

APPENDIX C

TRANSCRIPT 3

c: I'm Dr Berry...I have a letter from your family doctor....
It's not Dr Conser it's Dr Chandler....?

I think if we go into details about your family.....

First of all....what's your first name....?

mp: It's Patrick.....

c: So when it says husband you mean your husband....?

fp: That's right.....

c: And you go to St Thomas's.....?

mp: Yes...

c: How often...?

mp: Well it's probably time I went again...it is actually only very mild...
it's probably about two years since....since last time I was at the
Outpatients....

c: What sort of medication are you on....how long have you been taking
it.....?

mp: I've been taking the medication of one sort or another since 1981.....

c: So that's about 12 years...you were quite grownup then....

mp: That's right, I was taking my A levels at the time....

c: How often do you have a seizure now....?

mp: I haven't had a full seizure for a while....since about 1985.....
I was getting frequent controlled attacks since about two years ago....

fp: They changed your tablets....

mp: Yes they changed the medication...

[difficult to hear]

c: Anything else....? We'll go through your family but anything else
to do with your general health?

mp: My general health.....I was getting discomfort in my chest last year and I went to the Doctor and I was given an ECG and all sorts of tests and I think it was just... [difficult to hear]

c: You've not had any surgery or anything....?

mp: No...

c: And what about your general health?

fp: I suppose....I think I just suffer from stress-related things...there's nothing major...when I get too stressed I get ill....

c: Headaches....?

fp: Do I suffer from headaches....?

c: No I mean when you say stress related....?

fp: Oh, I come down with a virus...with flu...or something strange like that...

c: What sort of work do you do.....?

fp: I'm a Loss Adjuster...

c: And you...?

mp: ? [not possible to hear]

fp: I had to have an ECG a couple of years ago as well because they thought I had Tachycardia...but it was just stress....

c: And you're not cousins or related to each other....?

fp: No...

c: And you don't have any children....?

And if we go through your families....do you have brothers and sisters...?

fp: I have one brother one sister....

c: And do they have children....?

fp: My brother has one child, my sister has two....

c: And are they all well...?

fp: Yes they're fine....

c: And did either of them lose any babies...?

fp: My sister had a miscarriage when she was three months pregnant...

c: And your mother, did she lose any babies...?

fp: No....

c: Are your parents alive?

fp: My father's dead....he was 72....he died of a heart attack...

c: Is that recent.....?

fp: Four years ago....

c: And did he have brothers and sisters....?

fp: He's got a brother and sister still alive....

c: And do they have children....your cousins...

fp: My aunt has two and my uncle has two as well...

c: No problems....?

fp: No

c: And on your mother's side...

fp: I'm just trying to think....she has an extended family which I really don't see all that much....I'm just trying to think.... one of her brothers is dead...he died of cancer last year.... but he was 75....

c: Hmmm

fp: She's got three sisters...one of them is a half sister, and she's got another brother.....who is well....

c: So it's quite a big family....do you have a lot of cousins?

fp: Yes I do...

c: Everyone have children....?

fp: They all have children....the only complication my mother's half-sister had seven children, and one of them, she was born with the cord wrapped round her neck...and she was blue and she wasn't

breathing....and she is handicapped...but they put it down to complications at birth....

c: So there's nobody that you're concerned about in your.....?

fp: Nobody that I'm concerned about...no....

c: And your family, how many brothers and sisters...?

mp: *Two brothers and four sisters....*

c: And it's one of your brothers....

mp: *That's right...the only member of the family who has children... he has three daughters...*

c: Evelyn.....?

mp: *That's right....*

c: How is she getting on....?

mp: *She's now able to walk...she has to use the supports....but she's obviously...*

fp: She's quite a handful really....

mp: *She's quite a handful...she's very headstrong...she's very ...I really don't know what's going to happen there....I don't know what's going to happen long-term....*

fp: One of their other daughters collapsed last year and she stopped breathing...she's been in Great Ormond Street in a coma for three months...they never knew what happened....

c: That's one of Evelyn's sisters.....?

fp: That's right, yes...

c: So that happened to her second child....

mp: *That's right, yes...she was an exceptionally intelligent girl...I don't know if you ever met her, if they ever brought her in here....*

c: And so how old was she when this happened....?

mp: *She would be seven....one day when she was at home she just collapsed... stopped breathing...and by the time they got her into the hospital.... Great Ormond Street....*

fp: Her whole system collapsed....

c: **And now...is she still....?**

mp: *Well they expected her to die...but she made a remarkable recovery considering the state she was in...she can now speak...she's back at school two days a week...but she'll never be the same....*

fp: There's quite a lot of things with your brothers and sisters.....

c: **So that's that brother.....**

fp: He's the only one to have children....

c: **And the other brother....**

mp: *Well he's only 22...he's perfectly healthy....*

All my sisters....they all....

fp: Gynaecological...

mp: *....they all seem to have gynaecological problems....*

fp: One of the sisters she has alopecia, and she's been told she won't be able to have children....she's got fibroids and ulcers and things.... the three girls all have gynaecological problems and it's unlikely that that any of them will be able to have children.

c: **For what reason....?**

fp: They've never actually gone into the reasons, have they....?

mp: *It's not actually discussed...it's...I don't actually understand... there's no history of it in the extended family...*

c: **Well...it's difficult without....sometimes people say "I'm unable to have children...." and they want people to stop...to get off their back...and tell them to.....**

So one has alopecia and infertility...and the next one....they just say they're not....are they?

fp: Fiona is on all sorts of tablets....and they did tell her once if she planned to have children....because...

c: **Which is Fiona? The one with the alopecia?**

mp: *That's right....*

fp: And she's been in hospital hasn't she....with gynaecological problems

mp: [Not possible to hear]

c: **But what sort of problems...heavy periods....? Painful periods....?
there's an enormous number of things....endometriosis is very common....**

mp: *Oh...right...*

c: **Is she trying for a family....?**

fp: No.....

mp: *No....*

fp: Perhaps she could be but I don't know enough about her to get that sort of information out of her.....

c: **It's just difficult...there are an awful lot of things it could be...
and if people are feeling a bit under the weather, they say "Well I've
got gynaecological problems...." and other people if they are trying for
a family....and that's how it came to light....**

Now you mention Fiona...the other three sisters....

mp: *Two sisters....*

c: **So you've got two sisters...**

So Fiona we've talked about....

mp: *Well, Frances...when she was at University, she would have been 21 at the
time...she had a nervous breakdown....*

fp: She's never been.....

c: **Did she have anorexia....sometimes you have disruption of your periods
and difficulties with that....**

mp: *She's never fully recovered....she was doing exceptionally well and then she
just completely....*

c: **And the next sister.....?**

mp: *Stella. She's OK...Out of the four of us probably...*

fp: But she did have problems....

mp: *Well that's right, when she was born....she was receiving physiotherapy
when I was growing up...she was born with her...her left arm was...she*

had to have physiotherapy to bring it up to strength....

c: And your fourth sister....?

mp: Bridget...Fiona has....Bridget is the one who definitely....she has been attending clinics....I'm not sure of the details....gynaecological problems...she has been attending clinics for some sort of....

c: Gynae problem....

mp: And erm...I think I'd have to ask my mother for...

c: It's just to have some idea of the kind of problem...and is she trying for a family....?

mp: No....Frances is the one who is reasonably....interested.....

c: And were there any other problems in the family...did anyone lose any babies...

mp: No...

c: And are your parents alive....?

mp: Yes...my mother...

fp: Psoriasis...

mp: My mother has psoriasis...

c: Sclerosis of the liver....

mp: No! Psoriasis....

c: Psoriasis...

So on your mother's side....does she have brothers and sisters....?

mp: She's got....erm....she has....erm.....

fp: Rita who died

*mp: Yes. Well she had two sisters and she's got....
[long pause] three...three brothers and two sisters....
one sister who is now dead...*

[This is difficult to transcribe because the male patient is difficult to understand and also seems to be getting more and more nervous]

c: What did she die from...?

mp: She collapsed one night and....well....she was....about two years before she died she was in a bad car accident....and after that she got alcohol problems and she collapsed one night....

c: Did she have children....?

mp: No she never had children...she actually married a cousin....so whether that was the reason for that....

fp: She desperately wanted some though...

mp: She did, yes.

c: And the other sister....?

mp: My aunt Stella she has a child, yes...

c: A boy? A girl?

mp: A girl....

c: And your mother's brothers?

mp: Erm.....

fp: Well your Uncle Ivan has three children, one of them has alopecia as well and she's also got hormonal problems the same as Fiona..and incidentally she's also called Fiona...so the alopecia and the hormonal and the gynaecological problems...their situation is very similar, actually....

mp: That's right...and there's my uncle....

c: And then the other two children of Ivan....are they OK....?

mp: Yes they are....then there's...Kieran...they've not actually got any children...as far as I know they were trying...

fp: They were definitely...

mp: And there is....another Uncle....

c: You said there were some people with epilepsy....? Is that on your father's side....?

mp: That's on my father's side...it comes from my father's side...well all...

c: And so as far as you know....Ivan we've talked about...Keiran we've talked about...there's another uncle...whose name you've forgotten....does he have children....?

mp: He's got children...

c: And there's no problem...

mp: There's no problem...three children...no problem...

c: And on your father's side, does he have children....

mp: He does...he had two brothers one who died...

c: What did he die of...?

mp: He drank....

c: And what, as a young man....?

mp: Yes he was about 35 at the time....

c: And did he have children....?

mp: No, he didn't, no....

c: And the other brother....?

mp: Tom...he's the one with the child who is similar to me and as far as I'm aware it's under control.....he's got three sons and two daughters...

c: So it's Tom you say has three sons and two daughters....and it's one son who has epilepsy...

fp: And there's supposed to be a cousin of your father's as well with epilepsy....

c: But that's getting...that's further away.....

fp: Yes...

And Tom's other children....?

mp: They have [mutter, mutter] there's only Bryony who has children and they're all fine....

c: How many does she have....?

mp: She's got three boys....

The other two, one of them never married.....the other hasn't....

c: And your father, is he in good health...?

mp: Yes.

c: And how much of a problem is your mother's psoriasis is it...are her joints affected or is it just her skin....?

mp: It's her skin...it's not as bad as I remember it when she was working fulltime as a nurse, but I remember when I was growing up it was very bad....

c: And nobody else got psoriasis?

fp: Well there's bits of eczema....

c: No...that's not....

So what is it that you're chiefly concerned about....?

mp: Evelyn, mostly.....

c: Evelyn is very straight forward. I don't know if you talked to your brother about the cause of her problem...has he talked to you about the root of your problem....?

fp: No he hasn't....

mp: Well we discussed it briefly with the expert but he said as far as he was concerned it was very unlikely that....it would be, you know....

c: Yes...she has a small piece of one of her chromosomes missing.... so that's the cause...it's well-explained...we don't know why she lost that piece of chromosome...but it's because she has that piece of chromosome missing that she has her problem...

fp: Hmmm

c: Now her parents have both been tested, and they have normal chromosomes....so that is something that happened in Evelyn, and doesn't have any bearing for other people in the family....

fp: And how? Right...OK....so it was just spontaneous then....

c: Yes...I'm afraid spontaneous chromosome abnormalities can occur, and they can occur in anybody....but from your point of view, she doesn't have a hereditary problem, it's genetic, but both her parents have been checked and it hasn't come from either of them, so you're not at any particular risk for having that happen.

fp: What we're principally concerned about is that there are so many medical things in Pat's family that...

c: Yes, there are a number of things....but Evelyn is straightforward...

fp: Yes, but Evelyn is the catalyst....

c: Yes, that's right. So she in a way is the most serious problem and she's one that you don't have to worry about....

fp: Yes...

c: The other thing is the epilepsy...epilepsy does have a slight family tendency....very much as you described in your family...it doesn't behave in a regular way but in a family there may be more than one person with it. And when a person has epilepsy of the type that you have there's about one chance in 30 that it will come out in the child...there is that chance, but it's not a big chance.

mp: *Is there any way of predicting that if it were to happen it would be more severe than I had...?*

c: No...I mean it would be similar...it might come on earlier but it would be the similar kind of thing...do you get an aura?

mp: *I do, yes...*

c: Yes...do you know if when you were a baby you had any febrile convulsions?

mp: *No....I remember when I initially went for the.....[difficult to hear] they asked this and we said "No".*

c: Because this type of epilepsy is sometimes associated with febrile convulsions and there seems to be some increased risk of febrile convulsions in children but so that again....they are very alarming....but it's something to be aware of...it's best to avoid, if the child gets ill, allowing the temperature to get too high

fp: Hmm

and this would be something you could discuss with your family doctor....

there are ways of cooling a baby.....but most people who have febrile convulsions don't end up with epilepsy...

fp: No...

c: They are quite common. So epilepsy could reoccur....it's something to be aware of...but not something to be too alarmed about...

The other problem....psoriasis and the alopecia...it sounds as if in your family people may be a bit prone to make antibodies....alopecia can arise from making antibodies, psoriasis can arise from making antibodies....now

we all make antibodies usually against outside agents infectious agents....and that's good, and the people who are good at making antibodies over the past generations have survived...but now we have antibiotics and immunisations and things so we don't need to be quite so clever at making antibodies and nowadays there are people in the past who would have survived because they were so good at making antibodies can sometimes be at a disadvantage, because people can make antibodies against themselves and sometimes that happens with psoriasis and sometimes that can happen with with alopecia and that has a slight family tendency so...but you have neither of those things and so I think that's probably the kind of explanation for them...

fp: Hmmm

c:the two Fionas and your mother....again a family tendency that is there but there's lots of people in the family who don't have those things and again I think that's something most families have something that they're a bit more prone to....some people have asthma, some families have diabetes....so I think there's that in the background but not again something that you should be too.....

fp: Hmmm

c: And the gynaecological problems...there are so many, and so many women have some kind of gynaecological problem during their lifetime....

fp: Hmmm

c: ...without the people actually wanting to have children, it's difficult to know how serious they are...people often say "I may not be able to have children" because that is said as a possibility, and people latch on to it a bit...and I don't think that should be taken too seriously....

fp: Hmm

c: And again, your sister's nervous breakdown....I think there does seem to be a general concern with stress...but that again, families vary and there does seem to be something...with a child...some children get stressed if their parents are always worried about them, or their parents expect them to achieve more than they can...

fp: Hmmm

c: So I think it's going to be a matter of learning to take life as it comes and trying to develop the lifestyles which you can live with....

fp: Hmm

c: I don't know what your plans are, but when you have children, if you will be continuing working....that can be quite stressful...childcare arrangements....

fp: Hmmm

c: **And I think it's a matter of knowing your limitations and what precipitates stress and devising lifestyles and enabling you to have a family and not be stressed out...**

mp: *Hmmm*

c: **Having children is very enjoyable...but it does bring added stresses to life... and it's a matter of working out ways of living with the stresses and remembering....it's unusual...you brother's family has had terrible tragedies happen which**

fp: Hmmm

c: **....it's very unusual for two main things to happen within the same family...**

mp: *That's right...*

c: **Life is full of uncertainties...and I think, partly, yours is a large family and it does illustrate the sort of things that can happen.... uncle drowned, your aunt in a nasty road accident, not really getting over that....there are on the other hand large numbers of people who are well and....**

fp: Hmmm

c: **The important things I think are: Evelyn's problem which you don't need to worry about, and the epilepsy which you are a bit more at risk of than other people...**

mp: *Hmmm*

c: **But on the other hand that's not a terrible...and you've lived with it...**

mp: *And you say if they were to get it from me it would be unlikely to be any more severe than...*

c: **We would expect that....again, it's not possible to say that definitely**

mp: *Right...*

c: **But on the whole we would expect it to be similar....**

fp: Hmmm

Could I just you a question?

c: **Hmmm**

We have for the last few months actually been trying to have a child and the thing is both of us do a lot of travelling through work and also because Pat works at British Airways we get cheap travel, and so we travel a lot....

c: Hmm

And we travel a lot long distance....Is there ever a risk if I was pregnant or trying to be pregnant you know at that stage...of either the scanners in the airport or actually flying....sort of the high level radiation...

c: Scanners are OK...

fp: On a regular basis though....

c: Concorde...frequent Concorde flights you get a certain amount of cosmic radiation...

fp: But could they actually affect the fetus...?

mp: We don't go on Concorde!!

c: No...you don't go on Concorde! I think travelling is an added stress and it's possible that you have miscarriages or something like that

fp: Hmmm

c: ...because it's tiring...but there's nothing to suggest that Air Hostesses and people who do a lot of travelling have babies with problems more than other....

fp: So even frequent flying, long distances, you think it wouldn't...?

c: No, other than the effects of stress which is more likely to lead to miscarriage than....

fp: But it couldn't do any damage....

c: No it couldn't do any damage...

fp: Even on a regular basis.....

mp: No...

c: The other thing you have to think about is the immunisations and the medications....if you are going to be travelling you need to be sure that you get your immunisations sorted out before you become pregnant are you rubella immune, have you checked...?

fp: Yes...

c: **So it's the sort of incidentals with travelling, rather than the air travel itself....you don't want to go to a tropical country and get some tropical illness in the first weeks of a pregnancy or get malaria and have a high temperature....so it's those general things that you need to be sensible about...**

fp: Hmmm

c: **Lots of people become pregnant on holiday....**

fp: But this would be like every month we do a lot of travelling...I mean on a regular basis....

c: **Yes, but what I'm not quite sure is whether you travel to Katmandu or Perth or....**

fp: America....

c: **So you're travelling to 1st world countries, you're not exposed to a lot of infectious illness, you don't need extra immunisations**

fp: Hmm

c: **The only risk would then be the stress of the actual travelling and the time zone changes which some people cope with better than others**

fp: Hmmm

c: **It doesn't sound as if you're exposed to extraneous illness where you would need extra immunisations and medication**

OK Anything else?

fp: No, I'd just like to say "Thank you"

mp: Thank you very much....

fp:you've explained everything very well....and I think really we felt.... you know...all these family histories ending up with

c: **Well that's right...I think your brother....to have those two things happen, it is frightening when you see these things happen**

fp: Hmmm

c: **...the problem is that tragedies can happen to anybody**

fp: Hmm

c: ...and there is little that can be done to avoid most things....
particularly in your situation where there aren't any extra tests
that can be done....

fp: Well so that's great..that's all we need to know...

c: **OK, so I'll write to your GP...shall I put you something in
writing.....?**

fp: No, I don't think that's necessary...thank you very much

mp: *Yes thank you very much indeed...*

fp: Thank you for that reassurance...

APPENDIX D

TRANSCRIPT 4

- c: **Come and sit on one of the comfortable chairs. My name's Dr Flintner (pleased to meet you), I'm one of the geneticists here. Has somebody checked outside that we've got the right address and things like that for you?**
- 5 p: What address have you got?
- c: **Um I'll have a look. O'h I haven't got an address for you, we've only got the **** manor address.**
- 10 p: [gives address]
- c: **Are you on the telephone?**
- p: No.
- 15 c: **And is Dr C. your GP.?**
- p: Yes.
- 20 c: **And what's your first name?**
- p: M.
- c: [confirms surname] **When's your birthday?**
- 25 p: 17.05.58.
- c: **Right. And are you working at the moment?**
- 30 p: No.
- c: **What's your trade?**
- p: Steel fixer.
- 35 c: **Steel fixer?**
- p: Yeah.
- 40 c: **Is what your holding there for me, or is it something**
- p: No, it's a questionnaire, really, I've to fill in when I go home.
- c: **O'h, that's your homework! OK. Now, I'm here today really to ask what other**

45 questions you've got; and we've got plenty of time, so

p: What I want to know is what is this genetic disorder that he's got, what is it - I don't know anything about it.

50 c: **The clynfelters syndrome? (yes) Right. This is your son C. who's got it is it?**

p: Yep.

c: **Do you have any other children?**

55 p: No.

c: **Right. I can certainly tell you all about that. C. is, he must be - what - two and a half now.**

60 p: He's two and a half, yeah.

c: **Right. OK. Um, I will tell you all about that. Can I just ask you first a few questions, just about the rest of the family? (yes) Just to see if anything else emerges that we might also want to talk about.**

65 p: That's OK, fine, no problem. Yeah.

c: **Have you got any brothers and sisters?**

70 p: Yes, I've got 4 brothers and 1 sister.

c: **Are they all well.**

75 p: They are, yeah.

c: **Do they have children?**

p: My sister has 3, I think. **(right)** and one of my brothers has about 3 or 4 **(right)** the rest of them 'aint married.

80 c: **Right. And are your parents still alive?**

p: They are, yeah.

85 c: **And are they OK.**

p: Not really, no. The father has a lot of problems with the mother. The mother has had a back pain for years and years **(um)**. She gets special injections to kill the pain.

90 c: **O'h so it must be severe pain.**

p: It is, yeah. Apparently it's something to do with the spine.

95 c: **O'h I see.**

p: And the father has had ulcers removed twice or three times (**um**). He's had appendix removed, he had - I can't put a name on it, an operation for something else as well.

100 c: **Right. OK. Is there anything else on your side of the family that you wanted to particularly mention?**

p: Um, there's asthma and cancer.

105 c: **Right, who has got cancer?**

p: O'h my uncle on my father's side died of cancer.

c: **Right. OK. And who's got asthma?**

110 p: My aunt on my father's side, died of - what's it called again - an asthma attack. (**right**). And my uncle on my mother's side, he died from brain haemorrhage.

c: **Right, OK. And what about C's mother. Is she well?**

115 p: No, she's not well. She stabbed me last year.

c: **She?**

120 p: Stabbed me last year (**o'h dear**) in the back. She'd had schizophrenia.

c: **Right. Where is she at the moment?**

p: I haven't a clue to tell you the honest truth.

125 c: **OK.**

p: I've never even asked.

130 c: **Right. So you've not seen her for quite some time.**

p: I've not seen her for over a year.

c: **Right.**

135 p: Actually I haven't seen her sincesince she stabbed me. I've seen her in court a few times - just briefly, that's all, I didn't talk to her or nothing.

c: **Right. What's her name?**

140

p: Miss G.

c: [Repeats name] (yeah). **OK. Where's C. living at the moment?**

145 p: He's with foster parents in S.

c: **Um, but do you see him?**

150 p: Yes, I see him once a week. I used to see him 3 times a week but the social services have cut down my periods of seeing him, (um) so I've asked the court to define my contact with him (yes). And next May, on the 25th May, I go to court.

c: **You'd like to see him more often would you?**

155 p: Yes I would, yeah. I signed a contract with them (um) with the social services. I've signed a contract with them, but I see C. 3 times a week for 2 hours each time, and that my contract was flexible (um) and they use a little bit of the flexibility, not much. That was through the foster parent. If she wanted him, wanted me to take him out for 2 or 3 hours longer where she could get some things done around the house, or she

160 could do some shopping, (um) I'd do that for her. But they're in breach of their contract.

c: **Are they not letting you have access then. Is that the trouble?**

165 p: No. That's the trouble. They're not letting me have access. (um) You see there's a custody hearing coming up as well on the 1st of August and her, his uncle as well as people in the custody order as well, decided to get custody. (um) The man doesn't even know the child, didn't even see the child and they've given him 2 contacts a week with him, and I only get 1. His father only gets 1 and his uncle gets to see him

170 twice a week.

c: **Is that your brother or his mother's brother?**

175 p: No, his mother's brother. (right) The man doesn't even know the child (um).

c: **O'h dear.**

p: They start throwing shit in my face through their solicitor, saying that they go round their kids school, take photographs of them and all this. I am not interested in their

180 kids, I don't want to have anything to do with their kids ..

c: **This is the foster parent's children.**

185 p: No, no, the uncle's (o'h right) children (um). He says that I go around there taking photographs of the kids. A solicitor sending me letters through my solicitor and I went to my solicitor and I says, I says to him I says, I never even been there I can even prove it. She says, are you sure you can prove it? I says, wait here, I says, I'll make a 'phone call and I did. Two people are [inaudible] those people I says, will arrive on

190 such and such a date, I says, and they'll tell you. (um) So, then she wrote back to them and they never answered the letter (um). They're just pissing me off, you know.

c: **Um. Must make you very angry.**

195 p: It does at times, yeah. Because I don't socialise or nothing, I'm a very private person (um). I keep to myself, I don't bother people, don't argue with people or nothing. If somebody comes to the door looking for somebody and you say 'never heard of the person' and just close the door, even if the person was in (um). If they don't want to answer the door, fine. Somebody comes looking for them, that will tell them they're there - it's none of my business. Tell them to come back some other time when they're at home. (yes) Don't go to pubs, I don't drink either; I don't go to pubs. Go for walks, I go for long walks - I like walking and reading - I read lots of books.

200

205 c: **When did you hear about, um, the fact that C. had had the blood test and his diagnosis of**

p: My social worker told me about 2 or 3 weeks ago.

c: **So it's very recently.**

210 p: Yeah, very recently.

c: **Were you aware that he was having any tests done?**

215 p: No, at the time I wasn't aware that he was having any tests done. All I knew was that he was going to see, er, last year, he's seen Dr. er, o'h what, Dr. H. (um) And I was there, we've seen Dr H.

c: **Dr H. is a paediatrician isn't he?**

220 p: Yeah. (um) And they, the doctor checked him for everything - hearing - his sight was bad because he had a squint in his ... I think it's his left eye. I'm not sure if it's his left eye or his right eye (um) for he's wearing glasses and since he got his glasses he's improved 100%.

225 c: **That's good.**

p: And the social services are saying, they're saying, he trips over things. Well, I was never told he needed glasses until about 4 weeks ago (um). Nobody knew that and the foster mother told me. She says to me, M. - C. is going to have glasses he went for tests today (um) he'll be getting his glasses next week she says. The social services were saying when he used to trip over things and he had no interest in anything (um), they were saying o'h he's backward and all this; he hasn't been properly parented and all this and, just talking absolute crap, you know (um) and then when he got his glasses changes - he could see everything and he was (much better) I said to the social workers, I says, look you people, I says, you're no good for nothing, you're a

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240 heap of crap I says - like that (um) and they says why, I says you've been blaming me, I says, because the child wasn't able to do this and able to do that, I says the child wasn't able to do it because he didn't have the vision to do it I says. (um) He was half blind I says. You didn't do your job properly I says. Look at him now, since he got his glasses, I says - he doesn't trip over things, I says, he doesn't bump into things I says (um). No, this is - o'h we see, yeah, yeah. They try to cut it all down, you know, and just say o'h he's improved a little bit, and all this stuff: A little bit...

245 c: **You can see a big difference can you?**

p: [sounds to be getting more and more irate and frustrated] A massive big difference. When I come out for a walk ... there's ... flowers growing there and he never even bothered with them before (um). Probably couldn't see them. They were about 15 - 20 foot away from the pavement (um) and all of a sudden he let go of my hand he rushed over and said o'h dad flowers (um). Probably never seen them before - couldn't see them because he was half blind (um) And they're playing it down and another thing they said about this thing, why the reason I'm here today is, well because of this er what do you call it, er (clynfelters) the social services said the less people 255 that know about this the better. I said what do you mean (um), well when it comes to court we don't want them building their case on it.

c: **That's a bit hard to understand isn't it.**

260 p: I said to the social service you must be joking, I says. (um) So I went to my solicitor and I told my solicitor what they said and the solicitor (um) and my barrister they went mad (um) they went crazy. You know, this court case should have been cleared up months ago. When we went to court they didn't have the proper representatives there and they didn't have their papers ready they hadn't had the reports or nothing 265 (um) social services, they just don't care (um) it's as simple as that. Well then told me he was forced to be sent for tests, they never organised it they never got the appointments done or nothing (um) so it had to be up to the foster mother to do them; take them to the hospitals and then get the appointments done (um) they weren't doing it.

270 c: **But she's done that has she?**

p: She's done it, yeah.

275 c: **So it sounds as if she is**

p: She's a very good person She's very good with kids (yes that's what he needs) and the social services told me as well that she, she didn't have to know that C. had that, er, that thing that I can't pronounce. They said it's none of her business, she doesn't have to know (um). I told my solicitor and my barrister that and they said o'h she's got to know. (um) So the next time I went to her - that was last Wednesday - I went around to see C. and I took him out for a meal and I told her, I said I've got something to tell you I told her about it, and, she knows a little bit about it - she's heard of it before but she was really angry because the social services said that she had 280

285 no right to know about it (um), you know, (um) they're not doing their job properly.

c: Shall we talk a bit about what clynfelters is, it's (what is it anyhow) a shame it's got such an awkward name, isn't it. (yeah) It's clyn-felters and clynfelter was just a doctor a while ago who first described the condition. It's not a serious condition and in fact it could easily have been missed, it's just that C. happened to have the blood test done, which showed it up. And many men who have it, nobody knows they have it - perhaps all their lives. Or, sometimes they just turn up in their 20's or 30's with their wives when they've found that they've not been able to make their wives pregnant. But it's not a serious condition and its often something that isn't picked up in childhood, and it doesn't have any major, um, effects on C.'s health. Um, it just causes a few comparatively minor things, that if I describe them to you, you may well say 'well, yes, actually that does fit with what he's like', it seems to go together really, it seems to make sense. What it's caused by is that he has an extra chromosome. Er, probably, you don't know very much about chromosomes and you don't actually need to know a lot about the technical side of it, but we do actually know what causes clynfelters syndrome. Right from the time that he was made, he has had that extra chromosome and he's got it in every cell in his body.

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305 p: So what can be done to get rid of this chromosome?

c: Well, you don't need to get rid of it and there is no way that you can get rid of it - it is there and it will always be there.

310 p: So, in other words there's no treatment for it.

c: There isn't a cure for it, that will get rid of the extra chromosome, but any particular needs which he does have will be able to be met (yeah). Um, I will write to you after we've met today, to put down on a piece of paper for you everything that I've told you, but then if you want to make notes - well that's, that's fine. (OK, that'll be better if you write to me and let me know because it will save me time). Yes, and if there are things in my letter which you don't understand, please let me know (yes) and I'll try and explain them better. I'll try not to use complicated words which are unhelpful.

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320 p: Well, I've got Black's medical dictionary at home but it doesn't say a lot about it, you know (no). There's only a little

c: What they tend to say in the old text books and dictionaries is actually often not very accurate either. Um, because in the past we only knew about people who had clynfelters who also sometimes had various medical problems as well and it's only more recently that we've realised that there were very many ordinary men out there, who are leading completely normal, ordinary lives and have just never been diagnosed. So we now realise that, actually, on average, it's a much milder condition than we used to think and much milder than many of the old text books will say. (yeah) OK. Now what boys with clynfelters tend to have, is, as they grow up, they tend to be quite tall and often quite slim, so they're often quite,

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335 slim young men and in particular they have quite long arms and legs. Not abnormally long, just perhaps longer than their dad's or their mum's, or perhaps any brothers and sisters that they might have had. So, to look at, he will always look completely normal, but the chances are that he's going to be quite tall when he grows up. During childhood, sometimes people notice that the speech seems to come a bit later than one would have expected.

340 p: Yes, his speech is very late.

c: But he will learn to talk and it will eventually be (yes he is learning to talk at the moment, yeah) fine. That does mean to say, though, that sometimes speech therapy is helpful.

345 p: He's having speech therapy.

c: Well that's wonderful. (yeah) But it's not that his speech is delayed because of any problems that there might have been at home. It's part of the condition and I think perhaps its quite helpful for you to know that.

350 p: Yes, that's what they're saying you know. That's what they've been saying all along, the social services, been saying all along, before it was found out that he had that cline thing. (um) That he's seen me being stabbed and that was why he wasn't responding and he wasn't talking (um) and that he wasn't developing properly and all this.

355 c: Well, it's not because of that. It's all part of clynfelters. (yeah) Boys with clynfelters tend to learn to speak later than other children. They eventually get completely normal speech but speech therapists say

360 p: How long would it take him before he gets his normal speech?

c: I can't - I've not met him and I can't predict exactly what stage it will be, but what I do know is that speech therapy is what he needs (yeah) and that I would hope that by the time he's an infant, in infant school, his speech should be fine. He may continue to need extra help (yeah) throughout his primary school but if everybody

365 p: Yeah. He's doing sign language as well. (is he?) Yeah.

370 c: Well that's helpful if it helps him communicate and it will (it does, yeah) certainly stop the feeling of frustration that could otherwise build up. Now, another thing that people often notice with boys with clynfelters, is that they can tend to be a bit clumsy. (he is a bit clumsy, yeah) And, it sounds as if he may also have, because of his vision, tended to be a bit clumsy.

375 p: Yeah. Well it's got a bit better, it's got really better (I'm sure it's got better now he's ...) because he's got his glasses now, you know (yeah). I notice sometimes he gets a headache as well, when he's wearing the glasses and he takes them off (um) but then when he puts them back on he's back to

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- c: The eye thing is not part of the clynfelters (yeah) but if your vision is poor you do tend to drop things
- 385 p: Well my brother has exactly the same thing as he's got in his eyes. (right) His left eye, he wears glasses as well.
- c: Right, OK. But even once his vision is corrected he may still tend to be a little bit clumsy (yeah) and although he might not, at first, be very good at sports, often actually learning to play something like football helps improve the co-ordination and helps boys become less clumsy. So, once again, although it may be that at first he doesn't seem to be a boy who takes to sport very well, if he enjoys it and has a teacher who will encourage him (yeah) to keep going at it, that may be something that will actually help him improve, so that he's less clumsy.
- 390
- 395 p: Yeah, that's great.
- c: OK. Now, most .. many boys with clynfelters, and it is a condition that only affects boys, many boys with clynfelters do cope alright in normal schools, but often they need a little bit of extra help, particularly with the reading and the writing and the sums (yeah). Sometimes it may be that the teachers feel that in fact they would be better off in special school where they'd get more individual attention from the teacher, so I can't predict now exactly what his schooling requirements will be. I think what's more important is that he's properly assessed (yes) by the school and the school says what would be best for him and what would help him do best, helping to learn to read and write and do his sums - which is what really (yes) you want him to be able to do by the time he leaves his primary school. So, it may be that he will need a bit of extra help, but that's something that he should be able to get.
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- 405
- 410 p: Yeah. Is there anything that can be done medically to balance this?
- c: He, er, nothing will be needed during his childhood years, um, and there is just one other thing to mention now - which is that boys clynfelters tend to be quite shy and quite quiet and quite gentle lads (he is). They're not the sort who are going be out picking a fight.
- 415
- p: He's a very lovable child (well, thats)and very sharing, (um) but he's ... when strangers come around he tends to shy away.
- c: He's probably quite shy. But that's not necessarily because of what's happened to him in the past, it's part of the clynfelters. The shyness, gentleness, the quietness, not the sort of lad who will be running away from home and running off to go and explore other things. He's probably the sort of lad that'll tend to want to stay close to people and places (yes) that he knows. And may need a bit of encouragement as a teenager, to actually go out and try new things and explore.
- 420
- 425
- p: Well he's doing that more now when I take him out he, he tends to explore a lot of

- 430 things, you know, but he never goes too far **(um)** away from me you know. **(That sounds typical)** He never goes too far away, he's, if he goes about 20 yards away he starts calling me **(um)** like you'd think he's almost getting lonesome, you know what he is **(um)**, specially in the park now, when I take him to the park. Let him just wander around there **(um)**, he plays on the swings and everything. But he'll still run back to me and he'll take me around to where he wants to go, you know **(um)**. It's like [inaudible]
- 435
- c: Some, some boys when they become teenagers, they do become slightly more outward going, as teenagers do, a bit more bold. For other boys with clynfelters, there comes a point where they, perhaps, seem to be shy and quiet and you think that maybe it would help them if they had something (yeah) that made them become a bit more assertive. [p: sneezes] Perhaps, if I say aggressive, I don't mean in an unpleasant sense, but perhaps a bit more of how you expect people to develop as they're growing up into adults.
- 440
- 445 p: He is a bit aggressive to tell you the truth, because **(um)** he'll t'ump me with his fist. [laughing] (will he?) He will, yes.
- c: Well, that's probably just normal 2 year old, I don't think that's because of the clynfelters. On the whole they are very unaggressive children. But what I was going to say is you asked whether anything could be done (yeah) and for some boys with clynfelters, when they get to teenage years they do find that some injections do help them to grow up in the way you expect normal teenage boys to grow up. So while nothing special needs to be done now, when he got to being a teenager, what I would suggest is that you consider consulting an endocrinologist - that's a doctor who specialises in hormones - and it may be that some injections of male hormones will help him grow up in the way that other teenage boys normally do. He may not need it, but that's something which you can consult a specialist about at that time.
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- 455
- 460 p: Will he ever be able to have kids?
- c: That's the one thing that he won't be able to do.
- [long pause]
- 465
- p: Sad. S'life isn't it.
- c: Um.
- 470
- p: So in the long term its not going to affect him?
- c: No, not seriously in any way.
- p: But when he's, when he's growing up is, it's going to affect his speech for a little while isn't it.
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480 c: He'll need a bit of extra help (yeah) with learning to speak and he may need some extra help at school. But I think perhaps for you it might be quite helpful to know that this sort of description of the sort of boy (yeah) is because of the clynfelters syndrome.

p: How common is it?

485 c: It's not that uncommon. Let me see if I can give you a, about 1 in a 1,000 boys born has it.

p: And how does it happen?

490 c: We don't know exactly how it happens, we know that at the time he was actually conceived - at the time he was made - he got 1 extra chromosome, and because there was 1 extra chromosome in that initial ball of cells before he developed into a baby, that 1 extra chromosome then occurs in every cell in his body. Because as the cells divide and divide (yeah) and divide, so that extra chromosome gets passed into all the cells in his body. It's just one of those things that happens.

495 p: Is it ever likely to happen again - suppose I had more kids, would it happen?

c: It's very unlikely to happen again.

500 p: And is there any way of finding out which of the parents the extra chromosome came from?

c: No.

505 p: So, in other words, it's a freak mishap of nature.

c: Um.

p: Have you got any, er, reading material about it?

510 c: Um. There is, I think, an association, a clynfelters association, which is run by a nurse who has a son with clynfelters, and I can give you her name and address (please) and I believe she has produced some leaflets which you could ring up and ask for. I also believe, from other parents that I've mentioned her name to, that she's a very nice person to talk to on the 'phone (yes) because she has an older son with clynfelters, she actually knows quite a lot about what these lads are like as they are growing up, and she may well be helpful and I'd be happy to get that (yeah) name and address for you.

515 p: That would be great.

520 c: Um. There's just one thing that I'd like to go back to, and that's the business about C. having children (yeah), perhaps that seems the one thing which is rather negative about clynfelters, but I do want to tell you that he will be able to get

525 married and have a normal sexual relationship with his wife, and there would be ways, other ways round them having children (yeah) if they wanted to. (Um).

p: That's all in the future as you say.

530 c: It's a very long way off.

p: It's a very long way off. Yeah. That'll be his, it'll be up to him to work out.

535 c: Yes. With his partner (yes) in due course. But that's why, I think you may remember, I told you at the beginning, that some men with clynfelters only get diagnosed when they turn up in the (yeah) infertility clinics. It's the first time they'd ever realised that they had something.

540 p: It's amazing you know, you see so many, so many husbands and wives, specially people that have been divorced and they get married a second time, and most of them are younger, in their 30's they get divorced, they be 30 (um), 35 up to that, and when they get married they find out that they can't have any kids (um) although they've had kids from previous marriages (um). That's probably what's wrong isn't it.

545 c: Well, people's fertility does (yeah) drop off as they get older. People are at their most fertile, generally, when they are in their 20's. But, certainly, you're quite right in saying that infertility is quite common and about 1 in every 10 couples is not able

550 p: It is very common. 'Cos I've seen it at home. I've seen couples getting married at home and they can't have any kids. (um) And they're young (um). They get married very young, where they come from (yeah) from 16 to 19.

555 c: Whereabouts in Ireland do you come from?

p: The West Coast, County Mayo (um). Right beside the Atlantic ocean, where all the beautiful beaches are. (um) Sand like salt, flow through your fingers - its beautiful. Didn't stay long in it though. Joined the navy, merchant navy - thirteen and a half. (gosh, that's young) well, yeah, all the rest of them were younger than me, so the money was needed to raise them. There wasn't a lot at that time. Things are better now though. They've got factories over there now, big fishing industry there now, there was nothing there when I was growing up (um). School was 6 miles away, we had to walk 6 miles to school. Now the school is next door to them - they've got a new school built. They've got a technical college built. They've built a new hospital, 560 new church. They've got a fishing fleet there and they've got a factory, that makes, er, what's it called again now? They got these knitting machines, they knit garments in the factories (um), men and women. And, er, they've got another factory that makes fishing gear, so they've done well.

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570 c: A lots changed hasn't it.

p: It has, yeah. But as change, it's been 14 years since I was back there.

c: **That's a long time.**

575 p: And there was a, there wasn't a lot there that time. There was one factory there that time, the knitting factory. But they have come a long way on now.

c: **Are you homesick?**

580 p: No, never. When you go away young like that, you never get homesick because when I went away at thirteen and a half I was always busy, I used to be doing 2 or 3 shifts at a time, on ships, so you're always too busy to think about home. You get a break every 6 months for 2 weeks, so you spend the 2 weeks at home, and then you're away again. Sometimes, there is times when I regret having doneall that, moved away

585 from you know, and not getting too near my family properly. Sometimes they're like strangers to me now you know. (um) My youngest brother now, he'd be about, about 24, 25 I think (um).

c: **I suppose in a way that must make it even harder when you feel you're not being able to see your son (yeah) as often as you'd like to as well.**

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p: Prefer it if I had him back, tell you the truth. I miss him terribly, you know (um). Even though other people say, o'h you never miss a child, you know - but they're wrong, you will. I used to look forward to going to see him on Tuesday and on

595 Thursday.

c: **Who is it who has restricted the access now?**

p: The social services.

600

c: **O'h I see. Um. I was just wondering what you would like me to do. I've said I would write to you (yeah) to go over the sort of things that we've discussed today and just to sketch, once again, the outline of what sorts of things we mentioned about young boys with clynfelters. Who else would you like me to write to?**

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p: Could you send all that information as well to my solicitor.

c: **Yes. Tell me who that is. O'h shall I send you**

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p: Send them to me and I'll send them a copy 'cos I haven't got their address with me.

c: **Yes. I'll send you an extra copy and then you can give it to her.**

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p: Send me an extra copy to give to her becausethe way things are going the social services are building their case on what happened to me, not what's wrong with C. (um) That's what they're building their case on.

c: **Yes. I mean, what's important is that C. gets what's best for him isn't it (yeah, thats, and)and it sounds as if it is important for people to realise**

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p: It is very important....

c: **...that the condition which he has (yeah) does have certain implications. They're not life threatening implications but it does mean**

625 p: They're not life threatening, but still they're, they're serious because at the moment its affecting his speech and its affecting his co-ordination and lots of other little things like that.

630 c: **But that's all to do with the clynfelters. (it's all to do with ...that) And we have a very specific reason for that now.**

p: Well, I'd like my solicitor to know and my barrister to know all about this (yes) the way they can stand up in court and say, that the social services are building their case wrong (yes) that this is why C. is the way he is and that because

635 c: **And if they would like some more technical information, (yeah) that is information about clynfelters, I'd be very happy to send it to them if they want to write (OK) and ask me for that. I can guide them towards some more up to date information about clynfelters.**

640 p: I've got your address, I think, here.

c: **It should be on your appointment letter. The problem is that a lot of the old text books actually say some very misleading things, and it would be nice if your solicitor and barrister actually had the most up to date information. That's my name - there. That's the address there and that's our telephone number (OK).**

645 p: So, I give them your address and telephone number.

650 c: **Yes. She's very welcome to contact me. What she will need is a thing from you saying she has your permission to ask for that.**

p: Yeah, well, she'll, she keep me informed.

655 c: **She'll give you something to sign, um, because I'm not allowed to send anybody else information any information about your.....**

p: Yeah. Same thing happened to me when I had to go to court ...

660 c: **That's right. Well, you're obviously familiar with all of this.**

p: They wanted my hospital records in court. The court requested them (yes) but they couldn't give them to them until I'd given them permission, so I had to sign some papers to give them permission, so I'll have to do the same thing with this now.

665 c: **Now, I'll get the clynfelters association, name and address and telephone number for you (yeah) on the way out, and I'll give that to you and certainly, if you do**

670 **want to contact this lady ...**

p: I think it would be very good to contact this lady because

c: **I believe she has some**

675 p: I don't really want to read up about it, you know.

c: **I believe she has a leaflet that she's written that she could send you.** (yeah)

680 p: Because I've heard of lots of things in my time, about, different things that happen to people there. Kidney infections and they have ulcers and all these things, well I never heard of that.

c: **No. Perhaps there's just one other thing that I should say, just to avoid any confusion. Is that clynfelters syndrome has got nothing whatsoever to do with Down's syndrome.**

685 p: I know that.

c: **O'h you know that.** (I know that) **It's just that Down's syndrome is also caused by an extra chromosome but its a completely different chromosome** (yes, I know that). **Good.**

690 p: That was one thing that it said in Black's medical dictionary. [c:laughing(right)]. That they weren't related in any way.

695 c: **Good. OK. Do you feel that the sorts of things that we've talked about have been helpful?**

700 p: Yes, very helpful because when I came....before I came in here I hadn't a clue ...what this thing was, I hadn't a clue what it was. Because, as I said, when I read up on Black's medical dictionary it was only just about that much, and it just said that it was an extra chromosome and that was all it said, and that it wasn't related to anything else (um) and that's it, that's all I knew. **(OK)**. I didn't know anything else. I thought it was something really serious. **(um)** I was really worried when I came in here. But

705 you've explained it to me.

c: **You did look very worried.**

710 p: Because, the way the social services were going on about it, you know, they were saying o'h it's steadily and all this and the other, they gave me the impression that it was a killer disease that he had, you know **(no, that's not true)**. That was the impression I'd got from them. You know, and the way they were talking about the less people know about it the better, you know

715 c: **Well, it makes it sound as if its something to be ashamed of doesn't it.**

p: Makes it sound as if the child was going to die within the next 6 or 7 months, you know. They had me really worried.

720 c: **He has a normal life expectancy.**

p: That's good. So, I don't think they know what they're doing either, social services (um) they're crap. If I had my way I wouldn't have anything to do with them. (um) They treat me as if I was the plague or something (um) because when they ask me questions I don't answer them. I've been told by my barrister and my solicitor any questions that's asked of you by them, don't answer them, just keep them in the dark because they'll only just use them against you again and again and again and again. (um) So I don't bother answering any questions I just tell them - go and see my solicitor. When I say that, they back out, you know.

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730 c: **I am sorry it all seems to be so, so much of a struggle. It must be very hard.**

p: It's a very hard struggle at the moment, it's very hard. Because I'd prefer to have my son back and say no, no, what this is, and they know how the other things that's wrong with him (um) you know. And I know him better than anyone knows him.

735 c: **Well, and you now know a lot more about (yeah) him and why he is the way he is, than you did before you came here, I hope.**

740 p: I don't trust his uncle either, you know, because I don't think that his uncle will be able to handle him. Because he's going to need a lot of help.

c: **He will need a lot of help and support (he will, yeah) and gentle encouragement and he may also need extra help at school (yeah) but that should all be available.**

745 p: When I go to see him now on a Friday, he start to run towards me and starts shouting and roaring (um) and shoots off the top of me.

c: **Um, he's pleased to see you.**

750 p: Yeah. When they cut down the contact, the foster mother was telling me, I used to go there on Thursday, and on a Friday - sometimes, some Thursday's they'd tell me to come to the office in Grove Park (um), the social services. She says to me, she says, Thursday and Friday he had his chair ready and his coat and he had his wellies put on, he was waiting for you (um). He knew exactly the time when I was going to arrive there. And she said she had an awful time with him (um) crying and shouting and asking for me, you know.

755 c: **The other thing that's just crossed my mind and, I , I don't know whether this is a good idea or not. Um, it, it sounds as if you have a good relationship with the (I have yeah,) foster parents and they sound as if they're very caring people (they are very caring people) and if they wanted to know more about clynfelters, I would be very happy to see them as well, if you think**

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765 p: I'll tell them - I'll give them your address and I'll tell them to write to you if they want to know more about it.

c: **And obviously if you all wanted to come together that (yeah) would be fine, I don't want to see them behind your back, he's your son, but, if it would be helpful for them ...**

770

p: No, that doesn't worry me at all, if you want to see M. H. the foster parent, that's fine by me, you can see her or her own, she'll tell me anyhow.

775 c: **Well, I'd like to make the offer through you, that if you think it would be helpful for them**

p: I think it would be really helpful for them, because, that was why my solicitor told me to tell them about it **(yes, and I'm sure that's helpful)** and when I told them what the social services said that she shouldn't know about it and that it wasn't her business to know about it, she said well I'm the foster parent, I'm the number one person who should know about it, she says.

780

c: **Well I agree with that. I'm also worried that the social services don't actually seem to know very much about what clynfelters is**

785

p: They haven't a clue what it is.

c: **Um, and if I can help with that, in any way, then I hope you'll tell me.**

790

p: Yeah, that would be a great help. I'll let her know. I'll be seeing her the day after tomorrow.

c: **OK. We'll**

795

p: And I'll let her know. I'll give her your address **(that's fine)** and your 'phone number **(right)** and I'll tell her that you offered **(yes)** to give her all the information about him and she might come along and see you.

800 c: **That would be fine.**

p: That would be fine would it. **(um)** OK. So, that would be great you know. Because the social services don't know anything about it **(um)** and here's me sure now, from, from the way they described it to me **(um)**, you know, they never even told me, o'h it'sthey made a big issue out of it as if the child was going to die within 6 months [inaudible] you know **(um)**. They really scared me.

805

c: **Yeah. Well it's not true.**

810 p: No. Well I won't be discussing anything about it with them **(um)**. The only people I'll be discussing it with is the foster mother, with solicitor and barrister, you people -that's the only people that I'm going to be discussing it with.

c: **That's fine.**

815 p: You know. **(that's fine)** If Maxine, the social worker, wants to find out about it, let her go about it in her own way and that will help her - because I don't like her **(um)**. To be quite honest with you I don't like the woman.

c: **Makes it very difficult to work with her**

820 p: Everything they've asked of me, I've done **(um)**. But everything I've asked of them, they've done nothing for me. **(um)**. They've treated me as if I was the plague **(um)**, so I just keep quiet, watch what they do and listen, take a few pointers here and there, take them to my solicitor and they'll work for me. They make mistakes, I capitalise on their mistakes - it's as simple as that. **(OK)** So now that I know more about this, this is great. So, I'll write to them. I'll ring her, ring her from the hotel.

825

c: If we go out to the reception area I can get her name and address and telephone number for you **(yeah)** and you can take it home with you.

830 p: And then I'll probably write to her as well, but I'll ring her up first.

c: **OK. Do you have any other questions?**

835 p: No, not really, no, not at the moment. Probably think about it [laughing]

c: **Well, you can always get back to me.**

p: I'll think of a few I suppose when I get home.

840 c: **Well you're welcome to write to me (yeah) and if you actually feel that perhaps you would like another appointment that's fine, just ring up and say that you have some questions and, you'd like to see me again. Um, you probably wouldn't have to wait more than a couple of weeks if you wanted to come back and see me again (yep. OK) OK.**

845

p: Alright. That's great. Well, that's about taken off my heart

c: **That's good. Alright, let's go.**

850 p: You said in your letter that you might want to take some blood.

c: **No, I don't need to take any blood (that's good). There's another load off your heart!**

855

APPENDIX E

UMDS

GUY'S AND ST THOMAS'S
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DATE: 17 October 1995

FROM: Theresa Marteau

Total pages: 1

RE: GENETIC COUNSELLING

Dear John

I am writing to confirm that the genetic counselling consultations, of which I have sent you transcripts, were tape recorded with the permission of each counsellor and each counsellee.

Best wishes.

Yours sincerely



Theresa M Marteau