doing a CT scan or an MRI scan, but they were not.

Q. Well, now, I can help you with that because I asked Dr Webb about a CT scan. Apparently, Dr Sands in his early conversation on the Tuesday morning, whenever it was on the Tuesday, had spoken to Dr Webb and specifically raised with him two things, apparently. One: should I be arranging a CT scan? Two: should I be administering diazepam? He got a no to the former and a yes to the latter, and I think the no to the former was: not yet, I'll come and see. I think that was effectively his evidence. Ultimately, you know that his view was that he'd wait until the morning and, if she doesn't wake up then, we'll do a CT scan then, which

might be associated with a lumbar puncture.

But on what an early CT scan might disclose, I asked him about that on Friday. So it's 30 November and I think it comes -- the question comes on page 223 at line 25, right down at the bottom:

"I thought the yield from a CT scan with the story that I'd been given was going to be very low."

In other words, the history that he had taken.

So then he goes on to talk about what he thought he might get:

"In somebody who has a learning disability and has had a previous history of epilepsy, who has now come in with what we now think are seizures with an intercurrent illness, the yield from a CT scan in that situation would be very small."

Well, if I pause there, can you assist with that?

A. Yes, I don't quite understand the meaning of this "who has a learning disability and previous history of epilepsy", how that is modifying the situation. There's obviously a point along the CT scan line in which you either are nearly finding it or you are definitely finding, and you just have to choose where you're going to go.

Q. If you'd had CT scans of Claire's brain earlier from when she was previously admitted, would that assist you

by comparing one with the other or not really?

A. Oh, I think it would. Sorry, you mean having had it earlier?

Q. Yes.

A. Earlier than the previous? No, I don't think that would be particularly helpful, no.

Q. Her early ones wouldn't be relevant to this?

A. No, I don't think so, no. I think performing a CT scan at an interval -- and this was going to be at least 24 hours, I think, from the original, wasn't it, from the time that she had originally become unwell --

Q. Mm-hm.

A. -- even though she hadn't gone into hospital? So I think that was likely to be helpful.

Q. She became unwell when she came back from school, really, so that'd be some time in the afternoon of Monday.

A. Yes.

Q. And his view is -- I think it's first being suggested to him that he might have asked for a CT scan at 2 o'clock when he comes to see Claire.

A. Yes.

Q. I think that was your view too, if they hadn't done one earlier, that is certainly something that he could have been asking. What he is saying here is that: well,

given the presentation, he doesn't think he was likely to find much that would have helped. Then he goes on to say:

"If it was early encephalitis without fever [which he, I think, conceded was a possibility] in that situation the yield would [also] be small."

A. I think it's quite likely it would have been positive in that situation. And of course, we're somewhat ignoring the fact that she would have had another sodium done because I think there was an agreement that she should have had a sodium done at 2 o'clock in the afternoon of the Tuesday.

Q. Well, some time in the afternoon, I think he expected that it would happen, but in fact it doesn't seem to. I'm actually just looking at what he calls the yield from the CT scan.

A. That would require careful looking, but I think it would be very likely to be positive.

THE CHAIRMAN: Sorry, I think for completeness what he was saying -- and I will be corrected if I'm wrong -- was that the CT scan would show if there was a lesion, which he thought was unlikely, which showed there was haemorrhage, which he thought was unlikely -- and was there something else?

MS ANYADIKE-DANES: He deals with that at page 225, which is

where he goes on to talk about that. Firstly, he says:

"I wasn't expecting her to deteriorate quickly."

At line 12. He goes on at line 14:

"I didn't think the yield from a CT scan -- which would involve her leaving the hospital and going over to the adult hospital -- was likely to be high. While I understand the experts have expressed a different view, in fact, the differentials, when you think about them, are extremely unlikely."

This is the differential diagnosis that the experts have suggested they might be looking for or considering:

"So for example, it's extremely unlikely that she would have had a subarachnoid haemorrhage or a bleed because that's a stroke essentially and it presents very acutely. It's very unlikely she would have had hydrocephalus because that is not detectable with papilloedema. And she didn't have a neurosurgical presentation: there hadn't been a history of trauma or definite focal weakness; she was moving all four limbs."

So the upshot of the whole thing is that his view is that for the sorts of things you might be looking for, you're unlikely to have found them on a CT scan.

A. Yes, but the one thing that she was likely to have, she did have, and that was found the following day.

MR SEPHTON: Can I just ask what the doctor means when he

says, "positive". First of all, when does he say a CT scan would have revealed anything and, secondly, what is the thing that that CT scan would have revealed?

A. The CT scan would show infilling of the areas around the brain so that it would appear like a full brain, which was ... And that would be, I think, from 24 hours from the beginning of the onset.

THE CHAIRMAN: So I think you described this before: in all our brains, there is a space or a gap --

A. Yes.

THE CHAIRMAN: -- and if you have rising intracranial pressure, that gap is diminishing, is it?

A. That's right.

THE CHAIRMAN: So a CT scan will show if the gap is diminishing and the stage to which it has reduced?

A. That's right.

THE CHAIRMAN: And that will indicate to you whether there is a developing problem --

A. Sure.

THE CHAIRMAN: -- and the stage to which the problem has developed?

A. Yes.

THE CHAIRMAN: Okay. How quickly would a CT scan be turned around? If Dr Webb had taken the view at 2 o'clock that it was required -- and we don't know how long -- let's

suppose it could be arranged by 3 o'clock, just to take that as a stab. How long would it take before a result comes through?

A. Oh, they come through immediately. The only question is then getting a radiologist to look at them.

THE CHAIRMAN: Okay. Is it something that Dr Webb himself could interpret or does he need a radiologist to interpret it for him?

A. He would be a perfectly reasonable person to look at it, but it would require two people to think about it in the context of this particular patient.

THE CHAIRMAN: Okay.

MS ANYADIKE-DANES: Just in ease of Mr Sephton, you are saying that whatever you could reasonably expect or be concerned about was developing, that is something that you believe you would be able to see on a CT scan at 2 pm?

A. Yes.

Q. And if you hadn't done one at 2 because you had been lulled into believing that you were getting a positive response from your anticonvulsant therapy and it was worth pursuing that for a little bit, should one have been done at 5 pm?

A. Yes.

Q. I have two other areas I want to canvass with you,

I think, unless I'm asked to deal with anything else. One is to do with the explanation to parents. Running alongside the whole issue of trying to identify what is the cause of Claire's presentation and what is an appropriate treatment plan to develop for her is actually what the parents know or can or should be told about the condition and the cause of the condition of their daughter. That goes through the whole of the day, really, into the evening and then ultimately, when they come back, when unfortunately Claire has suffered her respiratory collapse, at that stage what they should be told or should have been told by the two consultants, who have had an opportunity apparently to discuss their views before going to speak to the parents. So that's a whole long continuing issue.

What I want to ask you is: we know that Dr Steen, the paediatric consultant, did not see the parents during the day, so it's Dr Webb who saw the grandparents at the 2 o'clock examination and Claire's mother at the 5 o'clock examination. So there is an interaction.

Can you help us with what you think the parents should have been being told or at least what information should have been provided to the junior paediatric staff or the nurses with the intention that that ought to be passed on and explained to the parents? Let's take

2 o'clock.
A. Well, it partly depends upon how sick you think Claire was. There are sort of different views about this, but assuming you thought that she was sick and really quite unwell, you would need them to know that and that you were so far not providing any reasonable explanation -- apart from the status epilepticus, which you couldn't easily prove -- for that.
So I think that's ... There's no ... It's very difficult to argue very hard from a single level of 132 of what more you would make. You could say that there has been some evidence of a low sodium occurring, but you'd have to say, "But we would need to repeat that".
Q. Well, this is 1996. It may well be in 2012 there's a fair bit more interaction with the parents or, rather, the amount of information that you give parents may be more now than it was then. But in 1996, on the basis of what Dr Webb thought was the problem -- because it's only fair to judge by his thought process as opposed to what people think he might have thought was the problem -- at that time, 2 o'clock, he thought Claire was in non-convulsive status epilepticus, she'd responded a little bit to the diazepam and then that response had not been continued and he was going to try her on further anticonvulsants. So that's where he is,

really. It's obviously something he wants to treat, he recognises that she's ill, but he believes that he can formulate a treatment plan to address that. Somebody will correct me if I've got that wrong, but I think that's where he was at 2 o'clock.
If that's what you think, you do have a sick child, there's no doubt about it, and Dr Sands thought she was really quite neurologically unwell. What do you think that Claire's parents should have been being told at 2 o'clock?
A. Well, they should have been told that she was sick, they should have been told that they were treating for a particular disorder of non-convulsive status and that she wasn't so far responding fully appropriately and there would have to be a time limit to that.
Q. There would have to be a time limit to that when they would revisit the situation?
A. Yes.
Q. In fairness to Dr Webb, he does revisit the situation. It's not entirely clear what he does somewhere in the mid-afternoon about the midazolam, but he certainly prescribes that. Exactly what other interaction there is, it's unclear, but he prescribes that. And then he comes back to see Claire at 5 o'clock --
A. Yes.

Q. -- when I think he accepted from me that there was a bit of a stocktaking going on as to where things stood and what the implications of that were.
A. Yes.
Q. And that's when he meets, for the first time, Claire's mother. His view at that stage is that he thinks there's still non-convulsive status epilepticus. It's not entirely sure why she hasn't responded better to the amount of anticonvulsants, although some children don't. He feels that the encephalitis is likely to be slightly more of a problem than he thought it was before, and he's got a regime for that. He thinks that she is unwell, but he thinks he's got a plan, and he expects her to respond and recover. And what then, in those circumstances, should he be communicating to the mother?
A. Well, I think he should be communicating that. I think that we are caught up a little bit with where does the CT scan stand in this argument as well because a CT scan would be a pretty regular part -- or an MRI scan -- of the assessment of a child who has encephalitis. So that would be one aspect of what would be planned to be done. I know that it was planned to be done the following day.
Q. That presumably was what he would say to them: if she doesn't wake up, we'll do one tomorrow?
A. Yes, but in fact you don't wake up that fast from an

encephalitis. It's a slower process.
THE CHAIRMAN: I think, to be fair to Dr Webb, he has told us what he meant by "if she doesn't wake up", and he doesn't literally mean if she doesn't wake up; he means if she hasn't recovered or isn't clearly on the road to recovery. On its face, "not waking up" means that she's unconscious.
A. Sure. I was making a point about the general rule of this thing that you don't get better that swiftly.
MS ANYADIKE-DANES: Sorry, that might be a different point. You don't think that you do recover your normal state or are on the way to doing it in that way?
A. No, you may never, of course, recover either if you're badly affected by an encephalitis. So there's quite a reasonable chance of coming to greater harm.
Q. So if he did think that although maybe not as likely a diagnosis as the non-convulsive status epilepticus, but still worthy of note and worthy of treating, if he did think that, what should he have been telling them about the encephalitis aspect?
A. Well, I think he'd have to be warning them that this was only, if you like, partially treatable and that there would be some potential hazard in terms of neurological functioning to how she was going to be afterwards.
Q. And if the mother had wanted to know from him because

they were trying to make arrangements for the evening, on the basis of what he has described, if they'd wanted to know whether they ought to stay that evening, it's obviously an area you have to be very careful of because you don't know what people's arrangements can be and you don't want to make people feel guilty.

A. No.

Q. But if it can be communicated, would you be communicating that this might be a time when you might be thinking if your arrangements permit for you to stay or, or are you saying it's unlikely that anything very serious will happen in the evening? What are you saying?

A. It's very difficult, retrospectively, to actually judge this matter.

THE CHAIRMAN: Surely at 5 o'clock if she hasn't responded in the way that he had hoped to the status epilepticus and if he is now factoring in, to a greater degree, encephalitis and he has to warn the parents that this is now more on the horizon than he had thought before, and while he's still hopeful, this can cause long-term damage, that conveys to Mr and Mrs Roberts that things aren't as positive as they might have thought earlier.

A. No.

THE CHAIRMAN: And they then make their decision about

staying or not staying or shifts between them and the grandparents and so on; isn't that right?

A. I agree, it's just the severity of the events that happened over that night, which could not be anticipated, particularly from not having the diagnosis.

THE CHAIRMAN: But if we're looking at what Dr Webb was thinking, Dr Webb told us yesterday he still thought that Claire was going to improve. In fact, had he not thought that, had he realised how serious the trouble was, he wouldn't have left, which is perfectly consistent with his willingness to become involved throughout that day.

A. Yes.

MS ANYADIKE-DANES: Dr Webb meets Claire's mother at 5 o'clock, but Dr Webb was really coming to, I would imagine, see what was happening in relation to the treatment plan that he had devised for her, not primarily to be making contact with the parents in particular. At least, I don't think that was his evidence.

So on the basis that you'd be wanting the parents to know something about what's happening with the child, should he perhaps, in different terms, have been communicating to the junior clinicians and the nursing staff the sort of thing that you've just been explaining

to the chairman so that, in his absence, they are able to explain matters to them?

A. Mm.

Q. He's not her consultant.

A. No.

Q. Should he have been doing that or is he entitled to expect that because he's attended, usually, by a junior member of the paediatric team, they're keeping their consultant informed and, in due course, that interaction or communication with the parents will be made by the child's own consultant?

A. Yes, I mean, it's quite difficult in this situation to know what was actually happening. I would expect to have the opportunity, as the consultant paediatric neurologist, to want to talk with the consultant concerned. So thus, I would normally have done it by that route and we would have got over that problem. If that consultant, the general paediatric consultant, is not available and is just not available, then I think you have to give the thing to the registrars and say, "You'll have to deal with this in this way", and say that they've had warning of the problems, but I'm hopeful that she will improve.

Q. But if you have the opportunity, as he did, to speak to the mother, then irrespective of what you think the

consultant is going to do thereafter, do you take the opportunity to yourself broach these sorts of matters?

A. I think it depends on the circumstances, but I think I would have done.

Q. And then I have really just two further areas that I'd like to discuss with you. One is a continuation of this issue of communication with the parents. It happens, actually, at the time when the parents come back into the hospital. Claire has suffered her respiratory collapse and it is quite clear from when the two consultants meet with them that there is no way back, if I can put it that way, and they meet -- it's not entirely clear who meets when, but certainly Dr Steen meets them at least on three occasions before the CT scan that confirms what the position and then, after it, and explains matters to do with the brainstem death test and so forth. She may have met them a third time in the evening.

Dr Webb may have met them only on two occasions, before the CT scan and after the CT scan. In any event, it seems clear that it's Dr Steen who does much of the explanation, but he's there.

The issue arises in this way: I had asked Dr MacFaul at the stage when it is clear that there is no way back, probably after the CT scan has been received, what he

thought was an appropriate explanation, a proper explanation to give to the parents. This is what I put to Dr Webb to receive his comment. It's yesterday's evidence. It starts at page 212 and you see what I'm putting to him at line 21. What's in quotations is what Dr MacFaul's explanation is as to what he would have said, and that's the explanation that I put to Dr Webb to get his comment. So you can see:

"I would have explained that Claire had suffered brain swelling [and so forth], stopped breathing, and that damaged her brain irretrievably. The brain had swollen from an underlying disease and the complications of that. If that had been diagnosed, then there should have been fluid restriction. If there hasn't been, then that's a matter of fluid management."

And he goes on to say:

"There is no reference in the discussion to the epilepsy being --

Sorry. I think this is a slightly different point.

The point that I had put to him really is having recited what Dr MacFaul had said, Dr MacFaul came to the view that really the parents ought to have been told that there was the possibility that her -- you see it on the previous page starting at line 10:

" ... the possibility that her fluid management was

inadequate."

That's what they really should have been told. And if her fluid management was inadequate, that had certain implications because, of course, the fluid management is something that the clinicians have control over.

Dr Webb, when I put it to him in that way, had a different view of that and he didn't think that it was right to characterise it in that way, that her fluid management was the problem, which would imply, really, if you work that through, a degree of culpability on the part of the clinicians.

Do you have a view as to whether at that stage the parents ought to have been told that part of Claire's condition resulted from fluid management?

A. I think it's difficult not to see that that is one aspect of her management which hadn't been taken appropriate care of. So she had really up to 24 hours without having her sodium level performed.

Q. In fairness to Dr Webb, part of what he says is that it wasn't clear that there was a fluid management problem because it wasn't clear that she had received too much by way of fluid, too much for a child to receive per hour. I think it's 64 ml an hour was what she was receiving.

He then refers to the fact that her fluids were

restricted and although I think he concedes that the Solution No. 18 was restricted, but because some of that medication was being given intravenously in normal saline, there wasn't a total restriction on her fluids. But in any event, he did not take the view that she had been overloaded, if I can put it that way, with fluids, and if she hadn't been overloaded then one shouldn't have been explaining to the parents that there was a fluid management issue.

A. Yes, but she was not given the appropriate levels of either half-normal or normal saline from whatever stage -- and shall we call that, say, 8 in the morning of the Tuesday?

Q. Mm.

A. Having got a new sodium level measured, hopefully that would have led to a change in regime. So she had not been given that regime from that time in the morning. But of course, it's very hard to admit that you have made a mistake.

Q. Yes, Dr MacFaul conceded that, that that would be hard, but if you were wanting to give them a full explanation, you would have to include that.

A. Yes.

Q. If one uses the expression "a fluid management problem", does that encompass more than just literally what type

of fluid you gave, how much you gave of it and what rate you gave of it? Does fluid management also include the testing of the electrolytes to determine what the administration should be? Is that part of management?

A. Yes.

Q. So if you wanted to be critical, if I can put it that way, of fluid management, it wouldn't necessarily be confined to whether they should have been giving Solution No. 18 or not at this stage or that stage, it would also be your view that they should have carried out serum sodium tests at certain stages and they simply didn't do that. Is that part of management?

A. Yes, and it would be appropriate to the particular occasion, so sometimes it would require only, you know, twice a day, sometimes it might even be more often.

Q. Dr Webb then went on to develop the issue as to whether he thought, and if so at what stage, if ever, Claire became fluid overloaded. You may recall from Claire's medical notes and records there is a note that Dr Stewart makes at 11.30. I will pull it up for you very quickly so you can see it. It's at 090-022-056. There we are, you see it on the left hand side.

So the serum sodium level has come back of 121.

THE CHAIRMAN: This is Tuesday night at about 11.30, professor.

MS ANYADIKE-DANES: Thank you, Mr Chairman.

He's responding to that, and he gets hyponatraemia, because that's 121, and then he's querying the reasons for that. The top query is "fluid overload and low sodium fluids"; the second is "SIADH". His impression is a need to increase the sodium content in fluids, and then he records that he has:

"... discussed with the registrar and she says to reduce the fluids to two-thirds of the present value, which is 41 ml per hour, and send urine for osmolality."

So the point that I put to him was whether that consideration by Dr Stewart wasn't perhaps indicating that there might have been a fluid overload, or at least he thought there was.

A. Mm.

Q. And Dr Webb's view of that was, well, he didn't think that there was a fluid overload at 11.30, because he didn't see any evidence at 11.30 that she had been given any more than she should have been given, if I can put it that way.

A. Yes. I think the fluid may have been in the wrong space, though, and she required more intravenous high sodium in order to bring up the level. So I think that's -- it's not just a matter of the whole body, it's which space they're filling.

Q. Then the final area that I would like to deal with with you, or ask you to comment on, starts at the note that Dr Webb makes just before he's going to start the brainstem test. You can see it at 090-022-058. You see there just under "CT, cerebral herniation", there's a line saying:

"Under no sedating or paralysing medication."

I put that both to Dr Aronson and Dr MacFaul. Dr MacFaul had already addressed that in his report and he thinks that's just an incorrect statement, because she was, she had received anticonvulsant therapy, which would have that effect. Dr Aronson was also of the same view. I think at one stage I had pulled up for you a chart that we had that showed what she was receiving. I think it's --

A. She had a 23 level of phenytoin.

Q. She had a 23 level of phenytoin --

A. And her sodium was 127, I think, or 129.

Q. Yes, well, her phenytoin level was 23 at -- well it was recorded being that at 11.30. She had another phenytoin level test taken at about -- it's not entirely clear -- 3 o'clock, maybe, and that produced 19.2, I think. Dr Aronson's view is although that's within the range, which is 10 to 20, it was so close to the top end of it that in his view, he would have wanted to see that range

reduced to 10 or below 10 and just waited before you started the first brainstem death test.

A. Yes.

Q. And Dr MacFaul was also of the view -- well, he primarily focused on this particular statement in the notes, which is the precursor to doing the brainstem test, and he simply was of the view that he couldn't with confidence say that, given the regime she'd been on. I just want to pull this up. It's 310-020-001.

Just to refresh your mind. This is what she's having. I think Dr Aronson's view is that the rectal diazepam isn't having any effect, but he said that the phenytoin has quite a long half-life and she'd had 635 milligrams of that at 14.45, and then she'd had an hour's infusion of it at 23.30. Then the midazolam, she'd had 12 milligrams of that when what she should have been having was 3.6. And she's then almost immediately afterwards on an infusion -- I think it is 2 ml per hour -- and then that infusion is increased as you can see it there. It looks as if it stops at about 3 o'clock. It certainly is not running when they first record her in the paediatric intensive care.

Then she's received the sodium valproate, although probably not the infusion of it, but certainly the 400 milligrams of the sodium valproate. So that's the

anticonvulsant therapy, and you can see -- well, in this chart we've indicated how that correlates with episodes during the day, but that's not the point. Then you see the respiratory arrest at 3 o'clock and you can see the first brainstem test is taken at 6 in the morning. Both of the doctors felt that that first test should possibly have been postponed, given what was likely to be in her system.

So the question for you is: would you have been happy writing in her notes that she was, at 6 am, under no sedating or paralysing medication?

A. No, I would have put the appropriate riders to that. Then the question would be: do you actually then do the test or not do the test? And I think ...

THE CHAIRMAN: I think you gave evidence about this before, professor, didn't you --

A. I did indeed.

THE CHAIRMAN: -- on 5 November. You said that the question that we were looking at yesterday about question 1(f) on the form, you thought the answer to that question was correct, and you thought it was not terribly important to have waited for the midazolam to come down.

A. I mean, the change in her was absolutely dramatic and remained that way for three hours. The fact that you're going to do it later as well makes it ... This quite

often happens in the management of these children.
THE CHAIRMAN: So this isn't a point that you're particularly concerned about?
A. No, I think not.
THE CHAIRMAN: Okay.
A. I think you'd be -- you'd want to be absolutely sure where you were for the last ... But I think the change is so dramatic and apparently so permanent that it's ... I think it's tough not to just wait because you can go on waiting really quite a long time.
MS ANYADIKE-DANES: When you said you'd put a rider in the note, what exactly do you mean by that?
A. The phenytoin level was 23 and 23, although it's a bit high, is not one that would normally affect the pupil reactions or the response to pain.
Q. I think when Dr MacFaul was dealing with the matter in relation to her electrolytes or her serum sodium levels, which were also slightly out of range --
A. Yes, they were. I thought they were -- were they 129?
Q. 124 and 125.
A. Oh.
Q. Oh, 129 and 152, sorry, at the end. That was another child who had that. 129 and 152.
A. Okay, that's down a bit, but that doesn't do anything to you --

Q. The point I was going to make was following on from how you have just answered the chairman. You said how you could address that is you answer and you put the rider then by giving actually what the level is --
A. Yes, exactly.
Q. -- on the form.
A. Yes.
Q. So it's quite clear that you have considered the matter, but your overall view is that it's not affecting or is not likely to affect her in terms of a reversible situation?
A. Yes.
Q. Is that something that might have been done in relation to her --
A. Yes, I think so.
Q. -- medication?
A. Yes, I think so.
Q. You acknowledge what it is, but you go on and do the test because you don't think that waiting will lead to a reversible situation?
A. Yes, I think that's right.
Q. In fairness, I think none of the experts thought the situation would be reversible; it was their concern about how you adhere to the brainstem death test.
A. You can get into a secondary situation of hypothermia as

well and you have to then keep trying to warm the child and this can get really quite difficult because that is more of a force.
THE CHAIRMAN: But the basic position is that the child's position is not reversible --
A. No, exactly.
THE CHAIRMAN: -- therefore you don't want to keep the parents, who are already going through the most awful time, any longer than needs be?
A. That's right.
MS ANYADIKE-DANES: Mr Chairman, I don't have any more questions to ask, but I think there are some questions to ask. I wonder if you'd give us five minutes.
THE CHAIRMAN: I'll give you no more than five minutes because it turns out that the professor has to leave at 1 o'clock, not 1.15, so we've got very limited time. Okay?
(12.41 pm)
(A short break)
(12.46 pm)
MS ANYADIKE-DANES: I have two very discrete points to raise.
One relates to a statement that you made earlier, Professor Neville, about how the 132 may was lower than the bottom of the range, which is 135, and it may have

indicated a fall. What nobody could know, of course, because it wasn't being measured, is what the rate of that fall might have been.
A. Yes.
Q. And the question that I have for you is: once that 132 level was received and then communicated to the clinicians, should they have been taking that as a baseline or should they have had it in their mind that that might indicate that she was in a falling serum sodium condition, if I can put it that way?
A. I think she should have been taken to be in potentially a falling situation.
Q. And with nobody being entirely sure of when she had dropped from whatever is her normal position, which presumably would be something between 135 and 145, if that's the normal range, nobody knowing how quickly she had fallen from her normal range --
A. No. No, that's right.
Q. And if she had -- all this is speculation, I entirely accept that, but in a sense much of it is speculation until they start getting some hard evidence about her. If she had fallen rather speedily for whatever reason, could that have been part of an explanation for her presentation when she was admitted?
A. Yes, it could have been. I have a feeling that it would

not be the only explanation.
Q. Yes. I think your view was that there was likely to be something else going on as well?
A. Yes.
Q. But could that have contributed to her presentation?
A. Yes.
Q. Thank you.
The other question that I have for you relates to the communication that went out after the autopsy report had been received. I don't know if you have seen the autopsy report.
A. I think I must have done, actually.
Q. I'm going to pull up one thing alongside it.
A. I'm sure I did. Was that the first autopsy report?
Q. Sorry?
A. Was that the first -- the --
Q. Yes. If we can pull up the final page of it, which is the conclusion, 090-003-005.
A. Is that the one that contains somewhat misleading information perhaps? I don't know. Anyway.
THE CHAIRMAN: Yes, there is an issue about the accuracy of the autopsy request form and that feeds in, to some degree, to a question about the accuracy of some of the factual information in the autopsy report.
A. Yes.

MS ANYADIKE-DANES: Yes. It's a very short brain-only, and part of the inaccuracies are in the clinical summary, but in any event this is the "comment" bit, which is actually their conclusion or their attempt at a clinicopathological correlation is here. What I had wanted to put to you is, alongside that, the letter that was written to the Roberts, or at least Claire's GP, which is at 090-002-002. What I wanted to ask you is how accurate or how much does that letter reflect what the pathologist had found at autopsy?
A. Well, the finding of a neuronal migration defect was later countermanded by Dr Harding and by another neuropathologist.
Q. Dr Squier, yes. But Dr Steen wouldn't have known that at this stage.
A. No, exactly. So that's what she was given in order to send out the letter --
Q. Yes.
A. -- so she gave that information.
Q. Ultimately, its features are cerebral oedema with a neuronal migrational defect and a low grade sub-acute meningoencephalitis.
A. Yes. But Dr Steen doesn't quite say that, does she? She starts, really, with the abnormal neuronal migration --

Q. Yes.
A. -- and explains how that would have arisen if it had arisen --
Q. Yes.
A. -- explains the encephalitis ...
Q. Is there any difference between saying, "The cerebral tissue showed that ...", as opposed to saying, "The features here are those of ..." I think certainly when Dr Herron and maybe also Dr Mirakhur, the pathologists, were asked about that, their view was that they were less conclusive about these things because they didn't feel they could be sufficiently conclusive.
A. I thought they were saying the same things, but ...
THE CHAIRMAN: I'm not sure -- we're asking a neurologist to comment on a letter written by a paediatrician. I'm not sure if this helps very much. I've already got evidence on this.
A. The problem seems to be that it doesn't say very much about brain swelling --
MS ANYADIKE-DANES: Yes.
A. -- Dr Steen's letter.
Q. If we pull up in substitution for 090-002-002, 090-001-001. This is the letter Dr Webb wrote to Claire's parents. He had his own view as to what had happened, which he has put in Claire's medical notes and

records. I'm not going to pull it up to confuse matters further, but just to tell you what he included, he said:
"SIADH, hyponatraemia, hypoosmolality, cerebral oedema and coning, following prolonged epileptic seizures."
That's what he included in his note at 4.40, but of course at that stage he hadn't had the benefit of a pathologist's report. So now he has the autopsy report, and this is the letter that he writes to Claire's parents. The question is: so far as you are concerned, how accurate is that description of what had happened to their daughter and why?
A. Well, it's uncertain about the status epilepticus, isn't it?
Q. Mm-hm.
A. And a later report failed to find any evidence of that.
Q. Yes.
A. But I don't know when that will have been available. It wouldn't have been available for this letter.
Q. That's why I'm asking you. Is that a fair enough letter or should he have said a little bit more?
A. Well, the neuronal migration defect was one that was put in, so I think it has to be accepted as part of what goes in. And the low grade infection, I think is what is in there as well. So I think, yes, it's probably

fair.
Q. And do you see any reference to the metabolic cause or --
A. No.
Q. Where it says:
"... with the clinical history of diarrhoea and vomiting, this is a possibility, although a metabolic cause cannot be entirely excluded."
Do you see reference to that?
A. No, sorry, where's that?
Q. That's taken from the autopsy comment, that there is a possibility of a metabolic cause.
THE CHAIRMAN: I think the point is that it's not there, professor.
MS ANYADIKE-DANES: Yes. And how significant would it have been to have included that and explained it? That, incidentally, as I understand from the pathologists, is the bit they couldn't really address, the whole issue of SIADH, hyponatraemia and so forth. They say there's nothing that they're going to find as pathologists of that, but that's something that clinicians would have to address.
A. I'm not sure that that's going to help a great deal, really, because it's just a potential cause.
THE CHAIRMAN: It's not really going to help Mr and

Mrs Roberts to say that there's a possibility of something which can't be excluded, is it, in this letter?
A. It could be there, yes.
THE CHAIRMAN: Yes, but Mr and Mrs Roberts have a number of other reasons to be concerned about the information which they received at different times.
A. Yes.
THE CHAIRMAN: Including, in this letter, the fact that there is a possibility of something else cannot be excluded.
A. Yes.
THE CHAIRMAN: Would that be on the fringes of what they might be worried about?
A. Yes, it could be.
THE CHAIRMAN: Okay.
A. The trouble is it's got several things that are not even true.
THE CHAIRMAN: As it turns out, yes.
MS ANYADIKE-DANES: Then finally, because I know I'm going to be asked, should it have included any reference to low sodium, SIADH or anything of that sort?
A. I think, to be complete, it should contain hyponatraemia as a cause.
MS ANYADIKE-DANES: Thank you. That's it, Mr Chairman.

THE CHAIRMAN: Okay, thank you. Mr Sephton?
MR SEPHTON: Sir, there are a couple of matters that I wish to raise. In my closing submissions, I will be making remarks about what weight ought to be given to the evidence of various experts.
THE CHAIRMAN: Yes.
MR SEPHTON: And one of the things I will be pointing to is that it is an expert's obligation to indicate, first of all, his expertise, where he's making criticisms, and secondly, where there's a range of acceptable views, whether the expert has identified that and explained his reasons.
THE CHAIRMAN: Yes.
MR SEPHTON: I wished counsel to the inquiry to raise those issues and I've been told that she is not allowed to do so. I simply put down a marker at this stage that --
THE CHAIRMAN: Let me deal with those two issues. The second one that you have just raised is whether the professor has acknowledged sufficiently that there are views other than ones which he expressed.
MR SEPHTON: Yes.
THE CHAIRMAN: His reports contain a number of references to him saying, "This isn't the only view, there are other views"; isn't that right?
MR SEPHTON: No, I don't accept that.

THE CHAIRMAN: Let me take you to an example. Do you have his statement at 232-002-004? If we could bring that up. Thank you. He's asked about the appropriateness of the prescription at admission for IV fluid therapy. And he says in his answer:
"On Claire's admission, many would have administered IV fluids of 0.45 or 0.9. The use of Solution No. 18 in a drowsy child should have been at least with a warning."
But then he continues at the end of that paragraph:
"I have commented ... on this as being potentially unwise ..."
Then he says in the third line of the next paragraph:
"Although not everyone would have done so."
Is he not acknowledging there that he's not being prescriptive and saying that this is absolutely wrong, but it's a view which not everyone would have taken, but it's a view which many did take?
MR SEPHTON: I accept that in relation to that issue, clearly.
THE CHAIRMAN: Well, are we really going to pore through his reports section by section to find out what bits he conceded and what bits he didn't? Because I re-read his evidence last night and there are significant parts in

it where he does accept that there are other views. I have to say, if any of the expert witnesses has been far from being dogmatic, it's Professor Neville.

MR SEPHTON: Very well. I have made my point.

THE CHAIRMAN: I entirely accept that you're entitled to say in the closing submission that although he may have made some concessions of the type that I've just taken you to, he should have made more.

MR SEPHTON: I wouldn't want it to be said that my closing submissions are unfair because witnesses haven't been given the chance to deal with the points.

THE CHAIRMAN: No, I understand.

MR SEPHTON: I've raised the matter and there it is.

THE CHAIRMAN: Thank you very much.

Okay, professor, thank you very much. I think you're about to leave us, so if you go on ahead.

(The witness withdrew)

We're going to have the video link, ladies and gentlemen, from about 2.30, but in order to get it set up, could we re-group at 2.40? I understand that the volume of questioning for Dr Scott-Jupp is not very extensive and, in any event, we can't go beyond 4.30, when the link will go down. So we'll break now until 2.40. Thank you.

(1.00 pm)

(The Short Adjournment)

(2.40 pm)

THE CHAIRMAN: Ladies and gentlemen, we have some bits and pieces to sort out after Dr Scott-Jupp's evidence, but let's get the link up, if we can, and take Dr Scott-Jupp.

DR SCOTT-JUPP (continued)

Questions from MS ANYADIKE-DANES (continued)

(The witness appeared via video link)

THE CHAIRMAN: Doctor, can you see us in Banbridge?

A. Yes, very clearly.

THE CHAIRMAN: Great, and we can hear and see you too.

Thank you very much for making yourself available again today. You weren't able to finish your evidence last time, but we are most of the way through it. Ms Anyadike-Danes will now pick up the questioning where she left off a few weeks ago. Okay?

A. That's fine. Yes, I'm ready.

MS ANYADIKE-DANES: Good afternoon, Dr Scott-Jupp.

A. Good afternoon.

Q. There are just a few issues. Unfortunately, because of the pressures of time, we couldn't quite get through your evidence. One of them relates to the serum sodium result at 23.30.

A. Yes.

Q. The question really is what you think ought to have been done about that result in terms of the way the fluids ought to have been addressed. Just to help you with that, do you have with you there a copy of Claire's medical notes and records?

A. I'm afraid I don't, no. I only have my own reports.

Q. That's all right. I can read it out to you. It's a very, very short extract of what happened at 11.30. At 11.30, Dr Stewart, who was a junior SHO, made an entry in Claire's notes. He had received the blood results indicating Claire's phenytoin levels and he also received the serum sodium level. The serum sodium level that he recorded was 121 at that time. He also made a note that she was obviously hyponatraemic. But he made a note in relation to how he thought that had arisen. The first line of which is:

"Query fluid overload and low-sodium fluids."

And the second line of which is:

"Query SIADH."

He then noted his impression -- sorry, can you still hear me? Hello? I think we've lost him. (Pause).

He also noted:

"Query: need to increase the sodium content in fluids."

Just for those who can pull it up, this is

090-022-056. And then he noted:

"Discussed with the registrar."

His record of the outcome of that was to reduce the fluids to two-thirds of their present value, which would make it 41 ml an hour, and also to send the urine for osmolality. Although he had thought that perhaps a way of addressing that was to increase the sodium content, that's not what the outcome of his discussion with the registrar was.

So Dr Steen's response, just so that you have that -- and I think one gets that in the transcript. You won't be able to see that, but just for the purposes of those in the chamber here, it's 17 October 2012, page 106 at line 7 to line 9 in page 107. She says that to reduce it to two-thirds was in line with the textbooks at the time.

Dr Bartholome, who was the registrar that Dr Stewart spoke to, in her transcript, 18 October 2012, page 52, line 20 to page 53, line 4, says that she didn't want to correct matters too quickly without knowing what the urine osmolality result was.

So that's their explanation. And I'm conscious you don't have all the notes, so I'm giving you the information, if I can put it that way. You have your own report, which I think is 234-002-008, and

Professor Neville in his report at 232-002-011, says that Dr Stewart's assessment of the significance was appropriate at SHO level, the significance of the serum sodium level, however he would have expected Dr Bartholome to take further action, including inducing diuresis by mannitol and ventilating Claire to reduce intracranial pressure.

So that's the landscape, if I can put it that way. My query for you is: was the two-thirds restriction appropriate in the absence of a urine osmolality result?

A. I think the urine osmolality result often in this situation is not immediately available and my practice in that situation would have been to restrict fluids without necessarily waiting to acquire a specimen because the likelihood of doing harm by continuing on the higher infusion rate of the fluids is greater than the likelihood of doing harm by reducing the rate. That'd be my view in that situation.

Q. Would you have also increased the sodium content?

A. Yes. In 1996, as has been discussed many times at this inquiry, it was less common to use 0.45 or 0.9 per cent saline, but I think in this circumstance where there clearly is a low sodium, I think both actions should have been taken to increase the sodium content and to reduce the quantity of fluid given.

Q. Can I ask you, apart from the fact that Claire had a very low serum sodium result, would your view as to what step to take be influenced by the fact that she had these neurological presentations or she had obviously had some sort of neurological problem? Does that affect what you do about the fluids?

A. Yes, it would. At this point nobody had made a diagnosis of raised intracranial pressure or cerebral oedema. That was clearly what was developing -- it is easy to say that with hindsight. It would have required -- sorry?

Q. Yes, we can hear you.

A. Sorry, I thought I heard an interruption.

It would have required somebody with sufficient insight to consider that as a possibility at that point. And it's not always obvious, as is clear from this case -- at least it wasn't obvious to the doctors looking after Claire at that time that that was developing. It's common practice to reduce fluids where it is known that a child has cerebral oedema or raised intracranial pressure, for example, after a head injury.

Q. Yes. As you probably know now from the transcripts, the registrars are very stretched in the evening shift. They have a number of beds they have to look after and there is really only one of them. They do have access

to consultants who are on call. There has been a suggestion that really what she ought to have done at this stage is get hold of the consultant.

Dr Webb, who you may recall, was the consultant paediatric neurologist, felt at this stage he would quite like to have been informed that Claire had reached that stage since it wasn't what he expected to happen to her. And it's possible that the consultant paediatrician who was on call, or Dr Steen, who was Claire's consultant, should have been contacted.

You may not be able to speak for what a consultant paediatric neurologist would consider, but if an experienced consultant paediatrician is contacted and given the information that was available in relation to Claire, would you have expected not only for the rate to be reduced, but also for the sodium concentration in the fluids to be increased?

A. The sodium, yes. It was, at that time, a controversial area. As you've already heard the discussion between previous expert witnesses, I think you would have had a variation, a variety of opinions of what different people would do at that stage. But I think even then, in 1996, there was an increasing appreciation of the need to reduce fluids where there was a suspicion of raised intracranial pressure and to bring the serum

sodium up slowly, not too quickly.

The debate in some circles, as I think has been covered by other expert witnesses, is whether one should have used hypertonic saline -- that is saline that is more concentrated than normal saline, greater than 0.9 per cent. Personally, I wouldn't have used that and we very rarely ever use that. I would have used, in that situation, either 0.45 per cent or 0.9 per cent saline in order to bring up, to slowly increase the serum sodium concentration.

Q. So not only would you have reduced the rate of the fluids being administered to her by perhaps the two-thirds, but you would have also increased the sodium concentration of those fluids?

A. Yes.

Q. And then the issue becomes by what degree, but you would have increased it.

Can I also ask you: at that time, would you have been thinking of the possibility of SIADH? You have certainly thought that somebody might have thought that raised intracranial pressure was developing. Would it be reasonable to have considered the possibility of SIADH at that stage?

A. Yes. On the receipt of that very low sodium result, I think that was high on the list of possibilities, in

fact the most likely explanation of that very low sodium at that time.

Q. Thank you. Then if I can go on to another area, which is after Claire's collapse. She has a respiratory arrest, she collapses and is ultimately transferred to paediatric intensive care. At that stage, at some point reasonably soon after that, Dr Steen arrives, Dr Webb arrives, and Claire's parents do as well. And there is a discussion between them to try and explain to Claire's parents what has happened and what is effectively the prognosis.

You, in your report at 234-002-010, thought that the discussions with Claire's parents were appropriate given the information that was available and the clinicians' views at the time. Professor Neville thinks that the cerebral oedema caused or aggravated by hyponatraemia should have been explained to the parents. Obviously, there is a range of time in which you could be talking to the parents when you have increasing amounts of information. One is before the results of the CT scan, another is after the CT scan has been received, and you see what the position is, and then of course there's the position after the brainstem tests have been carried out.

But if we go to the point when the CT scan has been

received. At that stage, they're concerned that Claire's condition was irreversible and that would have been confirmed by the results of that scan, and they would have known presumably that what they're then preparing the parents for is ultimately the brainstem tests and what they would have believed to be her death. So that's the stage that they're at.

Can you help with, given the information that they would have had at that time, what you think, if anything, the parents ought to have been told about the role of Claire's fluid management in her condition?

A. I think this is very difficult. The situation is very distressing, it's the middle of the night, they've been called in because their child has deteriorated and ended up on an intensive care unit. That in itself is a lot of information to take in, particularly when they apparently had been reassured earlier in the day. To go into detail about blood results, about numbers, about quantities of fluid and that sort of thing may not have been appropriate at that time. And I think one has to judge what, in a very distressing state for the parents, is appropriate to say in that very acute situation. One can always come back and go over the things in the cold light of dawn, as it were, later, but I think it would have been more advisable at that time to just

communicate the most important aspects to the parents, that is that there was an acute deterioration, that there was brain swelling and that it was very serious and could be fatal, which was the situation that they were dealing with at the time.

Q. Does a point come on that 23 October day when you do start to explain to the parents in a little bit more detail -- maybe not even on that day, after that -- what you think has happened in terms of Claire's care and her fatal cerebral oedema?

A. Yes. There does come a point, but it's very difficult for me to be specific about when that should be.

It would depend on many things. It would depend on the perceived receptiveness of the parents at the time from their behaviour, how distressed they were, whether they were in a position to talk. And people are extremely distressed and tearful and it's sometimes difficult to take things in. It would depend on, importantly, whether both of them were there or whether only one of them were there -- I believe both of them were there in this situation. Sometimes one waits for the other parent to come in or a supporting relative before going into these sort of details. It would depend on the likely sequence of events that were going to follow. There was how quickly things were likely to proceed and

whether there was going to be time and how much information had to be given in a very short space of time or whether it could be left.

Q. Whatever you formed the view that it's appropriate to do, which is a judgment call --

A. Yes.

Q. -- do you at any stage go into the details of what role her fluid management might play?

A. I think in this case, at some point, I believe it should have been mentioned. Now, there is a case for saying that as in fact the most important issue at the time was them moving towards brainstem death criteria, which is obviously extremely distressing and that, I would imagine, dominated the conversation between the doctors and the parents at that time, and what might have been seen as a less pressing detail, the fluid management, might have been considered to wait. You may be coming on to this anyway, but after Claire had passed away, I think those aspects should have been discussed with the parents at some point.

Q. I don't know if you had an opportunity to see some of the transcripts of the evidence around this point, but Dr MacFaul in particular was -- hello? He's gone. (Pause).

A. I can see you again.

Q. Sorry. Dr MacFaul was asked about what the parents ought to have been told at whichever point the judgment is made that you can go into that kind of detail. And his view is that very definitely they ought to have been told about the fluid management issue because fluid management is something that's within the control of the clinicians and, if that has had any role to play in her deterioration and the development of her cerebral oedema, then that's something that, unpleasant and difficult as it is to broach, that the hospital has to say because that indicates that you have had a role to play in what has happened.
A. Yes.
Q. Do you have a comment on that?
A. I agree with that. The question is when. I'm sorry, I haven't been able to read Dr MacFaul's evidence in great detail. Did he have a view on when that conversation should have taken place?
Q. I didn't ask him in that way. I put to him the discussion that is recorded and asked: if you were going to have a discussion of that sort, should you have mentioned certain other things? Then he said, "If I was going to explain to the parents, this is what I would have said". So in fairness to him, I don't think I particularly tied him down to when you would do it;

I was more trying to extract from him what the content would be. I'm not sure that there is a great issue as to when it should happen, the question is: should the family ever have known that? As you may appreciate, they went some time without ever appreciating there was anything of that sort involved in their child's death.
In fairness, I also put the same point to Professor Neville, and he didn't go into details as to when you would do it, but he certainly thought, difficult as it was, that that was something that ought to have been communicated to the parents.
A. Yes. I agree with that. My only reservation is that to do it at the time when they had just come back in, when Claire had just collapsed, might have been an overwhelming amount of information for them to take in at that time.
Q. I understand. Then I wonder if I could ask you about the brain-only autopsy. Dr Webb's view is that unless, for some reason, the parents didn't want to have a full autopsy and although that's commonly the position, in this case that wasn't the case. But absent that, then he would have thought that you would have conducted a full autopsy and seen what the information that disclosed is to assist in determining exactly what had happened. Do you have a view about that?

A. Yes. I do. I think an expert pathologist would probably have a much more detailed and expert view than mine. But I believe that it might have been possible to gain more information on the nature of Claire's illness by doing a full autopsy. When I first read the notes, I was slightly surprised that they only did a brain-only autopsy, and I assumed, as others did, it was the parents' request, but apparently not.
Q. There may well be a difference in the evidence between Dr Steen and Dr Webb as to how that came about. But in any event, at the time when it's being raised, it would seem that both Dr Steen and Dr Webb are there. Is that the sort of thing that you feel they should both have discussed and reached a view on together, if possible?
A. Yes, I do.
Q. And that particularly if, for example, Dr Steen as a paediatrician had it in mind that maybe we could just proceed by way of a limited autopsy, confined to the brain, that if she was thinking in that way, might that be a particular thing that she could have raised with Dr Webb, who is the neurologist, to get his view about that?
A. Yes. One of the consultants, I presume, had a discussion with the parents about the nature of the autopsy.

Q. Yes.
A. And I can't recall whether either of them gave reasons for them requesting a brain-only autopsy in their evidence. But it seems to me that if the parents are prepared to give consent to an autopsy, which is a very difficult thing for them to do, if they're prepared to do that, distressing though it is, one might as well take the opportunity to get the maximum amount of information rather than just a limited amount. Because there is evidence -- and a pathologist would be able to tell you more about this than I -- but there's evidence of a surprisingly high number of alternative diagnoses that are found at autopsy, which are never even suspected while the patient is still alive.
Q. The autopsy form, request form -- which you can't see, but for reference here it's 090-054-183 -- is a standard form and then it's filled in by Dr Steen. It indicates the consultants as being Dr Steen and Dr Webb. Then it describes very briefly the clinical presentation. Then there is about a paragraph's worth in Dr Steen's writing as to the history of the present illness and Claire's past medical history.
So that you have it, her past medical history is indicated as being:
"Mental handicap, seizures for six months to four

years."

In the history of the present illness, there's reference to "vomiting" and "loose stools" and "speech becoming slurred" and "becoming increasingly drowsy" and she was felt to have subclinical seizures. And then there's a reference to the medication, which lists all the medication given, apart from the midazolam.

There is a record of the serum sodium dropping to 121 and when that happened. There's a query about inappropriate ADH secretion, but not the other potential query about fluid overload and so forth. Then it records when the brainstem tests were carried out and fulfilled. Under "investigations", it says that it is coming accompanied by her chart. The clinical diagnosis is given as "cerebral oedema, secondary to status epilepticus", with a query over "underlying encephalitis". And then over the page, the clinical problems are to be listed in order of importance, and there's space for four of them. And they are listed in the order of:

"Cerebral oedema, status epilepticus, inappropriate ADH secretion [and a query over] viral encephalitis.

It's not entirely clear what time that form was filled in and there may be a difference here between Dr Webb and Dr Steen as to whether there was discussion

between them before that was done. But given that Dr Steen had not been on the ward and had not actually treated Claire, is that form something that should have been discussed, so far as you consider it, between Dr Steen and Dr Webb?

A. I don't think they needed to discuss the precise wording of the form. I think the general issues of whether an autopsy was required and the extent of an autopsy -- it may have been that a junior member of staff could have actually physically filled the form out, somebody who was familiar with the case. Every trust has a different system of requesting autopsies, which is very different these days to what it was in 1996. So I don't think the actual paperwork is that important, given that the pathologist has access to the case notes anyway. So the pathologist can look at any detail he or she wants to find in the case notes without -- whatever is written on the form is a guide to the pathologist.

Q. Yes. When it comes down to the clinical diagnosis, Dr Webb's view is that what is written there doesn't entirely conform with what he had recorded in Claire's notes as to what he considered the clinical diagnosis to be. Leaving that aside, if you say that a junior member of staff could cull from the notes, if I can put it that way, the history of the present illness and the clinical

presentation and so forth, when it comes down to what was considered to be the clinical diagnosis or the differential diagnoses, is that something that you think that Dr Steen and Dr Webb should actually have discussed?

A. I think they should have discussed it in terms of what they were going to say to the parents to explain the nature of Claire's illness. I think discussing precisely what is written on the request form, which is just a request form, it's not a terribly important piece of the patient record. I think it is less important. And as I said, the pathologist is at liberty to look at the notes in detail and may choose to come to a different conclusion to what's written on the request form.

Q. If they have discussed what the differential diagnoses were for the purposes of communicating that to the parents, would you expect that to be recorded somewhere?

A. Yes, I would.

Q. And so if somebody was using the medical notes and records, perhaps a more junior member of staff, to draft up this form for the consultant to sign, would that be available in the medical notes and records --

A. Yes.

Q. -- if they'd done it that way?

A. Yes. You may be coming on to this, but what's written on the death certificate is rather more important than what's written on the autopsy request form.

Q. Yes, we are going to come on to that. If you give us a moment so we can pull it up. Maybe I'll go on to something else while we're waiting to get that up.

Whilst that's coming, can I ask you this: do you think, given what was known or what their concerns were in 1996, that this is a case that should have been reported to the coroner --

A. Yes, I do. I think even though thresholds for reporting to the coroner are lower now than in 1996, I think even then a child who had died very soon after admission to hospital with some uncertainty about the diagnosis -- they had a working diagnosis, but it wasn't certain. With that rapid deterioration in a child who was previously well who had not had a firm diagnosis of a potentially fatal illness made before this admission, that, in my view -- certainly in the English system and I believe it is very similar in Northern Ireland -- would have been an indication for reporting to the coroner.

Q. Thank you. And I can now give the reference here. You won't be able to see it, but I'll be able to tell you what's on it. The death certificate. 091-012-077.

There we are. You see the cause of death:

"1(a), cerebral oedema; (b), status epilepticus."

A. Yes.

Q. In fact, that's the same thing that is recorded on the second page of the autopsy request form because there's a particular section in this pro forma that says:

"Death certificate. If a death certificate has already been prepared, please copy it below for our records."

And that's exactly what that says. So the pathologist knows what is the death certificate that the clinicians have issued.

So in your view, when you said this is rather more important, at that time, on the information that they had, was that an accurate or an appropriate cause of death?

A. Sorry, can you just repeat 1(a) and 1(b) again?

Q. 1(a) is "cerebral oedema" and 1(b) is "status epilepticus".

A. Given the information that was available in the notes at the time, I think that was an appropriate thing to write on the death certificate, even though the discussions that you've had at length in this inquiry have suggested there were other things going on. But given the information that was available to the doctors

at the time, that was not an unreasonable thing to write. The question which I think you are going to move on to is: should they have included hyponatraemia on the death certificate? And I think --

Q. Well, I am going to ask you that. But before we do that, I'm going to ask you whether it was appropriate to include status epilepticus, given that it had not been confirmed in any way throughout her admission.

A. The situation would have been that Claire died on an intensive care unit, where she had been handed over to by the clinicians looking after her on the children's ward previously, who had made this working diagnosis and treated her for status epilepticus. That may have been an incorrect diagnosis, an incorrect treatment, but one would not expect the person writing the death certificate at that stage to go over that and pick over that and do a reassessment with hindsight at that stage. That's something that would be done later, probably with the benefit of an autopsy.

Q. I'll be corrected, but I think it might be Dr Steen who actually writes up the death certificate.

A. Yes. I think it was, yes.

Q. Of course, you are right in terms of the autopsy request form. Whether there was status epilepticus is one of the very things that she had wanted the pathologist to

consider, although they say that's not the sort of thing that you would be able to determine from the brain-only autopsy. My reason for asking you is, one, that in their view that wasn't anything that was going to be advanced by the autopsy, so it had not been confirmed during her life because there was no EEG that would have done that. And in the pathologists' view, it's not something that could be confirmed during their examination. In terms of what else was the differential diagnoses during her life, encephalitis was the other one.

A. Yes.

Q. And in fact, for some considerable time there was a concern that the underlying presentation was viral in some way. That's what's on the early notes.

A. Yes.

Q. Ultimately, it's something that Dr Webb thinks may be a part of the problem because he administers or prescribes medication and a treatment plan for it.

A. Yes.

Q. So what happens here is that there seems to be no reference to that whole viral aspect, if I can put it that way, of her presentation. But there is an inclusion of something which has been completely unconfirmed by the tests that would do so. And that's

why I'm asking you about the status epilepticus, whether it wouldn't have been more appropriate simply to have had the cerebral oedema, which is a fact -- and nobody denies that she died from the cerebral oedema -- and the autopsy report will disclose what led to the cerebral oedema?

A. Yes. I think if you put it like that, I would agree with you. The secondary diagnosis that is listed on death certificates, that's the 1(b), 1(c) is often more speculative than the more definite one that's listed at 1(a), and that's common practice in writing death certificates in any situation. In this case, I would imagine that Dr Steen chose not to write "encephalitis" because that is something that she may have expected to have been proven or disproven at autopsy. The cause of death can then be altered after an autopsy has been done in any situation.

Q. Could she have included, though, inappropriate ADH? Because remember when I was reading to you the list of clinical problems that she had included in the autopsy request form, you are right, she did put a query over the viral encephalitis, which was her fourth problem, if I can put it that way, but the first three, in order, were: cerebral oedema, status epilepticus and inappropriate ADH secretion. The inappropriate ADH

secretion is also something that Dr Webb had identified, so my question to you is: if she's going to have the status epilepticus, which has not been established, should she, by parity of reasoning, have included the inappropriate ADH secretion?

A. Yes. I think that should have been included.

MR FORTUNE: Sir, can we bear in mind that Dr Scott-Jupp does not have the advantage of seeing the certified copy of the death certificate? By way of a reminder to Dr Scott-Jupp, I represent Dr Steen.

In the medical records at 090-022-061, it's written that the death certificate was issued by Dr Steen. It's in her handwriting, "Cerebral oedema secondary to status epilepticus", so I accept that.

Insofar as the date of registration of the death is concerned, if we can go back to the death certificate, that's 24 October 1996.

THE CHAIRMAN: Yes.

MR FORTUNE: So it is before the autopsy has been performed.

THE CHAIRMAN: Yes.

MR FORTUNE: It is before the post-mortem autopsy report is prepared because that is dated 11 February 1997. So there is effectively some degree of speculation as to 1(b), although, as Dr Scott-Jupp says, everyone would agree with 1(a), cerebral oedema.

A. Yes.

THE CHAIRMAN: I think the doctor has acknowledged, Mr Fortune, that there is a degree of speculation in the secondary causes on the death certificate. But I think the particular question he was being asked about was if the clinical problems listed on the document that Dr Steen signed -- that's the autopsy request form -- if they were, one, cerebral oedema, two, status epilepticus and, three, inappropriate ADH secretion, whether that should not at least be reflected in the death certificate.

MR FORTUNE: The difficulty, sir, may be -- and perhaps we can ask --

THE CHAIRMAN: That's setting aside the encephalitis, which she had a question mark beside.

MR FORTUNE: The difficulty, and perhaps we can hear Dr Scott-Jupp on this, is whether you have, in addition to 1(a), (b)(i), (b)(ii), (b)(iii), and so you include status epilepticus, inappropriate ADH secretion and query viral encephalitis. It may be a matter of, let's say, poor form completion, but if I've heard Dr Scott-Jupp correctly, it would be open to the clinicians to have the certified copy of death revisited and the cause of death confirmed more appropriately once the autopsy had taken place.

THE CHAIRMAN: Yes.

MS ANYADIKE-DANES: Yes.

THE CHAIRMAN: That's right, doctor, is it, that the death certificate can be corrected or varied after the autopsy?

A. Yes, it can. It can. I believe it may not be present on that certificate, but some forms of the death certificate have a specific box that the doctor can tick to say further information may be available from an autopsy later. That is frequently present on some versions of the death certificate. I can't remember if it was in 1996 and it may vary between different parts of the UK. But there's a system for doing that and the pathologist could then re-register the cause of death for statistical purposes. In some cases, completely changing what the clinicians' view of the cause of death was.

MS ANYADIKE-DANES: Yes, it was. Dr Steen's evidence was that there was a box on the back, which could be ticked if you wanted to receive the autopsy report so that you could then take its findings into consideration for that purpose. I was putting it to you slightly differently.

I had used the autopsy request form as a convenient place from which to take what Dr Steen at that stage was regarding as the clinical problems. Mr Fortune has

said, yes, the autopsy request form wasn't completed at the time that the death certificate was being drawn up by Dr Steen. But in fact, as I had put to you earlier, the note that Dr Webb makes immediately after Dr Steen's entry -- he makes a note at 4.40, in Claire's records -- and you have a disadvantage in not having it before you, but for those here it's 090-022-057.

He has the chain of events, if I can put it that way, starting with SIADH, and that leads to the hyponatraemia, the hypoosmolality and, ultimately, the cerebral oedema, and that, being unchecked, leads to her coning, following prolonged epileptic seizures. So the SIADH is a definite line of development, if I can put it that way, to lead to her cerebral oedema. And the point that I was putting is: presumably Dr Steen has looked at the notes and records in order to produce the death certificate, and if she has seen the cerebral oedema, obviously that's what Claire had. If she's putting the status epilepticus as one line through to that cerebral oedema, whether she shouldn't have included the SIADH, which the paediatric consultant neurologist had identified as another stream into the cerebral oedema. That was why I was putting it in that way. And I think your answer was: yes, that might have been done.

A. Yes. It could have been included, it would have been

entirely justified to include it. I don't think it's -- I think it would be a mistake to read too much into its exclusion from the death certificate. That would be my view. The death certificate -- I just come back to what I was saying earlier -- is important in that it is seen by the family because they then have to register the death with the registrar. So in that respect, it's more important than things like the autopsy request form.

Q. Yes.

A. And of course, it's important for statistical reasons, which is its primary purpose anyway.

Q. You have said in the course of giving your evidence a couple of times, I think, that the autopsy request form itself is not so important, you get the main issues down there, because you furnish the pathologists with the medical notes and records and they look at that and if there is anything that is inaccurate, well, they're seeing the raw material, if I can put it that way.

A. Yes.

Q. The evidence that we received -- certainly from Dr Herron -- was, yes, even if you did get the medical notes and records, they were so pressed in their work -- I think he referred to, from time to time, conducting six autopsies in a day -- that really they relied very heavily on the details provided in the autopsy request

form. And Dr Mirakhur, who thought that you might have a look, if you had the opportunity, at the medical notes and records, her view was similarly that they didn't think that they would be looking through the medical notes and records to see if the clinical history had been accurately presented and they would be taking it as read that the clinician had provided that information, that information should have come from the medical notes and records, ergo that's what should be reflected there.

A. Yes.

Q. So it may be that local practices differ, but it's not so much a matter that they would be checking that. And if that's the practice, then doesn't that make more important, if you know that and you're the paediatrician, the care that is taken with furnishing that information?

A. It does. What you have told me does alter my view on that. I had assumed, perhaps naively -- I know that case notes always go with the deceased patient to the mortuary, and my assumption was that pathologists always looked at them. This may not always be true. It depends entirely on the degree of pressure the service is under, I imagine, and that would vary hugely.

Q. The final point I want to ask you is about the cause of death. You may not be able to help with some of these

specific points in relation to some of the tests that were received, for example in the cerebrospinal fluid, and whether that affects matters. But you've now had the opportunity to read the experts' reports --

A. Yes.

Q. -- and see the evidence in the transcripts and to see most of the key people's witness statements. What is your view as to how Claire died or why she died, more to the point?

A. I feel very anxious about giving a view here because I am outside my area of expertise in terms of the pathology. Neuropathology is a very highly specialised and difficult area anyway, paediatric neuropathology even more so. And there appear to have been conflicting views from different pathologists on what the actual findings were in Claire's post-mortem. So I'd like the inquiry to appreciate that I am speaking from the perspective of a non-expert here in neuropathology or any sort of pathology.

I was frankly surprised to read from one of the pathology reports that there was no evidence of viral encephalitis. I would have expected, from the clinical picture given, that there would have been. How significant that is, I can't comment on, and whether it's possible for some form of viral encephalitis to set

in place the chain of events that led to Claire's death without there being the classic changes that one expects to see, I don't know, and that's something that I imagine you'd have asked or will be asking expert pathologists on that.

Q. Yes.

A. Clinically, whatever the pathology says, I think the most likely chain of events was Claire had a viral infection that may or may not have originated from her bowel -- but that's not that important -- but which did have an effect on her brain, which caused some change in her conscious level, caused an encephalitic-type illness, which subsequently led to a probably relatively minor degree of brain swelling, but enough to cause inappropriate ADH secretion, which then set up a vicious circle, so that the increasing hyponatraemia as a consequence of the inappropriate ADH secretion worsened the pre-existing mild cerebral oedema, and that an accelerating vicious circle was set up and the cerebral oedema then became irreversible. That's my view of the course of events, from my reading of it.

Q. Thank you. I have only really two areas to ask you about, subject to what anyone else might want to say.

One of them is the brainstem death test itself. There has been quite a bit of evidence, which is not all

in one direction, as to whether the brainstem test form or, rather, the test itself should have been performed when it was performed. You don't have it, but for those here I'll give the reference: 090-045-148. It is signed by Dr Webb as the first doctor and by Dr Steen as the second.

The first test is done at 6 o'clock that Wednesday morning, so three hours after her respiratory arrest. The second test is done at 6.25 that evening. Are you familiar with the tests that are carried out and the way the form is structured?

A. Again, I have to say that it's not -- this is an area outside my expertise. I have never personally done brainstem death criteria on a child.

Q. Then I won't --

A. So I'm not really in a position to comment on that.

THE CHAIRMAN: That's fine, doctor. Thank you.

MS ANYADIKE-DANES: That's a complete answer to that.

Then the next thing that I want to ask you about is: do they have neurological grand rounds in your hospital?

A. No.

Q. Do they have any neurological cases in your hospital?

A. I think it's not a fair comparison because I work in a district general hospital rather than a children's

hospital, and of course we have -- there are adult neurological grand rounds, which I don't get involved in, and there are grand rounds for the entire hospital, most of which are not very relevant to me as a paediatrician because they deal with adult cases. But within our own departments we frequently have -- we don't call them grand rounds, but we have case discussions and clinical meetings to discuss not just neurological cases, but everything.

Q. Let's take that latter, which is something that you'd be more familiar with. Would you have expected some meeting of clinicians involved in Claire's case to discuss Claire's case?

A. Yes, I would. In recent years, since all children's deaths are investigated much more thoroughly, we're now obliged to meet it and there is now a system in place -- at least it is in England and I think it covers Northern Ireland too -- that all children's deaths need to be discussed by all the relevant people. That wasn't in place then. But nonetheless, even in 1996, I think there were some, just from a purely educational point of view, valuable learning points from the management of Claire that ... And it would have been a pity not to use those as an educational case, which is how junior doctors and students are taught. But quite apart from

the educational aspects, I think having a discussion with all the people involved and all the complicated aspects of it, I would have expected it to happen, really, yes.

Q. And if there was going to be any meeting that discussed Claire's care and treatment and the reason for her death, would you, if you had been her consultant paediatrician, expect to be invited to that?

A. Yes, undoubtedly. In fact, if I was not able to attend, I would ask them to defer the discussion to a time when I was able to attend.

Q. Thank you. I just want to refer you to the correspondence that was written on the one hand by Dr Steen to the GP, and on the other hand by Dr Webb to Claire's parents. The one from Dr Steen, which is essentially your discipline, if I can put it that way --

A. Yes.

Q. She writes to the GP. It's 090-002-002. And she says that the post-mortem results are now available. She does not furnish the autopsy report, and that's another issue as to whether you think that that would be appropriate. Let me stop there. If you'd had it available --

A. No. I mean, I frequently write letters to GPs when a child has died, but I wouldn't normally send the full

post-mortem report because it is lengthy and it's far more helpful to the GP to summarise the important points because most of it is not very relevant --

Q. Thank you.

A. -- and that would be the purpose of the letter.

Q. What she actually states is:

"The cerebral tissue showed abnormal neuronal migration, a problem which occurs usually during the second trimester of pregnancy, and would explain Claire's learning difficulties. Other changes were in keeping with a viral encephalomyelitis meningitis. Dr Webb and myself have since seen Claire's parents and discussed the post-mortem findings with them. They are obviously both finding this an extremely difficult and traumatic time, but do not want any further professional counselling at present."

Then it refers to their doors always being open:

"Mr Roberts wanted a short summary of the post-mortem report, which Dr Webb will send to him shortly."

So the bit that concerns the actual findings is really:

"The cerebral tissue showed abnormal neuronal migration."

And then how that relates to Claire's learning

difficulties, and that:

"Other changes were in keeping with a viral encephalomyelitis meningitis."

A. Yes.

Q. Just to help you, because I'm very conscious of the fact that you don't have it there in front of you, what the summary of the autopsy report actually says is:

"The features here are those of cerebral oedema with neuronal migrational defect and a low-grade sub-acute meningoencephalitis."

And then it also says:

"... with the clinical history of diarrhoea and vomiting, there is a possibility, though a metabolic cause cannot be entirely excluded."

And that reference to the possibility is because the reaction in the meninges and cortex, they thought, was suggestive of a viral aetiology, although some viral studies were negative and so that is when it goes on to say:

"With the clinical history of diarrhoea and vomiting, this is a possibility [and then the rider] though a metabolic cause cannot be entirely excluded."

So it's very short, it's about a paragraph, and that's what the autopsy said, and the issue is, if you are the consultant paediatrician writing to the GP to

advise the GP of what happened and how it happened, presumably so that he can discuss matters with the parents, is the letter to the GP a fair representation of what has come out of autopsy or, for that matter, what the clinicians thought if those were matters that couldn't be established at autopsy?

A. It seems that Dr Steen's letter was concentrating more on the underlying brain problem that Claire was born with, that long pre-existed this acute illness, to explain her previous fits and her learning difficulties, and that there seemed to be relatively little on the acute events that led up to her death. I suppose it would have been helpful for the GP to have information on both those things. Dr Steen was going on the report of the first post-mortem done by the pathologist in Belfast, I think.

Q. Yes.

A. And I think that given what she said that there was evidence of a viral aetiology and an encephalitic illness. I think it is reasonable. It may be brief, but I think as a GP, a GP doesn't want a lot of detail. That isn't what they would really need.

MS ANYADIKE-DANES: Thank you very much.

Mr Chairman, I wonder if you'd give me a minute. There is a follow-up.

THE CHAIRMAN: I'm not going to rise in case the link goes down, but I will give you a moment or two. (Pause).

MS ANYADIKE-DANES: There is one question. For those in the chamber, the reference is 090-022-060. If we can bring alongside of that an extract from yesterday's transcript, page 234, which is essentially a question that is generated by the line starting "Dr Webb/Dr Steen".

Dr Scott-Jupp, this might be a little difficult for you to address, but I'm going to try and help you with it. After Claire's collapse, at least three clinicians wrote in her notes. The paediatrician in paediatric intensive care wrote in her notes, as did Dr Steen and Dr Webb. And I'm going to read an extract from the note made by Dr McKaigue, who was the paediatrician in intensive care.

He writes quite a full note and then he comes to a place where he says:

"Dr Webb/Dr Steen have discussed Claire's clinical condition with her parents. They initially appear to be giving consent for organ donation, but Dr Webb will speak again to both parents at 10 am."

The note is timed at 7.10 itself.

THE CHAIRMAN: This is on the Wednesday morning after Claire's collapse at about 3 am.

MS ANYADIKE-DANES: Exactly.

So she has collapsed at about 3, she is transferred to paediatric intensive care. Dr Steen writes a note at 4 am, Dr Webb writes his note at 4.40. The first brainstem death test is done at 6 am. Dr McKaigue is writing his note at about 7 o'clock. So that's what's happened. I'll just give it to you again since that's rather a lot of information to take on:

"Dr Webb/Dr Steen have discussed Claire's clinical condition with her parents. They initially appear to be giving consent for organ donation, but Dr Webb will speak again to both parents at 10 am."

The question is: if he was able to write that at about 7 o'clock, does that mean that the issue as to whether that is a coroner's case or not has already been ruled out?

A. You mean because organ donation had been raised as a possibility?

Q. Yes.

A. No, it doesn't mean it's ruled out. I'm trying to remember what the policy was on organ donation in 1996 and I can't reliably remember and you may need to take advice from another expert on that. But I think there was -- I think it was at the individual coroner's discretion as to whether they would allow organ donation

if there was a possibility of it being a coroner's case, but I may be wrong about that. There may, at that time, have been a complete prohibition on any organ donation that was --

Q. I think you might be right about that because in an earlier case, Adam's, the case immediately preceding Claire's, there was that very discussion where the mother had wanted to do that and there's a record of the coroner giving permission for that to happen.

A. I think, as I remember, it did -- and still does -- vary from region to region, depending on the individual coroner's views.

Q. So is the upshot the fact that the parents are discussing issues to do with organ donation at that stage doesn't necessarily mean that the matter is not considered by the clinicians, or at least one of them, to be appropriate for a coroner's case and doesn't mean that decision to refer to the coroner has been ruled out?

A. No, it doesn't, but I think it would be highly advisable for a clinician to discuss with a coroner if it may be going that way before raising the issue of organ donation with the parents, I would have said. But at 7 o'clock in the morning, it may have been difficult to get hold of anybody.

MS ANYADIKE-DANES: Thank you very much. Mr Chairman. I don't think there's anything further.

THE CHAIRMAN: Mr Fortune?

MR FORTUNE: I have been toying with a topic which I find quite difficult to articulate. And it's simply this: could we find out from Dr Scott-Jupp whether, back in 1996, he would expect all consultant paediatricians, when faced with a situation similar to Claire's, to discuss the concept of fluid management in the way that Dr MacFaul has described and Professor Neville has described? It's not so much the timing; it's the fact of how the fluid was managed or arguably mismanaged.

THE CHAIRMAN: Sorry, just to clarify the question for Dr Scott-Jupp. We're asking him whether he would have expected all consultant paediatricians to discuss the concept of fluid management in the way that has been described by two of the experts, and that's to discuss it about Mr and Mrs Roberts?

MR FORTUNE: Yes. We accept that events moved on to 2004, and, of course, the situation would be markedly different now in 2012.

THE CHAIRMAN: Yes.

MR FORTUNE: But I'm trying to get the feel of 1996 and whether there was a universal expectation amongst consultant paediatricians or whether Dr MacFaul and

Professor Neville represent one school of thought and perhaps there are other schools of thought.

THE CHAIRMAN: Right. So what we're asking Dr Scott-Jupp isn't how delicately or otherwise it would have been raised or the precise time at which it was raised, whether it was 4 o'clock on Wednesday morning or later on Wednesday morning or even on Thursday -- doctor, have you followed the exchanges?

A. I think so. Mr Fortune is asking whether there was a consensus amongst paediatricians, in the context of a child being extremely ill or having died, whether they would all have discussed aspects like fluid management with the parents.

THE CHAIRMAN: Yes.

A. Is that what Mr Fortune is asking?

THE CHAIRMAN: That's the gist of it.

A. I think every case is so different, so unique, and I think it would not be fair to say there was any kind of consensus or any kind of universal policy on that. Certainly we do discuss things in more detail with parents now than we did in 1996. But even then, I think most consultants would have, if it seemed appropriate, as I said earlier, the right time, want to discuss aspects of management. What's particularly difficult about Claire's case, I think, is that when a child has

died and the original, fundamental cause of death may have been inevitable, however there were things about the treatment that were less than ideal and yet it may be that in the view of the person speaking to the parents the things that were not done optimally with the treatment were not actually the main contribution to the child's death, it's a difficult issue as to whether it's worth raising those.

These days, I think we would. In 1996, I am not so sure because it is not going to change anything, it's not going to bring the child back and one might have formed the view that whatever one would have done, the death was inevitable anyway. I'm not saying that was the case in Claire, but that might have been the view of the person talking to the parents.

Therefore, there might have, in 1996, been a tendency to perhaps gloss over some of the aspects of the care which, if one were to pick over them, might not have been ideal or the sort of care that one might expect as a high standard. Does that answer the question, Mr Chairman?

THE CHAIRMAN: In order to do that, doctor, don't you have to have formed some view about the extent to which the fluid management contributed to her death?

A. Yes, you do. I'm speaking in --

THE CHAIRMAN: Because the greater the possible contribution, even in 1996, the more difficult it is to gloss over it.

A. Yes, exactly. I'm speaking from the perspective of somebody who believed that the fluid management was not the primary cause of the death, but rather that viral encephalitis and cerebral oedema were the primary causes and the fluid management was a secondary contribution. I'm not saying that is my opinion; I'm saying how somebody who felt that might have chosen to discuss it with the parents in that context.

THE CHAIRMAN: Okay, thank you.

MR FORTUNE: Thank you, sir.

THE CHAIRMAN: Thank you very much. Doctor, we're going to let the link go. Thank you again for your contribution. We're very grateful to you.

A. Mr Chairman, do you mind if I just make one final comment?

THE CHAIRMAN: Please do.

A. It's just, I'm sure that other people have said this, but Claire's case -- and I think some of the others that you are investigating in this inquiry -- are tragic, but I think they are highly exceptional. I'm sure you realise this, but I just wanted to give my own view that the way in which her cerebral oedema and hyponatraemia

developed was alarmingly rapid and most children, even presenting in very similar situations, having received exactly the same treatment, would not have deteriorated so rapidly. There was something -- and I don't think we have any idea what it was -- that made her much more susceptible and vulnerable to all the things that contributed to her death, which another child of the same age and same situation may not have done that.

Our understanding and our level of scientific knowledge of the nature of these types of problems is still really quite primitive and we have a long way to go to understand why different patients react differently to treatments given and to illnesses that they have. It still is difficult to understand and comprehend quite why Claire deteriorated so rapidly in this situation.

THE CHAIRMAN: Thank you very much.

A. I hope you don't mind me adding that.

THE CHAIRMAN: Not at all, thank you, doctor.

(The witness withdrew)

TIMETABLING DISCUSSION

Ladies and gentlemen, that brings an end to today's evidence. Let me update you with where we're going next.

We have Dr Squier tomorrow morning from 10 am.

Dr Harding is now in Philadelphia. We think we have a video link set up with him for tomorrow afternoon. That's a little bit uncertain, but it will be in the afternoon because he's five hours behind us.

Then on Thursday, you will all already have received the inquiry opening on governance. So what will happen on Thursday morning from 10 am is that Ms Anyadike-Danes will highlight some particular aspects of that. I think Mr Quinn, you wanted to --

MR QUINN: I have a short opening, which will be available tomorrow morning.

THE CHAIRMAN: Thank you very much. Does anyone else intend to say anything on Thursday morning?

MR FORTUNE: Sir, on a matter of housekeeping, bearing in mind the transatlantic time difference, what time is the video link?

THE CHAIRMAN: I have asked for it to be at 3 o'clock our time, which is 10 am his time.

MR FORTUNE: And how long is it envisaged that the link will be open?

THE CHAIRMAN: We think a maximum of two hours is all that's required. Dr Harding's comments tend to be concise.

MR FORTUNE: I was merely thinking of the stenographer in this case.

THE CHAIRMAN: Yes. Then on Thursday, after the two

openings, we've got Miss Jackson to give evidence, and that will be the end of Thursday. As you know, we're not sitting on Friday. That takes us into next week.

Just on a couple of points, I think, Mr Sephton, in your absence last week, there were a couple of issues raised about documents from Dr Webb, which I'm afraid we rather overlooked yesterday. There were two categories of documents. One is picked up from his third statement, 138/3, page 2, in which he refers to published concerns about sending children to an adult facility for an emergency investigation such as a CT scan.

MR SEPHTON: My instructing solicitor has drafted a letter to the inquiry dealing with that point and will be sending it. I have today e-mailed Dr Webb to remind him about the matter that was raised right at the end of his evidence yesterday evening.

THE CHAIRMAN: That's about whatever e-mail exchanges he had with Mr Walby about his statement for the inquest? Okay, thank you very much indeed.

Beyond that, we have a four-day week next week and then a three-day week on the following week -- the week before Christmas -- that's Monday, Tuesday and Wednesday, and I hope that gives us the time we need. I think it should give us the time we need to complete

these aspects of the investigation into Claire's death.

In the week commencing 14 January, you will have seen Dr Rating's reports have been circulated. They have gone to Professor Kirkham. We have asked her for any comment that she wants to make. But both Dr Rating and Dr Kirkham will be giving evidence in the week of 14 January. And we also intend to use that week to finish off and catch up on the evidence of Dr Ian Carson, Mr William McKee, both from what was then the Royal Trust and which became the Belfast Trust, and the evidence of the inquiry's expert governance expert in Adam governance. That's Mr Aidan Mullan. So we're going to do those all in that week. That will inevitably be a five-day week and we don't quite have the witnesses in the order we would like because, as I understand it, Dr Rating is available on Monday and Professor Kirkham is available on Thursday, which is a bit less than ideal, but there it is. You have Dr Rating's reports and we have asked Professor Kirkham for her concise response.

Beyond the week of 14 January, we will be moving into the first element of the investigation into Raychel's death, which is the aftermath of Lucy Crawford's death. I'm not yet in a position to give you a timetable on that, but I hope to do so next

week. I think if we do have a five-day week in the week of 14 January, I think you can take it it's highly unlikely that we'll be sitting in the week of 21 January.

10 o'clock tomorrow morning. Thank you very much indeed.

(4.00 pm)

(The hearing adjourned until 10.00 am the following day)

I N D E X