

Penrose Inquiry

The following transcript is for Day 77 of the Oral Hearings of The Penrose Inquiry, held on 13th 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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Tuesday, 13 December 2011

(9.30 am)

COLIN

Questions by MS PATRICK

THE CHAIRMAN: Good morning.

MS PATRICK: Good morning, sir. Our first witness today is
Colin.

Colin, I would like to start by letting you know who everyone is in the room today. On the bench we have Lord Penrose and next to him Professor James, the medical adviser to the Inquiry. Seated next to you is Margaret, who you know, and coming along the front here, we have seated closest to you the stenographers, who are typing everything that is said this morning for the transcript of the hearing. Seated next to them is Maria McCann, who is the secretary to the Inquiry, and then Oli Stempt, who is in charge of documents this morning. When I refer you to parts of your medical records, he will arrange for that to appear on the screen in front of you.

A. All right.

Q. Seated next to me is Laura Dunlop, whom you have just met, the senior counsel to the Inquiry, and behind her is Lindsey Robertson, who is assisting us with this topic. Coming along the front we have the lawyers for

1 the core participants. Close to you are the lawyers for
2 the Scottish Government and in the middle the lawyers
3 for the Health Board and blood transfusion service, and
4 furthest away from you are the lawyers that you know,
5 those representing the patients, relatives and
6 Haemophilia Society.

7 A. Yes.

8 Q. You are being known for today's hearing as "Colin" but
9 that's not your real name?

10 A. Correct.

11 Q. And you provided the Inquiry with a witness statement
12 and you should have a hard copy of that in front of you.

13 A. I do.

14 Q. And the number of that is WIT0050286.

15 A. Yes.

16 Q. In paragraph 1 you tell us that you are 55 years of age.
17 Is that still the case?

18 A. Unfortunately no, I wish it was. In fact, no -- no, I'm
19 57.

20 Q. 57. And what is your date of birth?

21 A. [REDACTED].

22 Q. Where do you live?

23 A. I live in [REDACTED] in [REDACTED].

24 Q. Are you married?

25 A. Yes, I am.

1 Q. And do you have children?

2 A. I do. I have -- my eldest daughter [REDACTED] and I have two
3 boys [REDACTED].

4 Q. You tell us in paragraph 2 that you used to have
5 Haemophilia B and you contracted the Hepatitis C virus,
6 genotype 1. Was there a history of haemophilia in your
7 family?

8 A. Obviously there was but I didn't know at the time
9 because my oldest brother, who is no longer alive -- my
10 oldest brother, he wasn't a haemophiliac. There were
11 three of us after that. The other three brothers were
12 all haemophiliac.

13 Q. So you are one of four brothers?

14 A. One of four, yes.

15 Q. And the eldest brother did not have haemophilia?

16 A. No, he was not a haemophiliac. That can happen. It can
17 miss a generation; it can miss people out. Obviously
18 that was what happened there.

19 Q. So in the four brothers, were you number two?

20 A. No, I was number three.

21 Q. Have any of your brothers acquired Hepatitis C from
22 their treatment?

23 A. Yes, they both have that.

24 Q. And how are they both doing?

25 A. My oldest brother, he is doing fine. He went through

1 both treatments that were offered: interferon, ribavirin
2 and then the pegylated interferon and such like. He
3 suffered that for two years and went through hell with
4 the treatment and at the moment, according to the
5 situation, he is Hepatitis free, which -- we know is still
6 in his system but -- he still has the virus but it is
7 not active or effective. They can only test a certain
8 level so at the moment they are treating him as clear.

9 My younger brother, he is the same. He went through
10 the treatment but couldn't stay on it like myself. He
11 had to come off it because of health reasons but he is
12 also fine at the moment as well. He had a transplant as
13 well.

14 Q. He had a liver transplant?

15 A. Yes.

16 Q. Thank you. In paragraph 2 you tell us that your
17 clotting factor was less than 1 per cent?

18 A. Yes.

19 Q. There is some suggestion in your medical records that it
20 was in fact about 7 or 8 per cent, which we have
21 discussed. I was going to refer you to the documents
22 which mention this. The first of these is WIT0050510.
23 If you go to the bottom of this page, you will see that
24 it's dated 13 November 1973.

25 If you scroll up to the top, you were admitted after

1 extraction of three teeth. It's the last sentence
2 there, where it says:
3 "Factor IX assay prior to transfusion, 8 per cent."
4 A. Yes, I can see that.
5 Q. Yes.
6 A. Our circumstances, as I said, we used to carry a card
7 and we were always told that our clotting factor was --
8 severe haemophilic was less than 1 per cent, and it
9 stated that on the green card we used to carry for
10 having an accident or anything. So I think at any time
11 people -- the clotting can change.
12 Q. It can.
13 A. A long time ago, which is not in my notes, we had been
14 very healthy and active. I used to do a lot of running
15 and such like and my brothers and I, we did an exercise
16 for a doctor -- a Dr Rizza. It was found that when
17 you -- your blood -- if you had done exercise, your
18 clotting factor was better.
19 We actually -- the local park in [REDACTED]. He
20 came out and did a survey and we ran round the park
21 twice, he took blood off. We did it another three or
22 four times. And in the trials he found out that the
23 more exercise -- the more your adrenaline is going, the
24 better your factor is.
25 I'm not saying that's the case here but that was

1 found. And everybody when we speak to them and tell
2 people this, to deal with the clotting factor or to deal
3 with haemophilia, they say it was a load of rubbish but
4 we seen the results and as far as we were concerned, and
5 as far as I was concerned in my life, that was the case.
6 There was lots of times I didn't go to hospital with
7 bleeds and I had big gaps.

8 Q. We are going to come on to that when we look at your
9 treatment for haemophilia.

10 A. As far as we were concerned -- to your question --
11 1 per cent was what we had been told, being severe
12 haemophilia. That's what was printed on the card.

13 Q. Thank you. You tell us that you were diagnosed as
14 a child with haemophilia and you were never given
15 treatment prophylactically, you were only ever treated
16 for major bleeds at the hospital?

17 A. Yes.

18 Q. And you only attended hospital when the bleeds were
19 severe?

20 A. Yes.

21 Q. You tell us in paragraph 8, which is over the page, that
22 you were treated at Maryfield Hospital, Dundee until
23 1973 and then your care was transferred to
24 Ninewells Hospital, Dundee.

25 A. Yes.

1 Q. You say there that the only thing that has ever been
2 discussed with you about the benefits of Factor IX is
3 that it stops bleeding with your factor levels being so
4 low.

5 A. Basically, yes, it was to make our bleeding stop.

6 Q. I would like to refer you to WIT0050503, which is
7 a note of the admission you talk about in paragraph 3 of
8 your statement, where you tell us that you were treated
9 once, when you were young, at Maryfield Hospital in
10 1961.

11 A. That was a long time ago.

12 Q. Yes. It shows that you were seven years old at the time
13 and you were admitted on 5 August and discharged on
14 18 August. Under "Past History" it records
15 Christmas Disease first diagnosed four years ago.

16 A. Yes.

17 Q. And further down, on examination, your right foot and
18 ankle were swollen. The treatment you received for this
19 under "Course and Progress" was a compression bandage to
20 the ankle with a wire splint applied over the bandage.
21 This was left on -- I think it looks like -- for about
22 four days, when Elastoplast stirrup strapping was
23 applied to the ankle and you were allowed up. You were
24 then discharged home on 18 August.

25 A. Yes. Yes, I can remember that ankle actually.

1 Q. Yes. In paragraph 4 you tell us that you remember a
2 time when, in 1972, you had a bruised and swollen hand
3 and you were given Factor IX.

4 A. Yes.

5 Q. I wonder if you could have a look, please, at
6 WIT0050507. Unfortunately, the end of the year is
7 obscured in this letter but having looked through the
8 medical records, it appears quite clear that this is
9 dated 1972 and is about the incident you have spoken
10 about in your statement. It states that you attended
11 the ward complaining of a swollen, painful hand and it
12 was arranged for you to have an infusion of fresh frozen
13 plasma.

14 A. Yes.

15 Q. So it was plasma that you received at that point.

16 A. Yes.

17 Q. You recall that you had a "real adverse effect" to the
18 plasma.

19 A. Yes.

20 Q. And as you will see in the second paragraph it says:
21 "unfortunately once again he developed an allergic
22 reaction to the plasma" and had to be treated with
23 medication to alleviate this.

24 It states "once again" there, which suggests that
25 you had previously had an allergic reaction to plasma.

1 Do you remember that?

2 A. I do not, no, I don't actually. That's the only one --

3 there may have been something but that particular

4 instance was severe. The skin was bubbling up off my

5 body, it was starting to peel. It was serious, so

6 serious that I was going in and out of consciousness,

7 and as I say, the big bubbles in my body and arms -- the

8 skin was parting from my body. So whatever it was,

9 that's the only time I have had effects like that.

10 There may have been other side effects but nothing that

11 sticks out and I remember as clearly as that.

12 Q. Right.

13 A. I don't know if they had seen anything like that before

14 but there was quite a panic on when it happened, in the

15 hospital.

16 THE CHAIRMAN: Professor James says it is a well recognised

17 reaction but is very rare.

18 PROFESSOR JAMES: It's called Stevens-Johnson Syndrome.

19 A. So I have someone to blame for that now.

20 PROFESSOR JAMES: Yes, a pair of them.

21 A. Very good.

22 MS PATRICK: I would like to return to your statement,

23 paragraph 5, please. You tell us that until you were

24 ill in 1994, you only had treatment a maximum of half

25 a dozen times and it was always in hospital. Some of

1 these, I think, were in relation to dental treatment.

2 A. Yes, that's correct. One was very foolish. I went to
3 my local dentist and ended up getting teeth out, knowing
4 I was haemophiliac but stupidly got my teeth out, and of
5 course they wouldn't stop bleeding. So I ended up --

6 Q. Is that the time you didn't tell him that you were
7 haemophiliac?

8 A. Correct, yes. Mainly because of pain in the tooth, I
9 thought I had better go to the dentist.

10 Q. You tell us that your maximum stay in hospital was for
11 three or four days, and there was a period of many years
12 when you were never near a hospital.

13 A. That's correct.

14 Q. You were reluctant to get treatment for bleeds as in
15 your mind you felt it weakened your immune system.

16 A. Yes, in my own mind that's the way I looked at it,
17 because if I had a bleed and got factor, shortly after
18 that if I had another bump, it seemed to be one of
19 these, it was always worse, but I found out if I --
20 I went a long period never going because I felt better
21 not going because the bumps seemed to be more frequent
22 after getting factor, much easier and such like. That
23 may have been in my mind but that's the way I looked at
24 it.

25 Q. And how did having haemophilia affect you as a child?

1 A. I have to be honest and say it really didn't affect me
2 greatly as a child. I led quite a normal life. At
3 times I didn't even bother about it. I used to play
4 football, which I was told I shouldn't do. Even late on
5 in my teens, I was a good skier. I used to water ski,
6 snow ski, things that you should never do. And when
7 I was working, rather than go and get treatment, I used
8 to go to work with black and blue legs and arms because
9 I wouldn't go for treatment. It was only if it was
10 severe that I would go for treatment.

11 Q. Did you feel your haemophilia affected your school work
12 at all?

13 A. Not really, not at the school.

14 Q. And how old were you when you left school?

15 A. I was 15.

16 Q. And what did you do after you left school?

17 A. I went to work for Jaeger in the clothing trade in
18 Dundee.

19 Q. What were you doing there?

20 A. I was in the sales. In the men's sales side in Jaeger.

21 Q. How long did you work there for?

22 A. I worked there for about 18 months until they decided to
23 close the men's department.

24 Q. And then what did you do?

25 A. I actually started up on my own after that. I was --

1 I started a small clothing shop, at the time, in
2 [REDACTED], where I lived. I enjoyed the trade.
3 I was actually offered by Jaeger at the time to go to
4 Edinburgh, to another branch, but Edinburgh seemed
5 a long way away at that age to go and move.
6 THE CHAIRMAN: At this stage you are still fairly young --
7 A. Yes.
8 THE CHAIRMAN: -- to be taking the lease of a shop?
9 A. Yes. Two years later I bought the shop. Actually, when
10 I worked for Jaeger in the first year, out of all the
11 shops, I got the sales person of the year award for the
12 52 stores they had.
13 PROFESSOR JAMES: Golly.
14 MS PATRICK: That's impressive.
15 A. That was one of the reasons I realised I liked sales,
16 and that was the reason I decided to go into the work,
17 and I liked, as they called it at that time, the rag
18 trade. So that's what I went into.
19 Q. How long did you have your shop for?
20 A. About six/seven/eight years, in about there. The
21 biggest problem, when I was single it was fine, but when
22 you are married and you are both working, you are
23 bringing in a wage, but when my daughter came along and
24 my wife is not working, in a small town like
25 [REDACTED] you have only got a certain population you

1 are dealing with. It's not as if you are in Dundee
2 bringing the surrounding area into your shops. So the
3 sales are never going to grow to a massive level. So
4 once it got to the stage that I was not earning enough,
5 as I should say, that's when I decided to move --
6 change.

7 Q. What did you do after the clothing shop?

8 A. What actually I did -- well, I still had the clothing
9 shop. My brother and I, we started doing door to door
10 morning rolls deliveries for extra money, which actually
11 grew into quite a large business. We actually started
12 producing our -- we had our own bakery, although I was
13 not a baker, I never knew anything about it. That's
14 what we did, and then the shop closed -- in fact
15 I didn't close the shop at that point, I closed the
16 clothing trade shop and we opened up as a baker's shop.

17 THE CHAIRMAN: Can I ask you just a little about the
18 clothing shop?

19 A. Yes.

20 THE CHAIRMAN: At that stage were you still sourcing your
21 material through agents or were you getting it direct
22 from manufacturers or what?

23 A. Because my sales grew quite quickly, certain -- a lot of
24 things I bought through agents to get clearance lines,
25 things like that, to become cheaper than the high

1 streets in Dundee and places like that, but then
2 I managed to open up accounts with shirt companies like
3 Rael Brook and people like that, Wrangler for jeans.
4 Now, the biggest headache with even that, I was buying
5 them at a good price, Wranglers and such like, and
6 I could sell them cheaper than they could come into
7 Dundee. At that time you had Mr Beaujangles in Dundee
8 and places like that. I was maybe £5 a pair cheaper.
9 At that time that was a lot of money. But people would
10 still go to Mr Beaujangles, because it had his label on
11 it, and buy the same pair of jeans, and they would come
12 home on the bus and look in the window and see it £5
13 cheaper, but that's just the way people were in those
14 days.

15 THE CHAIRMAN: All of us have children and grandchildren and
16 the label still has a powerful --

17 A. I know that very well.

18 THE CHAIRMAN: The reason I was asking is that -- well,
19 maybe during the time you were getting from agents, they
20 would come to you, but when you started sourcing your
21 own materials, that must have involved a fair amount of
22 going out into the community and trying to contact
23 manufacturers and so on.

24 A. It did. It wasn't easy to start with because you would
25 go to some place and you would think this is great, but

1 sometimes the range was limited, sometimes the quality
2 wasn't there; and one thing I have always looked at, no
3 matter what I have done, if you are going to sell
4 anything, and especially in a small community, one, you
5 have got to offer service but, two, the quality has got
6 to be there. I couldn't sell cheap stuff that was going
7 to fall to bits because you just wouldn't get the trade.
8 So you had to look for quality goods, so you then had to
9 look for other suppliers that supplied quality products.

10 THE CHAIRMAN: So it just becomes more and more impressive
11 in a young man. Anyway, we are now about to become
12 bakers.

13 A. Yes.

14 MS PATRICK: I think we will move off that just now and look
15 back at your statement, at paragraph 9, please, which is
16 0287, where you state that it's common knowledge that in
17 1992 there was a screening for Hepatitis C in relation
18 to all people with haemophilia in the Dundee area.

19 A. Yes. I have now come to realise that that actually
20 wasn't quite true, and that's only in the last fortnight
21 I have realised this.

22 When we were tested late in 1995, my three brothers,
23 myself and my two brothers, they said we had slipped
24 through the loop, one, because I was never there,
25 hardly, at the hospital, but they wanted us in for

1 tests. We knew someone had been tested in 1992. So we
2 took it for granted that everybody else was tested, but
3 I now believe that Dundee didn't actually test until
4 1995. It was only the fact that we were the latter
5 three to be tested in 1995. But Glasgow and Edinburgh
6 were doing it in 1992.

7 Q. So you and your brothers were tested in 1995?

8 A. Yes, October 1995.

9 Q. You tell us that -- it has actually been taken out of
10 your statement -- you became very unwell in 1994?

11 A. That's correct.

12 Q. And you were admitted to hospital?

13 A. I was admitted to King's Cross Hospital, yes. That was
14 an infectious hospital in Dundee.

15 Q. And you tell us in paragraph 11 that you were admitted
16 after your GP came to see you with a soaring temperature
17 and rigors. You were taken, as you have said, to
18 King's Cross Hospital and were given morphine for the
19 severe pain, and blood tests were carried out to see
20 what was wrong with you.

21 A. Yes.

22 Q. If we have a look at WIT0050512, this is the discharge
23 summary from that admission to hospital. It's rather
24 bizarrely dated 4 May 1995, but I think we can take it
25 that that should be "1994"?

1 A. Yes, it certainly should be.

2 Q. It's referring to your admission on 1 April 1994, and
3 you were discharged on 10 April 1994. The diagnosis
4 being one of basically a kidney infection, I think I'm
5 right in saying?

6 A. That's what they started out saying. But weren't
7 getting anywhere and then they said to me at that point
8 it wasn't my kidneys, and they started doing another
9 test but I did read that in my notes that they said it
10 was a kidney situation.

11 Q. Yes. You were treated with IV antibiotics and it says
12 under "Progress" that your symptoms and temperature
13 settled and you were then discharged?

14 A. Yes, it took a long time for them to settle. I had
15 friends -- the way King's Cross is, people can't come
16 and visit by coming along corridors. It's like a motel:
17 all the doors are on the outside so nobody can come in.
18 And I have friends that I have known for years came,
19 they didn't think I was going to be coming out.
20 I looked that ill. The first week they had made no
21 progress in the first week. It seemed to be a sudden
22 change in week two, that things started to get better.

23 Q. It took a while to recover. You say at the end of
24 paragraph 11 that when you were allowed home you could
25 still hardly walk, and you were very weak and taking

1 morphine for pain.

2 A. Yes, that's right.

3 Q. And you then returned to hospital for check-ups?

4 A. It actually took me longer to recover from that than it
5 did from my liver transplant. That took so much out of
6 my system that, you know, my whole body was wasted. It
7 was very difficult.

8 Q. And you tell us in paragraph 13 that not surprisingly it
9 took you a long while to build up your strength after
10 this episode. The following year, October 1995, your
11 two brothers and you were called into
12 Ninewells Hospital, Dundee, for a Hepatitis C test and
13 you were told at the time that that was what you were
14 being tested for.

15 A. That's correct, yes.

16 Q. Do you remember how you were called into the hospital?

17 A. I can't really. We were all called in -- to be tested
18 for that, and we knew that at the time, to see if we had
19 the virus. That was the reason we were called in. As
20 I said, at the time we thought -- we believed that -- we
21 found out that other people had been tested in 1992 but,
22 as I say now, found out that everybody, I think, in
23 Dundee, was 1995. I think -- although we may have been
24 the last three to be taken in. I don't know. But
25 that's when we were tested, yes, 1995.

1 Q. I would like to refer you to the letter which I think
2 refers to this attendance at hospital, which is
3 WIT0050515. This letter is dated 29 August 1995 and
4 it's from Dr Cachia to your GP. It's noted there that
5 the visit date is 11 August 1995, which suggests that
6 your appointment was in August rather than
7 in October 1995.

8 A. Okay. If it says "August", but I was almost sure it
9 was October. It has stuck in my mind, for some reason,
10 it was October.

11 Q. Under "Treatment" in the heading, it says "Counselling"
12 and the letter states:

13 "I saw your patient for review in the haematology
14 day unit. He was identified as having haemophilia B as
15 a child but has never attended for regular review. This
16 is largely because he has had few haemostatic problems
17 and has enjoyed an active lifestyle without developing
18 any chronic joint problems. He has, however, had
19 treatment with both plasma and Factor IX concentrates in
20 the past."

21 A. Yes.

22 Q. It then goes on to say that you were previously tested
23 and found to be negative for antibodies against hepatitis B
24 and HIV:

25 "He has not been tested for hepatitis C antibodies

1 but I discussed the value of this with him and he agreed
2 to have blood sent on this occasion."
3 A. Right. Did you mention something about counselling at
4 that point? I can't see it here.
5 Q. It's in the heading, under "Dear Dr".
6 A. Oh, yes, "Counselling". Yes, I can see that. It's
7 amazing how headings can mislead.
8 When we went in -- the reason for going into the
9 hospital was to be tested for Hep C. For that.
10 I wasn't on a routine test -- a routine visit.
11 PROFESSOR JAMES: It looks as if you were tested right at
12 the end of August. So you are probably right. They
13 told you the result in October.
14 A. No, they told us the result in January 1996.
15 PROFESSOR JAMES: Really? Gosh.
16 A. We were called in January 1996 to give the results.
17 PROFESSOR JAMES: I beg your pardon.
18 THE CHAIRMAN: Is there a date for the test in the medical
19 records?
20 MS PATRICK: There is. I was going to refer you to the test
21 result now, which is WIT0050513. This is the first
22 test. The date of the report is 15 August 1995. The
23 date the specimen is taken is shown in the middle, at
24 the top, as 11 August 1995, which tallies with the date
25 of that appointment.

1 A. Yes, I agree.

2 Q. And it confirms anti-Hepatitis C-positive:

3 "Confirmed by a second assay. Compatible with past
4 or chronic Hepatitis C infection."

5 Going back to your statement, paragraph 13, you tell
6 us that your two brothers were given the results of
7 their tests in January 1996 and both were informed that
8 they had contracted Hepatitis C.

9 A. That's correct, yes.

10 Q. You state:

11 "I had not been given my results so I telephoned
12 the hospital and told them that my brothers had been
13 informed but I hadn't been informed of the result of my
14 test. I was told if my two brothers had Hepatitis C
15 then of course I had it."

16 A. That's what I was told, yes. They were informed and
17 they phoned me to find out if I had found out. "No,
18 I haven't heard anything. I take it then if you two
19 have been informed a day before me, then -- I'll phone
20 and find out," and of course, that's what I was told.
21 That was the wording:

22 "Of course you have got it."

23 It was actually a very short conversation.

24 Q. Who did you speak to?

25 A. At that point -- I'm trying to remember. I think it was

1 actually June Ward, the haematology nurse, if
2 I remember. I don't think it was Dr Philip Cachia, it
3 was often very difficult to get Dr Philip Cachia.
4 Q. I would like to refer you to WIT0050516, a note of
5 your attendance at the Haematology Day Unit. I think
6 it's likely that the date is 19 January 1996 because
7 there is a letter confirming this appointment and it
8 does tally with what is written in these notes. We will
9 see over the page that these notes are written by
10 Dr Cachia, and he records:
11 "Seen in Haematology Day Unit with his wife.
12 "Generally well. No bleeding problems since last
13 attendance.
14 "Blood testing -- confirmed Hep C Ab-positive
15 ...
16 "Hepatitis C discussed fully with [yourself].
17 Abnormal LFTs ... "
18 At that point your ALT is 213:
19 " ... discussed. Risks of developing cirrhosis and
20 hepatocellular carcinoma discussed. Value of further
21 investigation. -- Repeat LFTs every 4-6 months, Hep C
22 PCR and viral subtype and liver biopsy discussed.
23 Liver biopsy not recommended unless he would consider
24 a trial of Alpha Interferon if results [suggest] chronic
25 active hepatitis."

1 Over the page:

2 "Potential value of IFN therapy discussed,
3 including chances of response/no response, side effects
4 and lack of evidence re prevention of cirrhosis.

5 "Small risk of sexual transmission of hepatitis C
6 also discussed. [Your wife] will consider whether or not
7 she wants testing.

8 "Drinks regularly. Current intake 26 units per
9 week."

10 A. This was the only bit I mentioned when I got my notes.
11 Never in my wildest dreams did I say to them it's 26
12 units a week. There was long periods of time that
13 I didn't drink at all. And never would I drink 26 units
14 a week. So whether that was an average that he took --
15 in fact, I spoke to three or four people since then that
16 went and it's on their notes saying the same thing,
17 exactly, 26 units a week. So whether that was the man's
18 average drinking or whatever it was, but never did I say
19 that. With the amount I used to try and work and was
20 working, alcohol was very low in my priority list as far
21 as that's concerned.

22 Q. Have you ever drunk 26 units a week?

23 A. Maybe if I had been away somewhere with the guys for
24 a week, but other than that, no.

25 Q. At this time you do not think you were drinking 26 units

1 a week?

2 A. No, and from the day -- I know it doesn't refer to this,
3 but from the day that things got worse for me, I never
4 drunk at all for years, for about ten years. Not even
5 at New Year did I touch a drink because it had an effect
6 on the liver. And I knew that at the time when they
7 told me this. So I was taking herbal medication to try
8 and help my liver, so I would be trying to avoid taking
9 alcohol, (inaudible) 26 units a week to harm my liver.

10 Q. Thank you. So, to return to the notes and to finish:

11 "Potential interaction between Hep C and
12 Alcohol discussed. Recommendation to stay within
13 Government's current recommendations for alcohol
14 intake."

15 The plan is to check Hepatitis C PCR, recheck liver
16 function tests and alphafetoprotein, and check
17 Hepatitis B antibody status and review in four months.

18 A. Is this -- this is the January we are looking at here?

19 Q. It is.

20 A. The counselling that we got wasn't counselling. As you
21 will see with my -- what I have put in my statement. We
22 were all told, "There is bad news and good news. The
23 bad news is you have got Hepatitis C but the good news
24 is you have got a strain of the virus that is a low
25 strain and it will probably never affect you. So go on

1 and lead a normal life."

2 Until later, that was what we got. It was very
3 low-key, nothing, you know, how it was going to affect
4 you or anything at all. That was the full amount of
5 counselling, and then we will have sent off to see what
6 the situation was. But after that we did some research
7 ourselves to find out that we had the hardest strain of
8 the virus to get rid of.

9 Q. You say that, and we will come on to that in your
10 statement. The letter confirming this appointment is
11 WIT0050518. It's Dr Cachia to your GP. It basically
12 confirms what was written in those notes, and your wife
13 is subsequently tested --

14 A. She did get tested, yes.

15 Q. -- for Hep C virus and she was negative.

16 A. Yes.

17 Q. WIT0050519 is the result of your Hepatitis C PCR test
18 dated 6 April 1996.

19 A. That's correct because at that time Dundee didn't do
20 their own PCRs. It had to be sent to Edinburgh. So
21 that's why it took so long to get back.

22 Q. Right, and it showed you were genotype 1a?

23 A. Yes.

24 Q. The records show that your next appointment was
25 in April 1996 and that's WIT0050520. Once again this

1 is Dr Cachia to your GP about your visit to the hospital
2 of 26 April 1996. It records that you are generally
3 well and had no problems or complaints. You had no
4 further questions to ask about your Hepatitis C status
5 but volunteered that you were reducing your alcohol
6 intake because of your Hepatitis C status.

7 A. Yes.

8 Q. And further blood was taken for repeat liver function
9 tests.

10 A. In general, health was reasonably good. It was one of
11 these situations where I may have a bruise on the arm or
12 a bruise on the leg but, as I say, I didn't go for these
13 things and get factor. In fact, after one visit I had
14 been in I let them see a bruise, and they said, "You
15 should have been in for that". And I said, "Well, it's
16 healing up fine," but this time I had a black and blue
17 leg, right down the side of my leg. In fact they took
18 photographs of it for the records, but there was
19 nothing -- I didn't take any factor for it or anything.
20 So ...

21 Q. So after this you continued to attend the hospital for
22 monitoring.

23 A. Yes. It was more regular after that -- being tested.

24 Q. You tell us, if we could return to paragraph 15 of your
25 statement, that you felt your health began to

1 deteriorate?

2 A. Yes, it did. It was funny how it started to happen. I
3 was losing strength, losing concentration, and I just
4 put it down to maybe having a bug. In my whole life
5 I have never had the flu. I don't know what the flu is.
6 I very rarely take colds. So for being haemophiliac,
7 general illnesses I was never bothered with. But
8 I started getting aching pains, aching joints and it
9 wasn't right. I thought I had a bug for a while. The
10 more I went back to the hospital, they said, "It's not
11 that. It's the virus starting to cause you problems."

12 Q. And you say that your liver function tests were getting
13 worse?

14 A. Yes.

15 Q. So you were being told the results of these?

16 A. Yes.

17 Q. And what stage were you at in your life at this point?
18 How old were your children? Can you remember?

19 A. What year are we on now?

20 Q. We are on 1996.

21 A. 1996.

22 Q. We can work it out.

23 A. I'm trying to think. My brain is just ...

24 Q. Teenage children?

25 A. Yes, young teenage children. At that point, in actual

1 fact, in 1996 things were -- I wasn't working at that
2 time because things weren't good, and I had actually
3 never been 100 per cent, although my wellbeing was
4 reasonable. I had never been 100 per cent after 1994,
5 after I had been in King's Cross.

6 What it used to do, it used to be -- maybe once
7 a month I would have a few bad days. Then within
8 a period of time, it became it was more bad days than
9 good days, and that was the way it went on until it got
10 to the stage most days were bad, the way you felt. Some
11 days you couldn't get out of bed. A few days you would
12 be like that and then suddenly your energy would be
13 better. It was a difficult time.

14 Q. So this was since 1994?

15 A. Yes.

16 Q. And so was this at the time of the bakery business?

17 A. No, at that time the bakery business was gone.

18 A company in Glasgow took it over. Actually I was
19 working for them as the general manager, on them taking
20 it over, when I took ill in 1994. So I wasn't working
21 in 1998 at all.

22 Q. Could we turn, please, to WIT0050522? This was an
23 attendance in November 1996, a letter from Dr Gelly,
24 registrar, to your GP, about a visit on 1 November 1996,
25 and you were complaining then of being tired over the

1 last few months:

2 "This tends to occur in the late afternoons and can
3 be associated with aches in his shoulders and arms."

4 Your liver function test results are recorded in the
5 second paragraph.

6 A. Yes. I was going through a period there as well
7 actually, that -- I don't know if there is anything in
8 the notes but I had quite a few times over a couple of
9 years that I had cellulitis in the leg, and that knocked
10 my blood system for six. I was getting antibiotics.
11 For some reason it started. It could be a small spot in
12 my leg, and all of a sudden my leg was red and hot and
13 you felt you had a lead boot on. That happened several
14 times within the space of 18 months. It wasn't that
15 I didn't get any factor for that; it was basically
16 antibiotics -- or maybe one treatment for factor and
17 antibiotics, and that was it.

18 Q. What did the doctors say to you about the tiredness you
19 were feeling and the muscular pains? Did they say what
20 the cause of that was?

21 A. They put it down to the Hepatitis C virus being active
22 in my system. That was the typical symptoms that I had.

23 Q. Yes. Could I refer you to WIT0050524? This was
24 another review in January 1998, and by this time you are
25 feeling a bit better, according to this letter. Your

1 lethargy and weakness has completely cleared up and you
2 feel back to normal.

3 A. Yes. We had a period of time, for some reason, that it
4 was like the virus had stopped being active in my
5 system. I could feel myself getting better. I still
6 had joint pains but my actual wellbeing was a lot
7 better. I could go about and felt -- in fact I felt
8 reasonably normal by that time. They couldn't give me
9 any answer as to why that would be, but they said that
10 the virus can shut down and stop being active and, you
11 know -- through periods.

12 Q. It's recorded there that you had decided you didn't want
13 to have a liver biopsy unless "your liver function tests
14 go very wrong"?

15 A. Yes. Well, they -- initially anyway -- advised that it
16 would only be in a worse case scenario that being
17 haemophiliac, I should take a liver biopsy.

18 Q. Then following this appointment, the records shows that
19 you were referred to Dr Dillon.

20 A. Correct.

21 Q. Was he a --

22 A. The liver specialist in Dundee.

23 Q. Right. And you were referred to him to discuss your
24 liver function and the implications for your health.
25 The record of that appointment is WIT0050528. This is

1 a letter from Dr Cachia to your GP about a visit on
2 3 June 1998. It records:

3 "Dr John Dillon and I saw [Colin] in the Haematology
4 Day Unit to assess his Hepatitis C infection. [He] is
5 currently troubled by lethargy which can be severe at
6 times and is associated with muscular aches and pains
7 extending into his shoulders and joints. He also has
8 episodes of feeling breathless which come on without any
9 of his precipitating factors and are associated with a
10 choking sensation at the front of his chest. This does
11 not extend into his neck or arms. He sweats profusely
12 but does not have palpitations or chest pain."

13 Your liver function tests remained significantly
14 abnormal, with an elevated ALT between 180 and 240. In
15 the third paragraph it's noted:

16 "[Colin's] symptoms of lethargy and generalised
17 aches and pains are consistent with active Hepatitis C
18 infection and, along with his markedly abnormal liver
19 function tests, do give us cause for concern that he has
20 active Hepatitis or possibly even cirrhosis. We
21 discussed with him again the option of a liver biopsy,
22 which can be performed fairly safely with factor
23 concentrate cover, although the risks of haemorrhage are
24 still greater in patients with Haemophilia compared with
25 those with normal haemostatic mechanisms. We also

1 discussed with him the option of combined antiviral
2 therapy with Interferon and Ribavirin, which may be
3 available by participation in a clinical trial prior to
4 Ribavirin becoming fully licensed. [Colin] is
5 considering these options."

6 The records show that these periods of
7 breathlessness were investigated but nothing abnormal
8 was found?

9 A. That's right.

10 Q. And they became less of a problem for you?

11 A. They did. They came and went. My problem was that for
12 no reason, without any stress, your whole body would
13 break out in a sweat. At a point your shirt could be
14 actually soaking right through. There was no -- they
15 did quite a number over, not just that period,
16 gastroscopes down the front to check for varices and
17 things. As you will find later on, at one point they
18 did find varices, that they were concerned about
19 bleeding and one thing and another so -- but they
20 couldn't give me any answers to the sweating situation
21 at all.

22 Q. How did you feel about starting treatment?

23 A. I was keen to start the treatment. Anything that was
24 going to help the decline of my health.

25 Q. You also -- sorry, carry on.

1 A. In actual fact I pushed to get on the treatment, and
2 initially there was a bit of reservation in whether the
3 thing would help me or not. I said, "I won't know
4 unless we try, if it's going to help or not".

5 Q. You were obviously quite active in looking at options
6 that were open to you.

7 A. Being a generally active person, I wanted to try and get
8 the problem resolved, if it could be resolved.

9 Q. Yes. And around this time you started taking milk
10 thistle?

11 A. Yes.

12 Q. Was that at your own instigation?

13 A. It was my own instigation but it was after reading a lot
14 into different sides of hepatitis, liver, things like
15 that, and this was one of the things that a lot of
16 people were taking to help their liver functions, not
17 necessarily for Hepatitis C, but a lot of people were
18 taking it because it was supposed to be a liver cleanser
19 and it was supposed to help.

20 Q. Did you feel that it helped you?

21 A. After taking it for some time, I did, yes. Obviously
22 not initially but I felt it had some effect.

23 Q. How did you feel at that time about having a liver
24 biopsy?

25 A. Basically, I think, at the end of the day, it was

1 something I knew I was going to have to do but obviously
2 it's one of these things you try to put off so long as
3 you can because I knew the problem was the bleeding
4 aspects of it.

5 Q. So the risks concerned you?

6 A. The risks concerned me. Actually looking back, I wish
7 I had never had it.

8 Q. You tell us in paragraph 16 of your statement that you
9 started interferon and ribavirin treatment
10 in October 1998.

11 A. That's correct, yes.

12 Q. You tell us at some other point in your statement that
13 you were the first haemophilia patient in your hospital
14 to start this treatment?

15 A. I think I was. That was what I was informed at the
16 time.

17 Q. What were you told about the treatment before you
18 started it?

19 A. Basically I was told I would have like flu-like
20 symptoms and such like, like that. But it had different
21 effects on everybody, depending on their basic wellbeing
22 and health.

23 Q. Can you remember at this point what family life was
24 like, and work life?

25 A. Family life was up and down. I wasn't actually working

1 at that time and it was one of these situations that
2 I think my wife was concerned with my health, obviously,
3 and the family could see how I had been with ups and
4 downs because even they could come in and could see
5 I would be soaking with sweat and wasn't right, and then
6 the next week you would be looking reasonably well.
7 There was no rhyme or reason as to how you would be.
8 That was one of the reasons I really wanted to go into
9 the treatment and try and improve the situation.

10 Q. How did you find the treatment when you started it?

11 A. Over the first few days there was not a problem. At the
12 end of the first week, I soon realised how it was going
13 to be, I started getting -- once it got into my system,
14 the side effects started, but within a matter of two or
15 three weeks, the side effects were so bad I was bed
16 ridden, totally.

17 Q. Yes. A letter dated 29 October 1998, WIT0050530 -- we
18 do not need to refer to it -- records that you had had
19 the treatment for two weeks by this time, and for the
20 first week or ten days you were managing satisfactorily
21 with it.

22 A. Yes.

23 Q. But you had found yourself feeling unwell with joint
24 aches and a feeling of exhaustion, with more than the
25 previous flu-like symptoms you had at first?

1 A. Yes.

2 Q. So at this point you were keen to continue with the
3 treatment.

4 A. I think at that point I discussed with them that -- if
5 it doesn't get any worse than this, hopefully I will be
6 able to cope and stay with it. Unfortunately that
7 wasn't the case.

8 Q. If we look at WIT0050535, this is a letter dated
9 10 December 1998 from Dr Porter-Boveri to your GP,
10 recording what happened at a visit to the hospital on
11 2 December 1998. It records that:

12 "[Colin] has managed to continue taking the
13 combination therapy, though he has had severe side
14 effects. He gets joint pains and aches, muscle weakness
15 and feels completely washed out, weak and exhausted.
16 The effects are severe enough to make him want to stay
17 in bed sometimes all day and this happens several times
18 a week. [Your] neutrophils have also dropped ... "

19 And so the dose of interferon was halved. Ribavirin
20 continuing at the original dose. Your white cell count
21 then returned to normal and:

22 " ... he is not quite so severely affected with the
23 side-effects but is still pretty incapacitated."

24 At this point your liver function tests:

25 " ... do seem to have also returned a bit more

1 towards normal ... with a drop of ALT from a high of 283
2 in June this year to 119 at the beginning of November,
3 though these results do fluctuate somewhat, as you
4 know."

5 You are then due to see Dr Dillon for assessment and
6 decisions about further treatment. You tell us in
7 paragraph 16 of your statement, which we don't need to
8 look at, that you had to stop the treatment after only
9 12 weeks.

10 A. I didn't stop it personally, it was stopped because my
11 immune system was so low.

12 Q. I will refer to you the letter which deals with that,
13 which is WIT0050538. This is a letter from
14 Dr Porter-Boveri to your GP, dated 25 January 1999, and
15 it's about your visit to the hospital on 6 January 1999
16 and you have come up to see Dr Dillon. It records that
17 you had come in December for review of your combination
18 therapy and to decide whether it should be continued or
19 not, depending on the results.

20 A. Yes.

21 Q. "Unfortunately the PCR was not available at that visit
22 and he therefore had to wait to find out whether he had
23 responded satisfactorily to the treatment or not. This
24 morning we did have a result which was that the PCR is
25 still positive and that is taken as an indication that

1 the treatment is not working satisfactorily and should
2 be stopped. [Colin] has, as you know, been having
3 severe side effects and so, although having stopped
4 treatment is a severe blow, it has its good side as well
5 and I hope that he feels better soon."

6 A. That actually could be a bit misleading because you had
7 to be on the treatment for several months before it
8 would have any major indication with the PCR, to
9 a reduction in level. Some people were on it six months
10 and didn't see any difference but the second six months
11 suddenly had an effect on most people. So it was the
12 way it was put, but, yes, that was the case. I couldn't
13 have stayed on it anyway because my immune system was so
14 low. At one point they wanted to admit me to hospital.
15 I said no, with where they wanted to put me, half the
16 wards were closed down because of infection. So
17 I decided to go home.

18 Q. This does suggest that you were stopped because --

19 A. I don't think -- he is saying that but I know from the
20 haematology side they said to me at the time that
21 they couldn't continue anyway because my immune system
22 was so low. It was, I think, the PCR, whether it was at
23 that point in time -- how long had I been on it by then?
24 Because I only managed on it 12 weeks in total.

25 Q. Approximately?

1 A. Yes. So ...

2 Q. How did you feel about having to stop the treatment?

3 A. I felt devastated in some ways because my ALT had come
4 down and things but there was no way -- I knew
5 I couldn't continue because the side effects are so
6 severe. I mean, my father-in-law was actually driving
7 me in and out to the hospital and that was frightening
8 in itself. So -- but, no, I mean I was basically bed
9 ridden at the time. Stopping the treatment -- there was
10 two sides to it. One, I had to stop it but, two,
11 I couldn't suffer it any more than I had for the 12
12 weeks.

13 Q. After you stopped the treatment, how long did it take
14 for the side effects of it to wear off?

15 A. It took quite a while for the side effects to wear off.
16 Some wore off quicker than others. But the side effects
17 never -- not the side effects of the treatment but after
18 that I actually had a reasonable period of stabilised
19 health after that, where I was only suffering from the
20 aches and pains but my wellbeing was good. It seemed to
21 have done some good to the liver function.

22 Q. And so you carried on attending the hospital for
23 monitoring after then?

24 A. Oh, yes, on a regular basis.

25 Q. And you tell us in paragraph 17 of your statement, 0290,

1 that as time went on, your health worsened and it was
2 decided to carry out liver biopsy to ascertain the
3 condition of your liver?

4 A. Correct, yes.

5 Q. What were you told that the liver biopsy involved?

6 A. Take two small incisions and a small piece of liver
7 taken. There was nothing difficult about the procedure.

8 Q. There is an information sheet about it, WIT0050555.
9 Which is headed up:

10 "Laparoscopic liver biopsy, Patient Information
11 Sheet."

12 A. Yes.

13 Q. Have you seen this? Were you given a copy of this at
14 the time?

15 A. I probably was at that time. To be fair, I wasn't too
16 good at that time and -- obviously I did read it, yes,
17 and they said that even though I was haemophiliac,
18 I would be in four or five days in the hospital but it
19 was pretty straightforward, as long as I had my clotting
20 factor.

21 Q. Yes. If we scroll down a bit, you can see that it
22 details what happens each day, including the
23 administration of factor therapy throughout.

24 A. Yes, it gives you an indication of what they generally
25 do.

1 Q. And so you underwent the liver biopsy on 19 October 1999
2 and unfortunately there were complications with this.

3 A. There certainly was.

4 Q. You tell us that you had two PIC lines for intravenous
5 access. One was for factor and the other for taking
6 fresh blood, and after your first week in hospital --
7 was this after the liver biopsy?

8 A. Yes.

9 Q. Your face began to swell and you had pains in your body.
10 Your mouth was so swollen that you couldn't swallow and
11 you were dribbling, and your whole body had started to
12 bruise.

13 A. Correct.

14 Q. It was discovered that you had developed a thrombosis?

15 A. Yes.

16 Q. Which is quite unusual.

17 A. I think the doctors said I was the only one on record of
18 being a severe haemophiliac to have thrombosis. I could
19 be wrong but I think that was what they mentioned at the
20 time, and it was severe. When I say my mouth was
21 swollen, my face was out about four or five inches. It
22 was like that. It was like having a lump. And my whole
23 chest was black and blue and down my arm was black and
24 blue with the thrombosis. I complained about it when it
25 started, started getting the pains, and I could feel my

1 mouth, and every day they kept sending me for an x-ray,
2 which didn't do any good. They were coming back saying,
3 "Yes, everything is fine, there is nothing wrong," but
4 as the week went on, things just considerably got worse.

5 Q. And the discharge note dealing with this is
6 WIT0050562. I don't propose to look at it but it
7 records that you had developed a left auxiliary vein
8 thrombosis?

9 A. Yes.

10 Q. So you were required to remain in hospital until
11 1 November 1999 for that to be treated.

12 A. How long was that they had me in hospital for? Two
13 weeks?

14 Q. Yes.

15 A. Yes, I was home for two days and then back in for
16 another two weeks.

17 Q. So you were having to take tablets to thin your blood --

18 A. Yes, I was taking both. In the hospital they were
19 giving me clotting factor, X amount, and also something
20 to thin my blood because the problem was that the clots
21 were so severe that if a clot came away, I probably
22 wouldn't be talking to you now. Obviously, they had
23 never come across this before, so dealing with it was
24 a very difficult issue, which I can appreciate.

25 Q. You then had to be admitted a week later due to a viral

1 infection and had to remain in hospital for four days,
2 between 7 November and 13 November 199 --

3 A. I think it was all connected to the same thing, but,
4 yes, I had obviously picked up a bug but I was actually
5 home two days, home for the weekend and back in for the
6 beginning of the week, and that lasted for another
7 fortnight. So in total I was in for nearly a month.

8 Q. The result of the liver biopsy in October 1999 is
9 WIT0050559. It is dated 22 October 1999. This is all
10 quite medical but I think the best paragraph to look at
11 is the one just before "Conclusion":

12 "The overall appearances in these biopsies represent
13 chronic hepatitis C. The intensity of inflammation
14 corresponds to Grade 2 and the degree of fibrosis to
15 stage 2. Although there is architectural distortion
16 with some fibrosis the appearances fall short of
17 cirrhosis."

18 A. Yes.

19 Q. So you continued to suffer from the symptoms of the
20 Hepatitis C virus, some days being worse than others.

21 A. Yes.

22 Q. And then --

23 A. You never knew from day to day what it was going to be,
24 to be honest, and as I say, you could have three or four
25 days where you thought, "Oh, there is nothing wrong with

1 me, apart from a few aches and pains," and you could get
2 up the next morning and you would be just sore all over
3 and sweating and not right, like the flu symptoms again.
4 That's just the way it went.

5 Q. And in paragraph 21 of your statement you tell us that
6 you became quite keen to try, you say, pegylated
7 interferon but the records show that you were quite keen
8 to try ribavirin on its own.

9 A. It was mentioned, trying the ribavirin, but at the end
10 of the day they said they didn't know what effects it
11 would have, whether it would work, whether it wouldn't,
12 and they weren't willing to go down that road --

13 Q. No.

14 A. -- to try it.

15 Q. The records show that your doctors applied for funding
16 for ribavirin on its own to treat you but the clinical
17 director was unable to sanction the expense on ribavirin
18 for that purpose, as it was unlicensed for that purpose?

19 A. The reason I asked them for it and was pushing to get it
20 was because the results of the first interferon and such
21 like I had been on had reduced my ALT and my levels.
22 And the reasoning behind this was that the pegylated
23 interferon, you didn't take it so often and the side
24 effects were supposed to be a lot less. There were
25 supposed to be a lot less side effects. It was slow

1 release, and that was the reason I pushed to get it,
2 thinking, well, if I have reduced the liver functions
3 with the first one, if it doesn't have such severe side
4 effects, then I will push to try and get this one. But
5 they said no at the time.

6 Q. Could it have been ribavirin because that's what the
7 medical records show you were asking to be treated with,
8 on its own, and not the interferon?

9 A. No, I was asking for the pegylated interferon, the slow
10 release.

11 Q. Right.

12 A. It was pegylated interferon and ribavirin, they were
13 both together still.

14 THE CHAIRMAN: You were clearly taking a close interest in
15 the medication available at this stage.

16 A. Yes.

17 THE CHAIRMAN: How were you going about it?

18 A. There was a lot of information about -- as I say, on the
19 east coast side we weren't so well informed but the
20 Glasgow/Edinburgh area was more informed. So certain
21 things you would be able to pick up, and I was also
22 keeping ahead of -- even on the Internet, what was
23 happening, and then when I read about this -- well
24 actually, it was actually Dr Dillon told me about the
25 pegylated coming out in the future. That it was going

1 to be slow release and it would have less side effects,
2 but this was after I had finished the first treatment
3 obviously, and he said this could be some time down the
4 line but he said it shouldn't be such a severe
5 medication to take.

6 THE CHAIRMAN: You say that there was information available
7 in the Glasgow/Edinburgh area. Did you have contacts
8 there that you were drawing on?

9 A. Not really, if we had a haemophilia meeting and I was
10 well enough to go to it, we had a regular gentleman that
11 used to come from Glasgow up to our meetings, sometimes
12 from Edinburgh. So there could be people there and you
13 got information about what was happening, but the
14 pegylated side, that part of it was due to Dr Dillon
15 keeping me informed.

16 THE CHAIRMAN: When someone would come to the meetings, did
17 they bring literature?

18 A. They would bring information they had picked up, through
19 whether it be Glasgow Royal Infirmary or Edinburgh,
20 wherever it came from, whatever information they had.

21 THE CHAIRMAN: So you had a sort of exchange of whatever was
22 available.

23 A. Basically, yes. On this occasion it was down to
24 Dr Dillon telling me in the future this is going to
25 become available. And I think at the time, once it

1 treatment."

2 You were describing various depressive features
3 which generally wax and wane but he didn't feel there was
4 evidence to warrant a diagnosis of co-morbid depressive
5 disorder, and much of your current concerns centred
6 around the uncertainties about your prognosis and
7 possible treatment strategies:

8 He notes: "consequently, he has not yet made the
9 psychological shifts necessary for him to come to terms
10 with his deteriorating physical health, although I got
11 the impression that this was perhaps now beginning to
12 happen."

13 This perhaps highlights how difficult it was for you
14 to go from being such an active, busy, man, to suffering
15 from these symptoms?

16 A. In my mind it wasn't depression, that's obviously why
17 they sent me there. My attitude has always been if
18 there is something wrong then you sort it, but
19 unfortunately I couldn't sort this. It was something
20 that was just getting worse.

21 Q. We have heard you were obviously trying to do what you
22 could for yourself by researching the options open to
23 you.

24 A. Yes.

25 Q. The records show that in October 2000 you were referred

1 to the pain clinic at Ninewells Hospital in relation to
2 your muscular pains, and for help in controlling the
3 pain in respect of this. Do you remember going there?
4 A. Yes, I do.
5 Q. What was the outcome of that?
6 A. They gave me TEN -- what they call a TENS machine,
7 I think it's called, for pain but actually within the
8 first few days it actually made the situation worse.
9 Because of the like, muscle spasms, things like that,
10 that I had, it seemed to exacerbate and it made them
11 even worse. So I had to stop using it, and also they
12 put me on, I think it was different painkillers at the
13 time as well.
14 Q. Yes. Dihydrocodeine?
15 A. Yes.
16 Q. One of them?
17 A. Yes.
18 Q. And I think morphine was suggested but you weren't very
19 keen on taking morphine.
20 A. No, after the first event of morphine, having to take it
21 when I got home, I decided I would stay away from the
22 morphine aspect if they could get me something that
23 would -- you know.
24 Q. And the records around this time also show that you
25 started experiencing what you called "shutdown"; could

1 you explain to us what that was, please?

2 A. Well, I mean, it was like your whole body shut down.

3 Even when I was driving, I could feel that -- you were
4 losing the feel of even the steering wheel, and it was
5 just your whole body was on -- it was like somebody had
6 flicked a switch and your system wasn't working. You
7 couldn't concentrate, you couldn't think. It was
8 debilitating totally, and that was just the way it was,
9 that -- and I could have that two or three times in
10 a week and not have it for a fortnight. It was one of
11 these things that would come and go, and when it came --
12 you could feel it coming on and it was like being partly
13 paralysed but you weren't; that was the way it affected
14 you.

15 Q. How often did you experience that?

16 A. That went on for some months. It varied in how it
17 affected me but it was -- it was quite irregular but
18 they weren't all together, as I say, you would get
19 times -- times where it didn't bother you at all -- when
20 I say it didn't bother you, it wasn't bad, and other
21 times it just seemed to be -- whether it was stress in
22 the brain was causing it to shut down or because there
23 was something bothering me, I didn't know, but it seemed
24 to come and go. When I had it, it was pretty
25 debilitating.

1 Q. Then in paragraph 21 of your statement you tell us that
2 you started pegylated interferon and ribavirin
3 treatment, and this was on 4 May 2001. And before
4 starting this treatment, you were once again warned
5 about the side effects of it.

6 A. Yes.

7 Q. And you were also told that there was only a slightly
8 higher chance of this treatment being successful.

9 A. Yes. They did say that, the fact that the first one
10 didn't work, it was only slightly higher but obviously
11 the side effects, but I was told initially that the side
12 effects would be less. And if I recall -- I might be
13 wrong in saying this -- I think with the pegylated it
14 was only once a week you had to take the injections for
15 yourself, not three times a week as before. And
16 I thought, well, obviously that's going to make
17 a difference, but as you will see by the -- what it
18 says, it had a pretty disastrous effect on my system.

19 Q. Yes. I would like to look, please, at WIT0050595.

20 This is a letter from Dr Kumar, specialist registrar to
21 your GP, dated 10 May 2001, following a review in the
22 haemophiliac clinic on 9 May 2001. It states:

23 "He was started on PEG Interferon the first dose of
24 which was given last Wednesday. Unfortunately, he has
25 had the side effects which he had with the ordinary

1 Interferon in 1998. Within about 4 - 6 hours of
2 getting the PEG Interferon, he had shaking, nausea,
3 sweatiness and an unwell feeling which wained [sic] as
4 the day progressed, but he still gets a bit of nausea in
5 the mornings. We have given him the second dose of PEG
6 Interferon today."

7 You gave a history then of melaena, which was
8 a black stool and that, taken with your Hepatitis C
9 diagnosis, meant that they decided they wished to go
10 ahead and carry out an endoscopy to check that this
11 hadn't been caused by varices. It's noted there that
12 you had had an endoscopy in March 1999 which did not
13 reveal any varices. And you then subsequently, after
14 this appointment, underwent another endoscopy and the
15 results of this were normal.

16 A. Yes.

17 Q. If we look, please, at WIT0050599, these are
18 handwritten notes --

19 A. Are you sure? They are handwritten.

20 Q. Are you going to read them to us? I will have a go at
21 doing that, shall I?

22 This is when you are attending the hospital after
23 you have started the treatment. This one is dated
24 21 May 2001:

25 "Attended centre. Since first week increasing side

1 effects from ? Peg interferon. Chest tightness,
2 palpitation, aches and pain widespread. Wants to stop
3 therapy. Lower back pain to legs. Reduced haemoglobin,
4 neutrophils reduced, taking analgesia, little effect,"
5 and earache.

6 Then in the second column it details advice and
7 investigations undertaken, and it notes:

8 "Seen by Dr Cachia, continue ribavirin, miss peg
9 interferon this week."

10 PROFESSOR JAMES: Admit.

11 MS PATRICK: "Admit if symptoms worsen."

12 And you are going to be reviewed in a week. If we
13 move over to 0600, it records that you are feeling much
14 improved this week. The date of this is not so clear
15 but it seems likely, in the positioning of it in the
16 medical records, that this was after the last one:

17 "Restarted ribavirin Tuesday first week after
18 missing five days and Mondays PEG [interferon].

19 "Slight chest tight/palpitations 2 -3 hours
20 [after] ribavirin noted."

21 In the second column we can see that you discussed
22 with Dr Dillon about recommencing peg interferon, and
23 it's noted in the third column that you are keen to
24 continue therapy.

25 THE CHAIRMAN: The review date is 4 June. Does that help us

1 get a date for the meeting? Could it be 28 May? That
2 would fit in with the pattern.

3 MS PATRICK: Yes. If we move on to 0601, this is the review
4 on 4 June. Your neutrophils are reduced again,
5 complaining of chest pain, palpitations after ribavirin
6 most times and that you have missed a dose due to these.
7 Pain over kidneys/abdomen continues. General aches,
8 pains attributed to Hepatitis C virus, joints, muscles,
9 sweats.

10 Once again discussions with Dr Cachia, due to
11 decreasing neutrophils and side effects, miss interferon
12 and stop ribavirin. He will discuss with Dr Dillon and
13 pharmacist re. continuing therapy.

14 It's noted in the third paragraph that you are keen
15 to continue therapy despite side effects, especially
16 asks if you can continue ribavirin only. And you are
17 going to be reviewed two days later, on 6 June, re
18 decision whether to continue or not. And there is
19 querying considering a 24-hour ECG tape if palpitations
20 persist.

21 If we look over the page at WIT0050602, I think we
22 will presume this is dated 6 June 2001:

23 "Continued to feel very unwell on ribavirin, kidney
24 pain, palpitations, chest tightness. Stopped ribavirin
25 himself first Friday."

1 So you took the decision yourself to stop the
2 ribavirin:

3 "Due to quality of life and effects of therapy,
4 [Colin] has decided to stop therapy."

5 We see in the second column:

6 Treatments discontinued.

7 Side effects are being monitored and options for
8 long-term care discussed.

9 A. Yes, it was a partial joint decision. I knew myself
10 I couldn't continue on it but also once again my immune
11 system got so low that they advised me that even if I
12 wanted to continue, it would be unwise. So that was the
13 decision taken at that point.

14 Q. How did you feel when that decision was made?

15 A. It was difficult because I knew there was nothing else
16 out there. I knew after that there was nothing else
17 going to be able to help me. So it was a decision once
18 it was made, that was it.

19 Q. It cannot have been an easy decision?

20 A. It wasn't easy. That's why I wanted to continue even
21 with the side effects being so severe, but they said due
22 to the condition I was in and one thing and another,
23 that it would -- in the interests of my health, it would
24 be stupid for me to continue, and in their mind from
25 their side of it, they couldn't let it continue.

1 Q. How long did it take you to recover from the side
2 effects of the treatment?

3 A. It's difficult -- I can't just remember exactly but it
4 went on for some time. It got -- I got a lot better
5 over a period of weeks. My health did improve and the
6 reason I wanted to go for this treatment and push for it
7 was because I had better ALTs after being on the first
8 lot. I thought if this has any effect, it is going to
9 improve my liver functions, then I definitely want to
10 give it my best shot. So coming off it was ... but
11 after that, for some time actually -- a while after
12 that, I started to feel -- I wouldn't say completely
13 well but I felt better. I felt it had done some good
14 having it.

15 Q. Yes. You tell us in paragraph 22 of your statement,
16 which is 0291, that after that you tried to keep the
17 best health you could, but you obviously still had your
18 bad spells when you couldn't get out of bed, you were so
19 washed out.

20 A. That was like the shutdown situation. There was no --
21 I couldn't explain to the hospital, they couldn't
22 explain to me what was wrong. It's just like the body
23 wouldn't function. I would get out of bed and sometimes
24 your legs wouldn't -- I wouldn't say they wouldn't work
25 but they wouldn't hold you up, you felt that weak and

1 a few days later, it wouldn't be too bad again, and they
2 put it down to basically just the virus getting worse,
3 the side effects.

4 Q. And on a good day, were you good at taking it easy or
5 did you want to get on with things?

6 A. No, that was one of the problems, a lot of stress from
7 the wife about that. Because if I had a good day
8 I would tend to do too much and then that would make me
9 worse. So it took me a long time -- it's very difficult
10 when you have worked all your life, a lot of time, and
11 worked for yourself, you put a lot of hours in, and to
12 sit and do nothing wasn't in my nature. So if there was
13 anything I could do when I was feeling good, I did it.
14 And of course, I then paid the consequences for it, but
15 as the months past I realised I just had to do nothing
16 and accept it. That's the way it went on.

17 Q. And you tell us in paragraph 23 that in 2002 you had to
18 sell your business due to your poor health.

19 A. Yes.

20 Q. I wonder if I could update us. We heard your clothes
21 shop and then the bakery business. Where were you at --

22 A. After the first lot of treatment -- I was trying to
23 remember the dates -- after the first lot of treatment,
24 I started to feel a lot better. Obviously living on
25 benefits was just a nightmare. So I bought a franchise

1 for sweet sales, selling sweets, and that's what
2 I started doing, because that way I could hopefully work
3 the hours that suited me and the fact that the sweets
4 had a long shelf life, they were all pre-packed hanging
5 bags, I wasn't working to sell by dates. All the sell
6 by dates were a minimum of 18 months? So when I was
7 good, I went out selling and built up a business from
8 there.

9 Q. When did that start?

10 A. I was just saying to my brother, I think it was about
11 1998 I started that, doing that in between.

12 Q. And you said you were on benefits before that. What
13 benefits were you on?

14 A. Well, I got incapacity and then eventually I got DLA,
15 but that took a long time to get. That was when I was
16 on the first lot of treatment, they sent out an assessor
17 to assess me when I was in bed. I couldn't get out of
18 bed. If I wanted to go to the toilet, I had to crawl on
19 my hands and knees. The only other time I was dressed
20 was when my father-in-law took me to the hospital. So
21 it was not good going through the treatment, and before
22 that I hadn't been well.

23 But I felt that the treatment had helped, as you can
24 see by my ALT went down. A few months after that I
25 wasn't near right but I was a lot better, and that's

1 when I really had to find something to do. To go to
2 work for somebody, I couldn't go and work for somebody
3 and be there two days and off two days and work two
4 days, so that's why I decided to still work for myself.

5 Q. How successful was that?

6 A. Well, like -- I built it up to be quite a reasonably
7 good going business over the months. Eventually I took
8 someone on to work alongside me, who had been made
9 redundant, and I took him on to work alongside me. So
10 the days that I wasn't working, he would be working, so
11 the business was going the five days a week, Monday to
12 Friday. But during 2001, things were pretty grim for me
13 and being bed ridden a lot -- all I was doing in the
14 business was making phone calls from the house, actually
15 from my bedroom, to order things, to order -- because we
16 only dealt with a couple of companies. So basically
17 that's all I was doing. This other chap was doing most
18 of the business.

19 Q. Right. So it must have been a very difficult decision
20 for you to sell the business in 2002?

21 A. Well, it was. I had no option because basically the
22 fact he was then doing it full-time, I wasn't doing any
23 of it. It was paying him his wages, by the time you
24 paid expenses, it was leaving a little profit but not
25 enough to live on. So the headaches and the cashflow

1 outweighed the benefits of the business.

2 Q. And you say at this point your wife was spending a lot

3 of her time looking after you.

4 A. She was, yes.

5 Q. Did your wife work?

6 A. At that time she was working 30 hours a week at

7 ██████████. She had never had a day's illness in the

8 13 years she was there. She had never been off a day.

9 Q. What work did she do at the school?

10 A. She was classroom assistant, school auxiliary, things

11 like that. That's what she did. That made her ill as

12 well, unfortunately, me being unwell.

13 Q. You tell us in paragraph 25 that she became ill with

14 stress in 2004 and in 2005 she gave up work to look

15 after you full-time.

16 A. She should actually have given up before that because

17 she was quite ill at the time, but it was a wage coming

18 in and that was the way she looked at it.

19 Q. Right. You say after your business was sold, money was

20 exceptionally tight and you were living from day to day

21 but at least the stress of working was away.

22 A. Yes, at least I did not have the stress.

23 Q. Did you go back to claiming benefits at that point?

24 A. Yes, I went back on to incapacity benefit, which

25 I was -- because I had been on it before, I was lucky

1 enough that they put me back on what they call the
2 "higher rate". I think it was £11 a week more than the
3 standard rate. I think it was £56 to the £45, or
4 something like that.

5 Q. I would like to refer you to WIT0050625, which is
6 a document in relation to March 2004. The second page,
7 which you do not need to look at, shows that this is
8 a letter from Dr Kerr, acting consultant haematologist,
9 to Dr Dillon. It refers to your symptoms in the first
10 paragraph: exhaustion, blotchy skin and generalised
11 arthralgia and myalgia with associated sweats.

12 Your liver function test results are referred to in
13 the second paragraph. Your ALT at this point is 115.
14 It notes that an ultrasound scan had been carried out
15 and this shows evidence of portal hypertension, and
16 evidence of significant splenomegaly, the spleen
17 measuring 15 centimetres in length. There were noted to
18 be a number of prominent small vessels around the porta
19 hepatis, and these were felt to most likely represent
20 small left gastric varices. You subsequently underwent
21 an endoscopy around then and that showed four barely
22 visible varices, and you started propranolol treatment
23 for this.

24 Could I just go back to your wife's stress that you
25 mentioned. Did your wife receive treatment for this?

1 A. She went to the local GP and he put her on tablets to
2 help calm her situation, which she wasn't happy to take
3 because she had never been taking tablets, but the short
4 period of time she was on them, it made a difference.

5 I think not working helped as well. The only stress
6 she had was then me to worry about, and being there all
7 the time, I think she was more relaxed, because my
8 daughter at that time had just come out of teaching
9 college and she was actually going through one of her
10 courses at [REDACTED], and she used to come home at
11 lunchtime and give me my lunch from the school, and that
12 saved my wife a lot of hassle. But I think the best
13 thing she did was giving up. In that way it helped her
14 stress.

15 Within a few months, I wouldn't say she was well but
16 she was a lot better than she was when she left work.
17 I don't think she really actually wanted to leave work
18 because I think it was the fact that she was away from
19 me, she had something else to think about instead of
20 being there all day. I think when she did actually
21 leave, she saw the benefits of just being there.

22 Q. If I could refer you, please, to WIT0050639 which is
23 a letter from Dr Kerr, consultant haematologist, to
24 Dr Dillon, dated 6 July 2005. It's noted that your
25 Hepatitis C has now reached the stage where:

1 "... he has become cirrhotic, with splenomegaly and
2 gastric varices demonstrated on ultrasound scan and
3 gastroscopy."

4 And it's noted at this point that you would like to
5 meet with Dr Dillon to discuss the possibility of liver
6 transplantation.

7 A. Yes.

8 Q. "As we have discussed, it's likely that he may well need
9 this at some point in the future."

10 The outcome of this appointment is WIT0050640.
11 This is a letter from James Cotton, specialist
12 registrar, to Dr Dillon, sorry your GP, dated
13 26 August 2005. And it records your condition at that
14 time and in the second paragraph states:

15 "We had an extremely long discussion about many
16 issues today but, essentially, we covered the course of
17 his liver disease. As you know, he has previously been
18 treated unsuccessfully."

19 You had obviously been doing some more research
20 yourself and had brought in some cuttings from the
21 Daily Mail about stem cell transplantation, and it was
22 explained to you that this was at a very early stage of
23 experimentation and at this time was not a routine
24 treatment.

25 It's noted in the third paragraph that your liver

1 function is satisfactory:

2 "He is not at the stage that we would consider liver
3 transplantation."

4 Although it's noted that your bilirubin has crept up
5 to the early 30s over the last few years. Could we go
6 back to your statement, paragraph 27, which is 0292, you
7 tell us here that your wife and family started to notice
8 that when they were having a conversation with you,
9 there were gaps in your conversations, and on occasion
10 you appeared as if you were drunk. You state:

11 "I just couldn't coordinate and my wife asked my
12 consultant if this was caused by my liver functions. He
13 informed her, yes, it was the toxins building up in my
14 system and my body couldn't cope."

15 A. Yes, I would like to also point out at this time that
16 from 1994 up until this time, I hadn't drunk at all,
17 nothing. I had ten years without -- once I found out
18 I had a liver problem, I didn't touch alcohol, not even
19 at New Year. So the main reason was to try and make
20 sure that the liver wasn't getting damaged by anything
21 else.

22 Q. And these episodes are first noted in your medical
23 records in March 2006. How did your family find these
24 episodes?

25 A. I actually hadn't realised how bad it was. It was

1 actually the haematologist at Ninewells that had pointed
2 out to my wife -- just for one occasion she had come in
3 with me and I had went to get a blood test or something,
4 and they discussed the situation. They had noticed
5 that. So they obviously knew long before I did that
6 there was obviously gaps when I was speaking or
7 I couldn't think to what the next word was going to be,
8 or whatever it was. So they had obviously realised that
9 long before me. At that time I still had one son living
10 at home and he had noticed that -- quite a bit.

11 Q. Right. And in paragraph 28 you tell us that around this
12 time you sold your luxury bungalow to release some
13 money?

14 A. Yes.

15 Q. And I think this was a house that you had built?

16 A. I had it built for me, yes. The caravan move was
17 a temporary move till we could find exactly what we
18 were -- smaller -- we were going to move into because as
19 you know, if you have got a house and you have got
20 equity in it, you can't sell bricks -- or pay your
21 groceries with bricks. So we sold the house to release
22 equity and downsized.

23 Q. And if you hadn't had to release equity, would you have
24 stayed in the house?

25 A. Oh, yes. In the situation I'm in now, having been --

1 getting some compensation, I could have still been in
2 the house because we didn't have a massive mortgage on
3 it, because at the end of the day, there would have been
4 no point in selling it if there had been no equity in
5 it. And at the time actually, the only reason I sold it
6 so quick was that someone had come and seen it and made
7 an offer on it, and they weren't in the line of selling,
8 so they had the cash to buy. So that's why it was such
9 a quick move to sell, but I could have still been in it
10 now, which -- now I have moved into a much smaller
11 house.

12 Q. And you spent some time in a caravan. How long did you
13 spend in a caravan?

14 A. Believe it or not, the person came to see the house and
15 we eventually -- he turned round and said, "We are in
16 a position to buy". This was in November,
17 mid-November -- sorry, the beginning of November -- but
18 they said, "Only if we can get in in the first week
19 of December". So I said, "Well, I'll have to find out
20 if I can move in that time and if the title deeds can be
21 redrawn up".

22 So we moved from there -- we did get everything tied
23 up in five weeks and we moved out the second week
24 of December, or on 6 December/7 December that year, and
25 we moved into a residential caravan, which had gas

1 central heating and everything else. All our furniture
2 went in storage and we stayed there until April the
3 following year.

4 Q. And how did you and your family feel about leaving the
5 house?

6 A. It was -- as I say, one of my sons had bought a flat
7 with his girlfriend and the other one at that time was
8 staying at home occasionally, and when we had to move
9 into the caravan, by that time my second son, he had
10 moved in with his girlfriend in a flat as well. So
11 there was only the two of us in the house. I think,
12 from my side, it was the disappointment of selling and
13 I think my wife took bad with it as well.

14 I mean, you work hard, you know, you try to build
15 something up. Then really to live as near normal as you
16 can, not extravagant but, if that's what you have got to
17 do, that's what you have got to do. There is no point
18 in getting into debt.

19 As you will see, in 2007 we bought a flat, which
20 wasn't ideal for me, but by that time things were that
21 bad that I really bought it with my wife in mind. The
22 flat was only two years old, and buying the flat without
23 any size of mortgage, or a small mortgage, was easy. So
24 it was a good size apartment, it overlooked the river in
25 [REDACTED]. I thought, if I'm not here, at least she

1 is going to have something that she is not going to have
2 a mortgage on, because of life insurance and such like,
3 and it will be ideal. So that was the reason for buying
4 the flat, because it certainly wasn't my type of living.
5 When I say "flat", being a new building, it was modern.
6 It had French windows and a balcony and it was quite
7 a good size.

8 Q. You tell us that by this time your health was very bad
9 and you were totally bed ridden?

10 A. Yes, that was the grim period.

11 Q. Yes. In April 2007 you were referred to Edinburgh Royal
12 Infirmary for assessment for a liver transplant, and you
13 tell us in paragraph 30 that in June 2007 you were
14 admitted to Edinburgh Royal Infirmary for tests.

15 A. Yes.

16 Q. How did you feel about the possibility of a liver
17 transplant?

18 A. Well, I knew that the only way for me to stay alive was
19 to get a transplant. It was as simple as that. It was
20 a daunting prospect but you have to be realistic and
21 look at it and hope that all being well, that I would
22 live through it.

23 Q. Yes, and how did you find the assessment process?

24 A. The assessment process? A lot of tests. That's
25 basically what it was. Checking every day different

1 tests, a lot of scans. What I wasn't prepared for --
2 you are in for a week. What I wasn't prepared for was
3 the answers on the Friday. I was -- my wife was asked
4 to come down, you are taken into a room. You have got
5 all the senior people in front of you and the chap that
6 spoke to me, he said, "Well, there is no doubt about it,
7 you need a liver transplant."

8 He said, "You could get two years, you could live
9 another two years, you might live a year, but I'll give
10 you six months."

11 And at that you could have picked me up off the
12 floor because although you know you are ill, you are not
13 putting a term on your life, and he says, "I'll give you
14 six months." As I say, he made the point of saying he
15 is not a betting man. I bet now he wishes he was.
16 I didn't last six months.

17 Q. So you were then admitted to the list and you then had
18 to attend review appointments at Edinburgh Royal
19 Infirmary.

20 A. Yes.

21 Q. And at one of these in August 2007, WIT0050662, the
22 second page shows this is a letter from
23 Mr Ernest Hidalgo, consultant surgeon, to Dr Gilmour.
24 It notes in the third paragraph that you are jaundiced
25 with low grade encephalopathy, without clear flapping.

1 You are also suffering from significant peripheral
2 oedema and fluid retention as well. It's noted there:

3 "We had a long discussion about implications about
4 being on the waiting list and also discussed the
5 opportunity of being transplanted by means of
6 a non-heartbeating donor and also having a transplant
7 from a relative was also discussed and sadly there is
8 no one suitable within his family for donating."

9 What were these discussions about the implications
10 about being on the waiting list?

11 A. Well, obviously, there was no guarantee there was going
12 to be a liver that would be a match, so being on the
13 waiting list, it was a waiting game, and of course, not
14 that I would be going anywhere but you weren't to go --
15 couldn't go further than, say, half an hour from the
16 house, because you could get a call at any time. That
17 wasn't a problem because I was in the house all the
18 time.

19 The implications were quite simple, that I hoped to
20 get a liver in time but also, unknown to me at that
21 point, while they were looking -- my son [REDACTED], that
22 I didn't know at the time, had gone to be tested to see
23 if he could donate half his liver to me. I didn't know
24 that until after the transplant. But they didn't get --
25 my health deteriorated that quick that they never got

1 round to doing the final test and such like. They only
2 got round to the talking stages, what it meant and such
3 like. So they couldn't tell whether he would be a donor
4 or not because they didn't get that far.

5 Q. You tell us in paragraph 31 of your statement that
6 in September 2007, you received a call from the
7 transplant unit saying that they had a liver for you.
8 You were immediately taken by ambulance to Edinburgh
9 Royal Infirmary and you were prepped for surgery and
10 given Factor IX and platelets. You were ready to go to
11 theatre and one of the medical staff said to you, "Never
12 mind, tomorrow you will feel like a new man."

13 You were then told that the liver had arrived and it
14 was not suitable for transplant, as it had been
15 drug-abused. So you were stabilised and sent home.

16 A. That's correct.

17 Q. Which must have been a very difficult episode for you
18 and your family.

19 A. Very difficult. It was very, very difficult.

20 Q. You tell us in paragraph 32 that you continued to
21 deteriorate and in the last weeks of October 2007 you
22 were delirious due to the toxin build-up, hepatic
23 encephalopathy, which at that time was noted to be
24 secondary to dehydration. You were admitted to
25 Ninewells Hospital and the records show that was between

1 24 to 29 October 2007, where you were given intravenous
2 antibiotics. You had a pipe into the side of your
3 stomach to drain off the fluid and the infection was
4 brought under control by antibiotics. While you were
5 admitted to hospital at that time, you say that you were
6 taken off the transplant list --

7 A. That's correct.

8 Q. -- due to infection.

9 A. If you have any infection, they can't keep you on the
10 list.

11 Q. By Friday of that week, you had cleared the infection,
12 and so were you told then you were put back on the
13 transplant list?

14 A. No, I wasn't at that point. I was kept in over the
15 weekend, still on a saline drip and such like. They
16 reckoned they had cleared the infection. On the
17 Monday -- I know it was the last day of October,
18 I think -- I got -- my wife came and picked me up. They
19 wanted to keep me in but the ward I was in had a lot of
20 ill people and Ninewells at that point was going through
21 a period where it had quite a lot of viruses and such
22 like going about, and the toilet -- the amenities
23 weren't what I would say was very good. They were doing
24 their best. They have got problems. They couldn't help
25 that. I felt that at the stage I was at, I was so ill

1 that I would go home, and they said they would prefer if
2 I stayed and I said, "No, I would rather go home". If
3 I wasn't going to live, then I would rather go home.

4 Q. You say that you left hospital on the last day
5 of October 2007.

6 A. Yes.

7 Q. And you hadn't realised how yellow you were until saw
8 the colour of your skin against a doctor's white shirt?

9 A. Yes, I think before, obviously, I had been yellow but
10 this bout of infection in my stomach -- when I say "bout
11 of infection" and toxin, I have always been a size 7 in
12 a shoe. My ankles were that puffed up I had to put
13 a size 9 on. I was wearing a 40 waist trousers and I
14 have never been higher than a 34, that's how bloated my
15 stomach was with the toxins. After that I couldn't walk
16 because you were so drained. But I still decided I
17 wanted to go home.

18 And it wasn't until he came checking me before
19 I went. I was looking, by that time, more conscious,
20 when he put his arm across to do his -- the checks on
21 blood pressure and such like, that his shirt was lying
22 across my stomach. When I looked down, I was just
23 bright yellow on his white shirt. That was when
24 I realised how bad it was. So I think, although I had
25 been yellow for some time, I think the infection had

1 made it a lot worse and I had -- I still hadn't
2 realised, you see, until then.

3 Q. And so you returned home and you tell us in paragraph 33
4 that at 9 pm on Thursday, 1 November, you received
5 another telephone call from the transplant unit at
6 Edinburgh Royal Infirmary saying that they had another
7 liver for you. You asked if they could check that the
8 liver was okay as you didn't feel you were likely to
9 survive the trip to Edinburgh and back if it was
10 unsuitable.

11 A. That was right. It was a stupid thing to say but
12 because I had been in and been in the situation, and
13 obviously the girl at the end of the phone was only
14 making a phone call but in my mind it was important to
15 ask was it a good match, was it a good liver, was it
16 going to be okay for me, and she said, yes, it was a
17 perfect match and it would be fine.

18 Q. So you were conveyed to Edinburgh in a blue light
19 ambulance.

20 A. I certainly was.

21 Q. And you received a graft from a non-heartbeating donor.
22 Was that on 2 December 2007?

23 A. Yes, early hours of the morning, within an hour of being
24 in Edinburgh Royal -- they didn't have a bed for me. I
25 was put on to a metal trolley and taken into a box side

1 room, a store, and the doctors worked round me to put in
2 a venflons and give me platelets. That was in
3 a storeroom. Within three quarters of a hour, I was in
4 theatre. I know it is of no relevance but I was lucky
5 to get the liver, because it actually was police
6 escorted from the North of England. The story was that
7 all the transplant units down there were busy doing
8 transplants and that this was surplus. Whether it was
9 the fact I was the next emergency and it was a good
10 match, I don't know, but that's why it was police
11 escorted to Edinburgh, and it was a perfect match. So
12 whatever the story was on that, it was a lucky day for
13 me.

14 PROFESSOR JAMES: You might have well ended up with
15 a Geordie accent.

16 A. I could have done, yes.

17 MS PATRICK: A discharge document for your admission for the
18 transplant is WIT0050672. And you tell us that you
19 did take a turn for the worse for about 48 hours. This
20 is in paragraph 35 of your statement.

21 A. That --

22 Q. You were told it was a slight complication?

23 A. It actually wasn't due to how I was feeling because
24 I was feeling fine. They took me for more tests and
25 I think that there was an artery they couldn't see,

1 which was important and they wanted to check. So
2 I went -- I was actually going for a scan supposedly,
3 got the scan and then I was taken somewhere else, where
4 they did something, and the drugs they gave me just
5 knocked me for six.

6 My wife came in that night and I was flat out,
7 couldn't hold a conversation, couldn't speak and when
8 she had been in the day before, I was beginning to look
9 quite well because it was after the first week. So it
10 knocked me back for a few days.

11 Q. It's noted in the discharge document WIT0050673, which
12 is the second page of the discharge document, dated
13 22 November 2007, in the first paragraph, that you had
14 received the graft.

15 A. Yes.

16 Q. And you had become independent of infused Factor IX on
17 4 November and otherwise did extremely well. On 7 and
18 8 November there was a deterioration.

19 A. Yes, they said there was a deterioration, correct.
20 I actually didn't feel it but it showed in their results
21 because they were taking blood every day.

22 Q. I think there may have been a kink in the recipient
23 hepatic artery, that's suggesting, that was the cause
24 for that, and it was noted at that time your mental
25 state deteriorated a little and you became quite

1 confused. However, this settled and you were mobilised
2 and fit for discharge on 18 November.

3 The last paragraph there notes that you had high
4 glucose levels.

5 A. Yes.

6 Q. And you were started on treatment for this. Were you
7 told that you were now suffering from type 2 diabetes at
8 that point?

9 A. That's correct. I was told that most liver transplants,
10 people would generally have diabetes. That was what --
11 some people can have mild, it can be more severe, but at
12 that point it was quite common for someone to have it,
13 I believe. But since then I go -- I was going six
14 monthly for tests for the diabetes but now it's a year
15 and there is nothing at all whatsoever.

16 Q. And are you now controlling that with your diet?

17 A. Yes, normal diet.

18 Q. How long did you take the medication for?

19 A. I think, because it was like most of the drugs I was on,
20 about after three months, I was on about nine tablets
21 over the period of a day, most of them antirejection and
22 such like. One was for the bowel and such like.

23 Q. Actually I have got a document which shows the drugs you
24 were on, WIT0050675. This is dated 16 November 2007.

25 Are these the drugs that you were on?

1 A. That's correct, yes.

2 Q. Did you continue to take these after discharge from
3 hospital?

4 A. Yes, three months. Most of these were taken for three
5 months. I can't remember if the gliclazide continued
6 longer or they reduced the dose. I think they reduced
7 the dose. I don't think I was on the gliclazide for the
8 three months, but the rest I was on for the three months
9 and two of them I'm still on on a daily basis, the
10 tacrolimus and the azathioprine.

11 Q. Following your discharge home you continued to attend
12 both hospitals in Dundee and Edinburgh Royal Infirmary
13 for --

14 A. Initially it was always Edinburgh. It was weekly for
15 a period of time and then fortnightly and then monthly
16 and then six monthly, but when we got to the six
17 monthly -- Edinburgh do an outbound clinic at Dundee, so
18 I started going to Dundee for my six monthly check-up,
19 and then yearly for my biopsy to Edinburgh, my liver
20 biopsy, which I have had every year since.

21 Q. So how did you feel after the liver transplant?

22 A. Oh, I felt very well. It was a big change.

23 Q. A big difference?

24 A. It was just trying to build up energy and build health
25 back up. Actually the doctors said to me at the time --

1 I was only in 14 days in total, and that was with the
2 blip in the middle, and he said, "I take it you have
3 never smoked in your life". I said, "Never smoked
4 ever". He said, "I can tell, how quickly you have
5 responded to everything and how healthy you are in
6 general". And they also commented on my heart rate, how
7 steady it had been all the time. It's something they
8 have always said when I go in, that it always seems to
9 be fine. Whether that's down to not smoking or not,
10 I don't know, keeping fit, I don't know.

11 Q. And you have had liver biopsies since then?

12 A. Yes, yearly.

13 Q. I would like to refer you to WIT0050699, which is the
14 liver biopsy pathology report, dated 17 November 2008.
15 If we scroll down to the bottom, we can see that the
16 conclusion was that it showed fatty change which may
17 reflect metabolic, for example, diabetes or other
18 causes, such as graft Hepatitis C virus.

19 A. Yes.

20 Q. And secondly there was no evidence of rejection?

21 A. No, I have been very lucky that way. I'm only actually
22 on 2 milligrammes of the tacrolimus, 1 milligramme in
23 the morning, one at night and 75 mls of azathioprine at
24 tea time with a meal. That's all I'm on. I'm back on
25 extra strong painkillers for muscle and joint pain now.

1 That was almost virtually the same as last year's biopsy
2 report.

3 Q. So you think there has been no significant change in
4 that?

5 A. I don't think so. You probably have that there.

6 Q. I know that the November 2009 liver biopsy showed no
7 significant scarring or fibrosis. At a review
8 in August 2010, which is WIT0050716, I think you have
9 started at this point experiencing feeling tired again
10 and episodes of shutdown. But you feel well in between
11 times and your recent liver function tests have been
12 normal.

13 A. Yes.

14 Q. And you have also had joint pains.

15 A. Yes, the joint pain has come back. At that point I said
16 to them, "Is it just age?" They said, "I don't think
17 it's age" -- although I have had the transplant,
18 obviously I have still got the virus, and as the virus
19 wasn't affecting the liver, it's still active in my
20 system, but I'm still on the high dose of tramadol slow
21 release morning and night at the moment.

22 Q. It's noted here that you have seen Dr Dillon who has
23 advised you to retire.

24 A. I went back to work once again. Once I got to the
25 situation I felt better -- my wife advised me against

1 it -- but I went back to work as a manager for
2 a stocktaking company doing big stores.

3 Q. When was that?

4 A. September -- get the right year now. Is it 2000 and --
5 2008? Yes, 2008, I think I went back to work doing
6 that.

7 Q. How many hours a week were you doing?

8 A. That varied because the good thing about that was you
9 filled in a sheet. You got a sheet for the next month
10 and you filled in what you were willing to work. So
11 initially I was working what they would offer me. You
12 might get three days a week or you might get four days
13 a week or whatever. But when I started getting more
14 pains and such like, I cut down the days I was working,
15 because the problem is it wasn't just a Monday to
16 Friday, it was any three out of seven or any four out of
17 seven. I loved the job but the problem was it wasn't
18 just the job doing the stocktaking, at that point I was
19 doing the managing side, the computer side, producing
20 the documents for the shops. It was the mileage we were
21 covering. I had never experienced a company in my life
22 that was so disorganised but yet such a big company.
23 One day they would have me in Aberdeen and the next day
24 they would want me in Berwick, and the next day I would
25 be back in Aberdeen again for another store. I think

1 the travel had more to do with it than the actual
2 physical work, than the reason for it.

3 Q. Did you follow Dr Dillon's advice?

4 A. Yes, I did. I had to eventually because it got to the
5 stage, while I was working, that there was times
6 I wasn't well, and when you are working with a team,
7 depending on how big the store is -- for instance, at
8 Debenhams in Edinburgh here, we were doing a big
9 department and there was 30 people. So I had 30 people
10 working for me. And when you are not right and the
11 stress of it, it can cause major problems, and that's
12 what was happening. So not being able to concentrate on
13 driving properly and not feeling well when I went in, my
14 hands were all blotchy and my face was puffed up and he
15 said, "Enough is enough. You are just going to end up
16 back where you were". At that point I had cut down to
17 working about 16 hours a week.

18 Q. There is mention there of working night shifts?

19 A. Yes, that was after that. I actually -- I put it down
20 to the mileage I was doing, how I felt, because although
21 the job that you worked on, it was supposed to last --
22 each job was only supposed to last six hours on the
23 stocktaking, but being the manager you got paid for
24 nine. But none of the jobs ever lasted for six. By the
25 time you got finished, you went home, sent your job to

1 the office, picked up the next day's job, and you had
2 driven maybe 300 miles that day, it was -- so I thought,
3 "Right" -- I knew someone who worked in Tesco's in [REDACTED]
4 and they said they were looking for night shift staff,
5 and I thought, how hard can it be, stocking shelves is
6 not actually rocket science. So I applied for the job
7 and I was lucky to get the job, and actually it was
8 quite a nice team to work with, a team of six, it was
9 fine.

10 I started doing night shift. It was three days
11 a week, three nights a week, after a few months I had to
12 cut it to two nights a week because all I was doing in
13 between was sleeping, and after I finished my three days
14 I would spend two days in bed to catch up because my
15 body wasn't coping. So when I moved down to two days,
16 it got to the stage that the last week I was there, two
17 or three times the body just gave in altogether and
18 I almost collapsed. I said that was it, enough was
19 enough. It was actually after that that Dr Dillon said,
20 "Finish".

21 Q. Was it about then that you stopped?

22 A. Yes, it was then I stopped.

23 Q. And are you now retired?

24 A. Yes, yes. It doesn't come easy, I can tell you that.

25 Q. No. I would like to refer you to your last review that

1 we had in the medical records, which was WIT0050730,
2 which is a letter dated 26 September 2011 from Dr Dillon
3 to your GP. It's telling us how well you are doing.
4 You are well and stable and no particular problems or
5 issues. It's noted you are retired and feel very
6 positive about things at present and feel that you are
7 relatively well.

8 A. Yes.

9 Q. So how are you feeling now?

10 A. My wellbeing is fine. Aches and pains I still have.

11 The tramadol and the paracetamol -- I try to keep the
12 paracetamol to a basic but the tramadol certainly helps.

13 It's mostly the joint pains and muscle here, and my
14 hands, I was bothered a lot with across the knuckles.
15 Like last week, for instance, you wouldn't have seen my
16 knuckles. My hands were all puffed up. That comes and
17 goes.

18 My ankles puff up and it's hard to walk. Then you
19 are not bothered with it, it will go away again. I have
20 always got the shoulders and the arm pains. They do not
21 go away, they are there all the time but you get used to
22 that, but to me that's not being ill. That's just
23 having a pain. You just accept that and get on with it.

24 Q. What have you been told about future treatment?

25 A. I was at Dundee about three weeks ago to a -- I still go

1 to the haemophilia meetings, although I'm no longer
2 a haemophiliac. I go mainly because there have been
3 some young people and they look at me and they will
4 point out, well, here is what the transplant has done
5 for Colin, so life is not just -- you know?

6 But we discussed the new drug that's coming out.
7 They were telling me for some time about this. I
8 mentioned it to Edinburgh. I was down for a biopsy
9 in January of this year. They tried twice to take the
10 biopsy in one day and didn't get anything. Made a total
11 ... of it. Anyway, three weeks later I had to go back
12 in for a second biopsy, when they eventually got a good
13 result, which was done under a scan. But it's
14 something, I think, that -- you just get used to it.

15 Q. Yes.

16 A. It's what you ...

17 Q. And so from what you have said, you are obviously aware
18 that new treatment --

19 A. Yes, sorry, yes, the new treatment. Sorry, that's what
20 I was going to say. We were advised at the last meeting
21 that Ninewells have funding for the new treatment but
22 it's down to Edinburgh Royal whether I get the new
23 treatment or not, because I mentioned it some time back.
24 In fact I think it was February when I was in -- sorry,
25 it wasn't, it was when I went back for my results,

1 I think, in March, about six weeks later, and I spoke to
2 Dr MacGilchrist and I mentioned about the new treatments
3 coming out and he said, "We have to look very serious at
4 it. If the virus is not affecting your liver, we have
5 to look serious. We don't want to give you another
6 drug -- although it's showing the success rates are very
7 high -- I believe it's as much as 80 per cent success
8 rate -- we don't want to make you ill. We have just
9 made you better," he says. "Plus the treatment may have
10 side effects on your liver." But I said, "I'll look at
11 it when I go back this year and point out to them, well,
12 if I'm going to have to suffer the treatment to try and
13 eradicate the virus or do something like that, then
14 I would prefer to do it while I was well, rather than
15 wait until something happens and get unwell," and them
16 say, "We will try you on the treatment now." Because
17 I think that my system is probably more able to cope
18 with it the way I am than it would be if I were unwell.

19 Q. As far as you are aware, is this the only option open to
20 you, new treatments?

21 A. At the moment, yes.

22 Q. How do you feel about your future?

23 A. Because I'm keeping reasonably well -- I mean, there are
24 times, yes -- my future, as far as I'm concerned, is
25 quite good but I am learning now to -- "retire" is

1 a terrible word at my age and having used to been
2 working long hours, I take really bad with it, and it's
3 finding a hobby or something you can do to take up your
4 time. So it's -- but the future, yes, as far as I'm
5 concerned, as long as I don't get hit with a virus and
6 it affects the liver I have got, it's fine. But my
7 attitude is I'd rather -- I know they are looking after
8 me but I would rather we looked at it and made
9 a decision on yes or not whether we are going to go for
10 that.

11 So in the next, I would think, eight weeks or
12 probably -- where are we? Yes, by end
13 of January/early February I will be back in for another
14 biopsy. Hopefully, I will have a word then and see what
15 they are saying, because at that time last year there
16 was no funding for the new drug and it hadn't been
17 licensed, which it is now.

18 Q. In paragraph 42 of your statement, which is page 0295,
19 you tell us that from the time your children were in
20 primary school you feel you have missed so much of them
21 growing up due to your illnesses.

22 A. Oh, yes.

23 Q. What impact do you think your infection with the
24 Hepatitis C virus has had on your children?

25 A. It's very difficult to put -- you know what children are

1 like, they bounce back easy, but I know my daughter was
2 very concerned. She was that bit older and she was very
3 concerned. The boys just used to see me in bed ill and
4 bring me a cup of tea or whatever but there was long
5 periods of time where I wasn't doing anything with them
6 or such like, and now both of them are actually quite
7 good skiers and things, which I used to do myself, and
8 it's things that -- they have just got on with it. Now
9 they accept it fine; I have still got the virus but
10 I look well, so they are quite happy. But during the
11 time before, I mean, I think it did put a lot of stress
12 on them. I know it did, on the whole family.

13 Q. We have heard of the stress on your wife and the effect
14 of this, causing her to stop working and effectively
15 becoming your carer.

16 A. Yes.

17 Q. Did anybody else assist caring for you?

18 A. No, what happened was I had -- someone came to see me
19 and said they could, if they wanted, get a carer to come
20 in, but the fact that there was nothing else -- I was in
21 bed anyway; at that point there was nothing they could
22 do. So, really, caring was -- it wasn't as if I needed
23 bed bathed or anything like that. It was, you know --
24 so, with my wife, she just looked after me rather than
25 bring someone in. But it was offered at the time.

1 Q. Yes. You tell us in paragraph 46 that all of your close
2 friends knew that you had Hepatitis C.

3 A. Well, being in business, as I was, you have -- well, my
4 friends were always close-knit friends I had known for
5 years. You know, they didn't come and go. So I made --
6 because, if they had functions or anything on, I would
7 go to the function if I could, but they could tell by
8 looking at me I wasn't well. So all my good friends --
9 some of the guests at the function -- it may have been
10 just out for a meal at their house or wherever. But my
11 close friends knew what was wrong. I explained to them.
12 In fact they all came to see me in hospital in
13 Edinburgh.

14 Q. But your social life must have been affected by your
15 periods of illness.

16 A. Basically, for years there was no social life at all.
17 We didn't go to things. It was only after I started to
18 get better. I mean, although they knew I was ill,
19 I didn't socialise at that time with them because there
20 was quite a number of years where we didn't go anywhere,
21 holiday nor anything. There was nothing -- but --

22 Q. And as well as skiing, you used to like sailing, fishing
23 and walking and you had to stop all of these due to your
24 ill-health.

25 A. Yes, the skiing I had done for a lot of years. Sailing

1 I have done for about 30 years on the west coast and
2 fortunately I have managed to have a couple of sailing
3 trips since I have been well. So, two years ago I was
4 away for ten days. There was -- seven guys were away.
5 Unfortunately, my wife doesn't sail -- either
6 unfortunately or fortunately, whatever.

7 So we sailed a lot of the west coast. So it's nice
8 to get away, very relaxing.

9 Q. In relation to the financial impacts, we have obviously
10 heard about the impact of this on your ability to work
11 and earn money. You received two payments from the
12 Skipton Fund?

13 A. Correct, yes.

14 Q. And did you have a pension?

15 A. Yes, I had a small pension that I had paid into but,
16 because, when I came ill and stopped working, it became
17 paid up.

18 A social worker came to see me in Edinburgh, after
19 my transplant, or was it when I was in for the week? It
20 could have been when I was in for the week; I can't just
21 remember now. She came to me and she said to me, "You
22 are quite ill. What's your income?" She said, "Do you
23 have a private pension." And I said, "Yes, I have one
24 I have paid into but it has obviously become paid up
25 because for the last number of years I haven't been

1 working, I haven't paid into it." She said, "Well,
2 I think you should apply for that." I said, "Well, I'm
3 too young." She said, "No, I would still apply. We
4 will give a letter in writing."

5 So I applied for it and I got it. It's only a small
6 amount every month but it's worth coming in. Put it
7 this way, it pays the gas and electric every month. So
8 it's a bonus.

9 Q. But your own pension suffered as a result of --

10 A. Obviously, I stopped paying into it, so it never grew,
11 but at the time I think her attitude was -- it was
12 definitely before my transplant because they said to me,
13 "If you get it out, if anything -- she said nicely, "If
14 anything happens to you, at least your wife will get
15 half of it." Whereas, if I hadn't taken it out, she
16 probably wouldn't have got anything. So the fact that
17 I've come into paying --

18 THE CHAIRMAN: When did you make it fully paid up?

19 A. It was in the mid-1990s somewhere. It was --

20 THE CHAIRMAN: Probably a good idea. If you had kept it
21 going by now, it would have been suffering tremendous
22 reduction in value.

23 A. It wasn't worth a lot at the time but, yes, you are
24 quite right. But it's a small amount coming in every
25 month. But it does work, you know.

1 MS PATRICK: And you tell us in paragraph 44 that you have
2 been able to obtain a mortgage, but I take it that was
3 taken out some time ago. You say it was a repayment
4 mortgage.

5 A. That's correct.

6 Q. And you already had the life insurance which you took
7 out in the 1980s before your diagnosis with the
8 Hepatitis C virus?

9 A. Actually, after looking at the 1980s, it was actually --
10 my life policy was taken out in 1990. The reason I'm so
11 definite about that now is because I'm fighting with
12 them. For 20 years I have paid a premium for a fixed
13 sum and it's a whole of life policy, it's not a term
14 policy. So I was paying -- since 1990 I was paying
15 32.65 a month, £20 for life insurance and £12.65 for
16 being a haemophiliac.

17 So in 2010 I got a letter through from them, not
18 telling me that they wanted more money, telling they had
19 halved what I was insured for and reducing the money
20 I was paying by £4 a month. So I contacted them and
21 I said, "It's not up to you to decide if I want to
22 reduce my insurance. What you should have done is
23 written to me and said, 'To keep the value of your
24 insurance, you are going to have to pay this amount.'"

25 They disagreed with that but anyway I kept the

1 insurance at the same amount, which they moved from
2 32.65 to now 49.95 and then, in January this year, 2011,
3 they did the same again. They wrote to me and reduced
4 what I was covered for, not -- they didn't write to me
5 and say, "You need to pay more." So I'm now paying
6 72.60 a month to keep what I'm insured for for the same.

7 My solicitor is looking into it at the moment.
8 I have written to the financial ombudsman, who wrote
9 back to me saying that I complained to the insurance
10 company and -- several times but he couldn't see
11 anything to complain about.

12 I phoned him up, rather than write to him, because
13 I was so angry and I said, "You obviously didn't read my
14 letter, you only read the letter from the insurance
15 company." What I'm angry about is them sending me a
16 letter telling me they have reduced my -- last year it
17 was halved. They didn't write to me and say, "You have
18 got to pay an extra £30," they write to me and say, "We
19 have cut what you are insured for." And it was
20 supposed to stand for 30 days, my original amount, so in
21 year 2010, two days after I contacted them about this
22 and them not sorting it, I phoned up to see how much
23 I was insured for and I was actually insured for the
24 half amount, the lesser amount than they said. They
25 said it would stand for 30 days after the letter and

1 yet, when I phoned the office, they turned round to me
2 and said, "You are only insured for 35,000/36,000."

3 So that's what has been going on. So after my nice
4 phone call to him, he has now taken on board what I said
5 and looking into it further.

6 Q. So this is ongoing?

7 A. This is ongoing.

8 Q. Have you ever tried to take out life insurance since you
9 were diagnosed with Hepatitis C?

10 A. No, that's -- my only benefit was, in hindsight, taking
11 out a whole of life policy, not a term policy, because
12 it's past 20 years now since I had it. So most people
13 take out term policies, and why, in my wisdom, I took
14 out a whole of life policy, I don't know, but I did that
15 at the time.

16 Q. And you have paid for travel insurance. Has that been
17 affected by your Hepatitis C diagnosis?

18 A. I have to be honest and say I didn't inform them I had
19 Hepatitis C because -- I informed them, I think, I was
20 haemophiliac at the time but I didn't inform them I had
21 Hepatitis C.

22 Q. And have you incurred any costs as a result of the
23 symptoms of Hepatitis C and also attending appointments?

24 A. Oh, yes. Well, Dundee is only [REDACTED] miles away but it's
25 still a cost going in and out and parking and then into

1 (1.30 pm)

2 GORDON

3 Questions by MS PATRICK

4 THE CHAIRMAN: Good afternoon. Yes?

5 MS PATRICK: Sir, this afternoon the witness is Gordon.

6 Gordon, I would like to start by letting you know
7 who everybody is in the room today. On the bench we
8 have Lord Penrose and seated next to him is the medical
9 adviser to the Inquiry, Professor James.

10 You know Margaret, the witness liaison manager, next
11 to you. Coming along the front row, we have the two
12 transcribers, who are noting everything which is said
13 this afternoon for the transcript of the hearing.
14 Seated next to them is Maria McCann, who is the
15 secretary to the Inquiry and sat next to her is
16 Keith Fleming, who is in charge of documents this
17 afternoon, and when I refer you to extracts from your
18 medical records, he will arrange for them to appear on
19 the screen in front of you.

20 Seated next to me is Laura Dunlop, senior counsel to
21 the Inquiry, who you have met, and behind us is Lindsey
22 Robertson, who is helping us with this topic.

23 Along this side of the room we have the lawyers for
24 the core participants to the Inquiry. Next to us are
25 the lawyers for the patients, relatives and the

1 Haemophilia Society. In the middle we have the lawyers
2 for the health boards and the Scottish National Blood
3 Transfusion Service, and closest to you we have the
4 lawyers for the Scottish Government.

5 Some time ago you helpfully provided the Inquiry
6 with a detailed witness statement, and you should have
7 a hard copy of that in front of you. The reference for
8 it is WIT0050045. Your wife also provided a statement
9 to the Inquiry and I will refer you to parts of that
10 later. The reference for that is WIT0050018. In your
11 statement there are numerous references to documents
12 which unfortunately, sir, don't match the references in
13 court book, but I will highlight the right reference
14 number to each document, as we go through.

15 Your date of birth is [REDACTED] and you are
16 presently 65 years old. Is that correct?

17 A. That's correct, yes.

18 Q. And you live in [REDACTED]?

19 A. That's right.

20 Q. And you used to live in Edinburgh, living there between
21 1965 and 1985?

22 A. That's right.

23 Q. And you are currently retired, having been a [REDACTED]

24 [REDACTED]

25 [REDACTED]?

1 A. That's correct.

2 Q. In paragraph 2 of your statement, you tell us that you
3 acquired the Hepatitis C virus genotype 1 from one or
4 a number of blood transfusions which you received at
5 Edinburgh Royal Infirmary in December 1975 and/or early
6 1976, and that you found out that you had acquired the
7 Hepatitis C virus in 1995.

8 You tell us about the surgery you underwent
9 in December 1975 in paragraph 3 of your statement. At
10 that time you were about, I think I'm right in saying,
11 29 years old?

12 A. Yes.

13 Q. Were you working then?

14 A. Yes, I was. I was in full-time employment [REDACTED]
15 [REDACTED].

16 Q. What was your post there?

17 A. I was -- at that stage I was a [REDACTED]
18 [REDACTED].

19 Q. And you were taken ill in about October or November,
20 when you had a respiratory tract infection with pleural
21 effusions. You were then admitted to the City Hospital,
22 Edinburgh, on 1 December 1975 and diagnosed with
23 pericarditis?

24 A. That's right.

25 Q. Which is inflammation of the pericardium?

1 A. Yes, and by that stage it had constricted. So it was
2 constricting the heart.

3 Q. Right. So in mid December 1975, constrictive
4 pericarditis was diagnosed and you were then
5 transferred, on 27 December 1975, to the care of
6 Mr Philip Walbaum, cardiothoracic surgeon at Edinburgh
7 Royal Infirmary, for an urgent pericardiectomy, and you
8 underwent this surgery on 29 December 1975. You tell us
9 there that your blood loss was excessive in the early
10 post-operative period and you received a number of blood
11 transfusions between 29 and 31 December 1975.

12 You had to undergo further surgery -- this is over
13 the page, on page 2 -- to rectify bleeding from the
14 operation site, and about 1.5 litres of blood and clot
15 were removed from the pleural cavities. You then had
16 a difficult post-operative recovery period and the
17 complications included septicemia, cardiac arrest, low
18 cardiac output, which was successfully treated by
19 intra-aortic balloon counter pulsation, bilateral
20 pneumothorax, renal failure and gastric stress ulcer.
21 So that was quite a number of complications.

22 A. Yes, that's so.

23 Q. And you were quite unwell at that time?

24 A. Distinctly, critically unwell.

25 Q. And you say that in January 1976, whilst still a patient

1 at Edinburgh Royal Infirmary, you received further
2 transfusions of whole blood and packed red cells,
3 following a series of episodes of vomiting blood. And
4 you remained in Edinburgh Royal Infirmary until
5 12 February 1976, when you were transferred to the
6 City Hospital, Edinburgh.

7 In paragraph 5 of your statement, you tell us that
8 you can't recall having any discussion with anyone at
9 Edinburgh Royal Infirmary about the benefits and risks
10 of having a blood transfusion. You were obviously very
11 unwell at the time.

12 A. Yes, I was not terribly unwell before the operation, so
13 there would have been opportunity. I suppose at that
14 time I was mainly -- the discussion I had with the
15 cardiothoracic surgeon was very general, about the risks
16 of such surgery and how the post-operative pain would be
17 managed, but I very much doubt if there was any mention
18 of anything -- risks to do with blood transfusion, and
19 I personally would have taken it for granted that this
20 would have been available if it was needed and that
21 would be that.

22 Q. Yes. You tell us further down that paragraph that you
23 fully accept that the operation and associated
24 transfusions were necessary and potentially life saving
25 procedures.

1 A. Yes, I was given to believe very clearly that my cardiac
2 condition was sufficiently serious to warrant opening
3 the cardiothoracic theatre between Christmas and New
4 Year, 1975, when it normally would be closed, and that
5 gave some measure of an indication of the seriousness of
6 the situation.

7 Q. And for the record, sir, I should say that the discharge
8 letters referred to in paragraph 3 -- the letter dated
9 12 February 1976 -- is WIT0010555. The second one,
10 referred to at the end of that paragraph, ends "6",
11 instead of "5". Every number actually goes up a digit.

12 You tell us in paragraph 4 of your statement, which
13 is on the previous page, that in January 1976, you
14 didn't notice it yourself, but you were told by medical
15 staff and visitors, including your late mother, that you
16 became severely jaundiced.

17 A. Yes, that's so. Several people -- not just my mother,
18 but people associated with me -- for instance people
19 from my place of work -- came and I recall being told
20 that one of them, at the sight of me, left the ward
21 immediately.

22 Q. And you refer to the discharge letter from Mr Goldstraw,
23 which is WIT0050556, which we don't need to look at,
24 but he stated that:

25 "he developed severe jaundice, which was

1 progressive. However, the aetiology of this remained
2 obscure although Halothane appears to be incriminated."

3 So they were obviously wondering there if it might
4 be caused by the general anaesthetic?

5 A. Yes, but I understand that that was subsequently
6 discounted when Dr Niall Finlayson looked at my case
7 records in detail and I believe that it was found that
8 Halothane was not the anaesthetic used.

9 Q. Thank you. Turning to paragraph 6 of your statement,
10 having reviewed your medical records, you have noted
11 from them that, apart from a minor elevation of alkaline
12 phosphatase, which was raised before your
13 pericardiectomy operation, there was no other
14 abnormality in your liver function test results.

15 A. Yes, that is as consistently been described to me by
16 various doctors.

17 Q. Yes. If we could refer to WIT0050552. Sorry, these
18 copies are not the most easy to read. This is the
19 referral letter from Dr Innes to Dr Miller, dated
20 22 September 1975. It's noted in the second paragraph,
21 where there is a marking on the side, this is the
22 findings when you were admitted to hospital initially:

23 "Liver function tests normal apart from an alkaline
24 phosphatase of 185."

25 You tell us in paragraph 7 of your statement that

1 following your discharge from hospital, you continued to
2 attend Mr Macleod, general and GI surgeon at Edinburgh
3 Royal Infirmary, and he was checking your recovery,
4 following the surgery you had had in January 1976 to
5 rectify an acute gastrointestinal bleed. He noted that
6 your liver function tests were abnormal. You state that
7 generally your overall recovery from these operations
8 was good and you returned to work in June 1976.

9 A. Yes, that's right. The cardiologist discharged me from
10 the cardiology care very promptly after my discharge
11 from hospital. Mr Macleod continued to see me in view
12 of the post-gastric surgery symptoms, which, not
13 surprisingly, I did suffer from, and it was during the
14 follow-ups with him that the persistence of the liver
15 function test became apparent.

16 Q. Became noticed, yes. And you mentioned that you were
17 still suffering symptoms of the gastric procedure you
18 had undergone. Were these symptoms of nausea?

19 A. There was symptoms of nausea and dumping, tachycardia
20 and sometimes it was early dumping and occasional late
21 dumping.

22 Q. Can you clarify what you mean by "dumping"?

23 A. Yes. Immediately after a meal, when the stomach
24 contents have emptied into the upper small intestine,
25 there is a feeling of tachycardia, as the fluid moves

1 from the circulation into the intestine, which then
2 causes a slight lowering in blood pressure and an
3 increase in heart rate, and one is conscious of
4 palpitations and nausea. That's with early dumping.

5 I also did suffer from late dumping, which is due to
6 the same general sort of physiological conditions but
7 where longer after the meal one has an excessive insulin
8 response to the rather large load of carbohydrate
9 entering the intestine, so that there is excess insulin
10 secreted in response to that, which leads to one's blood
11 sugar falling to a lower than average expected level and
12 hence feelings of faintness.

13 Q. Yes.

14 A. But these symptoms were typical of that type of gastric
15 surgery at that time.

16 Q. So they were an effect of that?

17 A. Yes, definitely.

18 Q. And so in paragraph 8 you tell us about the monitoring
19 which Mr Macleod gave you at your appointments, and in
20 particular he monitored your liver function tests as
21 they remained abnormal.

22 A. That's correct.

23 Q. And you refer to a number of letters in this paragraph.
24 The correct number for each of these being one digit
25 above what was specified there.

1 THE CHAIRMAN: That's the position throughout. We can
2 correct them all in due course.

3 MS PATRICK: Yes, generally. Thank you, sir.

4 The letter WIT0050559, which is dated
5 27 September 1976, is a letter from Mr Macleod to your
6 GP. It's noted there that your ALT is 139 units per
7 litre and he notes that these remain raised:

8 "I do not propose to do anything about this at this
9 stage other than to keep an eye on it."

10 You tell us in November 1976, you refer to a letter
11 in which he states that he advised you to discontinue
12 alcohol for the next three months at that time. And
13 then he wished to recheck your figures. Did you do
14 that?

15 A. Yes, I did. Absolutely. I saw him again after three
16 months, after which he actually -- he confirmed that
17 that had not caused any benefit and he actually put in
18 writing to me that a modest ingestion of alcohol would
19 not be a bad thing.

20 Q. Right. So in the last letter referred to in
21 paragraph 8, he wrote again to your GP on
22 8 February 1977 -- the reference being WIT0050562 --
23 and noted that:

24 "Thus, despite abstinence from alcohol, he does have
25 persistent minor abnormality in his liver function

1 tests. I feel at this stage he should have the benefit
2 of an expert hepatologist's opinion and I am taking the
3 liberty of asking Dr Niall Finlayson to see him."

4 So you tell us in paragraph 9 of your statement that
5 you attended to see Dr Finlayson, consultant physician
6 at Edinburgh Royal Infirmary, in about March
7 or April 1977. You say that he reviewed your case notes
8 and examined you. He was most thorough and you wondered
9 if he had been involved in your jaundice episode
10 in January 1976. Your impression was that he was
11 puzzled about your abnormal liver function tests but
12 also that he was keen to investigate causes of this.

13 A. Yes, that's absolutely true.

14 Q. Tests for Hepatitis --

15 THE CHAIRMAN: I wonder, could I ask: have you ever been
16 given an explanation of why it might have been puzzling
17 at that stage that you had hepatic changes immediately
18 post operatively, and then these continuing
19 measurements?

20 A. Well, sir, Dr Finlayson carried out almost an exhaustive
21 range of --

22 THE CHAIRMAN: He would, I think, yes.

23 A. Exactly. And each time I went back to see him he had
24 thought of more investigations to do. And then
25 subsequently, when I came into the care of

1 Professor Monty Losowsky in Leeds, who was also the sort
2 of physician who would do a very, very comprehensive
3 range of investigations, at that early stage, before
4 a test for Hepatitis C was available, this remained
5 a mystery. Although, as I do mention, just a little
6 later in my statement, Dr Finlayson was aware of the
7 possibility of non-A non-B Hepatitis and he did discuss
8 that a little with me eventually but not in writing.

9 THE CHAIRMAN: I think Professor James may help us all
10 understand just exactly why there might have been
11 a small difficulty in understanding at that stage which
12 is now clearer.

13 PROFESSOR JAMES: Yes. I can vouch for the fact that both
14 Dr Finlayson and Professor Losowsky are the most
15 respected liver doctors of their regions and some of the
16 best in Europe. By chance I too am a liver specialist.
17 I was based in Newcastle. Just as we didn't understand
18 then what non-A non-B Hepatitis was, we didn't
19 understand then the phenomenon that you had, which was
20 the probably quite intense yellow jaundice only two days
21 after your pericardiectomy. But I think it's almost
22 certain that this is the sequence of events. We now
23 know that following major cardiac surgery, particularly
24 when there is a very significant fall in blood
25 pressure -- and we know how desperately ill you were

1 around the time of that operation -- actually you get
2 a condition called "shock liver". Effectively this
3 is -- I can say to you -- hypoperfusion of the hepatic
4 artery, which kills a lot of liver cells. So you get
5 a very high transaminase, just as if you had very bad
6 "hepatitis", but actually it's dead liver cells, as in
7 a paracetamol overdose, for example.

8 For some reason you also get quite profound
9 cholestasis, bright yellow, very raised bilirubin.
10 Almost always this settles down within two or three
11 weeks. Three months later your liver blood tests are
12 back to normal, but you had the misfortune to get two
13 for the price of one. So just as your blood tests were
14 settling down from this hypotensive episode, the low
15 blood pressure, so the fact that you had also acquired
16 the non-A non-B Hepatitis C sort of kicked in. But as
17 you appreciate, the mystery would have been, well, we
18 know that the incubation period of non-A non-B, you
19 know, for clinical symptoms is several weeks anyway. So
20 why did you go bright yellow two or three days after the
21 operation. And the explanation that I have just given
22 is almost certainly the correct one, but I emphasise
23 that, you know, that was not appreciated in the 1970s.

24 A. Thank you, Professor James. I had -- when I thought
25 about this carefully myself, I had assumed that we were

1 dealing with two separate causes of liver damage.

2 PROFESSOR JAMES: That's correct.

3 A. Thank you.

4 PROFESSOR JAMES: And I should add that the hypotension, the
5 bright yellow, the liver goes back to normal after that,
6 always. So there is no question of that being in any
7 way implicated in what subsequently occurred. That's
8 entirely due to the Hepatitis C.

9 THE CHAIRMAN: I hope that's helpful in giving you
10 a technical explanation.

11 A. Thank you, sir.

12 MS PATRICK: Sir, we were looking at your monitoring by
13 Dr Finlayson and the tests he was carrying out to try
14 and ascertain the cause of your abnormal liver function
15 test results. As we can see half way down paragraph 9,
16 tests for Hepatitis B antigen and antibody were
17 negative. Then if we go over the page to paragraph 10,
18 in paragraph 10 you list for us the further
19 investigations he carried out, including those for Q
20 fever, toxoplasmosis and infectious mononucleosis, all
21 of which were negative.

22 In paragraph 11 you tell us that Dr Finlayson
23 decided in November 1977 that, as your abnormal liver
24 function tests had persisted for about two years, he now
25 wished to carry out a liver biopsy and eventually, on

1 14 September 1978, you underwent a liver biopsy. How
2 were you feeling about your abnormal liver function test
3 results at this time?

4 A. At this stage I was remarkably well. I don't think
5 I could have complained of any aspect of my health.
6 I was energetic, I was back at work and generally
7 enjoying everything I did.

8 Q. And were you concerned about these abnormal test
9 results?

10 A. Not terribly worried about them but obviously I was not
11 entirely happy to see that I had a persistent hepatitis.

12 Q. You tell us in paragraph 11 that you don't remember
13 being told the results of the biopsy. There is mention
14 in a later letter, WIT0050768 -- a rather old copy of
15 a letter dated 8 October 1981. It's addressed to
16 Professor Losowsky, and I think this was when you were
17 referred to him for a second opinion in relation to the
18 dumping syndrome?

19 A. That's correct, yes. I asked Dr Finlayson to refer me
20 to Professor Losowsky, whom I already knew for other
21 reasons, and I was keen to see if he could make any
22 suggestions to alleviate the post surgical symptoms.

23 Q. Yes. And this is a letter from Dr Finlayson, and if we
24 look over at the second page, about the fifth or sixth
25 line from the bottom of the first paragraph, it starts:

1 "I should say on the liver side that he has not
2 developed any stigmata of chronic liver disease and the
3 liver biopsy that he had has shown a mild persistent
4 hepatitis."

5 So that seems to suggest that that was the result of
6 your liver biopsy?

7 A. Yes, that was the result of the Edinburgh liver biopsy
8 because I understand that Professor Losowsky
9 specifically asked Dr Finlayson to obtain the --
10 histology slides from Dr Hugh Gilmour, who is the
11 pathologist.

12 THE CHAIRMAN: Yes, the postscript to the letter shows that
13 being followed up.

14 MS PATRICK: Yes.

15 A. Oh, yes. Thank you, sir.

16 Q. And was Professor Losowsky able to help you?

17 A. Well, he certainly did a very comprehensive range of
18 investigations. I stayed in his ward for about a week,
19 I think it was, and a number of possibilities were
20 suggested. He introduced me to Professor Geoff Giles,
21 the late Professor Geoff Giles, to discuss whether any
22 surgical revision would be helpful, and the conclusion
23 was almost certainly not, unless something worse
24 transpired.

25 There were small suggestions to try and ease the

1 dumping but at the final analysis -- because the dumping
2 did change with the passage of time but it also proved
3 to be very erratic, not necessarily caused by
4 a particular food or a particular time of eating,
5 et cetera, that we have really had to leave it to run
6 its own course, and it still troubles me just from time
7 to time.

8 Q. Going back to this letter, we can see at the end of this
9 paragraph that he refers to:

10 "No specific cause for that hepatitis has been detected
11 but I would suspect that it is a chronic non-A non-B
12 post-transfusion hepatitis, dating from the time of his
13 original operation when a considerable quantity of blood
14 and blood products were given."

15 If we look, please, to WIT0010575, this is
16 a letter from Dr Finlayson to yourself, dated
17 30 August 1982:

18 "... to let you know that your liver function tests
19 continue to show a very minor increase in [ALT], which
20 would be wholly in keeping with a mild persistent
21 hepatitis."

22 It's noted in the PS at the bottom:

23 "Your viral serology studies, including a putative
24 marker for non-A non-B Hepatitis, have all proved
25 normal as in the past."

1 Was this the first mention to you of non-A non-B
2 Hepatitis?

3 A. This is the first mention in writing but at some stage
4 before this -- and I couldn't put a date on it --
5 I think that Dr Finlayson did talk about non-A non-B
6 Hepatitis, and I remember him telling me that
7 a transmissible -- an agent transmissible in chimpanzees
8 had very recently been discovered, and he was quite
9 buoyant that some progress was being made there. So it
10 certainly was discussed with me and I couldn't put an
11 actual date on that.

12 Q. Thank you.

13 A. Can I comment on the PS at the bottom here? Because
14 this was the first mention I had seen anywhere about
15 a marker for non-A non-B Hepatitis. And when I wrote to
16 the Inquiry, after the publication of the preliminary
17 report, I received a reply from Mr Tullis, saying that
18 he would like to follow this up with Dr Finlayson, to
19 see if he could shed light on what test was being done,
20 and Mr Tullis kindly -- I think he had to chase
21 Dr Finlayson to obtain it but he did kindly send me
22 a copy of Dr Finlayson's reply and the paper in which
23 a test -- a putative test was mentioned, although my
24 understanding of that paper -- and I have looked at
25 it -- I have it somewhere here -- is that it was not

1 a satisfactory test for non-A non-B Hepatitis but it was
2 something which was elevated in, I think it would be
3 primary biliary cirrhosis patients, but at least it
4 indicated -- and one of the authors of that paper,
5 I noticed, was from the Scottish Blood Transfusion
6 Service. So it was, in a sense, a heartening and
7 intriguing indication that people in that service were
8 actually engaged in, shall we say, virus hunting.

9 Q. Yes. Thank you.

10 If we could return to your statement, to
11 paragraph 12, you tell us there that you continued to
12 attend Dr Finlayson for monitoring. In paragraph 13 you
13 tell us that you moved to [REDACTED] in 1985. Why did you
14 move to [REDACTED]?

15 A. Because my -- I was offered a good permanent job there.
16 In Edinburgh my contracts had always been short-term,
17 fixed term, and at any rate, it was time for a career
18 move, so that's why I went to [REDACTED], and I must say,
19 have not regretted it apart from the fact that I miss
20 Edinburgh.

21 Q. Yes. You married in 1987?

22 A. That's correct.

23 Q. And I would like to refer you to paragraph 9 of your
24 wife's witness statement, which is the page ending 0020.
25 She says there that before you married you said to her:

1 "I don't know how long I have to live because of my
2 liver disease."

3 Do you remember saying that to her?

4 A. Not specifically in these words but I do know that I was
5 being -- I set out to be completely honest to her that
6 I had an illness that was not clear what the outcome --
7 whether there would be morbidity or worse associated
8 with it.

9 What -- I'm not sure exactly when that was said but
10 it wasn't said with, I think, a sense of dire
11 foreboding.

12 Q. No. Going back to your own statement, paragraph 13, you
13 tell us that having moved to [REDACTED], there was no
14 monitoring of your condition after that point and
15 in March 1988, in connection with an experiment that you
16 were validating for use in an undergraduate practical
17 class, you measured your own blood ALT and you noted
18 that it was high. And so you mentioned this to
19 a personal friend, Dr Mitchell, and he agreed to take
20 a blood sample and have your liver function test
21 measured alongside those of his private patients.

22 In a letter to you, he noted:

23 "The hepatocellular enzymes are indeed quite high
24 and I personally would be a little unhappy just to
25 ascribe them to chronic persistent hepatitis."

1 The reference to this letter, although I don't
2 propose referring to it, is WIT0010576. He suggested
3 that you seek further advice, "as at the very least they
4 require further monitoring."

5 You then attended your GP to ask for a referral to
6 Professor Losowsky in Leeds. I think you had spoken to
7 him first before going to your GP?

8 A. Yes, I had. I didn't go, at that stage, to
9 Professor Losowsky because of my illness; I was actually
10 giving a lecture to some of his students and he attended
11 my lecture and afterwards I said, "By the way, so and so
12 has said this and I would like to come and see you."

13 He said, "Please, delighted to see you, just get
14 your GP to write to me and we will sort it all out."

15 Unfortunately, when I went to see that GP, he --
16 well, bluntly he refused to refer me.

17 Q. You say that he said:

18 "Your medical history was exotic medicine."

19 A. Yes, I cannot forget that expression.

20 Q. And he advised you to abstain from alcohol.

21 A. Yes, and I did.

22 Q. And so from then on, no monitoring of your liver
23 function tests?

24 A. I'm not sure. That GP, I did go back to him and he saw
25 that my liver function tests had not improved. Now, I'm

1 not sure how many times I went back. Clearly I was not
2 very well disposed to him, since he was doing nothing
3 about it, and his advice on alcohol also had made no
4 improvement.

5 Anyway, furthermore, other eventualities occurred,
6 in that doctor died and I went -- that GP died, and
7 I subsequently saw, but not in connection with that
8 little sequence of events, another GP associated with
9 that practice.

10 Q. But that did not lead to any further monitoring of your
11 condition in respect of your liver function.

12 A. No, that's correct.

13 Q. In paragraph 14 you tell us that you attended the
14 orthopaedic department of [REDACTED] Royal Infirmary in
15 respect of back pain, and although blood tests at that
16 time indicated a degree of liver abnormality, this was
17 not investigated any further.

18 A. That's correct. I had a prolapsed lumbar disc, and
19 I must say, I was very surprised that the orthopaedic
20 surgeon wanted to do some blood tests, including a liver
21 function test, and I never heard the results of that
22 liver function test and it was a long time later, when
23 I came across the information, that indicated that he
24 had written to the GP. This was by now -- this was
25 Dr Andrew Henderson, who had succeeded the late Dr Allan

1 Craig. He had just mentioned that my liver function
2 tests were abnormal, but no action was taken.

3 Q. Right. You tell us in paragraph 15 that up until 1995,
4 you continued in good health and developed your career
5 in [REDACTED] until
6 1985, and then in [REDACTED], as well as
7 developing your personal interests. So by this time,
8 1995, what position did you hold at [REDACTED]
9 [REDACTED]?

10 A. I think I was still -- I was [REDACTED]
11 [REDACTED]. I became [REDACTED], I think it was 1996.
12 But certainly my career had developed and I must
13 emphasise, I felt remarkably well. It was quite
14 a stimulating job. I had a lot of responsibility and if
15 I was tired, I would naturally put this down to having
16 a lot of commitments, and I must say I enjoyed these
17 commitments and was not worried about my health.

18 Q. And the personal interests that you refer to there, what
19 were they?

20 A. Oh, various things such as fishing. I became a member
21 of several angling clubs in Yorkshire. And I continued
22 with my interests in photography. I found plenty to
23 fill every moment and every moment wasn't just for work.

24 Q. Then you tell us that in early 1995 you started to
25 suffer from exhaustion and in particular you lost

1 a considerable amount of weight over two to three
2 months. You went to see your new GP, and he carried
3 out some blood tests, including a liver function test,
4 and asked you to come back to see him in a week. When
5 you went back to see this GP, he told you that your
6 liver function tests were hugely abnormal. He obviously
7 thought they were very bad, you say. What gave you that
8 impression?

9 A. Well, his demeanour. He was a very astute GP and he
10 certainly thought we are going to have to do something
11 about this, and it certainly wasn't a wait and see, and
12 he said to me, "Oh, what shall we do?" I don't think he
13 was asking my advice, as it were. But I think he was
14 quite relieved that I had the obvious suggestion to
15 make, to refer me to Professor Losowsky, which he
16 instantly said, "What a good idea. I had better examine
17 you because the professor will not like it if I haven't
18 done so."

19 Q. So he agreed to make that referral and he did so?

20 A. Yes, very promptly.

21 Q. Your wife says in her statement in paragraph 11 -- we
22 don't need to refer to it, I will read it to you -- that
23 when the appointment ended, he stood up and gave you a
24 strong handshake, and you said to her that it felt as if
25 he was saying a final farewell.

1 A. Yes, I was very surprised. I was very shaken actually,
2 by this. I said something to the effect:

3 "Well, I'll come back and see you when I have seen
4 Professor Losowsky", and it was almost as though he was
5 saying, well, that may not be possible. And then, when
6 I shook his hand, he said -- and I'm not speaking quite
7 literally here: "Well, it has been nice knowing you."

8 I certainly was not in a comfortable feeling when
9 I left his consulting room.

10 Q. Thank you. So Professor Losowsky arranged for you to be
11 admitted to St James's University Hospital, Leeds, for
12 full investigation of your weight loss and fatigue. And
13 you were admitted there in April 1995 and stayed there
14 for about 19 days, during which he undertook a very wide
15 range of investigations, you tell us, and you list these
16 in paragraph 16 of your statement, which is on the next
17 page.

18 Could I refer you to WIT0050792. This is a letter
19 dated 8 June 1995 and it's from Dr Beh, registrar to
20 Professor Losowsky, to your GP. It records in the
21 second paragraph about your history and how it had been
22 noted that you had lost some weight. Your liver
23 function test had deteriorated in the last couple of
24 years. I take it that's not strictly true.

25 A. No, the liver function test had deteriorated over a much

1 longer period of time.

2 Q. And it was noted then that you were drinking
3 approximately 40 to 50 units per week?

4 A. I can't be sure how accurate that is. I'm -- I honestly
5 can't remember but at the time, I did think that that
6 was a slight overestimate on the presumption that what
7 I might have drunk on one day, I was drinking seven or
8 eight days a week. But honestly couldn't put a figure
9 but I was a regular drinker.

10 Q. On the next page it tells us that on examination you
11 looked generally well and you are not jaundiced, and
12 there was clubbing, which had been noted for many years.
13 Noted further down in that paragraph, there was
14 a 5-centimetre soft, smooth liver edge.

15 If we look down to "Progress and Investigations",
16 the first paragraph there lists your liver function test
17 results, showing ALT at 221. The Hepatitis C antibody
18 was positive but the serology for Hepatitis A and B were
19 both negative. At this time your alphafetoprotein was
20 significantly elevated to 200.9 on 28 April 1995. And
21 the other investigations were in relation to your
22 gastric problems.

23 If we look down at the second paragraph there, in
24 the middle, the ultrasound of the abdomen showed
25 a slightly enlarged liver with coarse texture but no

1 focal lesion.

2 It suggests at the bottom that:

3 "In view of the significantly elevated
4 alphafetoprotein, [your] condition will need to be
5 regularly monitored in the clinic and [you] will need
6 a repeat ultrasound at intervals."

7 On the next page it's noted that you were advised to
8 abstain from alcohol altogether and that you would be
9 seen again in six weeks' time. So did you abstain from
10 alcohol after that time?

11 A. I did for four years absolutely, and four years later
12 I was advised by somebody -- by this stage
13 Professor Losowsky had retired -- that provided I was
14 sensible and careful, a little alcohol would be
15 permissible.

16 Q. You then underwent a liver biopsy in May 1995 and the
17 report of that is WIT0050790. This report is dated
18 15 May 1995 and it records under "Comments":

19 "The biopsy shows established micronodular
20 cirrhosis, with continuing activity and liver cell
21 damage. The fatty change pericellular fibrosis and
22 small nodule size are suggestive of alcohol as an
23 aetiological agent, although occasionally there are
24 other explanations for steatohepatitis."

25 How did you feel when you found out that you had

1 acquired the Hepatitis C virus?

2 A. Very uncomfortable but more so, I think, the news of
3 cirrhosis, which was given -- the news was given
4 simultaneously.

5 Q. So that was carried out in fact during your admission,
6 that liver biopsy?

7 A. Yes, that's right. So towards the end of that
8 admission, Professor Losowsky, in a formal ward round,
9 came and said I can tell you the results of the
10 investigations and I suppose I was not unduly surprised
11 or devastated actually by the Hepatitis C bit, but the
12 fact that I had cirrhosis certainly was very unpleasant
13 and I said to him, "Gosh, that's irreversible, isn't
14 it?" And he said, "Yes". And I felt very -- well, not
15 at all happy.

16 Q. Did you know much about the Hepatitis C virus at the
17 time?

18 A. No, not much, but by this time I think I knew a little
19 about it. I'm not sure how much reading I had done.
20 I had not been an obsessive reader on my medical
21 condition, although progressively, as one realised the
22 significance of Hepatitis C and of the -- of treatments
23 that were becoming available, I did delve a fair amount
24 into the current medical literature.

25 Q. And you tell us in paragraph 16 of your statement that,

1 as far as you recall, there were no discussions, when
2 you were diagnosed, about the severity of the condition
3 or the health implications of it?

4 A. I'm pretty sure that's correct.

5 Q. Yes. And you don't think there was any discussion about
6 the risk of secondary infection?

7 A. That is true. As far as I can recall. I have
8 a reasonable memory of events around that time and I'm
9 sure that I would remember if that had been discussed or
10 something explicit had been said.

11 Q. Yes. You know that your wife thinks that something was
12 said to her about this. It's mentioned in paragraph 15
13 of her statement, where she says that:

14 "Within months of my husband being diagnosed with
15 Hepatitis C, at one of my husband's appointments with
16 Professor Losowsky, Professor Losowsky said that we
17 should consider having protected sex. My husband
18 does not remember this."

19 A. No, I don't remember it. This would have been at an
20 outpatient clinic, and around that time she used to
21 accompany me quite regularly to the clinics. I don't
22 have any of my own notes or particular details, and
23 I certainly didn't have any copies of medical
24 correspondence relating to these particular outpatient
25 clinics in the time between diagnosis and

1 Professor Losowsky retiring.

2 Q. You say also that your wife wasn't offered any testing
3 at the time of your diagnosis.

4 A. I'm pretty certain that that is correct.

5 Q. And you tell us in paragraph 18 that although no advice
6 or counselling was offered to you at the time of your
7 diagnosis, you don't resent this.

8 A. No, I think that's the case. Because of my background,
9 I had a fair understanding of a lot of what was going on
10 but obviously I'm not a medic, so I don't -- would not
11 pretend, either to myself or to anybody else, to have
12 a comprehensive understanding.

13 Q. So after this admission you continued to attend
14 Professor Losowsky's clinic for monitoring about your
15 liver and gastric symptoms. How did you feel at this
16 point?

17 A. Optimistic.

18 Q. Yes.

19 A. At some point my weight did start to increase again.
20 The Creon, which was suggested, had no beneficial effect
21 whatsoever and, of course, by the nature of how the
22 Creon would have worked if it was going to work, it
23 should work virtually instantly as being an immediate
24 digestive aid. With hindsight, I was surprised and it
25 is really very unlike Professor Losowsky not to have

1 Professor Losowsky offered you treatment with native
2 interferon. Could we look, please, at WIT0050797,
3 this is a letter from Professor Losowsky to your GP,
4 dated 19 January 1996. It's noted in the first line
5 that, as you said, you were gaining some weight, but in
6 the second paragraph that you are still complaining of
7 tiredness, probably increasing in the last month or two:

8 "I note also that his ALT has crept up rather and it
9 may be that his hepatitis C is more active than hitherto.
10 I discussed with him whether we might contemplate trying
11 a course of Interferon but I think the likelihood of
12 response is small in view of his age, duration of
13 disease, presence of cirrhosis and relatively little
14 inflammatory change on the liver biopsy. It may be, of
15 course, that his liver biopsy appearance would be
16 different now."

17 Your alphafetoprotein is still raised at 90, and in
18 view of this he arranged a further CT scan of your
19 liver. This was carried out in February 1996 and showed
20 no lesion.

21 You wished to start treatment in the Easter
22 holidays, so that it wouldn't interfere with your work?

23 A. Yes, and that was also Professor Losowsky's idea too,
24 the less interference with other activities the better.

25 Q. If we look at WIT0050799, this is a letter from Dr J

1 Vasani -- which you can see on the second page, but we
2 do not need to look at that just now -- to your GP dated
3 21 June 1996. It notes that you were admitted on
4 2 April 1996 for repeat liver biopsy and commencement of
5 interferon treatment.

6 It's noted under "Investigations" your liver
7 function test results at that time, and it notes in the
8 second paragraph that an ultrasound guided liver biopsy
9 was performed which showed the presence of established
10 micronodular cirrhosis with some portal inflammation
11 consistent with Hepatitis C infection. It was compared,
12 this biopsy, to the one taken in 1995, and the degree of
13 inflammation had not changed. At this time you were
14 commenced on interferon, 3 million units, three times
15 a week. Apart from a slight temperature, which settled
16 down quickly, there were no other complications noted in
17 the hospital.

18 The next page tells us that you were discharged on
19 that dose of interferon and would be followed up
20 regularly in the outpatients' clinic.

21 You tell us that during the course of this treatment
22 you felt substantial fatigue. I take it, more than you
23 had been suffering before then?

24 A. Oh, definitely.

25 Q. And flu-like symptoms. I think there is also mention in

1 your medical records of you suffering from a skin rash.

2 Do you remember that?

3 A. I'm not sure about that but in my subsequent -- my
4 second treatment with interferon, which was some time
5 after my liver transplant, I certainly remember the rash
6 at that time when I actually was referred to
7 a dermatologist.

8 Q. Yes. How did the side effects of the treatment affect
9 you in your day-to-day living at the time?

10 A. Well, it was a struggle. I continued to work. I have
11 felt really -- as far as I can remember -- I remember
12 more about the second course of interferon treatment but
13 I think the flu-like symptoms did not much abate during
14 the time of this first treatment because, as soon as one
15 was feeling one had got over the one dose, it was time
16 for another dose because it was three times a week
17 treatment. One ached and felt miserable.

18 Q. And you tell us that it lasted about 12 weeks. If we
19 look at WIT0050804, this is a letter from a senior
20 registrar in liver disease, Dr Hussaini, to your GP,
21 dated 28 August 1996, and in the first paragraph it's
22 noted:

23 "This gentleman has now completed five months of
24 interferon therapy, at a dose of 3 million units three
25 times a week. In August his ALT was still elevated at

1 259 and he was HCV PCR-positive. For this reason I have
2 decided to discontinue his interferon therapy."

3 So at that time you stopped the treatment?

4 A. That's right.

5 Q. Thereafter, you tell us in paragraph 20, you continued
6 to attend Professor Losowsky and then his successor,
7 Dr Davies, consultant hepatologist, for regular
8 monitoring. You developed considerable tiredness and
9 became essentially unable to cope with your full
10 workload.

11 Your wife describes this period in paragraph 17 of
12 her statement, which is page WIT0050023, she states
13 there:

14 "From 1995 to about 2001, my husband still managed
15 to work but he suffered from extreme tiredness. He
16 developed sleep problems in that although he was tired,
17 he was unable to stay asleep. It was a struggle for him
18 to get up in the mornings but he did so in order to go
19 to work as normal. His [REDACTED] output fell.
20 Intellectually he remained sharp but he was physically
21 exhausted. His appetite was poor and he was run down
22 and unable to keep warm, usually having cold hands and
23 cold feet. His condition made spontaneous home and
24 social life minimal. My husband's mood became more
25 thoughtful and introspective but he remained confident,

1 in control, analytical and stoic."

2 This is over the page. She notes that you also
3 became more prone to minor infections, such as colds and
4 spots on the skin.

5 A. Yes, I think her description is better than mine. It
6 certainly was a struggle but it was a progressive
7 struggle, and I suppose, as things progress, it's less
8 easy to see -- to -- one is essentially comparing today
9 with yesterday and the day before, rather than with
10 three months ago. I had to -- I continued to work but
11 certain aspects of my work, particularly the [REDACTED]
12 side of things, had to give way to the other
13 commitments. Obviously, one's [REDACTED] commitments had
14 to take precedence. It simply wouldn't have done to
15 have said, "I'm too tired to [REDACTED]," and
16 the same was also true with my administrative
17 responsibilities there. If -- it simply would have been
18 just unacceptable, and even worse from my own point of
19 view, if I had said, "Oh, I can't do the [REDACTED]
20 [REDACTED]. Just wait until I feel a bit rested," so it was
21 definitely a battle.

22 Q. Yes. The medical records show that in 1998 the
23 possibility of combination treatment of interferon and
24 ribavirin was discussed with you and you were quite keen
25 on this suggestion but then it was decided that as you

1 had been a non-responder to your previous treatment and
2 had developed cirrhosis, you were unlikely to respond to
3 this treatment, and it was thought that the risk of side
4 effects outweighed the chance of deriving any benefit to
5 you.

6 A. Yes, I was not privy to all the discussions. It was
7 clear that the consultant team in the liver unit in
8 Leeds had discussed this in some detail, and initially
9 I think they weren't unanimous as to whether or not to
10 offer further treatment at that stage. But it was
11 decided not to do anything further. And I must say,
12 I was not unduly disappointed because I had been
13 a non-responder the first time round. Of course, my
14 attitude to that did change a little when we come into
15 the next phase of my illness.

16 Q. Yes. And I think at an appointment you tell us about in
17 paragraph 20, one of Dr Davies's registrars suggested
18 that a liver transplant might be required at that time,
19 but Dr Davies called you and your wife in to discuss
20 this and his advice at that point was that the risk
21 outweighed the benefits.

22 A. Yes, I remember that quite well. I certainly indicated
23 that I was very tired and not really coping. My wife
24 was a bit -- I don't think it would be fair to say she
25 was sharp with the registrar but she did say something

1 like, "Well, where are we going? What's going on? Is
2 it just wait and watch and let's watch and wait, and it
3 will just go on and on?"

4 And she had known me, in connection with some
5 ██████████, from her previous job. I think she
6 was trying to be helpful but rather jumping the gun in
7 suggesting a liver transplant because I believe it was
8 actually the next morning -- or it might have been two
9 mornings later, at something like 7.30 in the morning,
10 Dr Mervyn Davies phoned me and said, "Can you come and
11 have a chat with me as soon as possible", and his
12 advice, as I say here, was very clear.

13 The risks at that stage would outweigh the benefits
14 but he was equally clear that either if I progressed to
15 liver failure or certainly to hepatocellular carcinoma,
16 this advice would be instantly reversed.

17 Q. Yes. And as you tell us in paragraph 21, in
18 about May 2001, a routine screening, including scans,
19 indicated that you had probably developed hepatocellular
20 carcinoma. If I could refer you, please, to
21 WIT0050825, it's rather difficult to read, I am
22 afraid, this report. I think the date is 19 April 2001.
23 But I think it suggests in the middle that:

24 "This time we were able to find several ..."

25 I think it then says five at least. We will see

1 what we can do with this:

2 "... to find several, five at least, hypervascular
3 nodules suggestive of HCC".

4 And at that point you were signed off work and
5 admitted for assessment for liver transplantation and
6 you were admitted between 8 to 11 May 2001, and you were
7 admitted to the waiting list for a liver transplant on
8 8 June 2001. How did you find this assessment process?

9 A. Well, I think to go back a stage, to be told HCC had
10 been detected or rather, as Dr Davies put it, strongly
11 suspected -- he said that Professor Robinson has only
12 been wrong once in 100 cases -- I think that was perhaps
13 the most drastic thing I have ever been told about
14 myself. There were several things sort of mitigated
15 just how awful it was: first, because I knew that this
16 was a possible scenario, I was aware that my
17 alphafetoprotein had been raised; I was a little bit
18 prepared in my mind, and I knew that I wouldn't have
19 been referred for both MRI and ultrasound scanning if
20 there wasn't some serious suspicion.

21 I also know the shock of it was perhaps a little
22 ameliorated because of the way -- I mean, Dr Davies did
23 this in a most kindly way. He was neither harsh nor
24 just matter of fact, but nor was he just gushing
25 sympathy. He had a very nice, middle of the road

1 approach, and he was incredibly efficient about
2 arranging -- well, in arranging to see me because he
3 rang me up and said, "Can you come" -- essentially he
4 said, "Can you come tomorrow?" I said, should my wife
5 come too and he said, "Oh, definitely". I said "Well,
6 I am afraid she has got an important commitment". So he
7 said, "Well, where are you now? Can you come now?"
8 This was five o'clock in the evening and I was a few
9 miles away. I was on the far side of [REDACTED] and he
10 was on the opposite side of Leeds, and it was rush hour.

11 He said, "That's okay, I'll just wait and if the
12 doors are locked, just knock on the window and I will
13 see you". So this gave one a fair bit of confidence.
14 And immediately we had discussed the situation, he just
15 popped along to the ward and arranged for the admission
16 just a few days later.

17 So there was a sort of calming influence of the way
18 in which this very bad news was given to me.

19 Q. Yes. And what was your wife's reaction to that news?

20 A. Pretty bad. She had been up tense, really, throughout
21 the whole saga, since my diagnosis with Hepatitis C, but
22 she was very supportive and it was only a little bit
23 later that her depression started to get the better of
24 her. But it clearly was an unhappy time for her.

25 Q. And as you tell us, it was quite a quick move from being

1 told this news to being admitted for the assessment for
2 the liver transplant.

3 A. Yes, it was a Thursday I was given the news, and it was
4 the next Tuesday morning that I was admitted. It would
5 have been the Monday if it hadn't been a bank holiday.
6 So I don't think anyone could get any faster than that.

7 Q. And could I refer you, please, to your wife's statement,
8 paragraph 20 on page WIT0050025? Your wife tells us,
9 about eight or nine lines down -- this is the assessment
10 process:

11 "Those were harrowing weeks. The 'ifs' and 'buts'
12 were too hard for me. I felt helpless and unable to do
13 anything which would change anything. It was like
14 walking on eggshells."

15 Her father had died of cancer in 1983 and further
16 down she mentions, about ten lines up:

17 "We were waiting and hoping to be admitted to the
18 transplant list. Another patient came back from seeing
19 a consultant and said to my husband that they could not
20 offer him a transplant and so he was being sent home to
21 die."

22 So it was obviously a very difficult, emotive time
23 for you both?

24 A. Yes.

25 Q. In paragraph 21 of your wife's statement, which is over

1 the next page, she tells that you were admitted to the
2 transplant list on 8 June 2001. You were advised to
3 live normally but keep a bag packed, and you were signed
4 off work to await transplantation and she continued her
5 part-time work, at the time, at a hospice. She says in
6 paragraph 22:

7 "The call came on 30 August 2001 that a liver was
8 available."

9 And you were admitted to hospital that night for
10 surgery at 6 am the next morning. She tells us how
11 grateful you are to the unknown donor and how she often
12 thinks of the family of that donor.

13 Further down, in paragraph 23, she tells us how,
14 when she visited you once in the intensive care unit --
15 this was following the procedure -- you were on a face
16 mask with forced ventilation and she was very frightened
17 for you.

18 So I think the complication which caused this was
19 a blood clot -- is that right? -- after the procedure?

20 A. There were two complications. One was that I was
21 bleeding post operatively, and the day after the surgery
22 I was re-admitted to theatre for tying off some blood
23 vessels and removal of the clot. The first night, the
24 evening and the first night after the operation, I was
25 in considerable pain and tremendous abdominal

1 tenderness. I was just covered with a sheet and if
2 anyone just touched the sheet, I would wince in pain,
3 and it was the next day -- it was quickly realised that
4 something was amiss and the team brought an ultrasound
5 machine to the bedside and whisked me off to deal with
6 that, and my wife was en route, actually, to visit me
7 and so the hospital were unable to contact her and when
8 she arrived, I think she got a bit of a -- they were
9 disappointed that they hadn't been able to contact her
10 and she thought she was being told off, and they said:

11 "Oh, it's all right. He is just off to theatre,
12 don't worry. No, he has signed the consent form. It is
13 all fine."

14 I think she probably did see me briefly just as
15 I was trundled off then, but a few days later, when
16 I had been back in the general -- the high dependency
17 unit, I had some breathing problems. My oxygen
18 saturations were low, and at that stage I was taken back
19 to ICU and given C-PAP ventilation for a period of time.
20 Obviously, I did not like that but again, it was a bit
21 of a frightening experience for her and certainly, with
22 the benefit of hindsight, one can see that every
23 individual episode added up to challenge her and cause
24 more worries, and indeed that actually describes what
25 still goes on.

1 Q. Yes. And how long did you stay in hospital after your
2 liver transplant?

3 A. 13 days.

4 Q. You were then discharged home, and how did you feel when
5 you were discharged home?

6 A. Well, delighted to be alive, delighted I was -- I was
7 going to say "freely mobile". I was able to go
8 upstairs. I know my wife had been expecting me to be
9 confined to my bedroom because there was an amusing
10 episode in relation to floor boards being up, "Oh, don't
11 worry, you will be all right, you don't have to walk
12 very far." But I think overjoyed at the success of the
13 operation.

14 Q. And you tell us that the diagnosis of hepatocellular
15 carcinoma was confirmed in your explant.

16 A. Yes.

17 Q. And as you say, you were keen to be up and about and in
18 paragraph 22 of your statement, which is WIT0050055,
19 you tell us that you returned to work in April 2002 with
20 due enthusiasm, and at this time your liver function
21 tests were approximately normal but you had been advised
22 by Dr Davies there was a strong likelihood of the
23 Hepatitis C virus recurring.

24 So when you returned to work, how did you feel at
25 that point?

1 A. Very glad to be back at work. I was able to resume --
2 I started working again full-time. I was able to resume
3 most of my activities, although at that point my
4 [REDACTED] activities had diminished and I wasn't really
5 in a position to pick them up, but, of course, as
6 happens in [REDACTED] life, they always found some other
7 duty to give me and mostly -- most of which I enjoyed
8 taking on.

9 When I say that Dr Davies advised me there was
10 a strong likelihood of Hepatitis C virus recurring,
11 I think that is probably an understatement and I think
12 he probably did say it is certain or -- to the extent
13 that anyone can use the word "certain" -- that hepatitis
14 would recur and that is exactly what was seen to happen.

15 Q. You tell us that by 2003 your liver function tests were
16 deteriorating and your level of energy fell. You
17 underwent a liver biopsy in October 2003 and the result
18 of this is WIT0050869. The specimen date is
19 17 October 2003. And if we look at the bottom it
20 states:

21 "This biopsy shows considerable portal fibrosis."

22 And under "Diagnosis":

23 "Liver biopsy (two years one month post-transplant)
24 fibrosis features consistent with recurrent
25 Hepatitis C."

1 You tell us in paragraph 23 of your statement that
2 in early 2004 you started treatment with pegylated
3 interferon plus ribavirin, under the supervision of
4 Dr Davies and Dr Millson. This is the liver biopsy that
5 was taken before treatment started. You tell us that
6 this treatment lasted 24 weeks, having started on
7 30 January 2004, and during this time you had numerous
8 outpatient appointments. How did you manage attending
9 these appointments in relation to your work?

10 A. Well, by several legitimate means. The times when I had
11 the most frequent appointments, where I had to go weekly
12 after the episodes of syncope, which I suffered, there
13 was -- I was able to move some of my [REDACTED]
14 commitments around a little then, but the liver unit --
15 somebody there, one of the SPRs who had been involved
16 with me before, whose name appears elsewhere in my
17 statement -- that's Dr Paul Southern -- because I was
18 going to be seeing him regularly, just to check on how
19 things were going, it was his suggestion that I should
20 come not to the ordinary liver transplant clinic but
21 I should attend a separate hepatology clinic, and if
22 I came before the clinic was due to start on a Wednesday
23 from 2 pm, and if I went at about a quarter to two, then
24 I could see him before the clinic actually started and
25 then hotfoot it back to do whatever work I was needing

1 to do.

2 It was an arrangement that worked very well for all
3 concerned.

4 Q. And you tell us that the side effects of this treatment
5 were substantial fatigue and flu-like symptoms. The
6 medical records show that you suffered nausea, headache,
7 aches and stiffness in your knees and you tell us that
8 the fatigue was particularly troublesome, especially on
9 the two to three days following each weekly injection.

10 A. Yes, I mean, I could describe it as "horrendous" really
11 but also, of course, my wife was observing the effects
12 on me and that didn't help her situation, but
13 nevertheless I managed to keep going at work, but the
14 matters caught up with me when I had two episodes of
15 syncope, which I can remember very clearly -- well,
16 I can remember immediately before and shortly after very
17 clearly, and they were a very humiliating and -- well,
18 first one was absolutely frightening, when I simply was
19 unconscious three quarters way through [REDACTED]
20 [REDACTED]. And I -- on the first
21 occasion, I hit my head on the bench, although the cut
22 was just superficial and looked worse than it probably
23 actually was, and I was taken then by emergency
24 ambulance to the local hospital. These -- and then
25 there was a repeat episode, but without such a dramatic

1 fall, a month later.

2 These episodes brought home to me the reality of
3 what a precarious situation I was in and really the
4 drugs were dangerous in one respect, and it also became
5 clear at some stage in all this that this response and
6 the dangerous nature of the drugs was the subject of
7 some lack of agreement in the team of the consultants,
8 one of whom was keen that I should have the treatment,
9 another was not so keen on it.

10 And I think there is -- or was -- another issue at
11 stake here. This is just my private interpretation.
12 When it was agreed that I should have the treatment,
13 NICE had not issued any statement about the eligibility
14 of either a non-responder to previous treatment or the
15 use of combination therapy in a transplanted patient
16 but, by the time the treatment actually started, the --
17 this NICE edict had been issued and therefore there
18 possibly was some controversy in the hospital about
19 the -- whether I should have been on the treatment for
20 that reason or not.

21 Q. And you say in that paragraph that you were advised not
22 to drive as a result of these episodes.

23 A. Yes, this was after the second episode. I was formally,
24 very formally, instructed not to drive until
25 a neurologist had seen me, and for a variety of reasons,

1 none very clear and not really very genuine reasons, it
2 took a very long time for this referral to the
3 neurologist to take place, and indeed it only happened
4 when I said to my GP, "Look, I really do want to get
5 this sorted out. Get me an appointment privately with
6 the neurologist," and that then worked and he assessed
7 me and said, instantly, "You may drive now unless you
8 feel unwell in any way," and this was a considerable
9 relief and took pressure off all sorts of other things.

10 Q. The outcome of that neurological investigation is
11 WIT0050888, and the actual page is 0890, where the
12 impression/management is discussed. This is a letter
13 from Dr Alastair Lansbury, consultant neurologist, to
14 your GP, dated 12 July 2004. And in this, under
15 "Impression/Management", he states:

16 "this gentleman's collapse is a combination of
17 things. Clearly he is unwell and the side effects from
18 his treatment have affected him perhaps more than he had
19 thought. We agreed today that he had been overdoing
20 things at the time and certainly the symptoms before his
21 collapse do sound autonomic in nature. There are no
22 features today to point towards epileptic attacks and, as
23 such, I feel that I was able to reassure him of this
24 today."

25 It refers to a cardiology opinion. Did you have to

1 see a cardiologist in relation to these events?

2 A. Yes, I did but I was allowed to drive before, so I could
3 drive to see the cardiologist. I had a 24-hour ECG
4 monitor and I saw Dr Rob Sapsford in Leeds,
5 cardiologist, who examined me and did an echocardiogram
6 and was -- he was entirely satisfied and noted that any
7 ECG changes seen would have been consistent with my
8 previous pericardiectomy but as far as he was concerned,
9 I did not need to see him again.

10 Q. Yes. So he reassured you that you were safe, from the
11 point of view of these episodes, to drive and did not
12 think there was any other cause for concern.

13 A. That's correct.

14 Q. You tell us at the end of paragraph 23, going back to
15 page 0056, that, as you told us when we were talking
16 about your earlier treatment, you developed a rash,
17 which required attention by a dermatologist. I think
18 you also, at some point, developed shortness of breath.

19 A. Yes, I can't remember just how bad it was but
20 I certainly felt not well.

21 Q. And your haemoglobin at that point was noted to have
22 fallen as well.

23 A. Oh, yes. My haemoglobin -- I have got -- was 10.1 at
24 the time of the first syncope and there was -- one of
25 the purposes of the weekly meetings in Leeds was to see

1 if this was going to fall further and whether some other
2 treatment, additional -- erythropoietin -- something
3 like that, might be required.

4 Q. You tell us also your body weight during the treatment
5 fell from 63 kilogrammes to 56 kilogrammes?

6 A. Yes, it was very obvious and as soon as I ceased the
7 treatment, it started -- my weight started to increase.

8 Q. Yes. And you ceased the treatment in summer 2004, as
9 there was no drop in your Hepatitis C viral count.

10 A. That's right.

11 Q. And so it was deemed to have been unsuccessful. How
12 long did it take you to recover from the side effects of
13 this treatment?

14 A. Hard to say. It was fairly quick, I think. I had, as
15 it were, trained myself to take things a little more
16 easily but I do recall being able, not long after
17 stopping the treatment -- being able to take my
18 post-vintage car down to the Midlands. So I was able to
19 get back to a reasonable life, although I wouldn't like
20 to say just how long because there was still the
21 background that we had before the interferon -- the
22 background, lethargy, et cetera, that it was before the
23 interferon combination treatment.

24 Q. You tell us in paragraph 25, at the end, on the next
25 page, that in 2005 you took ill-health early retirement

1 at the age of 59, on the advice of your doctors. This
2 was a matter of considerable disappointment to you as
3 the outlet for your [REDACTED] intellectual interests
4 was largely abolished?

5 A. Yes, that's so. I was entirely responsible for taking
6 the decision to take early retirement. It wasn't that
7 I was forced to. But it was clear to me that I was not
8 functioning as was essentially required of me and
9 I think I realised that I had perhaps made a misjudgment
10 as to how much I could do when I was on the interferon
11 therapy. So it did seem appropriate to go ahead and do
12 this.

13 But I must say, I did find it very hard to adjust
14 after having had a reasonably prolonged [REDACTED] career,
15 suddenly not to be going into work every day and not
16 just because of the work aspect; I used to be accustomed
17 to see a lot of people and talking to them, whether
18 they be [REDACTED] colleagues or all sorts of people,
19 and the plug was pulled, as it were, but I was able to
20 find a certain amount of things to do to keep me from
21 boredom.

22 Q. How have you been since then in terms of symptoms?

23 A. My -- right. My energy is definitely restricted. There
24 have been two other developments more recently, that
25 I should mention. Well, in paragraph 27 I refer to the

1 fatigue, loss of stamina, loss of muscle strength and
2 arthritis and arthralgia. I do have aches and pains
3 related to joints. Two other things to mention are
4 I developed glucose intolerance and in due course,
5 especially following my transition on to sirolimus, my
6 fasting blood sugars started to increase quite markedly,
7 to the extent that I'm now diagnosed as diabetic.

8 That is one thing which becomes relevant.

9 There is another thing which has become relevant
10 this year, and the formal decisions as to just what has
11 been going on are not entirely clear but I am regarded
12 as having interstitial lung disease, and the
13 immuno-suppressant sirolimus has been suggested as
14 a possible factor in the development of that, because I
15 have had chest infections this year which were
16 moderately serious and my pulmonary function is not very
17 good. I have been seeing a chest physician in [REDACTED].

18 My -- there are changes seen on the CT and x-ray.
19 My transfer factor -- the measure of diffusion -- oxygen
20 diffusion across my lungs -- is 33 per cent of what is
21 expected. So I am breathless. I have also lost a lot
22 of weight this year, which did cause -- well
23 particularly the chest physician to -- well, I was fast
24 tracked to the chest physician to look into this. There
25 is a possibility of pulmonary hypertension, which

1 I should hear about in January.

2 So there are -- there always seems to be something
3 looming on the horizon, which does seem to have some
4 links going back to either the Hepatitis C virus or --
5 and/or the immuno-suppressant agent. Something that
6 I -- I'm not sure if I had mentioned. I did have some
7 severe dental infections. I have hardly ever had dental
8 problems previously. You have got it there.

9 So I have had to have some extractions due to that.
10 But I guess that I should not be too surprised at being
11 susceptible to infection in order to have a sufficient
12 level of immuno-suppression to protect my new liver.

13 Q. And in relation to your liver, you underwent a liver
14 biopsy in August 2010.

15 A. Yes.

16 Q. And the result of that is WIT0050922. This is
17 a histopathology report, dated 9 August 2010, and under
18 "Comments":

19 "The appearances are those of recurrent Hepatitis C
20 infection with fibrosis stage 4 and necroinflammatory
21 grade 3."

22 If I could refer to you WIT0050923, this is
23 a letter from Dr Corless to your GP, dated
24 18 October 2010, in which, it's recorded in the second
25 paragraph the findings of your recent liver biopsy

1 in August 2010, but it's considered reassuring in that
2 there has been no progression over the past seven years
3 to cirrhosis.

4 It appears from that that you are to undergo an
5 annual biopsy follow-up. Is that --

6 A. Well, interestingly, this is the first mention that
7 I have seen -- well, when this document was sent to me
8 by the Inquiry, this was the first mention I had heard
9 of that it was likely I would have an annual biopsy.

10 Q. And in relation to future treatment options in relation
11 to your Hepatitis C, what have been told about this?

12 A. Well, I have been told about the advent of the new
13 generation of protease inhibitors. I have not been told
14 whether I would be considered as a candidate for them or
15 would not be. I don't know if this has been discussed.

16 Q. And so this is something that you hope to discuss with
17 your consultant in the future?

18 A. Yes, when I have raised it in the past, I have simply
19 been told that, well, at the time of discussing it, they
20 had not been licensed, the new drugs. Recently nothing
21 further has been said but I would expect that very soon
22 there will be some sort of a discussion, although what
23 the nature of that will be, in view of my being
24 a non-responder previously, and having various other
25 potentially negative factors -- age and so on -- I don't

1 know. I'll wait to see what I'm told.

2 Q. And what do you understand your prognosis to be?

3 A. That is something that has never been discussed,
4 certainly not explicitly, and I think I feel that I have
5 enough sense, as it were, not to ask because I suspect
6 the answer is not known and I really, in my personal
7 mind -- I feel that nobody knows and nobody will be too
8 surprised if I had an early demise or if I carried on
9 for quite a few years yet.

10 And it's certainly something I'm reasonably careful
11 not to discuss at home.

12 Q. Yes. I would like to move on to the effect of your
13 diagnosis with the Hepatitis C virus on your wife. You
14 tell us in paragraph 30 of your statement that she has
15 suffered from depression ever since your diagnosis of
16 hepatocellular carcinoma and your liver transplant in
17 2001, which caused her much anxiety. At the time of
18 your liver transplant, there was no offer of counselling
19 or support for your wife and this and your diagnosis of
20 liver cancer, as you have told us, were particularly
21 difficult experiences for her. You state:

22 "We now see that each stage in my diagnoses, clinical
23 investigations and follow-up has imposed an incremental
24 psychological stress on her. She has received
25 medication from her general practitioner since then, has

1 undergone a course of cognitive behavioural therapy from
2 a clinical psychologist in 2009 and is currently
3 [attending] a psychiatrist. This reactive impression has
4 an ongoing significant effect on our quality of life."

5 Could you tell us, please, what you mean by that?

6 A. Right. I should just explain that when the -- she gave
7 a statement, it was true that she was currently being
8 seen by a psychiatrist but that was just a short series
9 of appointments and she is no longer being actively seen
10 by a psychiatrist.

11 Well, it has had a very big effect. I have seen
12 a big change in all sorts of aspects of her behaviour
13 and she herself has seen that really since well -- well,
14 I first became technically aware when I was in hospital
15 recovering from my liver transplant, and I can recall
16 several episodes when she got quite agitated [REDACTED]

17 [REDACTED]
18 [REDACTED] and
19 a charge nurse came up to me and said, "Is there
20 something wrong with your wife? I don't understand what
21 she is going on about."

22 And certainly she has been very jittery about all
23 sorts of things. [REDACTED]

24 [REDACTED] I think she probably seldom
25 is angry about nothing at all but if there is

1 something [REDACTED]
2 [REDACTED]
3 [REDACTED]
4 [REDACTED] well
5 in certain aspects of company out, she will get quite
6 [REDACTED], something that was never, ever apparent
7 before. And I can see she does get very uptight about
8 all sorts of things. Even when I have been reading the
9 transcripts from the Inquiry, I am afraid she -- this
10 just obviously kindles in her mind unpleasant events of
11 the past, and certainly yesterday and this morning, just
12 because this is another stage in a long health-related
13 saga, she worries and is quite often tearful, and other
14 good friends of ours noticed this. And it isn't,
15 I think, just a straightforward husband and wife type of
16 disagreement or so.

17 I must say that her -- the psychiatrist that she
18 saw, he had long consultations with her and he had quite
19 a long discussion with me privately. He talked to me
20 for about 45 minutes. And he thought that her
21 depression was very intimately linked with my illness.
22 He did actually comment in the -- well, both verbally to
23 us and in his letter to our GP that he thought I had
24 a degree of reactive depression, although not such as to
25 require any intervention, so I think we have got a --

1 really quite a complicated situation, which is not
2 really getting better.

3 My wife takes a high dose of Venlafaxine and
4 a moderate dose of Trazodone, and she has been on these
5 for quite a while and if by any chance she has forgotten
6 to take one, she is really unable to function coherently
7 and very agitated and tearful, very tearful.

8 I think -- is that enough?

9 Q. Yes. I was going on to refer you to a couple of points
10 she put in her statement, just as examples of the
11 difficulties she has had. Looking at paragraph 27 at
12 the end, WIT0050029, it's just one matter which
13 perhaps shows the difference in people dealing with what
14 you have been through. When she refers to the fact you
15 were reading research papers, particularly about
16 percentage survival at five and ten years
17 post-transplant, this was obviously something you were
18 doing, but she said that she found this upsetting and it
19 made her feel very anxious.

20 So that would seem to be an example of two people
21 dealing with one matter in their own different ways.

22 A. Yes, I'm sure that is correct. Of course, due to my
23 [REDACTED] background, I have been accustomed to reading
24 papers about all sorts of things. Of course, she has
25 a scientific background too but perhaps not as immersed

1 in original scientific and medical literature. So
2 her -- I don't feel that my reading these papers has
3 been either obsessional or specifically because I'm
4 anxious about what --

5 Q. I don't want you to think I'm suggesting that.

6 A. Of course not, no. Next, it is something that comes
7 naturally to me but not easily to her, and essentially
8 anything that reopens memories or issues of my health
9 are clearly bad areas for her.

10 Q. Yes. Another part is at the end of paragraph 28 on
11 page 0030, when she describes a period when you had
12 a dental abscess and were in excruciating pain in spite
13 of strong painkillers and she went into overdrive to get
14 it sorted, when the NHS dental consultant said it would
15 be three weeks before there was an appointment, and she
16 says:

17 "In a way I felt good in doing something to get him
18 better."

19 A. Yes, I remember the episode well. When she wants to
20 make her feelings felt to other people, she does so and
21 she has a certain amount of experience in the health
22 service, having been a non-executive director of
23 a hospital and for a shorter period of time on a PCT.
24 So she knows a bit about what is acceptable and what
25 isn't and she -- sometimes she treads very close to the

1 line in being aggressive with people who do not pull
2 their weight or do something inappropriate. Luckily
3 a solution was found, whereby we went to a different
4 hospital immediately, and thanks to her persuasive
5 words, I think it was a dental SPR came and saw me and
6 immediately prescribed antibiotics and arranged for
7 a double extraction within -- well, the next possible
8 date, which was just a few days later. So this was
9 thanks to her. The good side of her forcefulness, shall
10 we say.

11 Q. I was wondering if this was an example of her actually
12 being able to do something to help you in comparison to
13 perhaps other times, when she might have wanted to help
14 you but there has been nothing that she has been able to
15 do.

16 A. Well, that's possibly the case but she had been very
17 supportive in looking after me and doing all sorts of
18 things for me throughout this. It's just a pity that it
19 gets spoilt from time to time with things going wrong.

20 I do -- I mean, when I mentioned that her -- I first
21 became aware of how bad things were with her when I was
22 in St James's post-transplant. There were times when
23 I was torn because I was looking forward to having her
24 as a visitor, very keen to see her, but also dreading
25 that she would react [REDACTED]

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[REDACTED]

6 So other people were noticing this.

7 Q. Yes. She describes it herself in paragraph 31, which is
8 further down, when she talks about how she was over
9 filling her days and episodes of moodiness and
10 inappropriate behaviour became more frequent. She then
11 states:

12 "The anti-depressant tablets I was prescribed were
13 revised [this is at a time in about 2004] and we plodded
14 on again. We had striven so hard for my husband's life
15 and had celebrated our time together and now I was,
16 sometimes, so low that I did not care if I would not/had
17 not woken up the next day. That is hard to say, think
18 and acknowledge to someone who has been through the
19 diagnosis of Hepatitis C, cancer and a transplant."

20 Can we turn to paragraph 33? She is describing your
21 present symptoms of Hepatitis C and over the page
22 describes that you are now more pensive and hesitant
23 than you used to be and have less self-confidence:

24 "We are a tight unit of two. We do things together
25 but do not often go out to places like restaurants,

1 cinema and the theatre."

2 Is that still the case?

3 A. Yes, I think it is. We particularly enjoy holidays. We
4 don't go on a great number of holidays but we go to the
5 Outer Hebrides once a year for a week or two, and for
6 the last few years we have been going for a week's
7 cruise off the west coast of Scotland, and she does
8 generally enjoy life in that sort of context. But
9 nevertheless, there are times, and certainly at home,
10 when she comes up, "I have had enough. I don't care
11 about anything" attitude. Which is -- it's very
12 difficult to know how to respond.

13 On one occasion it was so bad I wasn't sure that [REDACTED]
14 [REDACTED]
15 [REDACTED] she had an appointment with the GP and
16 essentially it was really, I think, to get a repeat
17 prescription. But she was in an awful mess and she got
18 up very, very early in the morning, about five or six or
19 something like that, [REDACTED]

20 [REDACTED]

21 [REDACTED]

22 [REDACTED]

23 [REDACTED]

24 [REDACTED]

25 [REDACTED]

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[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

She said "I'm just here because I need another of this".

He said, "Yes, that's fine. Now, let's have a chat".

[REDACTED]

[REDACTED] he was very

good about taking the heat out of her mind and

I think -- I don't think that was what led immediately

to the psychiatric referral but it certainly led to --

some of her orthopaedic problems, for instance, being

investigated a little more, and that did have

a beneficial effect, but you can see that there have

been some very uncomfortable times.

Q. Yes. Your wife did work before --

A. Oh, yes.

Q. And what did she work as?

A. Right. She graduated with a PhD in biochemistry and

then came to work in the department in Edinburgh where

I worked on a sort of [REDACTED]

[REDACTED]. When that contract came up, she went and

worked in similar teaching posts in another university

and then, because these were fixed term contracts, she

went into university administration and indeed was in

1 the [REDACTED], where
2 she had a very enjoyable job and she then left to get
3 married.

4 She turned into a bit of university administration
5 and then into administration in the health service, with
6 the old FHSA, which -- and the FPC, the family
7 practitioner committee, and then she moved -- again, I'm
8 not sure if it was part-time -- into the Magistrates'
9 Court Inspectorate when this had just been formed, which
10 was -- she enjoyed the work except that she found
11 travelling was a strain, and the big event that made her
12 leave that work was when I -- it was at the time when my
13 GP had given me this firm handshake and said, "Things
14 are not good", and she had spoken to me on the phone and
15 heard how I was upset and she was upset at not being
16 with me, and she had realised that the travelling -- her
17 travelling was -- was disruptive.

18 So she then did some other things part-time,
19 non-executive work for the hospital and a PCT, and was
20 again part-time and a coordinator for education in
21 palliative care in a hospice just ten miles from home.
22 So she has had a very varied career.

23 Q. And why did she stop working?

24 A. I think that the palliative care work -- I think that it
25 probably was because she was concerned about just

1 leaving me at home, but the business -- she stopped with
2 the non-executive work with the local hospital trust
3 because she had done her stint and the -- the change of
4 government wanted to put their own people in as
5 non-executive directors.

6 Her job with the PCT ended, essentially, in tears
7 because of her depression. She was not coping and they
8 were incredibly unsympathetic to this and told her to
9 "grow up and behave" and she -- she spoke to the GP and
10 initially the PCT wrote a letter addressed to the
11 Secretary of State, asking her to say -- for her to sign
12 to say she was resigning. The GP said, "You are not fit
13 to sign such a letter. Don't". However, this dragged
14 on and they continued -- the PCT continued to be
15 objectionable and eventually the GP said "Look, for the
16 sake of your health, I think you might as well just give
17 in" -- he wasn't very complimentary about them.

18 So that is the summary of her sort of working
19 career. She -- after all this -- did spend quite a lot
20 of time helping with the -- in an Oxfam shop sorting the
21 books and pricing the books, and that sort of thing.

22 But she is not actually -- at the moment she is
23 doing a part-time hourly paid work teaching in the
24 university, which she is mainly coping with but
25 occasionally, when the going gets tough, she is quite

1 agitated, but there is less and less of that type of
2 work becoming available as the university cuts back, and
3 it's the case that this current academic year, yes, she
4 has been doing a little but less than before, but not
5 because of her own -- her condition.

6 Q. Thank you.

7 In relation to your work, you have told us the
8 difficulties you had at the time you were working, when
9 you became ill, and also your disappointment at having
10 to finish your career earlier than you would have liked.

11 You tell us in paragraph 35 of your statement, which
12 is 0060, that your contract provided for salary during
13 sick leave, and although you would normally have been
14 restricted to half salary for six months, as a gesture
15 of goodwill by your employer, especially noting you
16 hadn't taken sick leave during your courses of
17 treatment, you were able to continue on full salary.
18 This was in the year 2001. So you didn't actually
19 experience any loss of earnings at that point?

20 A. No, that's right. It was, as I say, a goodwill gesture
21 [REDACTED], but I did point out that, as
22 said here -- that I had not taken much sick leave at all
23 and I also pointed out that I was doing, behind the
24 scenes, a little from home just to help colleagues.

25 Q. Yes, and you tell us in paragraph 34 you have been lucky

1 in having been able to pay into a final salary scheme
2 almost continuously from 1971 until your early
3 retirement in 2005. But your pension income is
4 substantially less than your earned income would have
5 been if you had been able to continue working. If you
6 hadn't had to retire early, when would you have liked to
7 keep working until?

8 A. Well, at least 65, possibly 67. My contract had both
9 possibilities. My pension contract was for age 65 but
10 my [REDACTED] contract would have allowed me -- and this
11 was of course before the new employment legislation --
12 would have enabled me to stay on until age 67.

13 Q. Yes. So you say you have lost the difference between
14 your pension and what your earnings would have been, and
15 in addition your pension pot is smaller.

16 A. Yes. It does make quite a big difference. One of the
17 difficulties I have is trying to work out what my salary
18 would have been, or what my final salary would have
19 been, especially because of the slightly complicated way
20 in which [REDACTED] salaries are calculated and how
21 increments are awarded. It's not as straightforward as
22 on the salary spine for [REDACTED].

23 An issue that arises in this -- I have mentioned
24 that my [REDACTED] output had dwindled considerably and
25 this is, of course, one thing which affects one's salary

1 and one's ability to apply for increments when one is in
2 employment, and it would be foolish speculation to
3 suggest exactly what my salary would have been but it
4 would have been realistic for me to have had several
5 increments progressively, as I moved on.

6 So the figures that I have put here, I think are
7 likely to be underestimates. It was very, very
8 difficult to guess reliably.

9 Q. You tell us also that you have had extra costs in travel
10 to clinic appointments and prescription charges. We
11 heard that you often felt very cold so you are saying
12 you have had increased fuel costs for home heating.

13 A. Yes.

14 Q. And you have also incurred the cost of your wife's
15 private psychiatric referral, and presumably your own
16 private referral to the neurologist?

17 A. Yes, that's correct.

18 Q. You have received both payments from the Skipton Fund in
19 2004. You tell us in paragraph 33 that your mortgage
20 and associated endowment policy were initiated before
21 your diagnosis with the Hepatitis C virus. So that has
22 never had to be declared.

23 So there has been no adverse effect on that as
24 a result of your infection with the Hepatitis C virus.

25 A. That's correct.

1 Q. You point out that travel insurance has presented
2 a problem and few insurers seem to accept the risks
3 presumably associated with the Hepatitis C virus.

4 A. Yes. I found there are relatively few travel insurance
5 companies which will consider somebody with my medical
6 history, and it's not that we do much travelling but it
7 is mandatory for, say, one week's cruise because
8 essentially, if one had to be evacuated from some
9 inaccessible place, it would be problematic and -- but
10 what I do notice is that my insurance is much greater
11 than my wife's.

12 Q. Yes. You give an example there of £130 more than your
13 wife for one week's travel within the UK or Europe.

14 A. Yes.

15 Q. Finally, in paragraph 37, you tell us that your life has
16 unquestionably been changed greatly, especially since
17 around 1995, by your Hepatitis C illness. Obviously the
18 great disappointment and frustration of not being able
19 to complete your ██████████ career up to your intended
20 retirement time and also the fact that your last ten
21 years of employment were much less productive than you
22 would presumably have liked them to have been. You
23 state:

24 "It is also a great disappointment that my activities
25 in retirement have been reduced from what I had

1 expected."

2 You do say at the end of that:

3 "Nevertheless, I wish to put on record that

4 I greatly value the thorough and conscientious attention

5 that I have received from most of my doctors."

6 You recognise your survival at eight and a half

7 years post-transplant --

8 A. Ten now.

9 Q. Ten now, exactly. Is a tribute to a great deal of NHS

10 expertise.

11 Thank you very much.

12 A. Thank you.

13 THE CHAIRMAN: Mr Di Rollo?

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

15 THE CHAIRMAN: Mr Anderson?

16 MR ANDERSON: I have no questions, thank you very much.

17 MR JOHNSTON: I have none either.

18 THE CHAIRMAN: I doubt whether, if we had heard the evidence

19 of a succession of the clinicians who have treated you

20 in the past, we would have known more about your

21 condition and the impact on your wife. It has been

22 a great privilege to listen to you, thank you very much.

23 A. Thank you very much, sir.

24 (4.33 pm)

25 (The Inquiry adjourned until 9.30 am the following day)

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I N D E X

COLIN1
 Questions by MS PATRICK1
GORDON96
 Questions by MS PATRICK96

