

Penrose Inquiry

The following transcript is for Day 79 of the Oral Hearings of The Penrose Inquiry, held on 15th December 2011.

This session comprised two closed sessions during which a patient or relative gave evidence anonymously to protect their privacy.

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1 Thursday, 15 December 2011

2 (9.30 am)

3 LAURA

4 Questions by MS PATRICK

5 THE CHAIRMAN: Good morning.

6 Yes, Ms Patrick.

7 MS PATRICK: Good morning. This morning our witness is
8 Laura.

9 I would like to start this morning by letting you
10 know who everybody is in the room. On the bench we have
11 Lord Penrose and Professor James, the medical adviser to
12 the Inquiry. Seated next to you is Margaret, who
13 I think you know, and coming along the front we have,
14 closest to you, the two stenographers, who are noting
15 down everything that's said for the Inquiry transcript.

16 Next we have Maria McCann, the secretary to the
17 Inquiry and then Oli Stempt, who is in charge of the
18 documents this morning.

19 You have met Laura and myself and seated behind us
20 is Lindsey Robertson, who is assisting us with this
21 topic.

22 On the other side we have the lawyers for the core
23 participants to the Inquiry. Those closest to me are
24 representing the patients, relatives and the
25 Haemophilia Society. Those in the middle are

1 representing the health boards and the
2 Scottish National Blood Transfusion Service, and closest
3 to you we have the lawyers for the Scottish Government.

4 The Inquiry has given you the name "Laura" for
5 today's proceedings, as a pseudonym. You helpfully
6 provided a witness statement to the Inquiry and this is
7 WIT0050297. I hope that you have a hard copy of that
8 in front of you.

9 A. Yes.

10 Q. Your husband has also provided a statement to the Inquiry
11 and that is WIT0050305. I may refer you to that
12 later.

13 A. Okay.

14 Q. In paragraph 1 you tell us that your date of birth is
15 [REDACTED]. So you are presently 47 years old?

16 A. Yes.

17 Q. Where do you live?

18 A. I live [REDACTED] in Edinburgh.

19 Q. And what's your present occupation?

20 A. I'm an office manager in [REDACTED].

21 THE CHAIRMAN: We are going to have to re-arrange the
22 microphones just a little, to make sure you are picked
23 up. That's better.

24 MS PATRICK: Is that better? Good. You have two children.

25 A. Yes.

1 Q. How old are they now?

2 A. My son is 24 and my daughter is 19 -- well, my son will
3 be 24 in a couple of weeks' time, and my daughter's 19.

4 Q. You tell us in paragraph 2 that you met your husband in
5 1983 and were married in 1985?

6 A. Yes, that's right.

7 Q. He has Haemophilia A and over the years has been treated
8 with plasma, cryoprecipitate and Factor VIII in respect
9 of bleeds.

10 A. Yes.

11 Q. I wonder if you could look at your husband's statement,
12 which is WIT0050305.

13 A. Yes.

14 Q. In paragraph 2 your husband tells us that he has mild
15 haemophilia with a 32 per cent Factor VIII level.

16 A. Yes.

17 Q. And so how often did he need treatment or has he needed
18 treatment since you have known him?

19 A. Not routinely, only if he has had an accident or a fall
20 or something.

21 Q. Yes. In paragraph 3 of his statement he tells us that
22 he was initially diagnosed with Christmas Disease as
23 a child, but this was later changed to Haemophilia A?

24 A. Yes, I think there was a lot of uncertainty when he was
25 young about exactly what the problem was.

1 Q. And before school he received treatment at the Sick Kids
2 Hospital, Edinburgh for an occasional childhood
3 accident --

4 A. Yes.

5 Q. -- and he thinks he was given plasma and cryoprecipitate
6 at that time.

7 A. Yes.

8 Q. He tells us that while he was in primary school, between
9 1961 and 1969, he had his appendix out?

10 A. That's right.

11 Q. And also needed to have his nose cauterised in the Sick
12 Kids Hospital as well, and he was given once again
13 plasma and cryoprecipitate.

14 A. That's right.

15 Q. In paragraph 4 he tells us that he had his wisdom teeth
16 taken out in 1980 and he thinks that he received
17 Factor VIII at that point.

18 A. Yes.

19 Q. And he didn't have any more bleeds until his 30s, and
20 since then they have only been occasional and as you
21 say, as a result of a fall or a knock.

22 A. Yes.

23 Q. And when he became an adult, he received his treatment
24 at Edinburgh Royal Infirmary?

25 A. That's right.

1 Q. And in paragraph 6 he tells us about a serious car
2 accident that he was involved in in October 1988, as
3 a result of which he required treatment for a head
4 injury at Borders General Hospital?

5 A. Yes, that's right. That's also why he doesn't have
6 a clear memory of some of the treatments that he had.

7 Q. Right.

8 A. The accident affected his memory slightly.

9 Q. And he required treatment with Factor VIII at that time?

10 A. Yes.

11 Q. Then once again in 1991, after a fall, he required
12 treatment for a knee injury at Edinburgh Royal
13 Infirmary?

14 A. That's right.

15 Q. And he has never been treated prophylactically nor had
16 home treatment?

17 A. No.

18 Q. In paragraph 8 of his statement your husband states that
19 in 1993 he received a letter from the haemophilia centre
20 at Edinburgh Royal Infirmary saying that he might have
21 been infected with a virus. Do you remember when your
22 husband received that letter?

23 A. I remember him going for the appointment.

24 Q. Yes.

25 A. And I remember he got a letter asking him to come for

1 the appointment.

2 Q. And did your husband have any idea what that might be
3 about?

4 A. No, he had no idea at all.

5 Q. He states that he went in for tests and in August 1993
6 had a follow-up appointment, when he received the
7 results of the tests, and he was told that he had
8 acquired the Hepatitis C virus.

9 A. As far as he was concerned, I think he thought it was
10 just a routine appointment. He used to go -- after his
11 car accident he used to go on an annual basis for just
12 a check-up, and I think he thought it was just part of
13 that.

14 Q. And he says there that he was told he had developed
15 antibodies and therefore would not need any treatment,
16 and he saw Dr Ludlam, Dr Dennis, Professor Hayes and
17 Dr Andrews. I think the medical records show that he
18 had antibodies to the virus in his blood but no trace of
19 the virus; the PCR level, the trace of the virus, was
20 negative and so he had basically cleared the virus
21 himself?

22 A. Yes, that's what he was told. And he told me that. It
23 didn't mean anything to me at the time.

24 Q. He says in paragraph 10 that initially he was told by
25 Dr Ludlam that the virus probably couldn't be passed on

1 and he continued to attend for regular blood tests.

2 A. Yes. That was probably as a result of me asking, was it
3 possible for the virus to have been passed on, and he
4 wasn't sure but he asked the question and that's what he
5 was told.

6 Q. And in paragraph 11 he says that you weren't offered
7 testing by the haemophilia centre at that time?

8 A. No.

9 Q. If we could return to your statement, please, to
10 paragraph 3, half way down that paragraph you tell us
11 that you didn't go to the hospital with your husband at
12 the time he was diagnosed with the Hepatitis C virus.
13 Is that right?

14 A. No.

15 Q. So you didn't attend these appointments with him?

16 A. No.

17 Q. You say that when he came home, he didn't seem to know
18 much about it but you asked him if you or your children
19 were at risk of contracting the virus and he said he
20 didn't know.

21 A. That's right.

22 Q. In the next paragraph, paragraph 4, you tell us that
23 a few weeks later you had an appointment with your GP.
24 Did you make this appointment specifically in relation
25 to the Hepatitis C virus or were you seeing your GP

1 anyway?

2 A. I remember being there because of one of the children
3 and the doctor was just asking -- I have known the
4 doctor for a long time and she was just asking generally
5 how the family were and I mentioned about my husband,
6 that this had come up about this Hepatitis C and she
7 didn't seem to know much about it, and I didn't know
8 much about it. It was during that conversation that she
9 offered to put my mind at ease by -- she said I could
10 have a blood test.

11 Q. So she carried out a blood test at that time?

12 A. Yes.

13 Q. You say that the results weren't conveyed to you after
14 then and it wasn't until you went back to another
15 appointment to see your GP, which was about four to six
16 weeks later?

17 A. I think that was a routine appointment for myself and
18 I just happened to mention during the appointment that
19 I had had this blood test and I had never heard
20 anything, and she said, the -- the doctor said at that
21 time, "Oh, yes, it came back positive," and I was
22 shocked, I was surprised that I hadn't been informed.
23 I'm not quite sure why.

24 Q. The test result is WIT0050333. It's dated
25 30 July 1993 and it's positive for the antibody to the

1 Hepatitis C virus. So when she told you that you had
2 tested positive for the virus, what else did she tell
3 you about it at the time?

4 A. Not a lot because I asked -- I said -- I asked her what
5 Hepatitis C was because I had never really heard of it,
6 and she said to me that it was what had been referred to
7 in the past as "non-A non-B". But that still didn't
8 really mean very much to me and she didn't seem all that
9 clear herself what the implications were, and she
10 suggested that I should contact the infirmary, contact
11 the haemophilia centre.

12 She wasn't very sure about treatments and she did
13 tell me that it was a virus that could take some time
14 to -- you know, to -- could be in your system for some
15 time before it came to light. But I really wasn't given
16 an awful lot of information.

17 Q. And so, as you tell us in paragraph 5 of your statement,
18 you then telephoned the haemophilia centre at Edinburgh
19 Royal Infirmary?

20 A. Yes.

21 Q. Who did you speak to there, can you remember?

22 A. No, I don't remember clearly -- no, I don't remember who
23 I spoke to. I would normally -- if I phoned the
24 haemophilia centre at all, I normally just asked to
25 speak to the sister, but I don't remember on that

1 particular occasion who I spoke to.

2 Q. And you informed the person you spoke to that you had
3 been tested by your GP and that you were positive for
4 the virus?

5 A. Yes.

6 Q. The person you spoke to seemed sceptical?

7 A. Yes, when I explained, they said that it was unlikely
8 that I would have contracted the virus through my
9 husband. So I think what they were trying to say was it
10 might have nothing to do with the haemophilia centre but
11 they would have me -- they suggested I could come in and
12 be tested by them, and I had known them -- the staff
13 there -- for some time, so it -- it was almost like
14 I felt like they were doing me a favour, saying, "Come
15 in, we will just double-check," kind of thing.

16 Q. If we have a look at WIT0050309, these are notes of an
17 appointment at the liver clinic, dated 17 August 1993.

18 A. Yes.

19 Q. They record:

20 "Came with husband, full discussion re Hepatitis C
21 investigation and interferon treatment with Dr Ludlam,
22 Dr Hayes. Agrees to endoscopy, laparoscopy and liver
23 biopsy."

24 A. Yes.

25 Q. So were you told why that was a good idea?

1 A. I remember the appointment with Dr Ludlam and Dr Hayes.
2 And my husband came with me because by then -- you know,
3 this was -- I had also been tested by the
4 haemophilia centre and I knew that I had this virus, and
5 my husband came with me so we could try and find out
6 some more about it.

7 They did explain that the virus could cause damage
8 to the liver and therefore if they took a liver biopsy,
9 they could see -- and they might be able to tell how far
10 the virus had affected my liver at that stage.

11 Q. So do you think this was your first appointment at the
12 haemophilia clinic or had you been in before for
13 a further blood test?

14 A. I had been in before that for a blood test. This was
15 when they confirmed the blood test had come back
16 positive. They set up this appointment. That's my
17 recollection.

18 Q. Yes.

19 A. I definitely had had a blood test before that.

20 Q. Underneath it's noted:

21 "Found by GP to be Hepatitis C-positive. Virology
22 are sub-typing Hepatitis C to establish if this is
23 a sexual transmission."

24 You tell us in paragraph 5 you don't know the
25 genotype of the virus --

1 A. No.

2 Q. -- that you have had?

3 A. No, I had never heard that reference "genotype". It was
4 never ever mentioned to me that there were different
5 types. I didn't know anything about that --

6 Q. No.

7 A. -- until I was asked the question.

8 Q. Yes. In fact further investigations were undertaken by
9 the haemophilia clinic?

10 A. Yes.

11 Q. You tell us in paragraph 8 that you had asked Dr Ludlam
12 if you could have contracted the virus through your
13 husband and he said that it was unlikely.

14 A. Yes.

15 Q. You were sure you hadn't had a blood transfusion
16 previously, although you had had major surgery on your
17 hand in 1982 at Edinburgh Royal Infirmary.

18 If we have a look at WIT0050336, this appears to
19 be a letter in response to an enquiry by the haemophilia
20 department --

21 A. Yes.

22 Q. -- as to whether you might have received a blood
23 transfusion at that time, and it's a letter dated
24 7 September 1993.

25 It's noted there that you suffered severe

1 lacerations on your right hand in January 1983, having
2 put it through a glass window. You were admitted to
3 Ward 6 at the Royal Infirmary:

4 "... but I have very little information on what
5 happened in the ward. There is no mention that she had
6 a blood transfusion."

7 A. I was 99.9 per cent certain I hadn't. But they wanted
8 to follow it up.

9 Q. If we look next at WIT0050337, this shows further
10 investigations that were carried out by the
11 haemophilia centre, and this is a letter from IW Young,
12 clinical assistant to Dr Ludlam, to Dr McLelland,
13 director of the blood transfusion service, dated
14 9 September 1993. It's basically asking the blood
15 transfusion service if it is possible to check through
16 your records to see whether in fact you did receive any
17 blood products at the time of your admission in respect
18 of your hand injury.

19 A. Yes.

20 Q. The response to this was WIT0050339. And this is
21 a letter from Dr Audrey Todd, consultant at the
22 Edinburgh and Southeast Scotland Blood Transfusion
23 Service, to Dr Young, dated 24 September 1993. It
24 states:

25 "I have checked her computer records to see if there

1 is any record of her receiving a blood transfusion but
2 there is no match at all with her married or single name
3 with the date of birth given. However, our computer
4 records are only complete from 1984. It is quite
5 a lengthy procedure to unearth the paper records for the
6 whole month..." and I wondered if it might be better to
7 look back at the notes from the Infirmary at the time.

8 It notes:

9 "It must be very unlikely that she would require
10 transfusion for hand lacerations, even if these were
11 severe ... "

12 And the quickest way of getting an answer to your
13 query would presumably be to consult Royal Infirmary
14 notes.

15 Another letter goes back, which is WIT0050340, and
16 this is from Janet Andrews, clinical assistant to
17 Dr Ludlam, to Dr Todd, dated 12 November 1993. It
18 states:

19 "We have been able to examine her orthopaedic notes
20 relating to her hand injury and there is no mention of
21 blood products being given. However, Dr Ludlam is very
22 keen to establish beyond all doubt that she did not
23 receive a blood transfusion and I wonder whether it
24 would be possible for your records for the days around
25 22 January 1983 to be examined. The reason we need to

1 is because [Laura] is married to a patient with
2 haemophilia, and although he is positive for Hepatitis C
3 antibody, he is hepatitis PCR negative. Whereas [Laura]
4 is antibody and PCR positive. It is obviously vitally
5 important to establish whether [Laura] acquired the virus
6 sexually from her husband or whether it came from
7 somewhere else. I would be most grateful for your
8 help."

9 The reply to this was WIT0050342. It's a much
10 briefer response from Dr Todd to Dr Young, dated
11 14 December 1993, stating:

12 "We have checked our archived paper records on this
13 patient for January 1983 and this shows no record of her
14 having received any blood products."

15 If we return to WIT0050309, which were the notes
16 of your attendance at the clinic. It's at the bottom.
17 This is a note of your attendance on 11 November 1993,
18 when you were seen with your husband. This appears to
19 be an appointment after the further test results.

20 A. Yes.

21 Q. Showing that you are Hepatitis C PCR-positive, and it
22 notes:

23 "Further discussion re Hepatitis C. Told that she
24 is Hepatitis C PCR positive and needs investigation,
25 whereas her husband is PCR negative and does not.

1 "She is quite certain that she did not receive
2 a blood transfusion.

3 "She has not had other sexual partners -- this is
4 her first marriage ...

5 "Household spread (toothbrushes/razors) -- denies
6 this as a possibility.

7 "No history of jaundice.

8 "Alcohol 1 to 2 units a week. Rarely more."

9 It indicates there further investigations that are
10 undertaken.

11 A. Yes.

12 Q. So other ways of you having acquired the virus were
13 obviously discussed with you in great detail and they
14 didn't --

15 A. It's not something -- we have never shared toothbrushes
16 or anything like that. I have never had any other
17 sexual partners. So yes, this was all discussed with
18 me.

19 Q. And you tell us further on in your statement that it was
20 some time after you had completed treatment, which was
21 in about 1997/1998, that you spoke again to Dr Dennis
22 about how you could have contracted Hepatitis C.

23 A. Yes, it was never actually confirmed to me prior to that
24 I had contracted the virus through my husband.

25 I knew -- I always felt it was a possibility. I knew it

1 had been -- they asked me about transfusion, et cetera,
2 when I had had my hand injury, but it was never really
3 referred to again and no one actually said or confirmed
4 anything and it niggled at the back of my mind. I just
5 wanted to know, and I did ask the question again later
6 on because I had never really felt I had been given a
7 clear answer.

8 Q. And you state in your statement that it was confirmed to
9 you that they were now aware of a few other cases where
10 secondary infection had occurred through sexual
11 transmission, and it was more than likely that was how
12 you had contracted it from your husband.

13 A. Yes, I remember having a conversation and it being
14 mentioned that one or two other cases had come to light.
15 I think actually it was mentioned down south, where the
16 infection had been spread to a partner, and so they now
17 realised that this was a possibility and also, because
18 they had done some investigation in my case, that it was
19 more than likely -- was how it was put to me -- that
20 that was how I had contracted it.

21 Q. And Dr Dennis subsequently completed the Skipton Fund
22 application form for you.

23 A. Yes, she did.

24 Q. And confirmed in that that you had contracted
25 Hepatitis C from your husband.

1 A. Yes, she did.

2 Q. One anxiety that you and your husband had was whether
3 your children could have been infected with the virus,
4 and I think it was recorded in the previous page at your
5 previous appointment on 17 August 1993 that "both
6 parents request Hepatitis C tests for the children"?

7 A. I was very worried. Because they couldn't give me
8 a straight answer. And because they had mentioned
9 things like sharing of toothbrushes, I really was very
10 concerned, although it was not something we would do in
11 the house, because, young children, sometimes just help
12 themselves to things, I was quite concerned.

13 Also I didn't -- in the back of mind, because my
14 daughter was only a year old, I was concerned that I had
15 had the virus while I was carrying her and I didn't
16 know -- no one seemed to know very clearly at that stage
17 whether that would have been a risk to her as a baby and
18 I just felt I needed to know for certain whether either
19 of the children had the virus.

20 Q. And so the haemophilia centre arranged for your son to
21 be tested and your daughter.

22 A. Yes. We arranged an appointment for me to take the
23 children to be tested.

24 Q. And you tell us in paragraph 8 -- we don't need to refer
25 to it -- that your daughter, who was 18 months old at

1 the time, it was difficult for them to obtain a blood
2 sample from her and so she had to be taken to the
3 Simpson Special Baby Unit in Edinburgh, where the blood
4 sample was taken, and she was obviously very upset with
5 this and you and your mother found the whole
6 experience --

7 A. It was quite traumatic for her because she didn't
8 understand what was happening and they couldn't find
9 a vein with her being a baby and so on, and it was
10 difficult.

11 Q. And both children tested negative for the virus?

12 A. Yes.

13 Q. You were admitted to hospital in January 1994 for
14 further investigations and you underwent an upper GI
15 endoscopy and a laparoscopic liver biopsy on
16 13 January 1994. How did you find these procedures?

17 A. Horrible. The endoscopy I remember being particularly
18 horrible because I wasn't given any sedation.

19 I know sometimes -- I have had them since and
20 sometimes you get sedation, but I wasn't on that
21 occasion. And I went -- I'm sure it was on the same day
22 or -- it was -- my recollection is I had that and then
23 just a short time afterwards -- I was in the liver unit
24 and going into theatre, and although it was a minor
25 procedure, probably, to the doctors, to me it was a big

1 thing and I found it quite traumatic. And obviously not
2 knowing what the outcome would be of it as well, was in
3 the back of my mind.

4 Q. Was the liver biopsy painful?

5 A. Not painful, just it was -- no, I don't remember it
6 being painful. It was uncomfortable and I had mild
7 sedation for that, if I remember rightly, because I do
8 remember being in the theatre.

9 Q. And they were both carried out on one day and you stayed
10 overnight in the hospital and returned home.

11 A. That's right.

12 Q. Do you feel that you had any symptoms of the Hepatitis C
13 virus at that time?

14 A. I felt quite run down that summer but prior to that in
15 fact, probably in the spring that year, and I wasn't
16 sure whether it was just having a young baby. At the
17 time I put it down to that but it was only later, when
18 I realised that I had the virus, I began to think, well,
19 that might have contributed.

20 Even when I had my daughter, I felt -- you know,
21 whether you have a young baby, it can take time -- when
22 you have a baby it can take time to recovery. I didn't
23 feel I recovered or got my energy levels back the way
24 I would have expected to at that time. But I put it
25 down to other reasons. But that would be the year

1 before.

2 Q. Could I refer you, please, to WIT0050346. This is
3 a letter from Janet Andrews to your GP, dated
4 10 February 1994, and it states the results of those
5 investigations:

6 "Endoscopy -- normal, with no evidence of ...
7 varices.

8 "Laparoscopy -- [result was that the] liver was seen
9 to be slightly increased in bulk, with yellow areas,
10 suggesting fatty infiltration.

11 "Liver biopsy -- reported focal fatty change and
12 a periportal chronic inflammatory infiltrate ... with
13 focal piecemeal necrosis. These appearances are in
14 keeping with Hepatitis C infection."

15 Were you told what these findings meant?

16 A. I remember being told that, because of the finding --
17 what they had found, it was likely I had had the virus
18 for some time and I must admit, that upset me because
19 from what I had been told by -- previously, the sort of
20 life expectancy, if you like, from contracting the virus
21 to, you know, a critical stage, was -- 10 to 15 years
22 was what I was told but no one could tell me how long
23 I had had the virus but this indicated I must have had
24 it for a little while.

25 So obviously, with, you know -- no certainty about

1 treatment, I was quite concerned about my life
2 expectancy at that stage and this just confirmed --

3 Q. So had you been told that the life expectancy was 10 to
4 15 years and you had had it for a while, did you feel
5 then that your life expectancy was a lot less than 10 to
6 15 years?

7 A. Definitely, and that obviously caused me a lot of trauma
8 because I had a young family.

9 Q. Did you discuss that with the doctors?

10 A. I don't remember discussing it with them. I remember
11 them explaining to me about the -- you know, what this
12 meant, and they probably could see that I was upset but
13 they couldn't give me any guarantees about treatment at
14 that stage, so it was just a case of, "Well, you know,
15 we will give you the treatment that we can." With no --
16 I don't remember having particularly lengthy
17 discussions about it.

18 Q. This letter records that it was decided at that clinic
19 appointment that you should be treated with interferon.

20 A. Yes, they explained that to me, that that was the only
21 course of treatment really that they felt -- well, that
22 was available.

23 Q. And you were asked to attend the haemophilia centre to
24 be shown how to give the injections?

25 A. Yes.

1 Q. And for pre-treatment blood tests. In fact all your
2 treatment was carried out at the haemophilia centre.

3 A. It was.

4 Q. You carried on attending there throughout.

5 A. I do remember at that stage asking the question: if this
6 treatment doesn't work -- because they couldn't
7 guarantee that it would work and I knew that -- what was
8 the worst case scenario? And I was told that in certain
9 cases, if the virus continued to develop, there was
10 a mention about liver transplant being a last -- the
11 worst case scenario.

12 Q. And this letter records that you were warned to expect
13 flu-like symptoms following the first six to eight
14 injections.

15 A. That's right.

16 Q. And how it was better to have the injection in the
17 evening and take a couple of paracetamol tablets at the
18 same time.

19 A. That's right.

20 Q. And most patients find that by the following morning,
21 the symptoms have subsided. A mild degree of depression
22 occurs in some patients but hair loss is not a problem
23 at this low dose.

24 A. Yes.

25 Q. Had you suffered from depression before then?

1 A. No.

2 Q. So you started treatment with interferon
3 in February 1994?

4 A. Yes, that's right.

5 Q. And in paragraph 7 of your statement, which is at 0299,
6 you tell us that you attended the haemophilia centre
7 every month to have liver function tests.

8 A. Yes.

9 Q. How did you find taking the treatment and injecting
10 yourself?

11 A. Quite scary to begin with. I went into the
12 haemophilia centre and the nurse was teaching me how to
13 do it -- do the injections. Because I had had
14 an injury -- put my hand through a glass door, since
15 then I have had a bit of a thing about glass. I'm not
16 very confident, and certainly one of the things you had
17 to do was break a glass vial of sterile water, and
18 I found that extremely difficult to do because I was
19 very nervous, and I actually I did cut my finger quite
20 severely and I had to be rushed over to another part of
21 the hospital to see if I needed stitches, and I know it
22 was probably because I was quite nervous that I did that
23 and -- I mean, the staff were really good, trying to
24 help me and I did -- I just decided I had to learn to do
25 it and that was it. But it was difficult. And the

1 thought of injecting yourself, I don't think appeals to
2 anyone. So I found that quite difficult to come to
3 terms with.

4 Q. In the second half of that paragraph you tell us about
5 the side effects of the treatment. You tell us that
6 while on the treatment you felt extremely tired,
7 generally miserable and depressed, and you physically
8 ached and had no appetite. Did you lose weight?

9 A. I was just going to say, yes, I lost weight. I found
10 myself -- I was very low all of the time. I just felt
11 completely flat. I found everything quite an effort.
12 I remember, you know, for example, my daughter's
13 birthday parties being a real effort to try and get
14 everything organised and much more so -- I just felt
15 physically exhausted, quite tired and just miserable all
16 the time.

17 Q. Yes, and you tell us also that you were quite a busy
18 lady at that time, looking after a five year old and
19 a baby and also running your own business as [REDACTED]
20 [REDACTED].

21 A. That's right.

22 Q. When had you started that business?

23 A. In 1992, the year before my daughter was born. My
24 husband and I wanted another child but I didn't want to
25 be working full-time and it was something I had always

1 wanted to do, and for 18 months I had studied and I did
2 the exams on my own -- in my own time. I was so excited
3 about qualifying, just because it was something I had
4 achieved that I had always wanted to do and I enjoyed
5 it. So when I had my daughter, it was ideal because
6 I could work in the evenings and the weekends when my
7 husband was at home and I didn't need to arrange other
8 childcare for my daughter. I didn't want to do that.

9 So, yes, I had been running the business, as I say,
10 since 1992 and I was building it up and I had quite
11 a good client base by that time, but I was finding it
12 very difficult. There was one day I found particularly
13 scary. [REDACTED]

14 [REDACTED] [REDACTED]
15 [REDACTED]
16 [REDACTED] I actually found
17 myself nodding off or -- you know, on the point of going
18 to sleep, [REDACTED], and I was so
19 scared and I just -- I just didn't -- it was so
20 frightening, to be supposedly in control and knowing
21 that you are not in control at all, and that was when
22 I realised that the treatment was really affecting me.

23 Q. You say you weren't able to concentrate to do your job
24 properly and as you have said there, felt unsafe?

25 A. I just wanted to sleep a lot of the time. I found

1 myself so tired that I found it difficult to do [REDACTED]
2 [REDACTED]. I found it difficult to concentrate on
3 [REDACTED] and it became more and more difficult.

4 Q. Yes. But you say there that due to financial pressures,
5 you kept going.

6 A. I didn't know what else to do because my husband
7 doesn't -- didn't have a particularly highly paid job.
8 We had a mortgage et cetera. I had bills, [REDACTED]
9 [REDACTED] my business was expensive because you
10 have to have -- [REDACTED]
11 [REDACTED]. Being [REDACTED], you know, you have to
12 [REDACTED]. So I had financial
13 commitments and I didn't really know what else to do,
14 and I did try to keep going as long as possible.

15 Q. Yes. And the medical records show that as well as these
16 symptoms, you also suffered from headaches. On one
17 occasion your period was late so you had to have
18 a pregnancy test and you also suffered from thinning of
19 your hair.

20 A. Yes.

21 Q. Did you receive help from other people during this time?

22 A. My family -- I have got a very close family but my mum
23 and dad were both working at that time, but they helped
24 when they could. My husband -- he was out of his depth
25 a little bit a lot of the time because he was finding it

1 increasingly difficult to cope, because he obviously
2 knew I was finding it difficult and we had young
3 children and he was trying to work full-time. But
4 I have got sisters as well and everyone sort of helped
5 when they could, with the children especially.

6 And there were some days when I just -- especially
7 at the weekend, I would ask my husband to take the
8 children out swimming or something because I needed
9 time, I needed to have a sleep. I just needed a rest.

10 Q. And were you signed off work for a time by the doctors
11 during that treatment?

12 A. No, not really because I worked for myself, I did not
13 have any insurance cover for medical -- I don't remember
14 being signed off.

15 Q. No.

16 A. I would just take days off if I needed to.

17 Q. There is a note in your records, WIT0050364 of you
18 having been issued with a Med 5 on 8 September, stating
19 that you had been unfit for work from 30 May 1994
20 continuously for four months.

21 A. I think I did speak to the doctor about that and, yes --
22 I think you are right, I think I did get a medical
23 certificate but it didn't -- financially it didn't mean
24 anything.

25 Q. So you kept going?

1 A. I did what I could but the doctor didn't think I should
2 be working.

3 Q. If we have a look at WIT0050347, this shows us the
4 effect of your treatment with interferon. The column on
5 the left is showing the dose that you received, the
6 weeks of treatment is the next column and your ALT
7 levels are in the third column, and they show that by
8 the second week they had halved.

9 A. Yes.

10 Q. And they reduced a bit more by the fourth week but then
11 went up again in the eighth week, and by quite a lot,
12 more again by the 12th week.

13 A. Initially there seemed to be a good response and I was
14 quite optimistic but then ...

15 Q. You will see the next column is showing your viral load
16 and this showed no change other than a slight reduction
17 on the eighth week. I think the last two columns relate
18 to an anti-interferon antibody, which shows that you
19 developed an antibody against the interferon treatment,
20 which may explain why it wasn't working.

21 A. Yes.

22 Q. The treatment was in fact stopped after 27 weeks --

23 A. Hm-mm.

24 Q. -- on 30 August 1994.

25 A. Yes.

1 Q. If we have a look at WIT0050359, this is the letter
2 from Janet Andrews to your GP, dated 30 August 1994,
3 confirming that you have now completed 27 weeks. The
4 results of the ALT values over the six-month period have
5 not shown any improvement and there has been no
6 reduction in the quantitative Hepatitis C PCR:

7 "It is therefore clear that she has not responded to
8 interferon and she should not continue with it. I have
9 explained this carefully to [Laura]. We will be
10 following her up carefully and will hopefully be able to
11 offer some other treatment in the not too distant
12 future."

13 A. Yes.

14 Q. How did you feel at that point?

15 A. Devastated. Because there was no clear indication of
16 how soon other treatment would be available. I found
17 that very difficult to cope with because, as I said
18 before, I felt -- I did feel I was living on borrowed
19 time to a certain extent. I know it sounds a bit
20 dramatic and I know we are talking about a few years,
21 but I just felt I was young, I had a young family.
22 I had this virus and nobody was able to offer me
23 a solution or a treatment to give me some sort of hope,
24 and they clearly couldn't say at that time how long it
25 would be before anything else became available.

1 Q. Did the side effects continue for a while after the
2 treatment finished?

3 A. I think they did, yes. I think the main thing was,
4 I suppose -- it might have been the treatment, it might
5 have just been how I was feeling but I felt quite low
6 for a long time afterwards. I found it -- I just
7 couldn't shake off that feeling of dread, if you like,
8 that I felt all the time and I was -- I suppose I was
9 quite -- I don't know -- I wouldn't have said I was
10 depressed but I probably was. I was certainly very low.

11 Q. Yes. If we look at WIT0050311, this is a note of your
12 attendance at the clinic three months after you finished
13 interferon. It's a handwritten note. We see the top
14 entry is dated 3 November 1994. It records:

15 "Three months off interferon. Tired. On
16 anti-depressants from GP to help her sleep. Seems down.
17 Has had a lot to cope with over the past year,
18 Hepatitis C, liver biopsy et cetera and young children.
19 Working very hard."

20 A. I think the other thing, in 1993 my husband had been
21 made redundant just about the same time that he was told
22 about the Hepatitis C. So we had had a difficult year
23 because, as I say, he was redundant and then he was told
24 about the Hep C, then I was told about the Hep C. Then
25 I had the treatment. It had just been an incredibly

1 difficult time for us, and not having, as I say, any
2 treatment or any hope of a good outcome, and I'm
3 normally quite -- I think I'm normally quite an --
4 optimistic person but that was quite a dark time.

5 Q. Yes. And did the anti-depressant treatment help?

6 A. I'm not sure. It helped a bit. It helped me to cope
7 with day-to-day things and -- but I do feel -- my
8 recollection is with, as I say, my daughter especially.
9 My son was at school but with the children, I feel that,
10 when I look back and think about how things were,
11 I wasn't a very fun mum at the time. I wasn't very good
12 at maybe spending time with them because I just didn't
13 feel I had the energy or the -- I mean, I did what I had
14 to do but it would have been different prior to that.

15 I mean, I had waited quite a few years -- I waited
16 five years to have my daughter, and I had been enjoying
17 having a little girl and it suddenly -- you know, I was
18 having to cope with all these other things, and that was
19 taking my time, coping with that was taking up all my
20 time and energy.

21 Q. Yes. If we look at the next entry there, which is,
22 I think, 2 February 1995, we can see that things had
23 improved for you by then. It's noted that you are much
24 better.

25 A. Yes, I had had a -- I think, if I remember rightly, it

1 was prior to that I had had a little bit of counselling
2 and I had been told to try and make time for myself, and
3 obviously I had been very busy with my business and with
4 the children and I didn't always make time for myself.
5 I was trying to do all the things I had been advised to
6 do and yet I had good spells and bad spells.

7 Q. You had been on anti-depressant medication for three
8 months and it's noted you put on weight and were eating
9 well and sleeping well and were much happier at that
10 time.

11 A. Yes.

12 Q. But, as you say, this could have been a good spell in
13 a --

14 A. That's right.

15 Q. So you continued to attend, as you tell us in
16 paragraph 10 of your statement, for regular check-ups
17 and you tell us that you were advised that you should
18 give up work, as you were very run down, both physically
19 and emotionally, and needed to build up your immune
20 system.

21 A. Yes, well, I was told that if treatment -- if and when
22 treatment became available -- they didn't actually come
23 right out and say that I hadn't given myself a chance
24 with the first lot of treatment but I kind of felt the
25 implication was there that, because I had been too busy

1 and trying to work and take the interferon and cope with
2 everything, that that had contributed to me being more
3 run down and possibly not given myself enough of
4 a chance to fight the virus. And it was suggested that
5 I should try and ease up a bit, to give my body a chance
6 to fight the virus, especially if treatment became
7 available.

8 Q. Yes. And you tell us there that your family were
9 extremely worried about you.

10 A. Yes, my mum especially. My mum and dad were extremely
11 worried, yes, and they talked to me about, you know,
12 financially how they would try and help if I could ease
13 up on work and so on.

14 Q. So you obviously tried to work less --

15 A. Yes.

16 Q. -- initially, because it says you worked part-time due
17 to the financial pressures, but as you were feeling
18 worse as time went on, you gave up your business
19 completely and handed the car back to the finance
20 company in 1996?

21 A. Yes, that was actually an extremely hard thing because
22 in our relationship I have always been the one that
23 looked after the finances and there is something -- you
24 know, I like to think everything is up-to-date and all
25 my bills were paid, and we actually had fallen so far

1 behind with payments on the car, we were starting to
2 struggle with the mortgage, et cetera. And I found that
3 extremely distressing because I had never been in that
4 position before. And I had a lot of communication with
5 the finance company about my car and I tried to explain
6 the situation to them, that I couldn't work the way
7 I had been working before, and try and negotiate some
8 sort of deal with them so that I could either manage the
9 payments or return the car or something. And I found
10 them not very understanding and this went on for a good
11 few months, a lot of negotiation.

12 And the final straw, I had a phone call with them
13 and I just remember being in floods of tears because
14 they just didn't want to know. They didn't understand
15 what I was -- they didn't want to know what I was going
16 through.

17 I eventually said to them, "Look, there is no way
18 I can make these payments. All I can suggest is you
19 take the car back." I had never ever been in a position
20 where I had had anything repossessed, and of course they
21 sent a company out to take the car away and I found that
22 just terrible. It wasn't the fact I wouldn't have a car
23 but it was just the fact that I felt I had let everybody
24 down because I couldn't keep up to date with my
25 commitments.

1 Q. You had done remarkably well to keep going until then.

2 A. I had never been in debt, but we were in debt then.

3 THE CHAIRMAN: You are all right?

4 A. Yes.

5 MS PATRICK: Thank you.

6 THE CHAIRMAN: If you want a wee break at any time, just let
7 us know.

8 A. I'm okay, thanks.

9 MS PATRICK: Just to finish that matter, it's stated there
10 that you lost a lot of money. Was that by returning the
11 car?

12 A. Yes, I was eventually able to -- the finance company
13 agreed that I should return the car and they just wrote
14 off the payments that were outstanding. So that helped
15 a bit. But we had fallen behind with our mortgage and
16 obviously I wasn't working the way I had been working
17 before, so we were in a position where, as I have
18 said -- we were actually -- I don't know how we managed
19 but our outgoings were more than our income, and my
20 parents were helping us when they could, and we just got
21 further and further into debt.

22 Q. We can see in the next paragraph that you started
23 treatment the second time in March 1996. Was this
24 before then?

25 A. It was about the same time. It was -- because I knew

1 the treatment was -- I was going to be starting that
2 treatment and because they had said to me, "It would
3 really be much better if you could give up work or
4 change your job, so that you are not under the same
5 stress and working the same hours. You really need to
6 give yourself a chance to let this treatment work." So
7 that was why I had to do something, and that was when
8 I handed the car back to the finance company.

9 Q. Yes. I wonder if I could refer you to WIT0050393,
10 which is a record of an appointment with Dr Ludlam.
11 This is a letter from him to your GP, dated
12 14 February 1996. It relays your previous treatment and
13 then in the fourth paragraph says:

14 "As far as her HCV is concerned, investigation of
15 her liver some time ago revealed moderate hepatitis,
16 without fibrosis or cirrhosis.

17 "There are two options now. One would be to monitor
18 her status ever few months and consider further
19 treatment, when new anti-HCV medicines become available.
20 The other option would be to start her on a course of
21 Wellferon. This is a mixture of Alpha Interferon and
22 there is some evidence that it is useful in individuals
23 who develop anti-interferon antibodies. The side
24 effects are likely to be very similar to the Roferon
25 ..."

1 Which you had been on before:

2 "... and she does not view these as being too much
3 of a problem, particularly if she took it at bed time.
4 She is going to think about the topics that we covered
5 in our discussion and will return again next week to
6 meet with myself and Dr Peter Hayes to review the
7 situation."

8 A. Yes.

9 Q. How did you feel at that point about the further options
10 open to you?

11 A. I didn't really feel I had any choice, I suppose because
12 I just wanted to get treatment as soon as possible and
13 I really didn't care at that stage about the side
14 effects. I would have put up with anything, just to be
15 able to start some sort of treatment.

16 Q. If we look at WIT0050395 this is a letter from
17 Dr Ludlam to your GP, dated 21 February 1996, recording
18 what happened when you attended the clinic on
19 20 February 1996. It records that he saw you again,
20 along with Dr Hayes, and they had reviewed the results
21 of ALT and HCV levels during your previous course of
22 interferon therapy.

23 A. Yes.

24 Q. In the second paragraph it states:

25 "Peter Hayes and I are of the view that it would be

1 reasonable to try her on wellferon, as this is a mixture
2 of interferons and is much more likely to be effective
3 in the presence of an anti-interferon Alpha IIa. She is
4 happy with this proposal but, as we agreed on her last
5 visit, we should perhaps wait two weeks before starting,
6 so that she can see how she feels having been off prozac
7 for by then a total of about three to four weeks."

8 A. I was never happy about being on prozac or anything.
9 I had never been depressed before and I was aware --
10 I thought the longer you were on these things, the more
11 difficult it would be to come off, and I was always keen
12 to get off that sort of medication as soon as possible.

13 Q. So you were obviously quite keen to get off that
14 medication before you started your treatment?

15 A. Yes, I was really trying at that stage to make sure that
16 I gave myself every chance to let this treatment work.
17 I didn't want anything to complicate things.

18 Q. So in paragraph 11 of your statement you tell us that
19 in March 1996 you started treatment for the second time
20 for Hepatitis C, and this was with wellferon?

21 A. Yes, I think it was March. Certainly about that time.
22 That is when I returned my car and the reason, as I say,
23 for doing that was because I knew I was about to start
24 the treatment.

25 Q. And again --

1 A. I didn't remember being on tablets at the time I made
2 this statement but --

3 Q. I think later on you were started on tablets.

4 A. Yes, I think I wasn't on tablets initially.

5 Q. No.

6 A. They were introduced part way through the treatment.

7 Q. They were. We will come on to that. So initially you
8 had to inject yourself three times a week, and once
9 again you felt dreadful. You functioned on auto-pilot
10 and at times couldn't get out of bed.

11 A. Yes.

12 Q. You were constantly tired and irritable.

13 A. Hm-mm.

14 Q. Could I refer you to WIT0050406? This is a record of
15 a review appointment. It's a letter from Dr Dennis to
16 your GP, dated 3 May 1996, and at this time you have had
17 treatment for eight weeks. It's stated there:

18 "She seems to be very well and is not finding the
19 injections too difficult. She has noticed that the
20 injections are quite uncomfortable to give, particularly
21 putting the needle through the skin, and she was
22 wondering if she could use Emla cream."

23 Did that help?

24 A. Yes, it did because my skin over time -- the elasticity,
25 if you like -- the more I injected -- the longer I had

1 been on the injections, the more difficult it was to
2 actually do the injection, and it had been mentioned to
3 me about this cream. I think what it did was it kind of
4 numbed the skin slightly so that it wasn't as sore
5 because it was becoming increasingly uncomfortable.

6 I did alternate which side of my tummy to inject and
7 sometimes I used my legs but, because you were doing it
8 three times a week, I was kind of running out of areas
9 to use.

10 Q. And it's noted here that you are continuing to take
11 prozac.

12 A. Yes, I did try to come off them but I just -- because of
13 the treatment, I just -- I wasn't a very nice person
14 when I wasn't on them because I was so down.

15 Q. Yes. It notes there that you had slight aches and pains
16 in your neck and shoulders. The second paragraph:

17 "Her recent results were very encouraging. Her ALT
18 has returned to normal, on 2 April 1996 her ALT was 29
19 and we were unable to detect any Hepatitis C RNA, by
20 quantitative PCR".

21 Were you told about these results at that time?

22 A. I knew the results were looking positive. I wasn't
23 given as much detail as that. I just knew that they
24 seemed -- the doctor said they were pleased with the
25 results. It looked like the treatment was having some

1 effect.

2 Q. Then unfortunately the results were not so good.

3 A. They sort of levelled out.

4 Q. They did. And if I could refer you to WIT0050413,
5 this is a letter from Dr Ludlam to your GP, dated
6 8 July 1996, stating:

7 "I reviewed [Laura] along with Dr Peter Hayes today.
8 As you know, she is currently on wellferon three times
9 weekly and unfortunately, although she got an initial
10 response, she has now relapsed. Dr Hayes and I are of
11 the view that she might well benefit from interferon A
12 (interferon) and ribavirin therapy. There is some
13 evidence from [blank] studies that this combination may
14 be more effective than interferon alone. Unfortunately
15 we are still waiting for ethical approval but
16 I anticipate this will be forthcoming in the few days."

17 Presumably it's supposed to read "the next few
18 days":

19 "I have arranged to see her again in one month's
20 time when I hope we will have the ribavirin for her."

21 If we look at WIT0050410, if we look at the second
22 paragraph, it notes you are keen to try the ribavirin
23 and interferon combination as part of a clinical trial
24 and you have seen a copy of the patient information
25 sheet and signed a consent form. Were you told that you

1 might experience more side effects or different side
2 effects?

3 A. I don't recall being told that there would be different
4 side effects. I knew that the side effects would be
5 similar but -- I remember thinking they would be
6 similar. "Flu-like symptoms" is probably quite a good
7 way to describe them. I do think, though, when I was on
8 the treatment, it made me more inclined to pick up
9 things, if you like. I think I was more inclined to
10 pick up a cold and I think that didn't help matters
11 either. And the "flu-like symptoms" is probably quite
12 a good way to describe it.

13 Q. You lost weight again.

14 A. Yes.

15 Q. It's noted in the last paragraph that if you were to
16 become more depressed:

17 "... then I think we must seriously review her
18 interferon therapy."

19 A. I didn't realise -- I don't remember -- that was never
20 mentioned to me. That suggestion was never made to me.
21 I don't think I realised quite how much it was affecting
22 me.

23 Q. It's noted there:

24 "The difficulty is she is keen to proceed with
25 treatment and her worry is related to the state of her

1 liver."

2 A. I think because they couldn't give me clear answers
3 sometimes, to the question that I asked about what kind
4 of future -- or what to expect in the future if I did
5 not have treatment, I obviously wanted to take any
6 treatment that I could get.

7 Q. There is a document in your medical records about the
8 clinical trial that you took this treatment as part of
9 and just for the record, it's WIT0050369.

10 Around this time you were referred to Dr Richardson,
11 who was the clinical psychologist attached to the
12 haemophilia unit. If we could look at WIT0050422.

13 Sorry, one point I meant to mention about the
14 previous letter was it recorded there that you had a new
15 job.

16 A. Yes.

17 Q. Yes.

18 A. Because of our financial situation, I really felt
19 I needed to get some sort of income but I knew I needed
20 to find something that wasn't going to be too stressful
21 or a huge commitment, and I was fortunate because I had
22 family who were willing to look after my daughter.
23 I was able to take a part-time clerical job, which
24 wasn't too demanding.

25 Q. How many hours a week was that?

1 A. It was mornings only. It was 9 to 1.

2 Q. Can you remember when you started that?

3 A. It was about 1996 and it was within a couple of months
4 of starting the treatment.

5 Q. Yes.

6 A. I was doing a -- it was sort of a temporary job. I was
7 doing medical cover for someone who was on medical
8 leave. So I knew it was only a temporary job and it was
9 just a few hours a day, and I felt I could cope with
10 that.

11 Q. Right. Back to the letter. This is the letter from
12 Dr Dennis to Dr Richardson, consultant psychologist,
13 dated 26 September 1996. It might just be easier if we
14 all read this letter. (Pause)

15 THE CHAIRMAN: Is there more?

16 MS PATRICK: There is no more below that. If we go on to
17 the next page, it's simply that she is very keen to try
18 this and would be most grateful for help.

19 If we look at WIT0050425, this is Dr Richardson's
20 response to Dr Dennis, dated 14 October 1996. It
21 records in the first paragraph that you are having some
22 difficulty coping at the moment:

23 "... although she said that she felt she was better
24 than when [you] and she had last discussed her
25 situation. She is once again feeling optimistic that

1 her current interferon and ribavirin treatment will be
2 successful in treating her Hepatitis C but she is very
3 aware that her result initially looked good on the two
4 previous occasions that she has received treatment."

5 It recounts in the second paragraph about your
6 husband's road traffic accident and the effect of this
7 on your marriage, and also that your son had been very
8 unwell and taken into hospital and your husband's
9 redundancy and your mother-in-law having had a stroke.

10 In the third paragraph:

11 "[Laura] felt that she had been depressed off and on
12 since [her husband's] accident, though admitted that she
13 had had depressive features even before that. She felt
14 that prozac had helped with her depression but stopped
15 it really because she was frightened that there might be
16 some kind of interaction with her interferon treatment.
17 She had no particular reason for believing this other
18 than that the staff at the haemophilia centre always
19 asked her if she was taking it. She did not describe
20 any particular depressive features at the moment, she
21 sleeps reasonably well and, although she feels her
22 appetite is not as good as it used to be, she eats
23 reasonably well. She described her main two problems as
24 being an inability to relax and the fact that she gets
25 emotional when she is talking about the Hepatitis C.

1 She also admitted that it has caused problems between
2 her and [her husband], and she does feel some anger towards
3 him since she was presumably infected by him, although
4 he now appears to be uninfected himself."

5 I appreciate this might be difficult for you but how
6 did you feel about this, that you had acquired the
7 Hepatitis C virus from your husband?

8 A. Well, I felt I was angry or annoyed with him because
9 he -- I didn't think he had asked enough questions in
10 the beginning. I think -- he has always been quite an
11 easy going sort of person and doesn't always worry about
12 things the way -- or think about things the way I do.
13 But since his accident, he had become less responsible,
14 shall we say, for things.

15 The accident had a huge effect on him and he
16 started to rely on me much more because he came out of
17 the accident not really remembering anyone, and the only
18 person that he trusted, or seemed to take to initially,
19 was myself. And, you know, people would come to visit
20 him and he didn't know them, so he would ask me was it
21 okay to talk to them. He was like another child for
22 a time and then gradually he recovered from the
23 accident.

24 So when it came to the Hepatitis C, I suppose I felt
25 a bit frustrated and angry that he hadn't asked enough

1 questions about what it meant and how it could affect
2 myself, and also when he had had treatment in the past,
3 I didn't feel that he had asked enough questions about
4 the implications of the treatment. I was the one that
5 usually said, you know, "What does this mean?" or,
6 "Could there be any effects from this?"

7 And because of that, I did blame him to a certain
8 extent. I just felt that he should have been more
9 responsible and should have asked more questions, and
10 therefore we would have been -- and when I think back
11 now, it probably was a bit silly but we could have been
12 better prepared or we could have tried to avoid the
13 situation by being more informed about the treatments
14 that were available to him.

15 But then -- I think also he didn't -- he didn't cope
16 very well when I was first diagnosed with the
17 Hepatitis C. He kind of stuck his head in the sand and
18 he didn't really want to know. He couldn't cope with
19 it, and I felt I was having to cope on my own and cope
20 with the children and cope with the financial worries as
21 well. And for all those reasons I was quite angry with
22 him at the time. I felt quite let down.

23 I think, you know, having had to cope with his
24 accident prior to that and then with the -- you know,
25 this as well and not getting the support that I felt

1 I should have been getting from him, it had a major
2 effect on our relationship and as time went on, it just
3 got more and more difficult to cope with and I think,
4 you know, he was out of his depth and he didn't know how
5 to cope. So we were kind of angry with each other for
6 a long time.

7 Q. Yes. In your husband's statement, he does refer to the
8 guilt he felt at being the one to have infected you. He
9 describes the strain on both of you as having had
10 a devastating effect on your relationship, and one which
11 has been almost impossible for both of you to come to
12 terms with.

13 A. He has never been very good at coping with finances, as
14 I think I have said before, and he always -- with the
15 children, it was usually me that sorted everything and
16 organised everything, and he was quite happy to have it
17 that way, and he worked full-time and he has a job that
18 takes him away sometimes quite early in the morning, and
19 sometimes quite late at night because he travels all
20 over Scotland at times.

21 So when I was unwell and struggling with my side
22 effects, I didn't feel, as I say, that I was getting the
23 support from him that I needed. And as I say, I also
24 felt to a certain extent he was responsible for -- the
25 position I was in and I wasn't coping very well with my

1 emotions at that time. So ...

2 Q. Could we just complete this letter? Thank you for that.

3 WIT0050426. That top paragraph we were looking at:

4 "She feels that the treatment makes her very tired
5 and she gets irritable with her husband and the two
6 children."

7 A. Yes.

8 Q. With regard to your inability to relax:

9 "It appeared that this was not so much that she is
10 very tense but that she finds it difficult to give
11 herself time to relax. She always finds something to do
12 around the house."

13 A. Yes, my husband doesn't cook and there was things like
14 that, you know, that I just didn't sometimes have the
15 energy, sometimes, to make an evening meal and -- but
16 because he just didn't know what to do, I had to. And
17 there was a lot of occasions like that, where I really
18 felt, you know -- I just felt I wasn't getting much
19 help.

20 I'm not very good -- at that time I had always been
21 so busy. I had always worked and had the children.
22 I liked to work. I liked to keep busy, but as time had
23 gone on -- I didn't realise until I had been talking to
24 Alison that I wasn't giving myself time to relax and it
25 was a -- something I needed to address.

1 Q. And in the second last paragraph there it notes:
2 "[Laura] does not really talk about her condition or
3 the treatment to anybody and we decided that it might be
4 beneficial for her to see [Dr Richardson]..."
5 When you attend the clinic.

6 A. My family knew that I was having the treatment and they
7 knew that I had to do the injection. I didn't really
8 like talking to people about what that meant, you know,
9 how it made me feel.

10 Q. Who did you tell that you had the Hepatitis C virus?
11 A. Nobody. My mum and dad and my sisters, that was it.
12 I did feel if there had been anything on the media,
13 for example, about Hepatitis C, it was getting -- people
14 were getting confused with it and things like HIV and --
15 a lot of people just didn't seem to know much about
16 Hepatitis C and I just didn't feel that I wanted to
17 start explaining to anyone. And I think also some
18 people had the wrong idea about how it could be spread
19 and I was concerned that, for example, in my job, that
20 if anybody knew, they would get the wrong idea about --
21 I just was worried I would lose my job. So I just
22 didn't tell people and I didn't tell my friends. My mum
23 and dad knew and my sisters and that was about it.

24 Q. And you did then continue to see Dr Richardson when you
25 attended your clinic appointments.

1 A. Yes, I couldn't actually tell you how many times I saw
2 her. I think I had a few -- I was supposed to see her
3 when I went to the clinic but sometimes for one reason
4 or another -- I did see her on at least a few occasions
5 but I didn't see her every time. She gave me like
6 a tape -- she made a tape for me to help me relax that
7 I could listen to in the evenings, and I did see her
8 a couple of times. At that time I don't think I was
9 very good at this counselling thing. I wasn't very good
10 at talking to people -- to people.

11 Q. Okay.

12 Sir, that may be a good break time.

13 THE CHAIRMAN: We will have a break at that stage. The
14 stenographer here can't go on working indefinitely.

15 A. No.

16 (11.01 am)

17 (Short break)

18 (11.27 am)

19 THE CHAIRMAN: Yes?

20 MS PATRICK: Before the break we had heard that
21 in August 1996, ribavirin had been added to your
22 treatment. I would like to refer to you WIT0050431,
23 which is a letter dated 15 January 1997 from Dr Dennis
24 to your GP, and it concerns a review appointment on
25 14 January 1997. It states:

1 "She remains well and is having few side effects.
2 She does have some tiredness as before and occasional
3 headaches. However, she is tolerating the treatment
4 well. Her most recent liver function tests
5 in December 1996 were normal with an ALT of 29, and in
6 addition we have been unable to detect any Hepatitis C
7 RNA by quantitative PCR since starting treatment
8 in August 1996."

9 So you are quite happy to continue with the
10 treatment at that point?

11 A. Yes.

12 Q. How did you feel when you were waiting for the blood
13 test results to see how effective treatment was being?

14 A. It was always quite nerve-racking and there was always
15 a delay -- I usually got a letter sent to the house and
16 it took a few weeks usually before the liver function
17 tests results, which are -- they were always the
18 clearest indicator of how the treatment was working.
19 Yes, it was always a wee bit nerve-racking until that
20 letter came and said it's looking okay.

21 Q. And it's noted in your medical records that on the last
22 two occasions, having relapsed within about three or
23 four months after starting treatment, you were concerned
24 that that might happen again.

25 A. It was quite possible it might have happened again.

1 Q. However, your blood test results continued to be normal.

2 A. Yes.

3 Q. And the treatment finished at the end of July 1997 and

4 your Hepatitis C PCR tests remained negative.

5 A. Yes.

6 Q. What were you told at that time that that meant?

7 A. Just that I was clear of the virus at that time. No one

8 actually said if it could come back or really what to

9 expect but they said they would be monitoring me just to

10 make sure that if it did return or the situation

11 changed, you know, it could be dealt with.

12 Q. Yes. You tell us in paragraph 12 of your statement that

13 you continued to attend the haemophilia centre for blood

14 tests, initially every month, then every three months

15 and then every six months.

16 A. Yes. Usually -- when it started off it was quite

17 regular, as I say, about every month and then it was

18 reduced to three months and six months, I can't remember

19 at what intervals, and then it went on to an annual

20 check-up.

21 Q. You say there that the check-ups continued for such

22 a long time because the hospital was unsure if there was

23 a risk that the virus would return.

24 A. That's right.

25 Q. Was that something you thought about, whether the virus

1 might come back?

2 A. Yes, and every year when I went and discussed, Dr Dennis
3 would say -- she was happy to see me again in a year's
4 time if I wanted to, and I said yes because they
5 couldn't say for definite if it would return and
6 I therefore felt it was important to be -- at least to
7 have an annual check-up.

8 It was only after -- when we got to the tenth year,
9 she still couldn't say for sure but she said she would
10 take advice from Dr Hayes, and she wrote to me and told
11 me what his advice had been.

12 Q. Yes. The side effects from the treatment, did they
13 persist for a while after you finished it?

14 A. Yes, for a while I couldn't say just exactly how long
15 but I think initially they did, but gradually they wore
16 off.

17 Q. How did you feel physically after the treatment
18 finished?

19 A. Physically -- I always seemed to feel tired a lot of
20 time, for quite a long time afterwards. I don't know if
21 that was a physical thing or to do with me feeling a bit
22 down -- you know, I think I was still on the prozac and
23 obviously the whole experience, especially things like
24 the financial aspect of our situation hadn't gone away.
25 So I was still trying to cope with that. So I couldn't

1 say for sure what was causing me to feel the way I was
2 feeling.

3 Q. And a letter in October 1999 -- I don't propose to refer
4 you to it -- was one of your attendances at the
5 haemophilia centre for review but it recorded that your
6 daughter had been unwell and that you still remained
7 concerned as to whether she might have acquired the
8 virus, and you were seeking advice as to whether she
9 should be tested for the virus again or not.

10 A. I don't actually remember that.

11 Q. No.

12 THE CHAIRMAN: What's the reference to it?

13 MS PATRICK: WIT0050451.

14 A. It may have come up as part of the discussion at the
15 time but I don't remember feeling particularly concerned
16 about it.

17 Q. No. I think you mentioned that your daughter was due to
18 be seen at the Sick Kids the next day, as she had
19 recently been unwell, and you were wondering whether
20 there was any need for her to be rescreened for
21 Hepatitis C. It was decided that it was extremely
22 unlikely but if blood was being taken for any other
23 reason, it would be reasonable to repeat those tests.

24 A. I think, as I say, it was mentioned more in passing
25 than being a real concern.

1 Q. And a review appointment in April 2000, WIT0050452.
2 There is a letter from Dr Stewart to your GP, dated
3 11 April 2000. It records that you remain PCR-positive:
4 "I told her the results are encouraging but that we
5 still do not have enough knowledge about the natural
6 history of Hepatitis C to say with complete confidence
7 how the disease may progress in the future."
8 A. Yes. So that was always in the back of my mind.
9 Q. Yes. Do you feel you got on with your life at this
10 point?
11 A. Yes, I think so. We went on holiday that summer, which
12 was quite -- you know -- yes, I think we were trying to
13 get back to some sort of normality and trying to do
14 things with the children. I was trying to get back into
15 doing more things with the children but I had more
16 energy then than I had had before.
17 Q. Yes. In paragraph 16 of your statement, which is 0302,
18 you tell us that in 1998 you had problems with your
19 gallbladder and it had to be removed --
20 A. Yes.
21 Q. -- in 1998.
22 A. I actually had a blockage in my bile duct. I don't
23 think -- I don't think it had anything to do with the
24 hepatitis, obviously, but the bile duct is obviously in
25 a similar area. And because of that blockage, I was in

1 hospital for five days because I was -- I had bleeding
2 internally and the blockage -- they think it was
3 a bile -- sorry, a gallstone, and because of that they
4 decided to remove my gallbladder.

5 Q. Yes. Then you tell us that in 2000 you were diagnosed
6 with breast cancer.

7 A. Yes.

8 Q. And you say that the cause couldn't -- the hospital told
9 you they couldn't say what the cause was but you knew --

10 A. They can tell to a certain extent. For example, if it's
11 hormonal. And in my case they said that hormones could
12 have contributed but that there were likely to have been
13 other contributors. They obviously cannot say with any
14 great certainty but I was told that stress would
15 certainly -- it could have been a contributor. And
16 I had no family history of that type of cancer.

17 Q. No. And you had to undergo a mastectomy, reconstructive
18 surgery, chemotherapy and five years of hormone drug
19 treatment?

20 A. Yes, and the Hepatitis C was obviously discussed as part
21 of the -- when the different treatments were being
22 considered.

23 Q. I was going to refer you to something about that, which
24 is WIT0050457. Which is a letter from
25 Miss Elaine Anderson, consultant at the Edinburgh breast

1 unit at the Western General Hospital. Dated
2 12 September 2000.

3 A. Yes.

4 Q. It's noting that you have three small cancers in the
5 right breast and that it will be proceeding with
6 a mastectomy.

7 A. Yes.

8 Q. In the second paragraph it's noted:

9 "I have discussed things with Peter Hayes and
10 Rosemary Dennis from the Royal Infirmary, who confirm
11 that currently [Laura] is PCR-negative for Hepatitis C
12 virus in her bloodstream, although still should be
13 considered as at risk during surgical procedure. They
14 suggest that chemotherapy should not be a problem
15 provided we continue to monitor her with PCR three to
16 four times a year for the first year, and then yearly
17 thereafter."

18 A. Yes, although that wasn't actually explained to me at
19 the time, that this was something that they needed to
20 do.

21 Q. Was your PCR level monitored during your chemotherapy
22 treatment?

23 A. As far as I know. I know they were taking blood tests.
24 I'm sure they would have been.

25 Q. Yes.

1 A. I was still being monitored by the haemophilia centre at
2 that time as well.

3 Q. Yes. There is a further letter, WIT0050458, which is
4 a letter from Professor Hayes to Professor Ludlam, dated
5 14 September 2000. He writes:

6 "...I think that since she would appear to have
7 responded to interferon and ribavirin by becoming
8 PCR-negative, we would hope that she is cured of
9 Hepatitis C and therefore, if the virus has gone, she
10 should not reactivate even if this is immuno-supressed.
11 However, of course, a certain number of people do
12 relapse after treatment and it is possible, although we
13 cannot detect it, that she might still be harbouring
14 Hepatitis C somewhere."

15 He suggests that a PCR test should be done every two
16 or three months:

17 "If she remains PCR-negative that would be great,
18 but if she was PCR-positive this, I believe, would
19 generally not be a life-threatening event, unlike, for
20 example, reactivation of Hepatitis B. If she did become
21 positive, we would consider retreating her but hopefully
22 after she had finished the chemotherapy. I would hope
23 that this would not be necessary. I understand
24 Miss Anderson also asked about whether she should be
25 considered high risk or not. I would have thought that

1 there was no simple answer to this as we believe that
2 she will have eradicated the virus, but I cannot be
3 absolutely certain. I would have thought, therefore,
4 probably it would be better to treat her as high risk,
5 unless this would have serious implications for her
6 management, when a common sense approach should be
7 undertaken."

8 Were you aware that these matters were being
9 discussed?

10 A. No.

11 Q. No. Were you concerned about the impact that
12 chemotherapy might have in relation to the Hepatitis C
13 virus?

14 A. Not particularly. Because I didn't really know about
15 this. The doctors' concerns -- I was more concerned --
16 I suppose I felt that -- I had suspicions that the
17 Hepatitis C -- the treatment for Hepatitis C and stress
18 and everything had contributed to me actually, you know,
19 getting cancer. I mentioned this on one of my
20 appointments. No one actually was able to say, "No, it
21 wouldn't have done," and that bothered me slightly.

22 Q. Yes.

23 A. I suppose I never really thought about the fact that the
24 chemotherapy could have implications.

25 Q. There is mention in a letter that you expressed some

1 anxieties about that. I'll refer you to the letter so
2 you can have a look at it. WIT0050466, which is
3 a letter from Yvonne Doherty, as you can see over the
4 page -- you don't need to look at it yet -- a chartered
5 clinical psychologist, to Ms Judith Kilshaw, breast care
6 nurse at the Edinburgh breast unit, dated
7 14 December 2000. It records some historical events,
8 which we have spoken about. In the second paragraph:
9 "[Laura] appeared, not surprisingly, to be
10 struggling with a perception that her life has been
11 one negative life event after another, and this had
12 resulted in her feeling that her treatment for breast
13 cancer would not be successful. She was also aware that
14 she has a tendency to not discuss concerns and worries
15 with others and was keen to not become as distressed as
16 she had previously done during her Hepatitis C
17 treatment. In addition, [Laura] had many anxieties
18 about how her chemotherapy might impact upon her
19 Hepatitis C."
20 A. I think I was more concerned about how the chemotherapy
21 would impact on my general health. I didn't realise
22 that the chemotherapy -- I sort of -- I certainly didn't
23 realise that the doctors were writing back and forward
24 to each other, and that Dr Anderson, Elaine Anderson,
25 had concerns. I don't remember being overly anxious

1 about the chemotherapy contributing to --

2 Q. It's noted further down that at your last meeting with
3 Yvonne Doherty, you appeared to be managing well and you
4 had started chemotherapy and this had reduced many of
5 your anxieties, and that you had also been able to look
6 towards the future. So you were discharged and it was
7 noted you would benefit from re-referral:

8 "if she had a recurrence at some future date,
9 particularly as she has a tendency to minimise her
10 distress and cope by resigned stoicism."

11 A. I was watching it with the chemo because I tolerated it
12 reasonably well.

13 Q. In fact a review appointment at January 2001,
14 WIT005068, showed that there was no deterioration in
15 your liver function during chemotherapy. This is
16 a letter from Dr Cameron.

17 A. Yes.

18 Q. Dated 16 January 2001. Could I refer you next to
19 WIT0050469? This is a letter about a review
20 appointment with Dr Dennis, dated 1 May 2001, and she
21 had seen you on 30 April 2001 and noted that you were
22 looking well and had completed your course of
23 chemotherapy.

24 A. Yes.

25 Q. In the third paragraph it states:

1 "She was keen for blood to be taken for
2 a quantitative Hepatitis C PCR test."
3 A. Yes.
4 Q. And so this was done together with some other blood
5 tests, and she said that she would write to you with the
6 outcome of these. She did write to you and that was on
7 18 June 2001, which is WIT0050470. It notes that the
8 results of your hepatitis PCR test were still negative
9 and your ALT was also normal.
10 A. Hm-mm.
11 Q. And you continued to attend the haemophilia clinic
12 annually.
13 A. Yes.
14 Q. Eventually, as you said, advice was taken as to whether
15 you needed to continue to do so and Professor Hayes
16 suggested that no more follow-up was required. So you
17 were discharged from the haemophilia clinic
18 in November 2006.
19 A. Yes.
20 Q. How are you now?
21 A. I have been fine but I have just had another spell in
22 hospital. I'm off work at the moment. I have had
23 inflammatory bowel disease and again, you know, there
24 was a lot of talk in hospital about the fact I have had
25 Hepatitis C. And they had to give me steroids because

1 it's an autoimmune disorder. And obviously there is
2 a lot of consideration every time I'm in that situation
3 about my immune system, because I wasn't responding to
4 treatment initially when I was taken -- when I went into
5 hospital in October.

6 And apparently there is some other drugs that they
7 can give you that might have been effective but because
8 of the effect that it might have had on my immune
9 system, and because I have had Hepatitis C, they were
10 concerned about giving me those drugs and I just
11 continued with the steroids and eventually we got -- we
12 think we have got everything under control.

13 So I'm now recovering from that. But I think I'm
14 about two and a half months down the line, and I'm a lot
15 better.

16 Q. Are you hoping to return to work soon?

17 A. Yes, I'm hoping to return to work after the holiday
18 period. I'm seeing my doctor, my GP, in the beginning
19 of January and I'm hoping to go back to work part-time
20 in a phased return.

21 Q. Good. I would like to turn now to the effects of the
22 infection with Hepatitis C on you and your family -- you
23 have touched on these earlier -- and the difficulties,
24 particularly when you had a young family, in basically
25 trying to be the mother you wanted to be to them when

1 you were unwell, and the difficulties of trying to keep
2 working in a job that you had started, which would fit
3 in with your family life.

4 A. Yes, it was also a job that I really enjoyed.

5 Q. Yes. Do you consider there has been any impact on your
6 children of this?

7 A. I think there has. On my son, I think he -- he was
8 quite protective of me, more so -- he might have been
9 anyway but I felt -- although he didn't actually know
10 much about the details of my Hepatitis C or the
11 treatment because I made a point of never having
12 anything to do with the needles or the treatment or
13 anything around him -- when the children were there.

14 I made sure that everything was kept hidden away and
15 they knew nothing. I tried to keep that away from them.
16 But I think children sense things and he was old enough
17 to sense that I wasn't very well and things weren't
18 quite right, and he is very protective of me.

19 With my daughter I think it affected her in quite
20 a different way. She is much more insecure than I would
21 have thought she would have been. Maybe it's a slightly
22 a similar thing because she was very loath to let me out
23 of her sight at times as a toddler, and even as she has
24 got older, I feel that they are all just very protective
25 of me.

1 It's difficult to say really because they were quite
2 young. I think it had more of an effect on my
3 relationship with my husband, and again, I think the
4 children sensed that and there were times when our
5 relationship was so strained that, you know, the
6 children were inevitably going to be affected by it. We
7 did try and keep it from them, obviously, as you do, but
8 you know, there are atmospheres and difficult times when
9 they just pick things up.

10 Q. Yes. You tell us more about that in paragraph 21 of
11 your statement. You state there, on page 7, that two
12 years ago you attended a series of couple counselling
13 sessions to address --

14 A. I think, you know, my husband particularly found it
15 difficult to accept that there were real difficulties --
16 real problems between us, and I think he found it
17 difficult to even consider the idea of counselling. But
18 our problems reached a point where it was either a case
19 of we gave up on our relationship or we went for
20 counselling. And although he was very reluctant, we did
21 go for a series of couple counselling sessions and it
22 certainly did make a big difference to us -- during
23 those counselling sessions, we did talk a lot about how
24 we both felt during, you know, the Hepatitis C period,
25 as I recall it, you know, when things were coming to light

1 and I was -- you know, the treatments and so on.

2 And I learned a lot about how he felt and I think
3 that helped me to sort of accept that it wasn't all his
4 fault. And I knew deep down it wasn't but I think his
5 way of handling the situation also contributed to the
6 problems, and we both kind of faced up to things and our
7 relationship is much, much better now and back on track.
8 It has just taken a long time. That has been a lot of
9 years before we reached that point.

10 Q. Yes.

11 A. But neither of us were inclined to give up too easily on
12 our relationship, which is why we managed to keep going
13 as long as we did, I think, and obviously with the
14 children -- to be quite frank, the fact we had debts, we
15 couldn't really afford to separate for a long time. It
16 was a case of, well, it's easier to stay together and
17 just deal with things.

18 Q. Yes.

19 A. And then of course, with me having had the cancer as
20 well, that didn't help matters. But as I say, things
21 reached a point at that time, where we had to do
22 something and the counselling was good. I had found
23 counselling very helpful for me in the past and it
24 allowed me to come off the prozac eventually and so on.

25 So I was quite optimistic that couple counselling

1 would be helpful and it certainly was. But I have to
2 say that -- sorry, I don't know if it's relevant at this
3 point but I think it would have helped my husband, had
4 he been offered counselling earlier, around about the
5 time maybe when I was getting counselling. It was
6 never, ever an option. It was never mentioned or even
7 suggested, and I think it would have certainly helped
8 him.

9 Q. You touched again there on the financial impacts of this
10 on your family, and at the time you stopped being
11 [REDACTED] you told us that you were in debt,
12 and your husband in his statement mentions that this
13 resulted in a bad credit history for you.

14 A. Yes, it did.

15 Q. And it has taken many years to recover from that. What
16 is the position now in relation to your finances, in
17 particular in relation to that debt that you had?

18 A. We are still in debt. We have never really managed to
19 get back on track, as such. Before this happened, we
20 didn't really have -- apart from a mortgage, we didn't
21 really have many debts. I don't think we had anything
22 at that time, or very little, but -- and we had always
23 intended, after I had had my daughter, to move house
24 because we were in a two-bedroomed flat and having a boy
25 and a girl, obviously, you know, eventually you think,

1 well, it would be nice to be able to give them a room
2 each, but that was delayed by a good five years.

3 And even then we couldn't get a mortgage easily. We
4 had to go to a broker who -- a local broker, who managed
5 to shop around and find us something but we had to pay
6 a slightly higher interest rate, for example, in order
7 to get the -- a mortgage to allow us to move; because we
8 had this -- not such a good credit rating as we would
9 have had in the past.

10 We had never had any problems with our credit rating
11 or our debts in the past. So that was difficult. And
12 then, when we got the mortgage, we also had difficulty
13 getting insurance for the mortgage, and I couldn't get
14 insurance -- we couldn't afford to pay the enhanced
15 premiums that they wanted for me. So we did manage to
16 the get the mortgage on the basis that my husband had
17 cover and that I just didn't have cover. If I was made
18 redundant or -- fortunately I had life insurance from
19 before I was ill, so that also helped. But I certainly
20 couldn't get any new life insurance at that time.

21 Q. So was it life assurance you were looking for in
22 relation to your mortgage?

23 A. Yes, to make sure that we were covered should anything
24 happen.

25 Q. And were you touching there on income protection

1 insurance?

2 A. Yes.

3 Q. Is that what your husband managed to get but you didn't?

4 A. Yes, I think I was offered it but it was going to cost

5 so much that we just couldn't afford it. And we decided

6 we would just have to take the income protection purely

7 on my husband's job and also because, where I was

8 working at the time, the risk of unemployment seemed

9 much less in my case than his, and we decided it was

10 a gamble that we would have to take in order to get the

11 mortgage.

12 Q. Were you told why your insurance would be so much?

13 A. Yes, it was because of the Hepatitis C.

14 Q. It was the Hepatitis C. You tell us in paragraph 22 of

15 your statement that, when you went on holiday in 1996 to

16 America, you had to pay an extra premium for your travel

17 insurance --

18 A. That's right.

19 Q. -- because of your Hepatitis C status, and you had to

20 take a letter explaining about your interferon treatment

21 and injections.

22 A. I did, yes, because I had to carry the medication with

23 me.

24 Q. And have you looked for travel insurance more recently

25 than that?

1 A. Yes, I always have to pay an enhanced premium. Now it's
2 because of the cancer and the Hepatitis C.

3 Q. Yes. Have you incurred expenses as a result of the
4 virus? You must have travel expenses to and from the
5 hospital presumably?

6 A. Oh, yes.

7 Q. Prescription charges?

8 A. I did, yes, at that time because I wasn't officially
9 unemployed or anything. So I had to pay prescription
10 charges, yes. And that was obviously getting quite
11 regular, prescriptions at certain times.

12 Q. Yes. Finally, you touched during your evidence on the
13 stigma associated with the Hepatitis C virus.

14 A. Yes.

15 Q. In relation to that you tell us in paragraph 23 that you
16 didn't tell work when you had a new job, even though it
17 was difficult to get time off work to attend the
18 hospital.

19 A. Yes.

20 Q. Is that still the case?

21 A. I still haven't told them. But then, I don't need to
22 attend the hospital now but for my annual check-ups.
23 Fortunately I have a very understanding employer who
24 didn't ask too many questions if I said I had a hospital
25 appointment. If they had been more inclined to ask

1 questions, it could have been much more difficult.

2 Q. You tell us in paragraph 24 about a time when you had to
3 go to hospital for a tooth extraction and you were made
4 to wear a paper gown because you had had Hepatitis C.
5 Was this after you had cleared the virus?

6 A. I can't remember whether it was between -- I think it
7 was but -- yes, I'm pretty sure it was because
8 I remember telling them, when they asked the -- when you
9 arrived and you go through the procedure, the nurse
10 asking you all the questions about your health, your
11 history, and I told them then, but I think they already
12 knew from my medical notes that I had had Hepatitis C
13 but I just didn't realise -- I just was a bit naive
14 about what that meant to the medical staff and I had
15 never thought about it.

16 It being a tooth extraction, I didn't associate it
17 or think about the Hepatitis C and what that would mean
18 to the hospital staff. But I did wonder why I had been
19 there such a long time that day and I had been told to
20 be very early, and I was one of the first to arrive and
21 then it turned out that they had re-arranged their list
22 to make me last because I was a risk. As far as they
23 were concerned, I was a risk in the theatre and they
24 didn't want to -- they would have to disinfect the
25 theatre, or whatever, after I had been in. And I wasn't

1 told that until well into the day when I asked why I was
2 still waiting. I thought -- I was in early and just
3 chatting to one of the nurses and she said quite
4 casually, "It's because you had Hepatitis C". And I was
5 quite shocked and quite upset.

6 And when they gave me a gown to get ready for the
7 theatre, it was a paper gown, and I noticed everyone
8 else had a cloth one and I just felt -- I really felt --
9 I just felt as if I had a real horrible disease that,
10 you know, nobody wanted to come near me.

11 Q. Yes.

12 A. It was horrible.

13 Q. In the last paragraph of your statement you say:

14 "This whole period in my life was a nightmare for me
15 and my whole family. It has taken many years to recover
16 from most of the effect, and some effects we will never
17 recover from."

18 A. I mean, even after all these years, I do get quite
19 emotional thinking about that period in my life.

20 I think I mentioned already, you know, I had a young
21 family -- we had come through a tough time the year
22 before between -- my son had been very ill and he had
23 been in hospital and my husband made redundant. My
24 husband had had the bad accident. We were just getting
25 over all of that and getting our lives back on track

1 having had the baby, and really looking forward to the
2 future, and then it just all fell apart. And it went on
3 for such a long time.

4 So I think it's a period of my life that I will
5 never ever -- fully -- I'll never forget. I don't think
6 I'll ever recover from it fully.

7 Q. Thank you very much.

8 A. Thank you.

9 THE CHAIRMAN: Mr Di Rollo?

10 MR DI ROLLO: No, thank you, sir.

11 MR ANDERSON: I have no questions.

12 MR JOHNSTON: No thank you.

13 THE CHAIRMAN: Thank you very much indeed.

14 A. Thank you.

15 THE CHAIRMAN: We will rise.

16 (12.04 pm)

17 (The short adjournment)

18 (1.30 pm)

19 ANNE

20 Questions by MS PATRICK

21 THE CHAIRMAN: Good afternoon.

22 Yes, Ms Patrick?

23 MS PATRICK: Sir, this afternoon we have Anne to give
24 evidence.

25 Anne, I would like to start by letting you know who

1 everybody is in the room today. On the bench is
2 Lord Penrose and next to him is Professor James, the
3 medical adviser to the inquiry. You know Margaret who
4 is seated next to you, and coming along the front here,
5 we have the two stenographers, who are noting down
6 everything that's said for the Inquiry transcript. Next
7 to them is Maria McCann, the secretary to the Inquiry,
8 and then Keith Fleming is in charge of documents today.

9 You have met Laura and myself, counsel to the
10 Inquiry, and seated behind us is Lindsey Robertson, who
11 is assisting us with this topic.

12 On the other side we have the lawyers for the core
13 participants to the Inquiry. The lawyers closest to me
14 I think you know, they are the lawyers for the patients,
15 relatives and Haemophilia Society. In the middle are
16 the lawyers for the Scottish National Transfusion
17 Service and the health boards, and seated closest to you
18 are the lawyers for the Scottish Government.

19 "Anne" is the name that the Inquiry has given you
20 today for the purpose of your evidence. You provided
21 the Inquiry with a witness statement some time ago and
22 that is WIT0051112. You should have a hard copy of
23 that in front of you.

24 A. Yes.

25 Q. Your sister also provided the Inquiry with a witness

1 statement and the reference for that is WIT0051209.

2 I'll refer to parts of that later.

3 In paragraph 1 you tell us that your date of birth
4 is [REDACTED] and you are currently 57 years old.

5 A. Yes.

6 Q. You are employed as an administrator. Where is that?

7 A. It's in the [REDACTED], in
8 [REDACTED].

9 Q. And how long have you worked there?

10 A. 17 years.

11 Q. Do you live in Edinburgh?

12 A. No, I live in [REDACTED] in Ayrshire.

13 THE CHAIRMAN: Which [REDACTED] are you in then?

14 A. [REDACTED].

15 MS PATRICK: In paragraph 2 you tell us that you were
16 diagnosed with Hepatitis C in 1995 and that you are
17 genotype 2B. You tell us that you contracted this virus
18 following a blood transfusion you received
19 in January 1986 whilst a patient at Crosshouse Hospital
20 Kilmarnock.

21 A. Yes.

22 Q. And at that time you were 31 years old, and you were
23 admitted for a myomectomy and you were under the care of
24 surgeon, Mr McDonald. As a result of this procedure you
25 required a blood transfusion. This was your first and

1 only blood transfusion.

2 A. Yes.

3 Q. You don't know exactly how many units of blood you
4 received but you think it was more than three units?

5 A. Yes, I think so.

6 Q. And you tell us that you had been a blood donor prior to
7 this operation.

8 A. Yes.

9 Q. But due to low haemoglobin levels afterwards, you were
10 not a blood donor following that procedure.

11 A. I wasn't, no.

12 Q. If we look at WIT0051126, this is a letter from
13 W Ayad, gynaecological registrar, to your GP, dated
14 17 March 1986. It confirms the procedure you underwent
15 on 28 January 1986. You were discharged home after that
16 on 6 February 1986. How long did it take you to recover
17 from this procedure?

18 A. About three or four months. It was quite a while.

19 Q. Could we look, please, at your sister's statement,
20 WIT0051209 at paragraph 3? Your sister tells us in
21 1995 she had a routine appointment at the family GP, and
22 I think that was your GP.

23 A. Yes, it was.

24 Q. And she remembers the doctor looking at her and she was
25 wondering what on earth was wrong. He looked at his

1 files and then looked at her again and you looked very
2 alike, so she thinks that he was maybe mistaking her for
3 you and he then asked your sister to ask you to make an
4 appointment to see him.

5 A. That's correct, yes.

6 Q. He never told her why this was necessary but she
7 obviously came home and told you this. And it appears
8 that you made an appointment to see him the next day.

9 A. Soon after, I'm not exactly sure which day.

10 Q. And at this point you were 41 years old. Were you
11 working in that job at the time?

12 A. Yes.

13 Q. Yes. How were you feeling at that time?

14 A. All right actually, okay.

15 Q. Yes. If we look at WIT0051128, which you refer to in
16 paragraph 3 of your statement, this is a letter from
17 Douglas Frame, associate specialist at the regional
18 headquarters and laboratories of the Glasgow and
19 West of Scotland Blood Transfusion Service, to your GP,
20 dated 16 October 1995. This seems to be the reason why
21 your GP wished to see you at that time?

22 A. Yes.

23 Q. It states:

24 "We have been reviewing the records of previous
25 donations from donors now known to be infected with

1 Hepatitis C. The health departments have decided that
2 the recipients of blood transfusions originating from
3 such donors should be traced so that they may be offered
4 appropriate counselling, testing and follow-up including
5 consideration of treatment. According to the available
6 records, the above patient [being you], was transfused
7 with a presumed Hepatitis C-positive blood component on
8 29 January 1986 while under the care of Dr MacDonald, and
9 Dr MacDonald is aware that I'm approaching you with this
10 request.

11 "In accordance with the Health Department's
12 guidance, the patient will need to be approached with
13 a view to counselling and testing to determine his/her
14 HCV status. If you are willing to undertake this role,
15 we will provide details of the blood samples needed and
16 where these should be sent, and we will offer any
17 further support or advice which you may need. If, on
18 the other hand, you would like us to notify and counsel
19 the patient, we are happy to do so."

20 It asks the GP to complete an enclosed
21 questionnaire, which also includes asking what his
22 intentions are in relation to counselling:

23 "Please be sure to inform me of the results of any
24 investigations for Hepatitis C performed on your
25 patients."

1 If we go over to the next page:

2 "In rare cases you may feel that informing the
3 recipient is inadvisable. In this situation I would be
4 grateful for details on the enclosed form."

5 The next paragraph:

6 "Please do not hesitate to contact me if you have
7 any questions or concerns arising out of this letter.
8 I shall be pleased to advise you regarding referral of
9 Hepatitis C recipients who may require further
10 assessment."

11 If we look next at WIT0051130, these are
12 handwritten notes of your GP and they show at the top an
13 entry dated 18 October 1995, which is in brackets, and
14 may suggest that he didn't actually see you at that time
15 but he was dealing with the letter, which we have seen
16 was received on 17 October 1995:

17 "NB. See BTS letter. GP will counsel. Awaiting
18 further info from BTS."

19 So it appears from that that the GP had completed
20 the questionnaire, which he was asked to complete, and
21 returned it to the blood transfusion service and was
22 agreeing that he would counsel you in relation to the
23 Hepatitis C virus.

24 If we turn next to WIT0051131, I think this is
25 a letter once again from Douglas Frame to your GP, dated

1 13 November 1995, thanking your GP for agreeing to
2 counsel and test you enclosing:

3 "1. A draft letter that can be used to contact the
4 recipient;

5 "2. Nationally agreed counselling guidelines and;

6 "3. A form LBF3 to document the outcome of the
7 counselling process."

8 It asks that your sample be sent to the regional
9 virus laboratory at Ruchill Hospital.

10 According to the GP notes, he then saw you on
11 24 November 2011. If we look back at these,
12 WIT0051130. It's noted on the third and fourth line
13 of the entry for 24 November 1995:

14 "Chat re Hepatitis C for bloods."

15 So that looks like it's the first appointment that
16 you had with your GP.

17 A. Probably.

18 Q. You tell us in paragraph 4 of your statement that at
19 that time he explained to you that there was
20 a possibility of you having been infected by the
21 Hepatitis C virus due to infected blood products. You
22 say that he made light of this information. Can you
23 remember exactly what he said to you on that day?

24 A. It told me that I had tested positive for it and not to
25 worry about it because it didn't really mean anything.

1 Q. Right. You say that he took bloods from you at that
2 time.

3 A. I honestly can't remember.

4 Q. You can't remember. You probably saw him a few times.
5 So at some point he took bloods from you.

6 A. Yes.

7 Q. You say he didn't warn you about the consequences of
8 a positive Hepatitis C result.

9 A. No.

10 Q. And you didn't receive any counselling at this time.
11 You then refer, in paragraph 5, to returning to your
12 GP for blood results and him advising you that you had
13 tested Hepatitis C-positive. So it may be that at the
14 first appointment he told you about the letter he had
15 received and tested you at that point.

16 A. He might have done, yes.

17 Q. And then you went back and received the results?

18 A. Yes.

19 Q. And once again you say:
20 "I received no advice from him about the
21 implications of a positive result. I received neither
22 counselling nor advice about my future health. All he
23 said was, "Don't drink and tell your dentist".
24 I received no advice about the risk of sexual
25 transmission. He told me nothing. He essentially

1 glossed over it. My liver health was not discussed.
2 I knew nothing about the virus. I had no knowledge of
3 this condition at the time. He said that no one would
4 want to see me because it was really nothing."

5 You firmly believe he didn't realise the seriousness
6 of the virus.

7 A. I think so, yes.

8 Q. I would like to refer you to WIT0051137, which, if we
9 go to the top, we can see is the form LBF3, which had
10 been sent to your GP by the blood transfusion service,
11 headed "National HCV Look-back Programme":

12 "Documentation of Recipient Counselling."

13 And the first page states your details, name, date
14 of birth, transfusion details. We see at the bottom in
15 a short note:

16 "This form should be used to document information
17 gained during the counselling session, it will also act
18 as the request form for referred for patient testing."

19 If we go over the page, this is headed up "To be
20 completed by counsellor". The GP fills in his own
21 details in section 1 of that page and date of
22 counselling visit, 30 November 1995. Then section 3, he
23 gives details about you, your date of birth, your
24 marital status, your ethnic origin and your country of
25 birth. In section 4 under "Please indicate the current

1 status of the patient," he has ticked "Well, with no
2 symptoms."

3 Then, having ticked that box, it suggests that he
4 should go to number 6, which is further down and we see
5 that, 6(i) is:

6 "Does the patient have any other potential risk
7 factors for HCV?"

8 It's ticked "History of skin piercing", and noted
9 "Pierced ears 1970."

10 THE CHAIRMAN: Not very adventurous.

11 MS PATRICK: Then if we go over the page, I am not sure that
12 there is a 6(ii) actually. We go straight to number 7,
13 and it indicates your average alcohol intake in units
14 per week, which is four, and notes, as you have told us,
15 that you haven't donated blood since receiving the
16 transfusion.

17 A. No.

18 Q. Under 9:

19 "Please indicate below any significant issues that
20 arise during the counselling visit.

21 "Nil."

22 Under 10, this details the results of liver function
23 tests, which presumably your GP had carried out on the
24 blood sample you had provided to him. He shows
25 bilirubin at 12, ALT, 48, AST, 32, and albumin, 45.

1 I would like to refer you also to WIT0051132,
2 which appears to be the counselling guidelines which
3 were sent to your GP by the blood transfusion service.
4 They are dated April 1995 and are headed up
5 "Transfusion-transmitted Hepatitis C: Guidelines for
6 Counselling Patients."

7 Under "Introduction" in section 2, it states:

8 "These guidelines are intended for use in
9 counselling patients identified through the look back
10 exercise as Hepatitis C positive. They give some
11 background to this exercise, explain the implications of
12 being found to be anti-HCV-positive, provide information
13 on ways of avoiding infecting others, provide advice as
14 to the appropriate steps to be taken and briefly provide
15 notes about the likely management at specialist centres
16 about which patients are likely to ask."

17 Paragraph 3:

18 "Patients found to be infected with Hepatitis C are
19 likely to have concerns both about their own current and
20 future health, and also about possible spread to others,
21 including their family. Patients may only gradually
22 come to terms with their situation and may require
23 several consultations. An independent support network
24 may be a helpful adjunct and the British Liver Trust can
25 be a source of appropriate information and patient

1 support."

2 Paragraphs 4, 5 and 6 are under the heading
3 "Background", giving a background of the discovery of
4 the Hepatitis C virus and screening for antibodies,
5 which has been carried out by the transfusion services
6 since 1 September 1991.

7 Over the page in paragraph 7, which is still under
8 the heading "Background", it's noted in paragraph 7
9 that:

10 "The diagnosis ..."

11 This is the third line:

12 "... of chronic Hepatitis C in recipients of blood
13 is likely to be an unwelcome surprise for most patients,
14 although public awareness has been heightened in recent
15 weeks with media coverage."

16 Had you heard of the Hepatitis C virus before you
17 spoke to your GP about it?

18 A. No.

19 Q. No. In paragraph 8 it's noted:

20 "Patients confirmed to be anti HCV-positive (see
21 below) should be counselled on the implications of the
22 test result and referred for a specialist opinion."

23 It goes on to say that the patient should be
24 questioned in a sensitive manner about other risk
25 behaviours for having acquired the virus. If we scroll

1 further down, there is "Implications of a positive test
2 result: the prognosis". It says, for example, in
3 paragraph 9 that:

4 "Cirrhosis may develop in 10 per cent to 20 per cent
5 of those infected."

6 Did your GP mention anything about a prognosis to
7 you when you spoke to him?

8 A. No, nothing.

9 Q. And then there is a section on "Epidemiology, modes of
10 transmission". Over the page there is a further
11 section, "Avoiding Infecting Others". In paragraph 13:

12 "In counselling HCV positive recipients, they should
13 be asked whether they have ever donated blood or
14 a tissue. Anti-HCV-positive individuals should not
15 donate blood, tissue or semen, and should not carry an
16 organ donor card and, notwithstanding the estimated low
17 risk of sexual transmission, the same advice should be
18 given to their regular sexual partners, regardless of
19 their HCV status."

20 Paragraph 14:

21 "Toothbrushes and razors must not be shared and cuts
22 or skin lesions should be covered with waterproof
23 dressings."

24 Paragraph 15:

25 "When seeking medical or dental care, patients

1 should be advised to inform those responsible for their
2 care of their anti-HCV status."

3 16:

4 "At present there is insufficient evidence to
5 recommend changes to current sexual practices, although
6 regular sexual partners should be counselled and offered
7 testing. Hepatitis C-positive patients should be
8 advised to forewarn and practise safe sex with new
9 partners."

10 17 deals with risk to children. The next section:

11 "Further assessment and follow up:

12 "All anti-HCV positive patients should be referred
13 to a specialist with an interest in the condition for
14 further assessment."

15 If we go over the page, paragraph 19 discusses
16 elevated liver function tests and what they may mean,
17 and then there is another section on notes about
18 management at specialist centres. It notes in
19 paragraph 20:

20 "Further counselling will be given at specialist
21 centres and treatment options can be discussed in more
22 detail."

23 Then there is quite detailed discussion about what
24 may happen after you have been referred to such
25 a specialist centre with regard to liver biopsies, which

1 is mentioned in paragraph 21. Antiviral therapy of
2 interferon at that point is mentioned in paragraphs 22
3 and 23.

4 If we go over the page, the last paragraph is
5 paragraph 25, which discusses other treatment approaches
6 that are under development.

7 This is information which it seems was provided to
8 your GP before you saw him. How much of this
9 information did he convey to you at that time?

10 A. No information. Any information I got was really from
11 Gartnavel Hospital when I went up there to see them, but
12 nothing from the GP.

13 Q. When you left the GP having found out you had the
14 Hepatitis C virus, what did you think?

15 A. I didn't really know what it was. I obviously knew that
16 there was something. If you have got a virus -- he was
17 making light of it and saying, "It's nothing," but if
18 you have a virus, it's obviously something. And a few
19 months later I got a letter from Gartnavel to say to go
20 up and see them, and that's when I found out the full
21 extent of what it meant.

22 Q. So between leaving your GP and going to
23 Gartnavel Hospital, were you worried about what your GP
24 had told you?

25 A. Yes.

1 Q. Did you make efforts yourself to try and find out more
2 about the virus?

3 A. I did, yes.

4 Q. What were those efforts?

5 A. On the Internet, I suppose, and also by contacting
6 Crosshouse Hospital, where I got the blood transfusion,
7 and that's where I met with the lady from the blood
8 transfusion service.

9 Q. You mention that in paragraph 8 of your statement, that
10 you were wanting more answers and so you attended
11 a meeting at Crosshouse Hospital with someone from the
12 blood transfusion service and a representative from the
13 hospital there.

14 A. Yes.

15 Q. And you found the attitude of the person from the
16 hospital quite upsetting at that meeting.

17 A. Yes. I remember the lady's name, it was Dr Peterkin.
18 And she was really very nice and the other person was
19 not.

20 Q. Did you find that meeting helpful?

21 A. Not really, no.

22 Q. And the purpose of that meeting was to have what?

23 A. I wanted to find out how it happened and what the
24 prognosis was. What could they do immediately was what
25 I wanted to know and he said, "Well, you are lucky we

1 did contact you to let me know. We have had a big job
2 doing this look-back exercise."

3 Q. Right, okay. WIT0051140 is the results of
4 confirmatory HCV testing, final report, dated
5 11 December 1995, confirming your infection with the
6 Hepatitis C virus.

7 Your GP did refer you to Gartnavel Hospital and that
8 was in January 1996. If we look at WIT0051141, this
9 is a letter to Dr Mills at Gartnavel Hospital. It's
10 a request for an outpatient consultation, dated
11 15 January 1996:

12 "Dear Dr Mills, Thanks for seeing this single
13 41-year old who is Hepatitis C-positive. She had
14 a blood transfusion on 29 January 1986 and has been
15 discovered through the BTS 'look back' programme. She is
16 well and has normal liver function tests. I enclose her
17 HCV testing. I phoned Douglas Frame at BTS who informed
18 me that specialist referral was advised in all cases.
19 I would be grateful for your opinion and advice."

20 You tell us in paragraph 6 of your statement that
21 you then received a letter from Gartnavel General
22 Hospital inviting you to attend the hepatology clinic of
23 Dr Mills.

24 At your first meeting there you were seen by one of
25 his team and you were gobsmacked at that time because

1 you were told more then about the virus.

2 A. Yes.

3 Q. So was that the first time you understood the full

4 implications of it?

5 A. Yes.

6 Q. And what did they tell you at that meeting?

7 A. Just the prognosis, what can happen and that anything

8 that was likely to happen would probably be about

9 20 years down the line, but by this time I had it for

10 nine or ten years, so that worried me.

11 Q. You say in that paragraph that he warned you about the

12 risks of liver disease, sexual transmission and

13 treatment options, and that you also discussed

14 interferon treatment.

15 A. Yes.

16 Q. If we look at WIT0051145, this is the letter about

17 that first appointment. It's dated 14 March 1996. It's

18 from James McPeake, senior registrar, to your GP. It

19 notes that on examination -- this is in the second

20 paragraph -- you looked well and there were no signs of

21 chronic liver disease:

22 "I had a long talk with her today about the

23 implications of Hepatitis C infection and I think the

24 next logical step would be to do a liver biopsy in order

25 to assess any ongoing damage. I have checked some

1 routine blood tests today and we will give her a further
2 appointment for the clinic once she comes in for her
3 biopsy."

4 How did you feel after this appointment?

5 A. A bit shocked really.

6 Q. And you tell us in paragraph 7 that your family was
7 shocked, so you obviously went home and relayed the
8 information to your family?

9 A. Yes.

10 Q. You live with your mother?

11 A. Yes.

12 Q. And you have one sister; does she live quite locally to
13 you?

14 A. Quite locally, yes.

15 Q. And another sister who lives abroad?

16 A. Yes.

17 Q. And you say in paragraph 7:

18 "None of us knew what Hepatitis C was."

19 So that was when you started reading up and learning
20 more about it.

21 A. Yes.

22 Q. You then underwent an ultrasound-guided liver biopsy on
23 26 June 1996. You tell us that it was a very invasive
24 procedure. Did you find it painful?

25 A. Yes, it was painful, yes.

1 Q. You tell us at the end of paragraph 9:
2 "I'm not a coward but I found this very hard."
3 To date you have had about five liver biopsies.
4 A. Hm-mm.
5 Q. The result of the liver biopsy is WIT0051147.
6 Actually it's not the result, it's the letter in which
7 the result is discussed, which is a letter from
8 Gwyneth Jones to your GP, dated 8 October 1996. It's
9 following a review appointment and notes that:
10 "[Your] recent liver biopsy reveals a mild hepatitis,
11 consistent with Hepatitis C. We have discussed the
12 possibility of commencing interferon treatment."
13 And you are planning a five-week holiday to
14 Australia but you were interested in starting that
15 treatment early in 1997.
16 You tell us in paragraph 10 that you were advised
17 not to put the interferon treatment off any longer. Was
18 that at that time or was that a bit later?
19 A. A bit later.
20 Q. How did you feel about starting treatment for the virus?
21 A. I knew that I had to do it.
22 Q. How were you feeling at the time? Do you think you had
23 any symptoms --
24 A. From the hepatitis? Yes, sort of flu-type symptoms
25 which I put down to the Hepatitis C.

1 Q. Yes. How were they impacting on your life at the time?

2 A. I learned to live with it really.

3 Q. If we look next at WIT0051148, this is a letter to you
4 from Liz Spence, the gastroenterology specialist nurse,
5 about starting treatment, dated 10 January 1997. She
6 tells you that she knows you have been waiting to hear
7 from her regarding starting the interferon treatment but
8 they have been dealing with some red tape matters. Do
9 you know what those red tape matters were?

10 A. No.

11 Q. Then the plan is that you will be seen on
12 20 January 1997 to be taught how to do the injections
13 and prepare you for the interferon treatment. And then:
14 "The stamp of approval is usually a formality but it
15 does mean I will have to confirm your appointment nearer
16 the time."

17 If we look at WIT0051149, this is a letter from
18 Liz Spence to your GP, dated 10 February 1997. It's
19 a pro forma letter confirming that you have started
20 interferon treatment for Hepatitis C infection on
21 29 January 1997.

22 You had been taught how to inject the interferon.
23 How did you find that?

24 A. Well, I managed it okay.

25 Q. You did? Yes. And it said:

1 "Side effects were discussed at length."
2 A. Hm-mm.
3 Q. What were you told about the side effects?
4 A. Just that there could be flu-like symptoms, hair loss,
5 tiredness.
6 Q. There are others listed there in the second paragraph.
7 Were you told about these?
8 A. Yes.
9 Q. Could I refer you to WIT0051144, which are handwritten
10 notes of your appointments following starting the
11 treatment. They are not the easiest to read but I'm
12 going to try and decipher them and you can tell me if
13 I have got them right. The first one is dated, I think,
14 12 February 1997, and you have completed two weeks of
15 interferon:
16 "Day 1 -- flu.
17 "Monday last experienced slight flu symptoms with
18 a headache persisting all next day. Cold during the
19 night."
20 The next entry, 26 February 1997. By this time you
21 have completed four weeks of interferon:
22 "Slight flu symptoms, easily coped with. Cramp in
23 legs during night."
24 Then four weeks later, another appointment,
25 26 March 1997. By this time you have completed eight

1 weeks of interferon:

2 "Leg cramp has now settled. Headaches and slight
3 flu symptoms persist. Worse on Tuesdays."
4 Was that after one of the --

5 A. The injections.

6 Q. The injections, yes:

7 "Settles with paracetamol."
8 Then four weeks later again, on 23 April 1997:
9 "Now completed 12 weeks roferon.
10 "Flu day following injection, Tuesday worse."
11 It can't have been your favourite day of the week at
12 that time:
13 "Tired especially day after injection, headaches."
14 Then we will see -- it could be 26 May:
15 "Coping with interferon well.
16 "PCR-negative at 12 weeks, transaminases reduced:
17 "Slight hair loss."
18 There is a letter which suggests you were at an
19 appointment on 15 May 1997 at the 12-week stage,
20 WIT0051152. This is confirming that handwritten note.
21 It's from Dr Mills to your GP, dated 15 May 1997.
22 Actually it was dictated on 6 May 1997. So that would
23 suggest that's the date of that previous entry. It
24 notes that you have coped well with the interferon
25 treatment:

1 "I'm pleased to report that she has had a good
2 response with reduction in serum transaminases to normal
3 and clearance of HCV RNA by PCR at 12 weeks."

4 It refers to the slight increased hair loss, which
5 was noted in the previous entry, and the plan that you
6 will continue with the interferon treatment to complete
7 48 weeks in total.

8 Were you told at that point about your 12-week
9 result and the fact you had cleared the virus at that
10 time?

11 A. Yes, I was, yes.

12 Q. Were you told what that meant in terms of the
13 Hepatitis C virus?

14 A. No, I was told that it had actually disappeared. And
15 the next time I went back, they said it had come back
16 again.

17 Q. At the time they told you it had disappeared, did you
18 know that it had the potential to come back again?

19 A. They did say that it can hide and come back again. So
20 they did say that, yes.

21 Q. So you did know that that didn't mean you had definitely
22 cleared the virus at that time.

23 A. Well, I sort of thought I had, yes.

24 Q. And the records show that your hair loss problem
25 lessened. If we look at WIT0051154, this is a letter

1 from Douglas Thorburn to your GP, dated
2 3 September 1997. This is in relation to an appointment
3 at about 24 weeks of interferon and you are now
4 PCR-positive and had an elevated AST, although ALT was
5 normal. So were you told at that point that the result
6 had changed?

7 A. Yes.

8 Q. And at this point it's noted that your thyroid function
9 tests revealed you to be hypothyroid, and at that point
10 you started medication with thyroxine.

11 A. Yes.

12 Q. And therefore you attended your GP for monitoring of
13 your thyroid function.

14 A. Yes.

15 Q. You continued on thyroxine for a long time. Do you
16 still take it?

17 A. I still take it.

18 Q. So you never stopped taking it since that time?

19 A. Never.

20 Q. If we look at WIT0051158, this is the review at 36
21 weeks of Alpha interferon. It's a letter from
22 Douglas Thorburn to your GP, dated 13 October 1997. And
23 it notes:

24 "The dose has been increased for the past 12 weeks
25 in view of biochemical breakthrough".

1 But they are now going to reduce it again for the
2 final 12 weeks. You continue at this point -- as we
3 know you do -- on thyroxine. It's noted that you feel
4 better:

5 "... although intermittently tired on starting the
6 thyroid treatment and the thyroid function tests that
7 I performed today will give us some assessment of
8 whether the dose that she is taking is satisfactory."

9 I think that the handwritten notes on that letter
10 suggest that it is satisfactory.

11 It notes that you are being given a further
12 appointment for 12 weeks and that you will have another
13 liver biopsy at that point.

14 If we look at WIT0051157, that's a report of the
15 liver biopsy that was then carried out. The liver
16 biopsy was carried out on 17 December 1997 and reported
17 on 22 December 1997. It's recorded that this is being
18 done post 48 weeks of Alpha interferon, and we will see
19 in the second last paragraph:

20 "The appearances are those of a chronic hepatitis
21 with minimal activity and without fibrosis. The
22 features are similar to the previous biopsy... and are
23 entirely consistent with Hepatitis C infection."

24 If we look at WIT0051160, this is a letter from
25 Dr Mills to your GP, dated 11 February 1998. It notes

1 that you have completed the 48 week course of Alpha
2 interferon in December 1997:

3 " She had a very good initial response to the therapy
4 with clearance of the virus at 12 weeks but
5 unfortunately had a breakthrough by 24 weeks and further
6 increasing dose of interferon at that time, which
7 unfortunately hasn't cleared the virus. She had
8 a repeat liver biopsy in December 1997, which again
9 showed very mild chronic hepatitis with no real change
10 from the initial biopsies."

11 So what were you told at this point? You were told
12 that the treatment hadn't worked?

13 A. Yes.

14 Q. Were you told that there was no real change in your
15 liver biopsies?

16 A. Yes.

17 Q. Did he tell you what that meant?

18 A. Well, they just said that I would have an annual visit
19 to the hospital and they would keep an eye on me and
20 probably there would be treatment in the future, but
21 obviously that would be a few years down the line.

22 Q. It's noted there what you have told us, that you were
23 continuing on the thyroxine. It's noted that you had
24 lost the extra weight that you gained as a consequence.
25 So did you gain weight during the interferon treatment?

1 A. Yes.

2 Q. How much weight did you gain?

3 A. About half a stone.

4 Q. So they are going to keep an eye on that, which they
5 have done.

6 A. Yes.

7 Q. How did you feel at that point?

8 A. When it finished, you mean?

9 Q. Yes.

10 A. I was just glad it was over, really.

11 Q. Did the side effects -- did they persist --

12 A. Yes, because the interferon is still in your system for
13 a while, as far as I believe, yes. It lasted a good bit
14 longer than the year. It was a year almost.

15 Q. So how much longer do you think that lasted after you
16 completed --

17 A. Maybe a few months.

18 Q. You have managed to keep working through the treatment?

19 A. Yes, I used sort of flexi time for appointments, because
20 initially I had to go up once a week to collect the
21 interferon to bring it back home to put in the fridge.
22 So it was once a week. I had to juggle time because I
23 didn't want to lose time at work. So that just added to
24 the pressure, if you like, just having to juggle the
25 time.

1 Q. Yes. But you managed to do that, by the sounds of it?

2 A. Yes.

3 Q. So after that the plan was that you would continue to
4 attend the unit for review?

5 A. Yes.

6 Q. If we look at WIT0051167, this is a letter dated
7 21 December 1999 from Dr Mills to your GP, following
8 a review at the clinic on that date. It notes:

9 "She remains entirely well apart from some slight
10 discomfort in the muscles of her upper legs. She has
11 lost four pounds in weight."

12 They discuss whether you would be interested in
13 stopping thyroxine but you are keen to carry on. Why
14 was that?

15 A. I felt as if I needed it, but the thyroxine tests show
16 that I do still need it because I still take it.

17 Q. It's noted:

18 "I have spoken to her about possible improvement in
19 therapy in the future. It seems likely that it will be
20 at least three years away until the next generation of
21 treatment becomes available for her. She has very mild
22 hepatitis anyway. I have arranged to keep her under
23 annual review at the clinic."

24 So other than your discomfort in the muscles of your
25 legs, did you have any other symptoms of the Hepatitis C

1 virus at this point?

2 A. It was quite a long time ago. I really can't remember
3 as far as back as that.

4 Q. At a review in March 2001 -- I don't propose referring
5 you to it -- it's WIT0051169 -- your liver function
6 tests were noted to be entirely normal and your thyroid
7 function was satisfactory.

8 If we look at WIT0051171, this is the letter
9 following a review in July 2002. This is a letter from
10 Dr Elizabeth McCrudden to your GP, dated 23 July 2002.
11 It notes that you have returned to the clinic for your
12 annual review. You remain in reasonably good health at
13 this time, although you are complaining of having more
14 flu symptoms than previously. You feel a bit headachy
15 some mornings and also tired about 3 o'clock.

16 So gradually over time there was a deterioration?

17 A. Hm-mm.

18 Q. It notes that it may be appropriate to retreat you with
19 the currently available combination of pegylated
20 interferon -- I think that should read "and ribavirin":

21 "After discussion we decided that this would be
22 postponed a year when we would also consider if it would
23 be time to repeat her liver biopsy."

24 Can you remember why it was decided then to postpone
25 treatment for a year?

1 A. I think it was actually my decision to be honest,
2 because I thought I don't want -- interferon was quite
3 invasive in my life the first time round and I thought
4 if I can carry on for a year and keep working, I will
5 consider it a year down the line.

6 Q. Yes. If we look at WIT0051172, this is the review
7 a year later. It's a letter from Dr Mills to your GP,
8 dated 2 July 2003. It's noted that your genotype is 2b,
9 under "Diagnoses". You tell him that you remain very
10 well, although you admit to occasionally being tired and
11 going to bed at 10 o'clock at night.

12 You continue on the thyroxine and he, at that point,
13 went over the results of modern treatment with you and
14 told you that you would have an 80 per cent chance of
15 clearing infection with 24 weeks of treatment, but it
16 may be lower in your case you having not responded to
17 interferon. Then at the end:

18 "As she has such mild disease, she has elected not
19 to go ahead with any further treatment at the moment."

20 So that was your decision again. You wanted to
21 carry on working and presumably --

22 THE CHAIRMAN: Sorry, was 10 o'clock an early bed time for
23 you?

24 A. Yes.

25 THE CHAIRMAN: I think that distinguishes you from some of

1 us. What was your normal bed time?

2 A. During the week probably about 11.30.

3 THE CHAIRMAN: So it's quite a big difference if you have to

4 go an hour and a half early.

5 A. Yes.

6 MS PATRICK: But it wasn't enough of a difference and the

7 symptoms weren't enough to make you want to start

8 treatment at that point?

9 A. Again, it was me that put it off, yes. Because of work,

10 because of the way it interferes with your life. I knew

11 I would have to do it again eventually but I sort of

12 kept putting it off.

13 PROFESSOR JAMES: I think you were doing the right thing.

14 A. Do you?

15 PROFESSOR JAMES: Definitely.

16 MS PATRICK: If we look at WIT0051173, this is the

17 appointment a year later, in July 2004, when you

18 attended on 29 June 2004. It's a letter from

19 Alan Clarke to your GP. It notes again that you are

20 remaining well, no particular symptoms. Your last LFTs

21 were normal. You are still not keen on therapy. But it

22 states:

23 "... if we had convincing evidence of progressive liver

24 disease, she would have to consider whether or not to go

25 ahead with pegylated interferon and ribavirin. We

1 discussed whether or not to do a liver biopsy and she
2 has agreed to this to aid in the decisions as to whether
3 or not she requires a further attempt at eradicating [the
4 virus]."

5 So you underwent a further liver biopsy and the
6 result of this is WIT0051176. The liver biopsy was
7 taken on 17 October 2004 and the report is dated
8 22 October 2004. The result of this was reassuring at
9 the time. It noted at the bottom:

10 "This liver biopsy is close to normal with only
11 scanty, minimal chronic inflammation in the parenchyma".

12 The formal scoring would be inflammation, grade 1
13 out of 18, and fibrosis, stage 0 out of 6. It states:

14 "By comparison with the previous biopsy, the
15 appearances are similar and certainly show no evidence
16 of progression."

17 So you were told this at a subsequent appointment
18 and you agreed once again to leave the issue of
19 treatment for a further year. You continued to attend
20 annually and your liver function tests remained normal and
21 you had no real symptoms that bothered you, I think, of
22 the virus during that time.

23 Paragraph 11 of your statement. There obviously was
24 some deterioration over time of your state and you tell
25 us that, prior to commencing your second course of

1 treatment, you were suffering symptoms such as flu-like
2 aches and pains and you had to stop going to the gym.

3 Did you do that quite a lot before then?

4 A. It was actually aerobics, yes. And I did it for years
5 and years, and that was a big deal when I had to stop
6 that.

7 Q. Yes. Can you remember roughly when you had to stop
8 that?

9 A. It was some time before the second bout of interferon.

10 Q. Yes, and were you just finding it too difficult? Were
11 you too tired?

12 A. Yes.

13 Q. You state you were also suffering intermittent insomnia
14 and you started to develop alopecia too.

15 A. Yes.

16 Q. If we look at WIT0051185, this is a letter from
17 Celia Aitken, consultant virologist, to your GP dated
18 10 December 2008, about a clinic appointment on
19 9 December 2008. It states:

20 "She tells me that she would like to start thinking
21 about therapy again and has noticed that her fatigue has
22 got more pronounced, such that she is now no longer able
23 to attend the gym. She is thinking about considering
24 starting treatment sometime next year and this will
25 largely be dictated by what happens to her job, which is

1 currently up for review due to closure of the local

2 [REDACTED]."

3 You are referred to Liz Spence to consider when the
4 treatment would be planned. So by this point you had
5 reached the stage that you felt your symptoms were
6 interfering with your day-to-day living and you felt you
7 had reached the time to start treatment.

8 A. Yes.

9 Q. In relation to your job, what happened at that time?

10 A. Well, it has gone on for a few years about -- things are
11 changing, as they do, and job losses are considered, so
12 that's another issue for me.

13 Q. Yes. It's obviously quite a big consideration for you.

14 A. Yes.

15 Q. Your job security and the impact the treatment might
16 have on that.

17 A. Yes.

18 Q. If we move on to paragraph 12, you tell us that
19 in July 2009 you had a liver scan at the liver clinic.
20 In fact there is a report in your medical records which
21 is dated April 2009. Does that sound about right?

22 A. Yes.

23 Q. Yes. It showed mild hepatomegaly with no focal
24 abnormality. So that's enlargement of the liver. And
25 you were told that your liver was enlarged and you say

1 that they could not tell me what this means?

2 A. No, they didn't.

3 Q. No. So did they just tell you your liver is enlarged?

4 A. Yes.

5 Q. So at that point, taken together, presumably with the

6 symptoms from which you were suffering, you decided to

7 start the second course of interferon and you tell us,

8 as you have already indicated, what a big commitment you

9 felt starting the treatment was?

10 A. Yes.

11 Q. Both on your working life and on your private life.

12 A. Hm-mm.

13 Q. You tell us that you don't drive to the hospital?

14 A. No.

15 Q. Do you drive?

16 A. Yes.

17 Q. Yes. So why don't you drive to the hospital?

18 A. I just think tiredness and the symptoms -- the effects,

19 sorry, of the treatment.

20 Q. Yes. So it meant, when you started the treatment, that

21 you were going to have to take two trains --

22 A. Yes.

23 Q. -- to go to your review appointments?

24 A. Hm-mm.

25 Q. And unfortunately it's not near your home or workplace

1 and so the commuting backwards and forwards would be
2 a three-hour return journey for you for your clinic and
3 regular reviews. You felt that you had to tell your
4 employers' human resource manager about the interferon
5 treatment prior to starting it, although you would
6 rather not have had to do that.

7 Was she sympathetic to you?

8 A. Yes.

9 Q. In paragraph 13 you tell us that you started a further
10 six-month course of pegylated interferon and in fact it
11 was ribavirin as well --

12 A. Yes.

13 Q. -- on 16 September 2009. Once again, you had to inject
14 yourself with the interferon and take ribavirin orally
15 in tablet form.

16 A. Yes.

17 Q. You tell us that Liz Little supervised the first
18 injection on Wednesday 16 September, and you obviously
19 deliberately arranged this for a holiday weekend.

20 A. Yes.

21 Q. So that it wouldn't impact so much on your work.

22 A. Hm-mm.

23 Q. You took a day's annual leave, the day after it, as you
24 knew from previous experience that the side effects
25 would be bad.

1 A. Hm-mm.

2 Q. You say in fact it was worse than you remembered. You
3 had very bad, flu-like symptoms and had to spend the
4 rest of the holiday weekend indoors and that the holiday
5 weekend was completely wasted. Your routine was to
6 self-administer the interferon injection on a Wednesday
7 evening and then you obtained permission from your
8 employer to start work later on a Thursday, at 11 am
9 instead of 8.30 am, to give you a bit more time to
10 recover from this.

11 A. Yes.

12 Q. Did that help?

13 A. It did.

14 Q. And you tell us your commute to work was a 45-minute
15 drive and also you arranged that you would leave work
16 earlier on a Friday, at 3.30.

17 So was this you cutting your working hours or were
18 you re-arranging them?

19 A. I actually cut them this time, yes.

20 Q. What was the change in your hours? How many did you
21 reduce them by?

22 A. I was going in on the Thursday morning about 11 o'clock,
23 instead of 8.30 but I would work right through. I did
24 not have any other breaks during the day. I did not
25 have a lunch break or anything. And that was by

1 agreement. And I worked through to catch up on what
2 I needed to catch up on.

3 Q. Yes. So in a week, did you work less hours or did you
4 make up for the time that you were missing?

5 A. I worked less but as I said, I worked through the lunch.
6 It felt longer.

7 Q. Did that affect your pay?

8 A. No, no.

9 Q. And as you tell us, you had to attend regular clinic
10 appointments in relation to the treatment and so you
11 lost many hours at work due to these.

12 You tell us in paragraph 14 that initially your
13 clinic appointments were every fortnight and they were
14 then reduced to monthly in the course of time:

15 "At one month into treatment my blood test was
16 Hepatitis C negative".

17 You continue to attend for monitoring of your liver
18 function tests and to collect the prescriptions from the
19 hospital.

20 You tell us on the next page about the impacts of
21 the treatment on your personality. You say that you
22 didn't realise at the time but your personality seemed
23 to be changing as a result of the treatment.

24 A. No.

25 Q. I take it you have heard about more of this from what

1 your family have told you rather than --

2 A. Yes.

3 Q. You say:

4 "I was described by my family as snapping at people
5 for no reason. I spent one weekend in bed communicating
6 with no one. I also noticed that I was suffering from
7 what I would describe as panic attacks."

8 Had you ever suffered from them before?

9 A. No.

10 Q. You also became anxious and one example was when a work
11 colleague stood in your office doorway talking non-stop.
12 Under normal circumstances you would have been able to cope
13 with that but during the treatment you found that you
14 couldn't and you became nauseous and panicky. It took
15 all your strength not to shout. You tell us that you
16 have shouted, "Get out of here", "Please go away", or
17 have snapped at people, as you have lost a sense of
18 self-control. You say:

19 "It's almost akin to a form of claustrophobia."

20 You couldn't cope then with your immediate doors and
21 exits being blocked, and to control yourself, you used
22 to pinch yourself very hard to try and get the feelings
23 to subside. You developed a strategy, which was to go
24 out and have a walk in the fresh air from work to calm
25 down, and you used this many times at home and in the

1 office.

2 When the nurse specialist returned from having been
3 away on leave, you obviously discussed this with her and
4 she was concerned about your psychological state and she
5 asked you to speak with a female trainee psychologist.
6 She told you that you pinching yourself is something that
7 people with panic attacks frequently do to themselves
8 and this nurse specialist has been very helpful and
9 understanding with all of your symptoms.

10 You obviously tried to make matters better for
11 yourself but in paragraph 15 you tell us that you soon
12 realised that control of your emotional state was
13 impossible whilst you were on the interferon treatment:

14 "In one rant I kicked a door instead of my mother,
15 who is 85 years old. I was consumed by uncontrollable
16 and involuntary anger. I'm so ashamed of this.
17 I jumped in my car and took a long drive in tears."

18 It was shortly after that event that you were able
19 to tell the nurse specialist about how badly you were
20 feeling. She told you that she considered the
21 psychological side effects of interferon treatment very
22 seriously and suggested that either you speak to your GP
23 and ask for anti-depressants or speak to a psychiatrist
24 at the Brownlee Centre in Gartnavel General Hospital.
25 This was the first time you had associated what you were

1 experiencing in terms of your mood with the treatment.

2 A. Yes.

3 Q. Had you been warned that the treatment might impact on
4 your mood?

5 A. Sorry?

6 Q. Had you been warned --

7 A. Yes.

8 Q. You tell us that the worst period in relation to this
9 was October to November 2009. You tell us in
10 paragraph 16 that you decided to meet with Dr Wong,
11 consultant psychiatrist, and he had a complete
12 understanding of the powerful effects of combined
13 interferon and ribavirin treatment.

14 You saw him first in October 2009 and he confirmed
15 the diagnosis of interferon-related depression and
16 prescribed you with anti-depressants. You say it took
17 at least three weeks before this medication became
18 effective and you attended a number of appointments with
19 him.

20 You say you never thought that you would ever see
21 a psychiatrist. Dr Wong has provided a report, which
22 I think you have seen, which is WIT0051702. This is
23 dated 1 December 2011. It notes you were referred
24 to him in November 2009 and you presented with a
25 a three-week history of deteriorating mood with

1 persistent depression, associated with emotional
2 lability in the form of tearfulness, a pessimistic
3 outlook and increased levels of anxiety.

4 "Her sleep pattern had become markedly
5 disturbed with very early wakening in the morning.
6 [Anne] had no previous history of mood disorder nor
7 sleep disturbance."

8 He noted that you had recently commenced a course of
9 pegylated interferon and ribavirin and stated:

10 "The clinical presentation, with regard to her mood
11 and sleep disturbance, was entirely in keeping with a
12 diagnosis of interferon induced mood disorder and
13 associated insomnia. She was commenced on
14 antidepressant therapy with eventual beneficial
15 response to both her mood and sleep pattern. She did,
16 however, continue to experience intermittent bouts of
17 anxiety until the completion of her Hepatitis C
18 treatment in March 2010. In the final two to three
19 weeks of that treatment, her sleep pattern did again
20 deteriorate with middle of the night disturbance,
21 secondary to disturbing dreams."

22 You tell us at the end of paragraph 16 that at one
23 stage things were so bad for you that you told your
24 sister that you could understand why someone might be
25 driven to suicide, and you cannot believe now that you

1 said that to her.

2 Your sister's statement, if I could refer you to
3 that, at paragraph 10, describes the impact of how you
4 were feeling on your sister and how she saw it and your
5 mother.

6 She states that she had been on holiday abroad at
7 the time you started your interferon. Before she went,
8 you were very tense about starting the second course of
9 interferon treatment. On her return from holiday, she
10 became very worried about you because she noticed
11 changes in your personality immediately. She had only
12 been away for two weeks and the medication in that time
13 had already changed your personality. For example, you
14 were irritable and narky.

15 She said she couldn't say anything to you without
16 you reacting in an extremely confrontational manner:

17 "She was twisted and volatile and really hard to
18 live with. It was a very difficult time. [Anne] had
19 episodes of daily anger."

20 Soon after September 2009, your other sister came to
21 ██████████ on holiday. She is by nature very mild
22 mannered but this other sister became angry with you
23 because you had been nasty to your mother, who is
24 85 years old, and in fact your mother felt threatened
25 and vulnerable living with you at that time.

1 And sadly your sisters lost trust in you and your
2 other sister witnessed a huge volatile row between
3 yourself and your mother. It was so bad that your other
4 sister had to intervene to protect your mother:

5 "It was awful and [Anne] stayed in her room for
6 about ten days. Prior to the interferon treatment
7 starting, the whole family was aware of the potential
8 side effects because [Anne] shared this information with
9 us. However, despite that, I did take the insults and
10 volatile behaviour personally. It's easy to forget that
11 this period of hostility was all because of interferon
12 ... "

13 And like you, she feels that the worst period
14 was September/October 2009.

15 She said your behaviour was really destructive:

16 "I worried about how I would speak to her because
17 she became hypersensitive. She became a monster. In
18 a rage she would behave with eyes flaring and voice
19 blaring."

20 She became really worried and had to keep a daily
21 eye and check on how things were, and she was
22 considerably worried about the impact this was having on
23 your mother. Your nephew started avoiding you and then
24 she notes that your treatment from Dr Wong made quite
25 a difference. She states:

1 "I know that her behaviour has deeply upset her. It
2 was very frightening to see my sister change
3 in September and October 2009."

4 She expresses your mother's and her concerns about
5 your health and how unfortunately you had to cancel a
6 recent holiday due to the volcanic ash:

7 "She desperately needed a break."

8 THE CHAIRMAN: It might be important to bring out the date
9 on which this statement was signed, since it indicates
10 this is very close --

11 MS PATRICK: It is very close. The date of this statement
12 is 30 May 2010.

13 THE CHAIRMAN: Your sister speaking soon after observing
14 these incidents.

15 A. Yes.

16 MS PATRICK: Yes, and describing the impacts of these on you
17 and on your family.

18 In paragraph 17 of your statement you tell us that
19 in addition to these intense psychological side effects,
20 you also suffered intense physical side effects too.
21 You had continuous flu and had to take regular
22 paracetamol. In the first three weeks of interferon
23 treatment, this was out of control and required no less
24 than six paracetamol tablets daily:

25 "I had to take paracetamol every week to two weeks.

1 My temperature fluctuated. I felt cold and clammy.
2 I was shivery. I felt hot. I had a dry mouth.
3 I produced less saliva due to interferon treatment.
4 I had dry skin and suffered alopecia. I saw my hair on
5 the pillow and in the shower. I suffered from poor
6 concentration. In the first two months of treatment my
7 concentration was exceptionally low. On a scale of 1 to
8 10, it was 0 to 1 only. Towards the end of the
9 treatment I was living with concentration levels at,
10 say, 5 out of 10. My immunity to fighting infection was
11 compromised. I had a non-productive dry cough for the
12 first six weeks of treatment, followed by a serious
13 chest infection, which lasted four weeks, requiring
14 antibiotics. My appetite was suppressed. I did not
15 feel hungry. I had to force myself to eat. In the
16 early weeks of interferon treatment I skipped many meals
17 and ate tiny portions. I was unable to eat starchy
18 foods, such as potatoes."

19 You did however crave ice cream and having lost
20 weight initially, about four pounds, you put that weight
21 back on again and you are now back to your pre-treatment
22 weight. You tell us that towards the end of your
23 treatment, you still had flu symptoms and panic attacks
24 every two weeks. You continued to suffer from spells of
25 anxiety and experienced butterflies in your stomach,

1 increased heart rate and clamminess.

2 In September 2009 you had to stop swimming as well.
3 So you obviously enjoyed keeping fit but this had quite
4 an impact on that.

5 A. Yes.

6 Q. You say:

7 "On the weekends off work, I used to relax."

8 Did you manage to keep working through all of this?

9 A. Yes.

10 Q. Did you lose any time off work?

11 A. No, but I think that's my nature more than anything
12 else. You know, pushing myself to go to work.

13 Q. Yes. You tell us that during the interferon treatment
14 you never had a good night's sleep. You had vivid,
15 nightmare-ish dreams which made you wake early, about
16 4 am, and you never got back to sleep. So you used to
17 catnap during the day, which you have never done before,
18 and you recharged your batteries in the Christmas
19 holidays 2009, by catching up on your lack of sleep.

20 If you went shopping with your sisters, you had to
21 sit down for 20 minutes at least, three times during the
22 course of an outing, because you were so tired. You say
23 your stamina on a scale of 1 to 10 was only 3 out of 10
24 whilst you were on the interferon treatment.

25 You tell us in paragraph 25, which is the page

1 ending 1121, that you finished your treatment
2 in March 2010, and at that time you were told that the
3 virus was detectable already.

4 THE CHAIRMAN: Ms Patrick, we should have a break since we
5 started early.

6 MS PATRICK: Yes.

7 THE CHAIRMAN: Do you want to finish that paragraph?

8 MS PATRICK: I will finish that paragraph.

9 You were understandably very upset about that.

10 A. Hm-mm.

11 Q. You say that the specialist nurse was shocked that the
12 virus could be detected so soon after finishing the
13 treatment. Having put such a great effort into
14 completing the treatment, you were exceptionally hopeful
15 that it would have worked, so that must have added to
16 your disappointment at that time.

17 A. Hm-mm.

18 THE CHAIRMAN: We will have a break at that stage.

19 (3.00 pm)

20 (Short break)

21 (3.24 pm)

22 THE CHAIRMAN: Yes, Ms Patrick?

23 MS PATRICK: Thank you.

24 Anne, could I refer you back to your statement,
25 please, to paragraph 27, which is WIT0051121?

1 It's worth saying at this point that your statement
2 was provided to the Inquiry in May 2010, and in
3 paragraph 27 you tell us how you were feeling at that
4 point, which was a couple of months after your treatment
5 had finished.

6 You tell us that, as at May 2010, you were still
7 metabolising the residual interferon within your system.
8 You were still lethargic but your concentration had
9 improved vastly. You, at that time, didn't have any
10 uncontrollable irritability and did not feel depressed
11 any more, and in fact you stopped your anti-depressant
12 medication, according to Dr Wong, in about March 2010.

13 Is that right?

14 A. Sorry, I missed what you said there.

15 Q. That's all right. According to Dr Wong's report, you
16 finished your anti depressant medication at the end
17 of March 2010.

18 A. He actually told me to finish but when I went to the
19 clinic upstairs, the nurse thought it was too quick and
20 she had prescribed more of it. Actually I'm still on it
21 at the moment.

22 Q. You are still on it?

23 A. Yes.

24 Q. And so, in relation to your irritability and feelings of
25 depression, do you think you still suffer from these?

1 A. I'm still on citalopram and not too anxious to come off
2 it, to be honest.

3 Q. You are feeling better on it?

4 A. Yes.

5 Q. You tell us that as at May 2010, you were still
6 suffering from anxiety and panic attacks. Do you still
7 suffer from these?

8 A. No.

9 Q. You also tell us there that you had tried to get back to
10 your aerobics class but your stamina was still
11 compromised. Is that still the position?

12 A. Yes.

13 Q. So you haven't managed that?

14 A. I haven't got back.

15 Q. What about swimming?

16 A. I haven't gone back to that either.

17 Q. No. So on an average day, how do you feel?

18 A. Now?

19 Q. Yes.

20 A. I just get on with daily life, I suppose. I don't think
21 about every ache and pain that I get. I just get on
22 with it really.

23 Q. Do you still feel tired?

24 A. Yes.

25 Q. Still going to bed earlier than usual?

1 A. Yes.

2 Q. Flu-like symptoms. Do you suffer from these still?

3 A. Yes, I would say that I do.

4 Q. And aches and pains?

5 A. Yes. But because you are so used to having them,
6 I don't really think about them.

7 Q. You tell us in paragraph 28 -- but I think we have
8 already heard from what you have told us already -- how
9 everything in daily life when you are on interferon
10 treatment becomes incredibly challenging, and your
11 relationships with your close family were tested.

12 The year of your treatment with interferon and
13 ribavirin has been a very difficult time for you all.
14 You say that your elderly 85-year old mother bore the
15 brunt of living with you and the associated symptoms of
16 the virus. She has worried about you for over 25 years
17 and this is most unfortunate:

18 "I do not know what my future holds for me and my
19 future is very uncertain."

20 I was going to refer you to letters about your last
21 few appointments at the hospital.

22 A. Okay.

23 Q. The first of these is WIT0051206. This is dated
24 1 September 2010 and is a letter from Professor Mills to
25 your GP. It notes that you underwent 24 weeks of

1 combination antiviral therapy. Whilst you had had
2 an encouraging response at four weeks, with almost
3 complete suppression of the virus, unfortunately the
4 virus still seemed to be present at the end of your
5 period of therapy and he was going to make a final
6 assessment of the outcome of the treatment on that day.

7 If we turn to WIT0051207, we can see the results
8 of that assessment. This is a letter from Dr Mills to
9 your GP, dated 15 September 2010. It notes the results
10 of the tests from the 1 September 2010. With AST, 56,
11 ALT, 86, gamma GT, 45, other liver function tests
12 normal. It's noted that you are HCV RNA-positive. It
13 states:

14 "She has therefore unfortunately not succeeded in
15 clearing the virus and will be classified as
16 a non-responder to combination antiviral therapy."

17 You then saw Professor Mills again on 2 March 2011.
18 The reference for this is WIT0051208. This notes that
19 you are still taking thyroxine and anti-depressant
20 medication, and he was able to give you a little
21 information about the potential for new treatments for
22 genotype 2 Hepatitis C. They are beginning to be tested
23 but will be a few years off before they are into
24 clinical practice. He repeats your blood tests and will
25 review you again one year from then. Have you been told

1 the results of those tests?

2 A. No.

3 Q. No. So what do you understand your options for future
4 treatment are?

5 A. Well, maybe more in a few years. But I don't know what
6 the treatment would be.

7 Q. So at the moment you are going to continue to attend the
8 liver clinic for monitoring?

9 A. Yes.

10 Q. Could I refer you to your sister's statement,
11 WIT0051213, paragraph 11?

12 This is your sister recording the impact of your
13 treatment on the family and how upset they are that the
14 treatment did not work. They feel your life has been so
15 challenging and the interferon treatment was horrendous
16 for you. The side effects placed the entire family
17 under pressure and they could not possibly have
18 envisaged the violent effects of this medication.

19 Over the page at paragraph 13 she states:

20 "My sister's life has been adversely affected by
21 Hepatitis C. I have worried about her for many years
22 and continue to do so. I do not know how her future
23 will pan out. She is ill just now. She tires very
24 easily. She cannot even cope physically with going
25 shopping and has to sit down every hour for a long rest.

1 She has tried to restart ..."

2 As you have told us, activities like aerobics, but
3 your fitness is still really compromised.

4 Could we return to your statement, please? At
5 paragraph 19 you tell us about the impacts of
6 Hepatitis C on your life and you say:

7 "[It] has had a profound impact. It has reduced my
8 life opportunity in terms of maintaining personal
9 relationships, obtaining employment chances and the
10 subsequent economic disadvantage suffered by me as
11 a result. In my opinion, this is why I remained single
12 and did not progress or encourage potential marriage
13 options. I was a young woman when this happened to me.
14 I did not encourage any long-term relationships. You
15 have to draw the risk of transmission of this virus to
16 someone's attention right away. My confidence to do so
17 was non-existent. I have missed out with the
18 opportunity of potentially raising a family of my own."

19 Would you say that the Hepatitis C virus has
20 affected your friendships?

21 A. Not friendships, no.

22 Q. No. Your social life, apart from --

23 A. In a way, yes, it has.

24 Q. Yes. In what way?

25 A. Relationships probably, or confidence.

1 Q. In that paragraph you touch on obtaining employment
2 chances. You have told us that there has been some
3 uncertainty about your occupation. Do you feel that you
4 have missed opportunity to obtain other work? Would you
5 have tried to move jobs?

6 A. No, I do like the job I have but because there is
7 uncertainty with that, or there was uncertainty with
8 that, that was always in my mind: what will I do if this
9 happens? Do I have to declare that I have Hepatitis C.
10 I don't know if I have to do so but I would imagine
11 I would.

12 Q. You are worrying what would happen if you were to lose
13 your present occupation and how you would obtain --

14 A. Exactly, yes.

15 Q. What is the situation at your work presently?

16 A. It has kind of settled at the moment. It sort of raises
17 its head every now and again but at the moment it seems
18 to be settled.

19 Q. Yes.

20 THE CHAIRMAN: Are you still doing research?

21 A. Yes.

22 THE CHAIRMAN: So there really is still quite an active
23 business, as it were, going on down there?

24 A. Yes.

25 THE CHAIRMAN: That has not been threatened recently?

1 A. No, education have moved, though. They have moved to
2 the [REDACTED].

3 MS PATRICK: You talk about your uncertainty with regard to
4 this in paragraph 23, which is just further down what we
5 are looking at. You tell us also that you have a civil
6 service pension fund. Has there been any impact on that
7 of your infection with Hepatitis C?

8 A. No.

9 Q. You tell us in paragraph 22 that you do have a mortgage
10 but you haven't had to disclose your diagnosis with
11 Hepatitis C?

12 A. No.

13 Q. You worry about how you will pay this if you were to
14 lose your job and be unable to find another one, and the
15 impact on this of both you and your mother. You tell us
16 in paragraph 20 that you have no life insurance. You do
17 not want to discuss this with potential insurance
18 companies.

19 Is that the reason why you do not have life
20 insurance, because you are concerned about what they
21 will say in respect of Hepatitis C?

22 A. Hm-mm.

23 Q. You tell us in paragraph 21 that when you have obtained
24 travel insurance, you haven't divulged your diagnosis
25 with the Hepatitis C virus to travel insurers.

1 A. No.

2 Q. You must have incurred some expenses in attending clinic
3 appointments?

4 A. Yes.

5 Q. Rail expenses, obviously, for during the treatment?

6 A. Yes.

7 Q. And petrol?

8 A. Yes.

9 Q. Have you had to pay prescription charges?

10 A. No, because I was on thyroxine, prescriptions are
11 actually free, which I didn't know.

12 Q. Have you incurred any other expenses as a result of your
13 infection with Hepatitis C?

14 A. Mostly I would say travelling expenses.

15 Q. In paragraph 24 you tell us that in 2004 you received
16 a payment of £20,000 from the Skipton Fund. You point
17 out at the end of that, when you asked your GP to sign
18 off the form, even at that point he didn't seem to
19 realise why you had the virus and he mentioned that only
20 three of his patients, who were all drug abusers, had
21 the Hepatitis C virus and he didn't differentiate your
22 status.

23 A. I think he was puzzled by the form. He didn't know what
24 the Skipton Fund was. So when I asked him to sign it,
25 he had never seen one before because, although there

1 were three people in the practice with Hepatitis C, only
2 one incurred it through a blood transfusion.

3 Q. Yes. Finally you tell us at the end of paragraph 21
4 that you are concerned about the stigma attached to the
5 virus and you prefer that people do not know that you
6 have it.

7 A. Yes.

8 Q. And it means you have kept these personal matters to
9 yourself and you are keen to preserve your privacy. Who
10 have you told about your diagnosis with Hepatitis C?

11 A. Very few people. Obviously my employer knows and
12 family, and I would say probably the doctor's
13 receptionists know as well. They have access to the
14 files.

15 Q. Thank you very much.

16 A. Thank you.

17 THE CHAIRMAN: Mr Di Rollo?

18 MR DI ROLLO: No, thank you, sir.

19 THE CHAIRMAN: Mr Anderson?

20 MR ANDERSON: No thank you.

21 MR JOHNSTON: No thank you.

22 THE CHAIRMAN: Thank you very much indeed. That's a great
23 help.

24 MS PATRICK: Sir, there are no further witnesses for C6
25 until January.

1 THE CHAIRMAN: No, we will adjourn briefly but I would like
2 your help about tomorrow. Having seen a bundle of
3 papers, I would like to know what's happening.

4 (3.42 pm)

5 (Short break)

6 (3.49 pm)

7 Housekeeping

8 THE CHAIRMAN: Ms Dunlop, my concern is that, having seen
9 quite a volume of paper, we might not be able to finish
10 tomorrow, but I understand the position is really that
11 to accommodate Professor Lowe, we must convene and see
12 how we get on.

13 MS DUNLOP: The position is that we didn't really have much
14 room for manoeuvre because Professor Lowe is going to
15 Australia between 8 January and 7 February. So, faced
16 with a choice between not having him at all because of
17 his absence in the Antipodes, or putting him into our
18 only available slot, which was tomorrow morning, we
19 chose the latter. But I freely accept it's not ideal
20 and we probably won't have enough time, particularly if
21 my colleagues in the front row want to ask him any
22 questions really at all.

23 THE CHAIRMAN: Do you have any feeling, Mr Di Rollo, for the
24 volume of material that you might wish to cover?

25 MR DI ROLLO: One of the difficulties I have, I am afraid to

1 say, is the amount of material that has been produced at
2 quite a late stage in relation to this --

3 THE CHAIRMAN: A lot of it is fairly familiar stuff.

4 MR DI ROLLO: It is. I understand that. I would anticipate
5 wanting to ask him some questions but I would have
6 thought -- I understand the problem, obviously, and we
7 will have to just try and do our best, I suppose, in
8 relation to this. I don't anticipate a major problem,
9 I don't think, but we will just have to wait and see how
10 we get on. It seems likely that he may not be finished
11 in chief, I suppose, depending on how far we get with
12 him tomorrow but ...

13 It may not be necessary to actually specifically put
14 to him matters. He says what he says in his statement,
15 which I have read, and it may be a matter for comment
16 rather than a matter for putting questions to him
17 specifically.

18 THE CHAIRMAN: There are obvious comments that might be made
19 given the generality of the assertions that are made,
20 not necessarily in his statement but in the composite
21 document.

22 Mr Anderson, what's your position on this?

23 MR ANDERSON: I would anticipate either no questions or
24 very, very few. And it may depend, of course, on what
25 questions Mr Di Rollo asks.

1 THE CHAIRMAN: Mr Johnston?

2 MR ANDERSON: At the moment I wouldn't anticipate --

3 THE CHAIRMAN: Are you significantly interested in the
4 content of this section?

5 MR JOHNSTON: I wouldn't expect to have anything much at
6 all.

7 THE CHAIRMAN: I think it really is a matter for the other
8 two.

9 MR JOHNSTON: Yes.

10 THE CHAIRMAN: I think what we must do is start and see how
11 we get on. If we don't complete his oral testimony, we
12 will then have to consider alternatives. We will start
13 as soon as we can. I have got another meeting, which is
14 why we are starting later, but I'll simply have to try
15 and bring that to a close pretty quickly.

16 Since the meeting is at half past eight, an hour
17 that some of you may not recognise as being part of real
18 life, never mind part of the working day, it may well be
19 over by the time you arrive. But I will see what I can
20 do to accelerate things and start as soon as we can.

21 Therefore I would ask you all to be here for half
22 past nine in the hope of getting it moving as quickly as
23 possible -- is that an acceptable way forward? -- and we
24 just see.

25 MS DUNLOP: Yes, certainly given that some of the material

1 is plainly teamwork and we will be having other members
2 of the team in January, that may also afford a partial
3 solution because questions can be put to them.

4 THE CHAIRMAN: Yes. Evidence from the chorus is always
5 subject to comment. Okay. We will rise at that and see
6 how we get on tomorrow.

7 (3.53 pm)

8 (The Inquiry adjourned until 9.30 am the following day)

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I N D E X

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13 LAURA1

14 Questions by MS PATRICK1

15 ANNE75

16 Questions by MS PATRICK75

17 Housekeeping135

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