

Tuesday, 11 June 2019

(10.31 am)

Opening statement by SIR BRIAN LANGSTAFF

SIR BRIAN LANGSTAFF: It's lovely for me to be here, but why, you may ask, has the Inquiry come to Leeds? The answer is simple. It's a matter of principle. This is a UK-wide Inquiry. Indeed, the first UK-wide statutory public Inquiry to deal with how it came about that so many died, so many were infected and so many more affected by their suffering, because blood and blood products caused infections which were not prevented or not quickly or sufficiently prevented. What has been called by many in a phrase which deserves thinking about rather than simply repeating as the greatest treatment disaster in the history of the NHS.

As a result of their infections many suffer from illness or the after-effects of illness and others do not have the money they might have, but for the infection of themselves or of those close to them. It is easier for them to come in person to an Inquiry in Leeds rather than in an Inquiry in London. So the Inquiry puts people first, UK-wide. It tries to make itself more easily accessible to the public it serves, and that you are here in the numbers you are -- there

1

out those central principles together with others at the preliminary hearings last September in London, but those who did not make it there may not, and all those principles bear repeating. So please forgive me when I just repeat them.

They are putting people at the heart of the Inquiry UK-wide the principle I began with this morning: being as quick as reasonable thoroughness permits, paying proper respect to every person's right to be heard, being as open and transparent as it is legally possible to be, being independent of government and frightened of no-one in the conclusion it draws, and listening.

Though all of those six are important, four are of particular importance at this stage of the Inquiry and so I will say a little bit more about each.

First, I promised that this Inquiry would put people at its heart, and the room you are in, I hope, symbolises that. The witness or witnesses are centre stage. The public in front. Lawyers and me to the side. The Inquiry is not about them. The Inquiry is not about me. It is focused on the evidence which a witness can give. Friends and supporters in the front row and, if a witness wants it, a family member or supporter beside them when they speak. There will

3

is hardly a spare seat in the room -- with the press interest that you have attracted shows how right that principle has been.

You will have noticed that this is not the only city we are visiting, but it is the only city which is not a capital city. I hope you will forgive me for a personal note. My father was a Yorkshire man who was brought up not very far from here and I rather think that he thought the north of England was a separate country and Leeds was its capital but, despite that, my personal feelings did not enter into the choice of city. Rather, it was what a core participant from Hull said to me several months ago when I floated where the Inquiry might sit in the north of England, and he pointed out that Leeds has the advantage of being central to the region. It is not on the west, Manchester. It is not on the east, Hull. It is not a little bit further north Newcastle or Newcastle -- I must get it right -- and it is not south in Birmingham. It is central to those.

As I am committed to do, I listened and heard what he was saying, so we are here.

I have already mentioned two of the principles this Inquiry lives by: putting people first and listening. Some of you may already have heard me set

2

be occasions when a husband and wife or family or brothers and sisters give evidence together and that is only right.

There are rooms to the side where anyone who needs space during the hearings can find it and the Red Cross are on hand to assist those who find some of the evidence or indeed their own memories difficult. Indeed, one of the witnesses who gave evidence just last week in London has I think gone on social media to give a particular vote of praise to the way in which the Red Cross dealt with him, so feel no shame or no difficulty in accessing the Red Cross if you want to.

But putting people first is not just about physical space or making the practical arrangements we make. It is about giving people time. Now, you will know that this Inquiry is here only for two weeks. You may think only indeed for two weeks. It will never be possible to hear orally from everyone who would wish to be heard, but you should know that is so wherever the evidence is taken, just as much, if not more so, than this is in Belfast or Edinburgh or Cardiff or here. Indeed, those of you who do think that Leeds is the capital of the north may notice that we are sitting for two weeks here whereas Belfast and

4

1 Cardiff have one week each.
 2 The reason for the fact that I can't hear
 3 everyone is simple. We don't have the luxury of time.
 4 People continue to suffer. People continue to die,
 5 but those who are not heard orally this week and those
 6 at other centres who would like to be heard, but for
 7 whom there is no time to speak orally, will be heard,
 8 if not orally in sessions now during or at the end of
 9 the Inquiry, then on paper. Every written statement
 10 will be read. I have read a huge number already.
 11 I will read every single one at least once by the time
 12 the Inquiry is concluded. Each will be different,
 13 inevitably. Each is important, and the evidence of
 14 all those who have made or will make statements is of
 15 real value, whether or not they give it orally. For
 16 those who hesitate, those who may be watching this on
 17 line by streaming as I speak, it is never too late to
 18 make a statement, because the Inquiry would like as
 19 complete a picture as you can help it paint.
 20 Second, can I repeat what I said last September
 21 about paying respect to a person's right to be heard.
 22 Putting people at the heart of the Inquiry must
 23 recognise that people have different perspectives to
 24 bring to this Inquiry: those wishing to attribute
 25 blame, those wishing to escape blame, those who wish

5

1 cases -- it is not possible in all, for reasons
 2 I shall come to -- but in most cases where a doctor,
 3 for instance, is subject to criticism by a witness,
 4 that doctor will have been told 21 days or more before
 5 the evidence is given that that criticism will be
 6 made. They will know who is making the criticism,
 7 whether or not the witness is anonymous to you or the
 8 general public, because they are entitled to know who
 9 is accusing. They have a right to respond by then or
 10 at any later time if they wish.

11 If they do respond by means of a written
 12 statement, that written statement will be published at
 13 the same time as the witness who has just given
 14 evidence. It is only fair that you should see both
 15 sides of the coin at one and the same time. It is
 16 paying respect to that person's right to respond to
 17 criticism just as it pays respect to the individual's
 18 right to make it.

19 Some of the witnesses you will hear this week
 20 wish to give evidence without their identities being
 21 known to a wider public than those of you here. Now
 22 I shall say more about that before each comes to give
 23 evidence, but for now may I just ask that you respect
 24 their wishes as best you can.

25 The proceedings are live streamed, but the

7

1 neither, but simply to understand why what happened
 2 did or to have an explanation for the actions that
 3 were taken, those who received blood products, those
 4 who were transfused with infected blood, those who
 5 were patients, those who were doctors, those who
 6 criticise doctors and those who are deeply
 7 appreciative of what doctors did for them. Sometimes,
 8 the same person will criticise one doctor and be
 9 deeply appreciative of another. All are people. All
 10 are entitled to be heard, and I would ask all
 11 participants to respect that entitlement however
 12 unpalatable or difficult they may find some of the
 13 ideas or explanations or accusations being expressed.

14 Third, linked with respect for what a person may
 15 say, openness demands that the statement of a witness
 16 redacted, blacked out, where appropriate, be published
 17 when that witness gives oral evidence, and fairness
 18 and openness requires that if that witness appears in
 19 the statement, read at first blush at any rate, to
 20 criticise someone necessary a manner which may be
 21 significant, that that person who is criticised has
 22 the opportunity to respond.

23 Where it is at all possible we try to arrange
 24 that that is something that witness can do by the time
 25 the person comes to give evidence. So in most

6

1 cameras filming in the room will not take any pictures
 2 of you and I must ask you please not to take
 3 photographs in or immediately outside the building of
 4 anyone else without asking their permission, and
 5 remember that if you are taking photographs of someone
 6 whose permission you do have, there may be somebody
 7 else in the background, so please just be careful. We
 8 have to respect people's wishes not to be readily
 9 identifiable and we don't know necessarily what their
 10 wishes are without asking them first. The press won't
 11 take any such photographs. Please do the same.

12 I mentioned that sometimes it might not be
 13 possible to allow a doctor 21 days or more before
 14 a witness comes to give evidence, and part of the
 15 reason for that is something which you may have
 16 noticed when looking at the programme for the week.
 17 It says at the top that it is liable to change at
 18 short notice. There is an example this week.
 19 Tomorrow one of our witnesses has proven too ill to
 20 come to the Inquiry, too ill even for the Inquiry to
 21 be able to go to him to take evidence in his home. He
 22 would have wished to give evidence, but he can't.

23 It underscores what I have said about the
 24 importance of time, which is not our friend, but it
 25 does mean that if it is possible, we shall obtain

8

1 somebody who is a reserve for the witness sessions to
2 give evidence not in his place -- how could you -- but
3 as a witness in those hours or the time that would
4 otherwise have been taken up by the witness who will
5 not be able to be here. I am deeply sorry that he
6 won't be. I am very appreciative of the fact we have
7 a late replacement, but one of the consequences of
8 that, of course, is that any criticism he makes will
9 not have the same opportunity to be answered, and
10 please bear that in mind when you are listening and
11 drawing conclusions about what's being said, because
12 above all this Inquiry must be fair.

13 Finally, and fourth of the four principles
14 I separate out for special attention, I am here to
15 listen. From reading all the witness statements and
16 documents, which I have, I know a lot more than I did
17 last September, and I knew more then than I did when
18 the terms of reference were framed and I knew a lot
19 more then than I knew when I was appointed to lead
20 this Inquiry just over a year ago.

21 I am grateful for the opportunities you have
22 given me to learn and the education that you have
23 provided, but I also know there is much more for me to
24 learn and that the oral evidence heard here in Leeds
25 will be an important part of that.

9

1 members of your family who can no longer be here.
2 **A.** That's correct.
3 **Q.** John, you yourself have haemophilia A, classed as
4 severe. Can you tell us a little about how that
5 impacted upon your life growing up.
6 **A.** We are from a big family of haemophiliacs, [redacted].
7 As a child we were in and out of hospital all the
8 while. In fact, we went to school at the children's
9 hospital. We spent more time there than the normal
10 schools.
11 So the impact, mainly lots of bleeds, usually
12 ankle bleeds or knee bleeds. That was the main causes
13 of going into hospital. It put us -- leads to being
14 in hospital for weeks on end, sometimes up to three
15 months in hospital as a child.
16 **Q.** Can you tell us a little about your parents.
17 **A.** Yes. My father was born in 1912, very Victorian
18 attitude, which was good in strength ways. He brought
19 us all up to be as normal as possible. Just because
20 we had haemophilia it shouldn't stop us doing what we
21 want to do in life.
22 My mother was more of -- she was born in 1934,
23 but she was more of a '60s babe. She'd talk about
24 sex, drugs and rock and roll and everything. She was
25 always in with everything. So completely ...

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1 Well, thank you for listening to me. Enough
2 about me. We should now listen to the evidence. Our
3 first witness is John Cornes and once this has been
4 cleared away, because it rather gets in the way of the
5 witness there, we shall hear his evidence. Thank you
6 very much.

7 Now, Ms Richards, I understand that he wants to
8 be known as John?

9 **MS RICHARDS:** Sir, that's right.

10 **SIR BRIAN LANGSTAFF:** John, will you please come forward.

JOHN CORNES, sworn

Questioned by MS RICHARDS

13 **Q.** John, if you want to sit down.

14 **A.** Thank you.

15 **SIR BRIAN LANGSTAFF:** May I just say for future reference
16 that whether people stand or sit to take the oath is
17 not important to the binding nature of the oath and
18 whatever people find most comfortable for them in the
19 circumstances we will respect.

20 **A.** Thank you.

21 **MS RICHARDS:** John, you come from a large family. You
22 [redacted] were haemophiliacs.

23 **A.** That's correct.

24 **Q.** And you are here to speak not only about your own
25 experiences but to speak on behalf of a number of

10

1 **Q.** You described her as a big strong woman and she was
2 capable of coming and embarrassing you kids in the
3 street when you were out playing?

4 **A.** Yes. She'd talk about -- if there was anybody new
5 coming to the house she'd love to talk about -- her
6 favour thing was talking about sex. She'd joke
7 about -- she'd love to embarrass anybody. She was
8 very protective to all of us.

9 She -- I can remember my oldest brother. He got
10 a clip round the ear hole from -- this was going back
11 to the '70s when you could hit the kids round the ear
12 hole. He had a smack round the ear hole from a woman
13 up the road and my mum was a bit like Les Dawson's
14 character, she'd go up and she knocked the living
15 daylights out of this woman, but she was -- because
16 she was very protective of the kids.

17 **Q.** Now, you as children were under the care of the
18 children's hospital that you described. Then about
19 mid-teens in your case you came under the care of the
20 Queen Elizabeth Hospital?

21 **A.** That's correct at the age of 15 under the QE.

22 **Q.** Two of your brothers, Gary and Roy, attended Treloar's
23 school.

24 **A.** That's correct.

25 **Q.** You were treated in your own case with both

12

1 cryoprecipitate and a number of factor concentrates.
 2 **A.** Yes, that's correct.
 3 **Q.** We have the records of your treatment from 1979
 4 onwards but nothing beforehand. Just in terms of your
 5 childhood and the period up to 1978-79 what, if
 6 anything, can you recall about the kind of treatments
 7 you were given?
 8 **A.** When we were kids the main -- only treatment was
 9 transfusions, so you'd be in bed for days, weeks or
 10 whatever with ice cold packs to stop the bleeding. As
 11 I said a few minutes ago, the main bleeds were knees
 12 and ankles. Then after the blood products -- that
 13 particular blood products was cryoprecipitate before
 14 Factor VIII.
 15 **Q.** If we just have a look at a document on the screen.
 16 It should come up in a few moments.
 17 Paul, it is 1170002, and if we could go to the
 18 fourth page, please, of that document. Thank you.
 19 So we can see from the first four entries there,
 20 John, for 1979 and 1980 these are records of you
 21 receiving a number of factor products: BPL, Lister,
 22 Factor VIII. Then we can see you received Cryo for
 23 the other dates there.
 24 If we skip on, please, Paul, another couple of
 25 pages.

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1 **Q.** So no advice or warnings about any risks of
 2 infection --
 3 **A.** No.
 4 **Q.** -- as far as you were aware?
 5 **A.** None.
 6 **Q.** In consequence of the treatment you received you were
 7 infected with hepatitis C.
 8 **A.** That's correct.
 9 **Q.** That's something you learned a number of years later.
 10 **A.** Yes.
 11 **Q.** We will come back to the circumstances in which you
 12 learnt that, but if we just lack on screen, please,
 13 Paul, at the same document, 117002, second page, we
 14 can see in the last part of this letter, point two:
 15 "With regard to the approximate date of being
 16 infected with hepatitis C, it would be some time in
 17 the late 1970s/1980s although a test was not available
 18 until the early 1990s."
 19 That's as much information you have about when
 20 you were infected?
 21 **A.** That's correct.
 22 **Q.** Now I want to ask you first of all, John, about what
 23 happened to three of your brothers starting, if we
 24 may, with your brother Gary?
 25 **A.** Right. I can remember Gary saying he's got to go to

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1 Just over halfway down the page we can see
 2 entries that are cryoprecipitate and then again we can
 3 see what look from the batch numbers to be factor
 4 concentrates and 1990 you are recorded as receiving
 5 8Y.
 6 **A.** That's correct.
 7 **Q.** Then just over the page, please, Paul. Top of that
 8 next payable we don't have the product detail but we
 9 have a number of batch numbers: 81, 82, 83 and 84.
 10 You were by this time a young man. What, if
 11 anything, can you recall about any information, advice
 12 or given to you about these treatments?
 13 **A.** We weren't given none, no advice on what the
 14 treatments -- the possibilities -- how it could affect
 15 us and what -- we didn't know anything about viruses
 16 or anything like that, so there was nothing to tell
 17 us. We didn't ask. They -- you know, like -- we
 18 didn't ask them the question. They didn't come
 19 forward with the possibilities of how it could affect
 20 us in the future.
 21 **Q.** What you have said in your statement, John, is:
 22 "They were seen as breakthrough treatments which
 23 helped my brother and I get back to school and then
 24 work to avoid being in bed for weeks."
 25 **A.** That's correct.

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1 the hospital for so many tests. They are talking
 2 about HIV. None of us knew at the time what HIV was.
 3 All we kept thinking it was some sort of cancer, which
 4 they would be able to cure and I can remember the day
 5 he came home. We -- all of us went over to the house
 6 and he was sobbing his heart out, and he actually said
 7 he thinks -- it looks as if he's going to die. That
 8 particular day was quite emotional, because we were
 9 all crying, yes. So -- and then -- do you want me to
 10 carry on about Roy.
 11 **Q.** If we just pause there, in relation to Gary, he had
 12 been told he had HIV --
 13 **A.** He had been told --
 14 **Q.** And hepatitis C, at some stage.
 15 **A.** Yes, that's correct.
 16 **Q.** He too had been infected through the products he had
 17 been given as treatment for his haemophilia.
 18 **A.** That was -- we are not sure if that was at Treloar or
 19 at the QE. I have never shown if it's the QE and same
 20 as, yes, the other brothers.
 21 **Q.** And what ultimately happened to Gary?
 22 **A.** He infected his wife because she wanted a child and
 23 they were told it was 50/50 whether she would be
 24 infected or not. Gary died in -- we had a Christmas
 25 party early, in the September. I think he ended up

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1 about 4 stone and he died in the November, Remembrance
 2 Sunday, 1992.
 3 Q. He left behind his wife.
 4 A. His wife, Lee and --
 5 Q. And a son. We will not name his son but his son at
 6 that time was very young.
 7 A. Yes.
 8 Q. And his death was of an AIDS-related illness?
 9 A. Yes. He died -- he got AIDS on the certificate
 10 besides a number of other things.
 11 Q. How old was Gary when he died?
 12 A. He was 26, second youngest brother, so ...
 13 Q. Now the impact on you of Gary's death was that you
 14 had -- you described it in your statement -- you had
 15 some kind of breakdown. You went AWOL.
 16 A. Yes, it was in between Gary and Roy dying. I went
 17 AWOL. I ended up wrecking my marriage. I became more
 18 of a workaholic. I have always loved work, so
 19 I became more of a workaholic and I spent a lot of
 20 time -- I'd do anything just to -- I had to get away
 21 from the family mentally, so I spent most of my time
 22 keeping myself occupied away from the family.
 23 Q. And you put it this way in your statement, that you
 24 didn't give a damn about things. You felt mentally
 25 detached.

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1 AIDSelwell, because it is Hazelwell. In other words,
 2 he asked the question -- he was in there. When was
 3 it, a couple of years ago. He only told me today
 4 about this. This is where all the AIDS family were.
 5 They all live round here.
 6 As I say, we did have graffiti. The reporters
 7 of them days were vile. That's why our family -- it's
 8 took a long time for us -- we have stood back and
 9 watched other people come forward with their
 10 information but we've stood back away from the press,
 11 because you think -- the press has changed over the
 12 years and there's different morals. They have become
 13 more respectable to people's situations.
 14 As I said, Roy was used by the tabloid press.
 15 We had a couple of weeks of headline news, all the
 16 while. Every day we was on the front pages of the
 17 papers. It was nothing good. It was all bad. When
 18 I say the press, it wasn't the press just in the UK.
 19 It was worldwide. Roy did lots of interviews. He
 20 tried to bring over his side of the story, but they
 21 just seemed to ridicule him at the time, and it did
 22 affect not just him. I felt sorry -- you know, I kept
 23 trying to put myself into his place and how would you
 24 feel, but it was a bad time for all the family, a very
 25 bad time.

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1 A. That's correct.
 2 Q. And, as you said, you split up at that stage from your
 3 wife?
 4 A. Yes, from his mother, yes.
 5 Q. Now, you mentioned your brother, Roy. What happened
 6 in relation to Roy?
 7 A. Well, Roy was the bigger picture of -- I have had
 8 several brothers die, but Roy was the -- I think --
 9 I am not sure if he was 20, 21. He was told about
 10 a month later after Gary died -- sorry -- not Gary
 11 dying but after Gary was informed he had HIV, that Roy
 12 had got HIV.

13 At the time Roy was Jack the lad. He was a good
 14 looking lad. He had several girlfriends, several
 15 flings. Roy had infected a girl with HIV and she died
 16 before Roy died. What happened, the press got hold of
 17 it. They came down on the family, not just to Roy,
 18 but to my mum's house, to the rest of my brother's
 19 houses, to my house and they ripped the family apart
 20 mentally.

21 In Birmingham we was known as the scum bags, the
 22 AIDS -- and I have only just found out. Ryan is
 23 telling me today there was a pub, pub local -- I live
 24 in Kings Heath, Birmingham. There is a pub and they
 25 don't call it by the name of the pub. They call it

18

1 Q. We have got one of the press pieces that you have
 2 provided to the Inquiry.
 3 Paul, it is 117006, please. No, that's not it.
 4 Sorry, 006: it is this. Thank you.
 5 So this is in the Independent newspaper,
 6 June 1994:
 7 "Haemophiliac accused of infecting women with
 8 AIDS dies."
 9 This records that Roy, just 26 years old, died
 10 in 1994 of an AIDS-related illness. It refers to:
 11 "Two years ago it was revealed that he had slept
 12 with several women who later contracted to the
 13 disease."
 14 It refers to one of them dying. It refers to
 15 Roy's own death in the Queen Elizabeth Hospital on
 16 27 May and refers to his wife saying:
 17 "People made him out to be a monster, but Roy
 18 was a kind, caring and lovely man. Our lives were
 19 wrecked when these allegations were first made ... if
 20 it hadn't been for all the lies and gossip, I am
 21 convinced Roy would still be alive today."
 22 Can we just leave that up on screen for
 23 a moment, please, Paul. You share the views there
 24 expressed by Roy's wife. He didn't know about the
 25 consequences of his infection.

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1 A. At the particular time -- because he did infect one
2 girl, who did die probably two years before he died,
3 but there was no -- with the HIV -- remember this is
4 before hep C was in the equation.

5 There was no information coming out from the
6 hospitals, from the government. You know, the
7 government to the hospitals, "You should be advising
8 these haemophiliacs this is what could happen if you
9 sleep with a partner". As I said a few minutes ago,
10 Gary was told because it was all more or less in the
11 same time -- Gary was told about Lee, it could be
12 50/50, but Roy didn't -- he wasn't told anything. He
13 wasn't given any info. As I said, he was a young lad.
14 To me he's a young lad.

15 I think his mind started -- when he was told
16 about HIV, his mind started getting -- everything
17 going out of control, because, as I said, the press
18 were on to him and everything else, but prior to him
19 infecting the girl, there was no information coming
20 forward.

21 Q. You said in your statement:

22 "Roy especially did not know the impact of how
23 it could be passed on as he was simply never told."

24 You have explained:

25 "The truth is we did not know much about the

21

1 my mother.

2 Q. So three of your brothers, Gary, Roy and Gordon, all
3 infected with HIV in consequence of the treatment they
4 received for their haemophilia and all three died as
5 a result of the infections within a space of some
6 three or four years of each other.

7 A. Yes, they were all 18 months apart. Gary was in
8 May -- sorry, Gary was November, remembrance Sunday in
9 1992. Roy was in the May 1994. Then Gordon was
10 December 1995. So they all actually died 18 months
11 apart.

12 Q. You have described in your statements some of the
13 events that happened around the time of their deaths
14 and at the funerals in terms of press attention and
15 subsequent treatment of the family. What happened?

16 A. It was very bad at Gary's funeral, because Roy had
17 been the centre of newspapers' attention. The actual
18 funeral at Gary's, instead of it being a private
19 funeral -- remember we are just an ordinary family.
20 We're not celebrities who are used to what comes with
21 being a celebrity. We are nothing. You know, we are
22 just an ordinary family.

23 We had them hiding in the bushes and there was
24 lots, at least 50 reporters in the bushes. It made
25 us -- it really infuriated us all knowing they are

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1 disease itself, the risks or the dangers."

2 A. That is correct.

3 Q. There is a reference in the bottom of this article to
4 Gary's death and then to your other brother Gordon,
5 who is HIV positive, has survived. That was 1994.
6 What happened to Gordon?

7 A. Gordon, he was told about three months after Gary,
8 because Gary was told first, then Roy about a month
9 later and then Gordon about three months after.
10 Gordon actually did not -- after he informed us lot
11 that he had got HIV he started to deny. "Oh,
12 I haven't. I have made a mistake and they have told
13 me wrong" and he hid from it, because he started
14 realising. He was my older brother and he started
15 realising the effects, and we could -- watching Gary
16 die -- I can remember watching him -- watching --
17 looking at Gordon and Roy at Gary's funeral, and then
18 looking at Gordon at Roy's funeral. What's he going
19 through? What mental -- what state is his mind in,
20 because he knows it's going to -- luckily nowadays
21 they've got lots of cures for AIDS, but it was in --
22 it was Christmas time 1994 when Gordon died and yes,
23 it -- he was bad for -- he -- I just felt sorry for
24 him. I don't know if the word sorry is sufficient
25 enough, you know, devastated. We all did, especially

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1 taking pictures. They didn't ask permission or
2 anything and all they wanted was just to get the
3 grieving AIDS family and get Roy, yes.

4 Q. When Roy died, you have said it was the same and you
5 have said this in your statement, John:

6 "People came to the cemetery to throw stones and
7 even wrote 'shit' on his grave. I remember there
8 being a comment, 'Hurray. He is dead'."

9 A. There was quite -- one of them was in one of the
10 newspapers as well, a comment. They actually put the
11 comment from somebody and I thought how are they
12 allowed to put things like that, but they did.

13 Q. Gary's wife, as you say, had contracted HIV herself
14 and she died in 2000.

15 A. Yes. She was a great woman, Lee, and she fought to
16 the end. I've got to say the three of them, they
17 didn't want to die. My family are all -- we love
18 joking and laughing and playing people up and they
19 wanted to live. They did live their lives until more
20 or less the end and Lee was the same. She ended up
21 leaving -- so I have got -- it has affected this, not
22 just me, because I have got problems, or one of my
23 brothers who's got the same problem as me.

24 [Redacted]

25 I have got a load of nephews and nieces from the

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1 brothers that have died and I have got nephews that
2 haven't got a mother or a father, so it's affected at
3 least 30 of the family. So I am here to represent not
4 just the infected but also the affected. I didn't
5 want to come. I didn't want to really do this, but
6 there is a need. I got up and admired what the
7 Tainted Blood group have been doing and all the people
8 that have been coming forward and I thought "I have
9 got to say my piece", but it is hard, so ...

10 **Q.** What was the impact of losing three of her sons in
11 that short space of time and in such a way on your
12 mum?

13 **A.** Well, my mum was a very -- as I said earlier, she was
14 a bit like the character in Les Dawson. She loved
15 gossip. She was a big woman. I don't mean fat, but
16 a big, strong woman and if the press look at
17 photographs of her before Gary died -- if fact, she
18 ended up about 6 stone. She went frail and you could
19 see the fraught in her face. She ended up having
20 a massive heart attack after Gordon and, yes, she
21 died, but because we always look at the positives.
22 I have always looked at positives in everything.
23 Apparently my sister lived with my mum at the time and
24 she was looking after her. My mum was found on the
25 side, on the bed with the phone. The last person she

25

1 John, found out you had been infected with hepatitis
2 C?
3 **A.** Yes. It was a matter of fact type of letter I had
4 from the QE and not just me. Two other brothers had
5 letters similar. They were later. I can't remember
6 the time span, but they were later when they had their
7 letters. I thought, "Oh, right. Hep C. Well, at
8 least it is not HIV". I don't mean that
9 disrespectfully but, you know, I thought, "I'm going
10 to be okay".

11 Yes, so it took a while before actually anything
12 was actually done from the QE hospital. Do I go on
13 about me having -- I had to have a liver biopsy?

14 **Q.** Absolutely. I was just going to ask you first of all,
15 John, before we talk about that, in terms of the
16 information you were given when you were told your
17 diagnosis, although you don't have a copy of the
18 letter anymore, you recall you were told by letter and
19 you have described it in your statement as being
20 a very matter of fact, detached way of informing you
21 with very little other information provided.

22 **A.** That's correct. There was no letter to ask, "Could
23 you come into the hospital. We need to talk about
24 a virus that you have received". It was just, "As you
25 may be aware, you may have hep C", blah, blah, blah.

27

1 was speaking to was my aunty, my mum's sister and they
2 were telling dirty jokes on the phone, so she died
3 laughing, but it was a heart attack that killed her,
4 so yes.

5 **Q.** In the years prior to her death you explained it this
6 way contrasting her with how she had been before:

7 "When she lost three of her sons and knew that
8 there might be two more", and we will come on to that,
9 "the shell crumbled. She became thin and gaunt."

10 **A.** Yes. Before she died, as I said, after Gordon she
11 started getting thinner and thinner and gaunt and all
12 the while -- you know, you always say to your kids --
13 I always say "I love you", and when you go you give
14 them a kiss. My mum became even more obsessive with
15 kisses and phoning. If you didn't see her a day, she
16 would be on the phone half a dozen times that day.
17 She would phone up just to hear your voice or
18 whatever. Yes.

19 She became frail and fraught and it is this
20 that's -- I think she would still be alive. She would
21 be about 85 or something like that now -- I think she
22 would be alive if it wasn't for what happened, because
23 she was a strong woman. The tragedy has brought --
24 ripped her heart out.

25 **Q.** And while this was going on in the mid 1990s you,

26

1 I can't remember what. I think it might have been
2 another year before I had the actual liver biopsy to
3 prove I had hep C, because in them days they used to
4 put a big needle inside you and pull the liver -- they
5 don't do it like that now. Yes.

6 **Q.** Do you know how the diagnosis of hepatitis C came to
7 be communicated to you in '95 in the first place?

8 **A.** No.

9 **Q.** Were you aware you were being tested?

10 **A.** No. I have no idea, no.

11 **Q.** So you have a recollection some time after that letter
12 you had a biopsy?

13 **A.** That's correct. They said I had got hep C. At the
14 time they -- I don't think they knew, because they
15 didn't say -- I asked "Can it be passed on through
16 sex?"

17 "No." They didn't -- I don't think they had the
18 information they have had in the last 15, 20 years at
19 that particular time of what hep C -- how it can
20 affect you, so ...

21 **Q.** How did the hepatitis C affect you, first of all,
22 physically?

23 **A.** Well, physically, remember, I am a haemophiliac. So
24 I have always had bleeds. It's just part of your life
25 being in pain. You spend half of your life in pain.

28

1 You know, to me it is normal. I get on with my
2 life. I don't allow it to stop, but the hepatitis, in
3 the early stages there was nothing and it wasn't --
4 the early stages it was nothing. Then I can remember
5 they started putting me on treatments and the first
6 lot of treatments, I had ribavirin and ...

7 **Q.** Interferon?

8 **A.** -- interferon. It didn't work. They waited two years
9 and they put me on -- they were doing this with my two
10 other brothers that's haemophiliacs as well. It
11 didn't work on them at all. They says, "We are not
12 going through it again. It made us bad", and
13 everything, and I thought -- then two years came down
14 the line. They said, "Would you like to try again".
15 I thought, "In for a penny, in for a pound. I am
16 going to do it".

17 It made me so ill. I carried on working.
18 I managed to carry on, because I have always been
19 a workaholic and work is my therapy. I ended up being
20 on 24 -- because I am diabetic as well. I ended up
21 being on 24 tablets a day, as well as insulin and
22 blah, blah, blah, blah. It made me so ill. Also,
23 which I have never really had, it caused depression to
24 the extent I didn't want to be here, so ...

25 **Q.** And you in the course of that second treatment and the

29

1 John, about issues relating to what happened to your
2 family is your dislike now or inability to drive on
3 motorways. How did that come about?

4 **A.** Yeah, that came about through when would my first
5 brother was dying, Gary, at the time I was in Cannock.
6 I was working in Cannock, which is in Staffordshire,
7 just if people don't know. I had a phone call, "You
8 need to get back, because Gary is going to die in the
9 next few hours". I must have done 120 miles an hour
10 on the motorway. I was going from Cannock and then
11 the next junction is Walsall and the junction after
12 that is Birmingham.

13 As I got to coming up to Walsall I froze.
14 I felt like -- I was like this, shaking inside and had
15 to pull off the motorway and ended up going all the
16 back way around to Birmingham and ever since then
17 I can't do motorways. I have tried to push myself.
18 One day -- it has been a long time ago, but one day --
19 I have done a couple of times where I have gone on one
20 junction and then got off the next junction. It is
21 usually of a Sunday morning when there is no traffic.
22 Yes, that affected me and it still does, just the
23 driving, so ...

24 **Q.** Then can I ask you about the physical effects in terms
25 of your longer term health of the hepatitis C and the

31

1 effects it had upon you that you have just described,
2 you said in your statement you had something of
3 a breakdown that point.

4 **A.** Yes. Nearly -- just under eight and a half, nine
5 years ago, I ended up -- I kept crying a lot and I can
6 remember feeling like again -- I am not that type --
7 I have always been a positive person and I think
8 everybody probably goes through a shitty spell in
9 their lives. I really felt like just getting the car
10 and smashing it at something, but I ended up being
11 persuaded to go to the doctor's and that particular
12 day, that morning, they actually sent me straight to
13 a psychologist who I ended up going to see for months,
14 a few months, and it all stemmed down from me hiding
15 from what actually happened to our family, because
16 I think all -- there is a lot of people in here that
17 have had problems with their families, tainted blood
18 and everything, and you actually -- you need to hide
19 from it sometimes, because you can't -- you can't
20 allow it to overtake your life, because it's -- it
21 will rip you apart, but luckily it did -- it helped
22 me. I did come out of the -- I am still on depression
23 tablets, on the low ones now, and I get on with my
24 life as much as I can.

25 **Q.** One of the details you recalled to me this morning,

30

1 treatment you have received for it. Your second
2 course of treatment, did that succeed in clearing the
3 virus?

4 **A.** Yes, it cleared the virus. I was chuffed at the
5 particular time, because it is nice to -- for anybody,
6 it is nice to do something and succeed, you know, to
7 get a result from it and, yes, I was cleared of it,
8 but what it -- what I have got is cirrhosis. My liver
9 is really quite bad, very bad.

10 **Q.** And you have checks is it every three months?

11 **A.** No. It's gone down to every month now. I don't know
12 if you want me to talk about what happened in April
13 this year.

14 **Q.** Please do.

15 **A.** Yes. April 3, I was sitting down. It was 8.45 of
16 an evening. Everybody has probably been through it,
17 you know when you're having a coughing thing and you
18 think, "Oh, I am going to bring up some phlegm or sick
19 or something". I went to the toilet and it came up
20 nearly two pints of blood.

21 My daughter called an ambulance. I was rushed
22 to the QE hospital and then you -- did you end up --
23 you ended up at the hospital as well. So I was a bit
24 like this and ended up bringing up more blood.
25 Apparently the varices -- I have got varices that keep

32

1 appearing in my -- that lower part here (*indicated*)
 2 from your liver down, and I had to have eight tied up.
 3 They kept me in hospital for ten days, but I was
 4 off -- for the first time ever I was off work for
 5 a month. That killed me being off work. It was
 6 like -- because I am not the type to -- I do sit and
 7 chill. I might watch something, or I will read a book
 8 or whatever, but I do like being active and it has
 9 hurt over the last -- I seem to be getting less active
 10 and doing things because it is wearing me out, wearing
 11 me out, wearing me out, but yes -- and then I went
 12 back in. I was in hospital for ten days. Had the
 13 month off.
 14 I went back -- it has been four weeks now,
 15 because I am due to go back next week to the QE. They
 16 found another four varices about to burst, so
 17 altogether I've had 12 tied up so far. They said they
 18 can carry on tying up the varices but one day will
 19 come when I have to have a stent put in.
 20 Once you have a stent put in apparently it can
 21 make you forgetful. There is side effects to anything
 22 you have done. I can remember being in hospital.
 23 I did cry for the first time in a long time again.
 24 I am not a crier, crier but I did cry in the hospital
 25 because I thought, "I have got lots to do. I don't

33

1 shouldn't be working for them.
 2 They don't deserve to have good employees.
 3 I think I am a good employee so, yes, work is good for
 4 everybody.
 5 **Q.** Your children would like you to work less, but you are
 6 determined to carry on.
 7 **A.** Yes. The older ones, [*redacted*] and [*redacted*], "why
 8 are you doing this? Why are you doing that?" They
 9 understand. They know I like work. I have always
 10 been like that. I have always liked work. I don't
 11 understand people -- although we are all different.
 12 I know we are all completely different. I have never
 13 understood in my head why people -- yes, you have got
 14 a problem but why is it stopping you from working.
 15 You know, you should keep yourself occupied. It is
 16 a therapy. I have always -- I keep saying that until
 17 I die. It is a therapy.
 18 **Q.** John, you have told us about your three brothers
 19 infected with HIV. There are three of you then
 20 infected with hepatitis C. You, one of your brothers
 21 who we are not going to name, who survives along with
 22 you?
 23 **A.** Yes.
 24 **Q.** And then your brother Alan.
 25 **A.** Yes. He died.

35

1 want to be here. I want to go out and be doing this
 2 and doing that and everything else", but, yes, so
 3 that's the way forward for me is more in hospital.
 4 One day I could have cancer. They have told me
 5 I could have cancer. This is what will happen in the
 6 stages. I have asked the question, "Can I have
 7 a liver transplant now?"
 8 "You can't have a liver transplant until you
 9 have got cancer", so it's a bit weird that you have
 10 got to get really bad before you can have, you know,
 11 those sort of things. There are not enough people
 12 donating their livers, so please donate your livers.
 13 **Q.** Notwithstanding your various physical health problems
 14 that you have described and also your diabetes and you
 15 have rheumatoid arthritis which causes you pain, you
 16 have carried on working.
 17 **A.** Yes.
 18 **Q.** You have to go down to part-time with the assistance
 19 of a supportive employer?
 20 **A.** Yes. I have got a great employer. Every day is like
 21 a Friday, because I work Monday, Wednesday and Friday
 22 and, you know, like they have been supportive. I have
 23 been open and honest with them from the beginning.
 24 That's the way you should be. If you have got a boss
 25 who is shitty about those sort of things, you

34

1 **Q.** What happened to Alan?
 2 **A.** Alan -- the three of us, Alan, my other brother and
 3 me, were cleared of hep C. I think I was the first
 4 cleared and Alan and my other brother have probably
 5 been the worriers in the family. They -- and the
 6 stigma of what happened in the early '90s of -- late
 7 '80s, early '90s, of what happened to our family, it
 8 stuck. I pushed it to the back where with them it
 9 stuck and it was always at the forefront of
 10 everything.
 11 This was in the March of 2017. Alan, he was
 12 with one of his sons just walking to the shop.
 13 I don't know exactly -- no. He had been to his
 14 daughter's and walking to a shop and he said he felt
 15 funny and all of a sudden he collapsed. He had
 16 a brain haemorrhage. He lasted -- so if that's the
 17 March, he lasted until Remembrance Day, so he also
 18 died, so my younger brother died on Remembrance Day
 19 and Alan died on Remembrance Day.
 20 He didn't -- he managed to pull through. Just
 21 everything collapsed on him sort of thing. In the end
 22 he died on Remembrance Sunday 2017. He has got
 23 several children. It was through -- on his death
 24 certificate it doesn't say he died of hep C or
 25 whatever or whatever, but that was a main contribution

36

1 to his death, we are convinced.

2 **Q.** That's because the stress, the anxiety, the worry he
3 lived with for so many years?

4 **A.** Yes. Definitely.

5 **Q.** I just want to ask you about notifications you
6 received in relation to the risk of vCJD. What can
7 you recall about that?

8 **A.** Yes. That was a letter from the QE again. I don't --
9 it didn't -- that was another letter that didn't come
10 in saying -- sent to us like -- professionally, really
11 you should be saying "Could you come to the hospital?
12 We need to talk about -- we have something we need to
13 talk to you about?" It was just a letter like, "As
14 you may be aware, this chap has died and you have had
15 a transfusion. He has died of CJD", so we are
16 infected with a transfusion. We don't know how it is
17 going to effect us. I mean, I have always been a bit
18 mad. I don't know -- until it happens we don't know.

19 **Q.** In fact, we have got a couple of the letters you
20 received. 1170003, please, Paul. This is a letter of
21 29 January 2001 from University Hospital, Birmingham.
22 As you have said, John, it starts:
23 "As you are probably aware now variant CJD is
24 a progressive and ultimately fatal disorder of the
25 brain."

37

1 doctor -- this doctor who is on, if everybody is
2 reading, he is a great doctor. I have got no
3 complaints about the doctors and the nurses at the QE
4 Hospital. They have always been great. It's been
5 a bit like McDonald's. You phone them up and you say,
6 "I have got a bleed", you go up and they give you
7 Factor VIII. I still have Factor VIII, but it is heat
8 treated, sometimes it is quicker than going to
9 McDonald's. Yes, so looking at that ...

10 **Q.** What you said in your statement about it is you are
11 still not sure how this is going to affect you. It
12 has all been very matter of fact "Here is a risk", but
13 you don't have the information available to enable you
14 to process that.

15 **A.** No, not at all.

16 **Q.** Can I just ask you a little more about the impact on
17 your own family life of the events that you have
18 described? You have told us how after your first
19 brother's death, Gary's death, your marriage broke up.

20 **A.** To his mother, yes.

21 **Q.** And then you had the breakdown that you have described
22 when you were on your second course of treatment for
23 the hepatitis C in about 2011. How did that affect
24 your second relationship?

25 **A.** It was the same sort -- I couldn't believe I was going

39

1 Then it if he just go down to the next
2 paragraph it refers to:
3 "We have recently been informed by the UK
4 bio-products laboratory that some batches of Factor
5 VIII and Factor IX concentrate made by them in 1996
6 and 1997 contained plasma from a blood donor who has
7 recently developed new variant CJD. I am writing to
8 inform you that having checked through our records it
9 would appear that you have received product from one
10 of the implicated batches."
11 The reference is made in the next paragraph to
12 a recognition:
13 "... this news may generate anxiety, we feel
14 that our patients are entitled to be informed of all
15 of the facts about their treatment."
16 They offer reassurance and provide a document
17 from the Haemophilia Society:
18 "Should you require any further information
19 about the new vCJD then please do not hesitate to
20 contact either myself or one of the nurses at the
21 centre."
22 I think you received another letter to similar
23 effect in 2004 and again you were told you had
24 received one of the relevant batches.

25 **A.** Yes. I was told that. I have just got to say the

38

1 through the same sort of -- it was worse actually,
2 probably, because I didn't know where I was mentally
3 and, as I said, the only thing that kept me going was
4 working.
5 I know that's sad to say that word, but that's
6 exactly what just kept me going. Through my second
7 partner who I have got three children with I needed
8 space. I needed total -- I just needed to be on my
9 own, so it did affect everything. I see my children
10 all the while. I mean, one of my daughters lives with
11 me. I love my children, so ...

12 **Q.** You have told us about the treatment that your family
13 received in consequence of your three brother's
14 infection with HIV. The stigma was such that some of
15 the younger members of the family changed their
16 surnames. We won't mention any names that were
17 changed, but --

18 **A.** Yes. It was [redacted]. He don't mind admitting it,
19 and my oldest daughter [redacted]. He is 39 this year
20 and she is 40 -- 41. She -- my wife -- I have only
21 been married once and we are the best of friends. We
22 see each other lots.
23 At the time -- because of what people were
24 writing on walls and the whole area was known as the
25 AIDS area and blah, blah, blah, [redacted] was -- was

40

1 she just about -- was she going to the senior
 2 school -- going into the seniors and my ex-wife wanted
 3 to change their surname, so their surname was changed
 4 to protect them from -- because if you mention the
 5 name Cornes, it would be like ... yes.
 6 **Q.** And you have a nephew -- we will not mention again any
 7 names -- but you have a nephew who did likewise and
 8 changed their name.
 9 **A.** Sorry?
 10 **Q.** You have a nephew who also changed their name, without
 11 mentioning any names.
 12 **A.** Yes.
 13 **Q.** You described to me, John, this morning what you and
 14 your family went through, it was a little like the
 15 treatment that in the aftermath of the Birmingham pub
 16 bombings. If you were Irish, you were treated in
 17 a certain way --
 18 **A.** Yes.
 19 **Q.** -- in the area in which you live.
 20 **A.** Yes, because when the pub bombings went off in 1974
 21 I think it was, I was 17 at the time and I can
 22 remember the atmosphere in Birmingham and I felt sorry
 23 for them, because I have got lots of Irish friends.
 24 If you was Irish, you would be beaten up and that's
 25 the way it was in Birmingham at that particular time.

41

1 Friday and I have got the week-end off.
 2 I don't sit at home on my -- I am out. Because
 3 I have had two families, my youngest son, he is 12
 4 next month. I take him tennis. I sit there, because
 5 I can't stand -- I can't stand up too long, but they
 6 all have activities. I have got one daughter who is
 7 down in London. She is in her second year of acting.
 8 She is a brilliant singer. She sang three times now
 9 at the Royal Albert Hall, so I am proud of all my
 10 children, because they have all done things. You
 11 know, they have pushed themselves and everything else.
 12 **Q.** You have made applications to the Skipton and I think
 13 now EIBSS. You have not had any problem yourselves
 14 with the applications?
 15 **A.** No. I didn't even realise I could claim anything. It
 16 was the liver specialist at the QE. He actually told
 17 me on the day that I had cirrhosis that I could claim.
 18 I said "right. What do I do". He actually -- they
 19 were great. They brought the forms. He actually
 20 signed the forms and said, "blah, blah, blah and you
 21 will get this". I thought "hmm". They were really
 22 helpful financially that way, yes.
 23 **Q.** John, you mentioned the counselling that you had had,
 24 but that was when you had your own breakdown and you
 25 sought help in 2011 or thereabouts. Were you ever

43

1 There was -- there was a real bad atmosphere in
 2 Birmingham, and the only way I can describe what
 3 happened to our family was exactly the same. The name
 4 Cornes, the AIDS family. That is the closeness I can
 5 feel. I can totally understand the way the Irish
 6 community were affected by the bombings and it wasn't
 7 their fault and it wasn't our fault what happened to
 8 us.
 9 **Q.** You have managed to keep on working in the way that
 10 you have described, but have there been financial
 11 impacts upon you, your infection and treatment in
 12 terms of ability to obtain insurance and mortgages and
 13 the like?
 14 **A.** Insurances have always been a taboo subject for any
 15 haemophiliac, whether you have got HIV or hep C or
 16 whatever. It always has been and some of them -- some
 17 companies, insurance companies, don't even know what
 18 it is, yeah. I have been lucky with buying properties
 19 because I have worked, but now, because I have gone
 20 part-time, financially it is -- I have got to find
 21 what's the best for me, so I am still working, which
 22 I love, and as I said every day -- every day going to
 23 work it is like the week-end because I go in on
 24 a Monday, I have got Tuesday off, I go in on
 25 a Wednesday and I have got Thursday off. I go in on

42

1 offered at any time throughout the 1990s and any time
 2 prior to that any counselling or psychological
 3 support?
 4 **A.** None.
 5 **Q.** Were your brothers or any other members of your family
 6 offered that?
 7 **A.** No, no. Not to do with them getting the HIV and what
 8 not. They have had none. I remember the -- I don't
 9 know what they call them -- parts of the government --
 10 it was one of the departments in the government. When
 11 all the press came out about Roy and what had
 12 happened, they actually had to hide him in hotels,
 13 because he felt as though you had people with nooses
 14 ready to lynch us all.
 15 **Q.** John, those are the questions I have for you.
 16 **A.** Thank you.
 17 **Q.** Is there anything that you would like to add?
 18 **A.** I appreciate that we -- I have had. I didn't want to
 19 do this as I said earlier. I appreciate -- I wanted
 20 to come out not just for me but also for my family and
 21 I have got -- I cry when I think of my nephews and my
 22 nieces that haven't got dads. Luckily I am still
 23 here. I don't know how long I am going to be here for
 24 but I will be a bugger to go.
 25 So -- but I just appreciate what's going on and

44

1 years ago I didn't realise -- until I started looking
 2 on the Facebook at the Tainted Blood group, I know Sue
 3 Threakall really well. Sue had has been a great
 4 woman. When you start looking at this particular
 5 group that I'm part of, you know you are not on your
 6 own, because we -- me and the rest thought we were on
 7 our own and we are not. You look and think "Christ,
 8 it is not just us. Look at what's happened to them".
 9 I think this is a fantastic thing what is
 10 happening now. I hope they get a conclusion soon,
 11 sooner than later.

12 **Q.** John, I am just going to ask Mr Snowden, who
 13 represents you, if there is anything else.
 14 No, there is nothing from Mr Snowden.

15 **A.** Thank you very much.

16 **SIR BRIAN LANGSTAFF:** John, I know you didn't want to be
 17 here, but thank you very much for coming and all the
 18 more thanks because it can't, I suspect, have been at
 19 all easy talking to us now in public, given what your
 20 family has been through as the AIDS family,
 21 particularly in the 1980s and the stigma that you have
 22 told us about. So thank you for your bravery.

23 **A.** Thank you very much.

24 **SIR BRIAN LANGSTAFF:** Well, we will take a break now until
 25 12.10, when we are due I think to hear from Graham

45

1 years later when I was 23 and Margaret was 33.

2 **Q.** Can you just tell us a little bit about what Margaret
 3 was like?

4 **A.** Margaret was an exceptional person, because besides
 5 all the things that you'd want from an attractive
 6 partner she was one of the most good and kind and
 7 gentle people I have ever met, a person of faith, like
 8 her brother, who is with his wife in the front row.
 9 You will find this difficult to believe, but it
 10 is absolutely the truth. In the 15 years when we were
 11 together from my 18th birthday until her death I never
 12 heard her say a bad word about anyone and I never
 13 heard anyone say a bad word about her. Now there
 14 aren't many people you can say that around. So she
 15 was a truly lovely, gentle person, a devoted wife and
 16 mother, wanted to spend time drawing and reading with
 17 the children and so on. So I hope I have given you
 18 a little bit of the picture there. She was a really
 19 extremely good human being.

20 **Q.** And, as you said, she worked as a primary school
 21 teacher and then subsequently as a lab technician
 22 until she stopped working when she had your first son
 23 in 1972?

24 **A.** That's right.

25 **Q.** The plan was for her to return to work part-time once

47

1 Binks.

2 **MS RICHARDS:** That's right, sir.

3 **SIR BRIAN LANGSTAFF:** 12.10.
 4 (11.41 am)

5 (A short break)

6 (12.16 pm)

7 **SIR BRIAN LANGSTAFF:** The next witness, Ms Fraser Butlin,
 8 wishes to be known as Graham, does he?

9 **MS FRASER BUTLIN:** That's correct, sir.

10 **SIR BRIAN LANGSTAFF:** Graham, please.
 11 **GRAHAM BINKS, sworn**
 12 **Questioned by MS FRASER BUTLIN**

13 **Q.** Graham, you are here to give evidence about your late
 14 wife, Margaret.

15 **A.** Yes.

16 **Q.** Can you tell us, first of all, how you met?

17 **A.** We met in a primary school. Margaret, who was ten
 18 years my senior, was a primary school teacher in Leeds
 19 and in an arrangement that was usual then, but not
 20 now, I had two terms before I went to university and
 21 I finished up at the same primary school for those two
 22 terms as an ancillary teacher, so I was 18 and she was
 23 28.

24 **Q.** And when did you marry?

25 **A.** We married 15 years -- no. Sorry. We married five

46

1 your boys -- your youngest had started school?

2 **A.** Yes. The idea was once he was 5 and started proper
 3 school, then she'd return to some part-time
 4 employment, probably in primary teaching.

5 **Q.** After Margaret gave birth to your first son in 1972
 6 she received various blood transfusions and then
 7 became jaundiced.

8 **A.** That's right. She was kept in hospital for three
 9 weeks in Hyde Terrace Maternity Unit in Leeds, which
 10 is where both my sons were born, and she received
 11 a series of blood transfusions. The baby was healthy.
 12 He weighed over 7 pounds and both [redacted] weren't
 13 discharged until three weeks after delivery.

14 **Q.** Then after the birth of your second son in 1974 she
 15 received further blood transfusions and again stayed
 16 in hospital for longer than normal.

17 **A.** Yes. We were advised after the birth of the first
 18 son -- our GP advised us that if we wanted to have
 19 more children, then we should get on with it,
 20 basically, and we assumed, probably correctly, that
 21 this was because of her age, because she was 36 when
 22 we had the first child, and then 37 when we had the
 23 second one or when she had the second one I should
 24 say, 20 months later. He was a nice healthy 8 pounds
 25 baby, but again she received blood transfusions and

48

- 1 was not discharged until 12 days after he had been
2 delivered.
- 3 **Q.** When each of those transfusions -- when each of the
4 transfusions were given to her, was she or were you
5 made aware of any risks involved in having them?
6 **A.** Absolutely not.
- 7 **Q.** And it was after the arrival of your second son that
8 she became particularly unwell. Can you tell us what
9 happened?
10 **A.** Well, she was never healthy again after the birth of
11 my second son, and she was within -- I can't remember
12 the exact date, but within a month or two she was
13 diagnosed with hepatitis. This diagnosis by the GP
14 was confirmed by a biopsy, a liver biopsy. So at the
15 time it was described not as hepatitis C but as
16 chronic aggressive hepatitis.
- 17 **Q.** She was hospitalised for six weeks during the summer
18 of 1975.
19 **A.** That's right. By the time my second son was 11 months
20 old she was hospitalised in St James's for
21 approximately six weeks.
22 **Q.** Because of the hepatitis?
23 **A.** Oh, absolutely, yes.
24 **Q.** When your wife found out about the diagnosis, were you
25 told of any risks of transmitting the infection?

49

- 1 **A.** I imagine that had liver transplants been available,
2 she might well have been a candidate for one, but
3 this, you know, is before all that was available, yes.
- 4 **Q.** Can you tell us a little of how Margaret coped with
5 that news.
6 **A.** I hope people will forgive me occasionally referring
7 to notes but I realise that I have only got one shot
8 at this and I don't want to go away this afternoon,
9 drive away thinking there are things I wish I'd
10 mentioned and forgot.
- 11 She never enjoyed good health again and the
12 effect on her was that when the seriousness of her
13 condition became clear, she was frightened, because
14 who wouldn't be, and not least because during her
15 hospitalisation in the liver ward she had seen other
16 patients in a more advanced state than she was, so she
17 saw what was coming, but despite the fact that she
18 knew that she'd never see her children grow up, she
19 was a very brave and resilient person, and we all know
20 that we're mortal, but an end date concentrates the
21 mind and the sensation for both of us and for other
22 members of the family, but not the children, of
23 course, who had no idea, is if you imagine that you
24 are on an aeroplane and you know it's guaranteed to
25 crash. It's slowly descending but you know that the

51

- 1 **A.** No.
- 2 **Q.** And were you told anything about managing the
3 infection?
4 **A.** Not as far as I'm aware, no.
- 5 **Q.** After she was discharged from hospital in 1975 what
6 was your wife's health like?
7 **A.** It was a story of progressive deterioration. She
8 became increasingly yellow. The whites of her eyes
9 turned yellow. Her skin turned more and more yellow.
10 She got more and more tired and exhausted, and this
11 continued until May 1979, when she was hospitalised
12 for several weeks, and then on discharge given six
13 months to live.
- 14 **Q.** What was she told during that hospitalisation? She
15 was told she had six months to live, but what else
16 about her condition was she told?
17 **A.** Well, I can't remember anything specific that she was
18 told. She was told that she was terminally ill with
19 chronic aggressive hepatitis. No-one ever attributed
20 a cause to this. There were no other risk factors
21 that anybody was aware of, and that was it.
- 22 **Q.** And in those days liver transplants weren't
23 available --
24 **A.** Absolutely, not, no.
25 **Q.** -- and there were no options for you.

50

1 aeroplane is guaranteed to crash. So it's obviously
2 very depressing, and the difference, if you like, is
3 that for the person infected, then the rest of us knew
4 that this was a tunnel we were going into, but we'd
5 come out the other end in whatever shape. Margaret
6 knew she wouldn't, you know. It's a wall at the end
7 of her tunnel -- not in this life anyway.

8 To a certain extent she went into a country of
9 her own, which I can quite understand. I mean, having
10 that kind of effective death sentence, you know, makes
11 you in some respects a slightly different person, so
12 she was frightened, but she was brave. She had faith.
13 She was a resilient person, and we had two little lads
14 to look after, and that's the best medicine anybody
15 can have.

16 So it did restrict -- the fatigue restricted the
17 time and energy she had available for family life. In
18 the later stages she would get up in the morning,
19 spend a little bit of time with them before they went
20 to school, then go to bed for the whole day, spend
21 a little bit of time with them when they came back and
22 so on, and we moved the bed into the front room and so
23 on, but the objective was to protect our sons really
24 and give them as normal a life as possible.

- 25 **Q.** And at that stage they were about aged 5 and 7?

52

1 A. They were 5 and 7 when she died, yes.
 2 Q. What was their understanding of the situation before
 3 Margaret died?
 4 A. Their understanding of the situation was limited,
 5 because we'd obviously protected them. So they knew
 6 that she was unwell. They knew that she was
 7 turning -- that their mother was turning yellow and
 8 spending increasing amounts of time in bed. Other
 9 than that, I don't think they had much awareness.
 10 They knew their mother was ill, but they had no idea
 11 of the seriousness, of course.
 12 Q. In January 1980 Margaret haemorrhaged. Can you tell
 13 us about that.
 14 A. Well, she had deteriorated rapidly and fortunately my
 15 parents live just down the road, so my sons were able
 16 to spend an increasing amount of time when they
 17 weren't at school at my parents' house.
 18 Margaret preferred -- expressed a preference to
 19 die at home. Our GP explained that this would be
 20 an extremely messy business, because a great deal of
 21 blood was likely to be ejected, but I wanted to abide
 22 by her decision and -- sorry -- I didn't care if she
 23 dyed the carpet crimson, but when she began to vomit
 24 blood whilst the GP was present as it happened, he
 25 persuaded her to go into hospital right at the end, if

53

1 other end of the tube.
 2 So it's not the way one would wish to die, shall
 3 we say, with this balloon wedged down your throat, and
 4 that was how she died in the early hours of Friday,
 5 25 January.
 6 Q. 1980?
 7 A. Yes.
 8 Q. And she was 43.
 9 A. She was 43, yes.
 10 Q. You were 33.
 11
 12 A. Yes.
 13 Q. And you had to go home to tell your sons that their
 14 mum had died.
 15 A. Yes.
 16 Q. You have described that as the hardest thing you have
 17 ever had to do.
 18 A. Far and away, far and away the hardest thing I ever
 19 had to do. As I say, they -- they knew that their mum
 20 was ill but they had no inkling of how serious the
 21 illness was.
 22 Q. But you told them a little white lie when you told
 23 them --
 24 A. Yes, yes.
 25 Q. What did you tell them?

55

1 you like, and called an ambulance. One of my abiding
 2 memories is of my children waving through the window
 3 of my parents' house down the road with no idea that
 4 they wouldn't see their mother again.

5 So the decision to go into hospital turned out
 6 to be a very good decision, because it effectively
 7 bought her a few extra days and the opportunity for
 8 her brother, who I see is in the front row, to visit
 9 her in hospital, and in between being in a coma she
 10 did have periods of great lucidity.

11 I was amazed at the volume of blood that was
 12 being pumped in and vomited out. I didn't really
 13 believe that anybody could have a lucid interval while
 14 they were going through that, but she did.

15 At the end in the last probably 36 hours --
 16 incidentally, I lived and slept at the hospital for --
 17 from the Saturday she was taken in on through till the
 18 early hours of the following Friday when she died.
 19 When she -- towards the end of this, her -- the
 20 varices in her throat exploded basically and they had
 21 to resort to a procedure called a Sengstaken Tube,
 22 which involves having a rubber tube pushed up your
 23 nostrils and a balloon inflated in your throat to put
 24 pressure on the blood vessels to stop the blood coming
 25 out. This was sustained by a kind of weight at the

54

1 A. Well, I told them the truth in the sense that I said
 2 their mother had sent a message that she loved them
 3 and was sorry she had to leave them but the white lie
 4 I told is I said she told us to be like the three
 5 musketeers. So I sat one each on my knee and --
 6 sorry -- and we swore an oath of one for all and all
 7 for one, and sealed it with a small glass of port,
 8 even the 5 year old.

9 Can I reassure any worried parents in the room
 10 none of us went on to become alcoholics as a result of
 11 this, you will be thrilled to hear.

12 The difference was that the 7 year old was able
 13 to grasp the finality of death and the 5 year old
 14 couldn't. He kept expecting her to turn up. So my
 15 sister-in-law and myself would be asked questions
 16 like, you know "When am I going to see any mummy", and
 17 the answer might be "When you get to heaven", and the
 18 question then would be "But how will I find it" and
 19 the answer, which I owe to Chris really is "Don't
 20 worry. She will find you", so it was hard for them
 21 and I have always been honest with them and -- but to
 22 this day I have spared them the most gory details
 23 about the final couple of days.

24 They were deprived of a loving and responsible
 25 mother, a primary school teacher and consequently

56

1 their educational support was probably less than -- it
 2 was certainly less than it would have been and they
 3 led a somewhat less comfortable life than their peers
 4 but fortunately they both went on to graduate and
 5 enjoy extremely successful careers occupying senior
 6 positions in their chosen fields.
 7 I must say, by the way, they both offered to
 8 come up and support me today but I persuaded them that
 9 if they were going to take time off work we had a lot
 10 more fun things to do together than go through this,
 11 so it's not that they don't support me. It is just
 12 I didn't want them to be here, basically.

13
 14 **Q.** You said a little bit about the effect on your
 15 children.

16 **A.** Uh-huh.

17 **Q.** What about for you?

18 **A.** Well, the effect for me was I hadn't expected to find
 19 myself a widower at the age of 33. So that was
 20 a surprise. You never ever fully recover from the
 21 death of a partner and even 30 years -- 39 years on,
 22 I'm no stranger to tears. I am hoping to get through
 23 this without them, but we'll see but I had two little
 24 lads to look after and a responsible job. So I took
 25 a week off work and then worked my backside off,

57

1 us about that?
 2 **A.** Well, financially I think I used the phrase in the
 3 statement -- financially, it was devastating. It was
 4 a torpedo through the ship. Entirely due to my own
 5 stupidity I was 23 when we married. I took out
 6 a mortgage. There was no bank of mum and dad and,
 7 like an idiot, I naively assumed that the lady I loved
 8 and myself were immortal, so neither my wife's life
 9 nor our mortgage -- and this was at a time of rising
 10 double figure interest rates -- were insured but
 11 I assumed that they would, like probably lots of us do
 12 when we are that age, that we would live forever. How
 13 wrong can you be? So we had extended the house and
 14 the mortgage substantially to accommodate our sons
 15 obviously, bedrooms and a playroom for them and so on.
 16 The expectation had been Margaret would resume
 17 part-time employment, as we said earlier, when the
 18 youngest son had started school.

19 Instead, I was faced with substantial funeral
 20 expenses and having to support three of us until my
 21 sons were through university on one income and also to
 22 pay for help in the house, which was quite expensive,
 23 although, as I say, I was very fortunate to have found
 24 the person that I did, but we managed okay. I had
 25 a decent job but I became for a time in the early

59

1 basically.

2 I -- I was very lucky, because I advertised for
 3 part-time help and engaged a lady, who has been dead
 4 for years now, a lady called Jean Chapman. Jean was
 5 already a grandmother, lived very close, and she had
 6 just lost her husband and been made redundant from
 7 Hepworth's, which was one of the clothing firms in
 8 Leeds. So she had had a big change in her life and
 9 she was a Godsend, because she was one of the few
 10 people who was available to work through the family
 11 teatime period. So she would collect my sons from
 12 school, feed them, did the cleaning and ironing and
 13 babysitting and, much more importantly, built a strong
 14 and loving relationship with them, which went on for
 15 many years after she had ceased to work for us, as it
 16 were.

17 I was also very, very lucky because I come from
 18 a large extended very humble family in Leeds, a kind
 19 of tribe really, and they were very supportive and my
 20 parents who, as I say, just lived down the road, were
 21 very, very helpful in all sorts of ways. I mean, they
 22 used to take my sons on holiday to Spain every year to
 23 give me a break. They used to do babysitting and
 24 other things. So they were very helpful.

25 **Q.** Financially, it was also very difficult. Can you tell

58

1 days, which are difficult, an authority on the precise
 2 price of everything in Asda as a result of this.

3 **Q.** Now, you can't say for sure that your wife was
 4 infected with hepatitis C from the blood transfusion
 5 she received.

6 **A.** No, no.

7 **Q.** We have had her death certificate, which, if we may,
 8 we will just put on the screen. It is document
 9 0288005, and we can see there that the cause of
 10 death -- just the other half -- is set out as
 11 bronchopneumonia, hepatic encephalopathy, bleeding
 12 oesophageal varices, and chronic active hepatitis.

13 **A.** Yes.

14 **Q.** Margaret had no other factors by which she might have
 15 contracted hepatitis?

16 **A.** None whatsoever.

17 **Q.** So really the best thinking is it was the transfusions
 18 that caused her to contract the hepatitis?

19 **A.** Well, I am not a medical person. So I have no
 20 authority to say that but there was certainly no other
 21 risk factors and, as I say, after that 20-month period
 22 she went from being perfectly healthy to being what
 23 turned out initially chronically and then very quickly
 24 terminally ill.

25 **Q.** You have tried to obtain her medical records --

60

1 **SIR BRIAN LANGSTAFF:** Just a moment.
 2 **MS FRASER BUTLIN:** Of course.
 3 **SIR BRIAN LANGSTAFF:** Later on you applied, did you, to
 4 the MacFarlane Trust and the Skipton Fund?
 5 **A.** No.
 6 **SIR BRIAN LANGSTAFF:** You didn't?
 7 **A.** No.
 8 **SIR BRIAN LANGSTAFF:** I see.
 9 **MS FRASER BUTLIN:** You have tried to obtain her medical
 10 records to try to work out what was known and what was
 11 understood at the time. Can you tell us what happened
 12 when you applied for her records.
 13 **A.** Well, I -- I approached the GP. I am very fortunate
 14 we are patients of one of the best group practices in
 15 Leeds in Horsforth and they did a very thorough trawl
 16 but could find no records. I was advised to approach
 17 the Primary Care Support England and their policy
 18 states that it's and I confirmed this in a phone call,
 19 that it was a waste of time trying to pursue anything
 20 with them, because their policy is that after
 21 a certain number of years records are no longer
 22 available, and I contacted the Leeds Hospital Trust
 23 and their -- I contacted them initially just last
 24 October and, as I probably said before, when you're
 25 going through these experiences you are not analysing

61

1 paragraph 2 and 3 that you had made the request but to
 2 date no concrete response of any kind has been
 3 received. If we go to the second to last paragraph,
 4 you have said:
 5 "I also understand that my request is one of
 6 many. That being said, over six months have elapsed
 7 since I made the request and I have yet to receive
 8 a tangible response of any kind -- not a single
 9 e-mail -- not a single letter."
 10 **A.** That's right.
 11 **Q.** As you say, on 13 May you received a response by
 12 special delivery indicating that no records were
 13 available.
 14 **A.** That's right. I mean, this is hardly surprising in
 15 view of the fact the events we are talking about, the
 16 transfusions we are talking about, were over 40 years
 17 ago now.
 18 **Q.** But the six month delay has caused you some concern
 19 that there was not a reply more promptly.
 20 **A.** Yes.
 21 **Q.** Those are the questions I have for you. Is there
 22 anything else you would like to say?
 23 **A.** Just that I'd like to make a brief -- with your
 24 indulgence -- a brief statement in conclusion.
 25 I wish to make clear in my evidence that I am

63

1 it you are just experiencing it.
 2 It is like being on a roller coaster. So you
 3 don't -- you know, it never occurred to me that there
 4 was even a possibility that infected blood played
 5 a role in this and, you know, I suppose it surprised
 6 everybody in subsequent years.
 7 When I approached Leeds Hospital Trust last
 8 October, I explained that the reason I was looking for
 9 these records was because I was due to give
 10 a statement to your colleagues in London to the
 11 Inquiry, so they were aware of that. Despite
 12 several -- they acknowledged receipt of my application
 13 form. Despite several attempts to chase the matter
 14 up, and bear in mind they had a clear legal
 15 requirement to provide records even for people who are
 16 deceased within a certain time limit, then I didn't
 17 receive a single e-mail or response.
 18 **Q.** You then wrote to them again on 9 May 2019 and we've
 19 got a copy of that letter, 0288003.
 20 **A.** Yes. Well, I wrote to them again, because by that
 21 time I was called to give evidence and that point
 22 I received a response in a matter of a few days by
 23 special delivery.
 24 **Q.** Just before we go to the response, if we just look at
 25 the letter you sent, you made this clear in

62

1 alleging nothing and I am criticising nobody. I have
 2 no knowledge of the presence or otherwise of infected
 3 blood in the Leeds Hyde Terrace Maternity Unit at the
 4 periods in question. Neither do I know whether and,
 5 if so, how many other mothers who received post-birth
 6 blood transfusions there went on promptly to develop
 7 and suffer serious life-changing illness, nor whether
 8 any statistical analysis, should it prove possible,
 9 would cast light on the matter. I don't know.
 10 I am here today because I feel I owed it to my
 11 late wife, to my sons and to others who may or may not
 12 have been affected in similar circumstances to furnish
 13 the Inquiry with such facts as I possess, which may or
 14 may not contribute a relevant piece to what I assume
 15 is a very large and complicated jigsaw puzzle and
 16 I don't envy Sir Brian trying to write his report.
 17 I would like to thank the Inquiry and all its
 18 staff both for affording me this opportunity and
 19 especially for the manner, both professional and
 20 humane, in which I have been dealt with throughout and
 21 I think, having talked to a few other witnesses, they
 22 would echo those sentiments.
 23 Finally, nearly 40 years on from the event in
 24 question I'd like to put on record my heartfelt
 25 admiration and thanks to all the staff of the health

64

1 service who treated Margaret and myself with such
2 understanding and kindness, namely our GP, the late
3 Dr Lawson, the consultants, doctors and nurses at
4 St James's and not forgetting even the staff in the
5 canteen, who served a very sad man with his breakfast
6 every morning for a week. Thank you.

7 **SIR BRIAN LANGSTAFF:** Thank you very much indeed, Graham.

8 **A.** Thank you. Can I run away now?

9 **SIR BRIAN LANGSTAFF:** It is entirely up to you. You are
10 free to stay, go, as you wish, but thank you very much
11 indeed for what you had to say.

12 **A.** Thank you for the opportunity. Thank you.

13 **SIR BRIAN LANGSTAFF:** I should add -- Graham, I should add
14 one thing. It was this. At the start of when you
15 gave your evidence you were saying that you had some
16 notes because you were scared that you might in this
17 one opportunity you had miss something.

18 Can I make it clear that if you or for that
19 matter anyone who comes to give evidence thinks after
20 the hour or so, however long it is, is over that they
21 have forgotten something when they think about what
22 they have said that night or later on, they are
23 entirely free to write to the Inquiry, and if the
24 Inquiry thinks that it would be worth hearing, as it
25 probably will be, they will ask you to put it into

65

1 **MS FRASER BUTLIN:** She wishes to be known as Jo-Anne.

2 **SIR BRIAN LANGSTAFF:** Jo-Anne. Could Jo-Anne please come
3 forward.

4 **JO-ANNE COHRS, sworn**
5 **Questioned by MS FRASER BUTLIN**

6 **MS FRASER BUTLIN:** Jo-Anne, you're here to give evidence
7 about your late husband, Keith.

8 **A.** I am.

9 **Q.** And you met him in 1980 and married in 1983?

10 **A.** We did.

11 **Q.** Can you tell us a little of what Keith was like?

12 **A.** When I met him, he was very conservative.

13 **Q.** Jo-Anne, I'm just going to stop you. Would you mind
14 coming a little bit closer to the mic so everyone else
15 can hear what you are saying as well.

16 **A.** He was quite a conservative, cautious person, was
17 getting himself back on track with his education, was
18 doing a Bachelor degree, was very excited to be part
19 of the student community in Sunderland and lived with
20 three other lads who were students with him, who
21 played cricket down the hallway in their student digs,
22 older, a mature student, but still one of the lads.

23 **Q.** You are very softly spoken, Jo-Anne. I am conscious
24 lots of people want to hear what you are saying. So
25 if you can keep your voice up, that would be good.

67

1 a supplementary statement, which will be read, so it
2 doesn't have to go and stay secret.

3 **A.** No.

4 **SIR BRIAN LANGSTAFF:** So if there is anything else from
5 you -- and this is really addressed through you to
6 everyone else -- don't feel after testimony has been
7 given, that's it. This is an ongoing inquiry. It
8 will last until it finishes, as I say, I hope within
9 a reasonable time, but that's -- I want to hear what
10 people have to say and I recognise that some people
11 may forget some things they would wish to have said.
12 So thank you.

13 **A.** Well, thank you very much: in my case Sarah has done
14 a very good job. So you won't be getting any
15 supplementary information from me I don't think, but
16 thank you.

17 **SIR BRIAN LANGSTAFF:** Well, Ms Fraser Butlin, we will take
18 a break now until 2.05.

19 **MS FRASER BUTLIN:** Thank you, sir.

20 **SIR BRIAN LANGSTAFF:** 2.05.
21 **(12.49 pm)**
22 **(Luncheon adjournment)**
23 **(2.10 pm)**

24 **SIR BRIAN LANGSTAFF:** Ms Fraser Butlin, how does our next
25 witness wish to be known?

66

1 **A.** Right. I will try.

2 **Q.** Keith had severe haemophilia A and from the 1970s you
3 understand he received Factor VIII?

4 **A.** He did.

5 **Q.** But you recall living a normal life of camping, seeing
6 friends and going out despite Keith's haemophilia.

7 **A.** Yes. We did a northern tour of Northern Europe before
8 we got married, visiting Germany, Holland,
9 Liechtenstein and enjoying some of the other cultures
10 that we came across, yes.

11 **Q.** Keith was infected with hepatitis B, hepatitis C and
12 HIV. Can we start off in relation to the HIV? Can
13 you tell us how you came to find out that Keith had
14 been infected with HIV?

15 **A.** It was during 1984 after we were married we had moved
16 down south and Keith had started a wonderful job as
17 a lecturer, and towards the end of 1984 he lost
18 an awful lot of weight. He was a very small framed
19 man, so to lose over 2 stone was quite a lot. We were
20 very worried and at the time there were news stories
21 in the distance about this new HIV/AIDS. Didn't know
22 a lot about it, but we had already connected with the
23 haemophilia haematology group in Addenbrooke's
24 Hospital. So we knew a little bit. We went back to
25 the consultant, reported the weight loss, and coming

68

1 up to Christmas she said, "Well, why don't you go and
2 have a test?" So we did and we didn't get the results
3 until the following year.

4 **Q.** And how did you receive those results?

5 **A.** Just after Christmas we received a letter with
6 "AIDS -- don't die of ignorance" franked on the front
7 of the envelope and I knew what it was. It had come
8 from Addenbrooke's, so I left Keith to open the
9 envelope. It was his mail. I was there, but quietly
10 sort of let him open the letter himself just after
11 Christmas.

12 **Q.** And how did you both feel when you opened that
13 envelope?

14 **A.** Keith cried. Very worried. Didn't know what that
15 meant, because there wasn't a lot of information
16 around at the time. I was very confused. Things were
17 going well in our lives and especially for Keith.
18 Pulled himself up by the boot straps and got himself
19 off to college. Got himself married and got himself
20 a job as a lecturer, something he had always
21 dreamed -- he dreamed for normality and I dreamed for
22 a man who would complement me.

23 I was very flighty, very busy, active in church
24 and Keith was, like I said, very conservative. So we
25 both met and complimented each other, but I was very,

69

1 she said -- she was very helpful and would have said,
2 you know, "We'll do what we can". I was tested. She
3 did mention that we should take precautions as
4 a married couple and I was adamant that this was my
5 husband. I wasn't going to treat him any differently.
6 I wasn't going to wear rubber gloves or anything else.
7 We were going to have a relationship as a man and
8 wife, although we didn't want to bring a child into
9 the world who may be affected, but that wasn't going
10 to stop us having a normal married life.

11 **Q.** In about 1985/1986 you found out that Keith also had
12 hepatitis C. How did that come about?

13 **A.** I believe it was during a consultation when one of the
14 haematologists was involved in a research project and
15 so he'd left the room and some papers were on the desk
16 and we were sat on the opposite side and I peered
17 over, just moved one or two. I perhaps shouldn't
18 have, I don't know, but I did, and I saw "non-A non-B"
19 and Keith had it.

20 I didn't know much about hepatitis and I was
21 really only learning about haemophilia to be honest,
22 learning a lot more, and, silly me, I used to think
23 "there's hepatitis A, hepatitis B. What's this non-A
24 non-B thing. Why don't they call it hepatitis B.
25 Then if he has hepatitis B, could there be D, E, G,

71

1 very confused. What did it mean? What would happen?
2 All of these thoughts run round your head and there's
3 nobody there really to answer, especially for Keith,
4 what it would mean.

5 **Q.** How do you feel about being told that information by
6 post rather than face-to-face?

7 **A.** At the time I didn't -- we didn't really think
8 anything of it. We just expected "Yes, you will be
9 all right. Tick the boxes. You will be fine. Move
10 on", but actually with the news that it bore it would
11 have been very, very helpful if someone who knew about
12 the situation had been there to actually say, "We're
13 there for you. We're there with you. We'll help you
14 through this. We're on top of the medical profession.
15 We will find out what we can bring you, how we can
16 mend this", but it was very quiet, a very quiet time
17 of no support really, not knowing what does it mean?
18 Who do we share this with? What do we do?

19 **Q.** You then did have some consultations with the treating
20 doctor?

21 **A.** We did.

22 **Q.** Were you provided with much information at that stage?

23 **A.** No. There were no leaflets, pamphlets, books, because
24 it was early in the history of AIDS in this country.
25 So I know Dr [redacted] was a very caring person and

70

1 whatever, X, Y, Z. What else is he going to pick up?
2 That was my thinking at the time.

3 **Q.** You have said in your statement that it came as
4 a surprise to both of you, but you didn't question the
5 doctor further on it:

6 "... as we believed that if it was concerning
7 then the doctors would have spoken to us about it. We
8 were more concerned about the HIV than the hepatitis C
9 at the time."?

10 **A.** And that's true. That was more overwhelming, this
11 HIV.

12 **Q.** In the summer of 1985 Keith had pneumonia and was very
13 unwell with that and with oral thrush. Can you tell
14 us about that time?

15 **A.** Well, the pneumonia was very debilitating. It took
16 about three months of hospital care, during which time
17 I was allowed to stay in the room with Keith, and it
18 was quite a rest for him really and they could treat
19 with whatever opportune infection came about. He was
20 there ready for the treatment.

21 At home leading up to that he had been on some
22 different anti-fungals, which would then affect his
23 taste buds and his skin and his mouth. He didn't
24 enjoy food, lost more weight, but the time on the
25 ward -- he was very well looked after.

72

- 1 Q. Now, at this time you lived in a second floor flat.
 2 A. Uh-huh.
 3 Q. You applied for some different housing. What was the
 4 reaction you received?
 5 A. Very -- very little response actually from the local
 6 housing authority. "Oh, there's a two-year waiting
 7 list for a bungalow" or "there's another big long
 8 waiting list for a ground floor apartment" and what
 9 have you. Dr [redacted]'s secretary, I believe she
 10 was a social worker, wrote to the local council and
 11 said -- well, I don't know. I didn't see the letter,
 12 but it was a while after that we were given a newly
 13 decorated house with a chair lift, which was
 14 fantastic. It was a miracle actually, because it was
 15 only -- it was one of seven homes in the local area
 16 which even had a stair lift, and they had left it in
 17 from the previous occupants, so it was made for Keith
 18 really.
 19 Q. You have described the social worker being on the back
 20 of the local authority pestering them --
 21 A. Yes, she was.
 22 Q. -- to give you proper accommodation?
 23 A. Yes, she did. She contacted them several times.
 24 Q. Not very long after the move Keith contracted
 25 pneumonia again and went back into hospital and he was

73

- 1 Q. You think that it was about 1986 that Keith was given
 2 an experimental treatment.
 3 A. Yes.
 4 Q. What was that?
 5 A. It was plasma which was already contaminated with HIV
 6 and I think the theory was because Keith's fighting
 7 cells and immune system was so low and so weakened,
 8 they thought if they introduced more of the
 9 contaminated plasma, it might help boost and trigger
 10 his fighting cells to then fight off other infections
 11 and it didn't. It didn't work. It didn't make any
 12 difference at all and we were desperate. That's why
 13 we went ahead. Keith was able to think through that
 14 and after a couple of these treatments we decided not
 15 to go ahead, because it didn't -- after tests they
 16 realised it didn't make any difference to his fighting
 17 cells and immune system.
 18 Q. And then in the autumn of 1986 he had been discharged
 19 from hospital following the pneumonia and you went
 20 upstairs to find him vomiting blood. What happened?
 21 A. It was horrendous. It was very much like a horror
 22 movie. I don't watch horror movies but -- or a war
 23 movie, and at one time he both vomited and had
 24 an accident and both ends was blood.
 25 Q. The doctor came and can you tell us what happened in

75

- 1 really very unwell again.
 2 A. Yes.
 3 Q. When Keith was in hospital, you cared for him
 4 considerably and you were regularly told you should
 5 wear gloves and at times that you should be masked as
 6 well.
 7 A. Yes.
 8 Q. What was your reaction to that?
 9 A. I refused, because I cared for Keith at home. He was
 10 my husband and, as I said previously, I wasn't going
 11 to treat Keith any differently. He would feel my
 12 touch, my hands, if he needed a caress, a cuddle, some
 13 support, I was there. I wasn't going to look like
 14 a spaceman. I wasn't going to not dare touch him,
 15 because we were normal people and he needed a normal
 16 wife to care for him and that's what I did.
 17 Q. At one stage Keith's consultant was asked by the
 18 nursing staff to tell you to barrier nurse Keith with
 19 masks and gloves?
 20 A. Yes.
 21 Q. What was her response to that?
 22 A. Well, by then she knew me and she said, "Oh, he'll be
 23 all right and she will be all right too. Just let
 24 them be", and so we were allowed to -- I was allowed
 25 to be with my husband as normal.

74

- 1 relation to Keith's treatment?
 2 A. Are you referring to that or the cerebral accident?
 3 Q. Just when he vomited blood the doctor came and they
 4 refused to admit him locally.
 5 A. Yes. He was very angry, the doctor. Made some other
 6 phone calls and he was taken to Addenbrooke's.
 7 Q. The GP had tried to have him admitted in your local
 8 hospital.
 9 A. He did, because he was such an emergency and he needed
 10 treatment. The hospital was only about a mile and
 11 a half away -- excuse me -- and the hospital wouldn't
 12 allow him to be admitted. So the doctor, Dr Heelis,
 13 arranged for an ambulance to come and take him to
 14 Addenbrooke's instead, which was 25 mile away.
 15 Q. When we get to late 1986, about a year before Keith
 16 died, he started to show signs of cognitive loss. Can
 17 you tell us what that was like?
 18 A. It's really difficult to say what was the worst part,
 19 because it was all dreadful seeing a loved one suffer,
 20 but seeing the man, the clever man I loved and married
 21 not being capable of being aware of his circumstances,
 22 not being able to have a conversation about -- excuse
 23 me -- about some film director or some photographs he
 24 liked to look at, not have an opinion, not being able
 25 to remember very many things, not having a long -- not

76

1 being able to remember or losing memory from about
2 ten minutes ago.

3 **Q.** You have described he also had mood changes.
4 **A.** He did.

5 **Q.** And could be like a Jekyll and Hyde with you.
6 **A.** Yes, something I hadn't -- I had never seen before,
7 because, as I said, he was very -- he was very
8 conservative and considerate person and was very
9 controlled, not giddy or flighty, just -- so to see
10 Keith get really angry or throw dishes on the floor --
11 he could -- he didn't mean to. He just changed.

12 **Q.** Would you like to take a break before we carry on or
13 are you okay?
14 **A.** No. I'm okay. And his mood swings were very erratic
15 and it was difficult to tell, when he'd take
16 a downturn, it was difficult to have a conversation,
17 anything meaningful. So yes, it was very, very
18 difficult.

19 **Q.** And you have described that in some of those mood
20 swings Keith threw dishes or food on the floor or was
21 verbally unpleasant with you.
22 **A.** He was.

23 **Q.** Throughout this time you had a lot of support from
24 your church community, particularly from about 1986.
25 Can you tell us about that.

77

1 temperament, which changed. So the officer would ask,
2 "Well, how are you being cared for?", and Keith would
3 say, "Yes, everything's met. Everything's taken care
4 of and we don't need anything", and I thought, "Well,
5 ask me". He did ask me and I did say, "Well, I need
6 to be here all the time. He's becoming confused", and
7 I didn't really like to say those things in front of
8 Keith, but I did, "We need -- I need some time. Keith
9 needs a different face maybe to sit with for a few
10 hours", and tick, tick, tick. Oh, well "doesn't
11 need" -- I think he must have verbally said this
12 because I can remember "doesn't need this allowance
13 yet".

14 **Q.** You were told Keith had to be ill for over six months
15 before you were eligible for the allowance.
16 **A.** Yes.

17 **Q.** At that point Keith wasn't even able to get himself to
18 the toilet.
19 **A.** No.

20 **Q.** And, in fact, Keith died three months later.
21 **A.** He did.

22 **Q.** Until March 1987, so from the autumn 1986 when he had
23 had the pneumonia, until March 1987, what was Keith's
24 condition like?
25 **A.** He needed 24-hour care. He didn't sleep well and at

79

1 **A.** The church we joined in '86 were very, very
2 supportive. We had at least 14 families would pray
3 and fast one day a week. We had two other friends who
4 would call me every day to say what did we need. Did
5 we need a ride somewhere. Did we need any shopping
6 bringing in. Did we need to go out for
7 an appointment. Did we need the dog walking or any
8 cat food bringing in, anything, always calling and
9 they were always there, which was a saving.

10 **Q.** I know from our discussions your Christian faith has
11 been important both to you and it was to Keith
12 throughout that time.
13 **A.** Yes.

14 **Q.** By 1986 you had given up work and financially things
15 were difficult?
16 **A.** Very.

17 **Q.** So you applied for carer's allowance and you were
18 turned down for it. Can you tell us what happened.
19 **A.** We were interviewed in our home by an officer who
20 filled out the forms and looked at our application.
21 He talked to Keith, who was having a very happy time
22 at the time. He was very able to answer some
23 questions, was very cheerful.
24 If he had talked to him the day before, it might
25 not have been that way because of his condition in

78

1 other times he slept a lot. He was very confused
2 mentally. Didn't know what to eat when or what to do.
3 He would just sit. We had a kitten and a puppy, well,
4 by then were two years old each. He would just be
5 could be content sometimes just to sit with the cat,
6 who would quite often sleep with him in bed if I was
7 downstairs doing laundry or cleaning or whatever
8 needed to be done, but his quality of life really
9 was -- he wasn't -- it wasn't beneficial. It wasn't
10 meaningful. It wasn't a life worth living really.

11 **Q.** And then in March 1987 Keith fell over the threshold
12 of the back door?
13 **A.** He did.

14 **Q.** Can you tell us what happened?
15 **A.** Again, he was quite confused. I was playing the
16 piano. My mum was down for a visit doing some dishes.
17 He'd gone out into the hallway, opened the back door,
18 which I didn't hear, but then I heard him fall, and he
19 mentioned about the toilet and I gathered -- figured
20 he had meant to go up the hallway to the downstairs
21 toilet and instead he had gone -- turned right and
22 went out of the back door and fell over and had
23 a really bad head wound. So then panic. Call 999.
24 Ambulancemen came. They knew us by now and they were
25 dressed up in their space suits. "Come on, Keith. We

80

1 will take you to the hospital", and I had a feeling in
2 the back of my mind, worry whether they were going to
3 admit him. So I rushed upstairs to put some things
4 together, a bag and some toiletries in case this was
5 another long-term stay.

6 They had taken him to the local hospital, which
7 was about a mile and a half away. So packed a few
8 bits and pieces. By the time I got downstairs, about
9 30 minutes later, he was back home, and I could
10 tell -- he was in a wheelchair and he was in a mess.
11 He had wanted the toilet and he was in a mess in this
12 wheelchair, and the only thing the emergency
13 department had done was put a little bit of antiseptic
14 spray on his wound on his head, and even the
15 ambulancemen were very sorry to bring him back.

16 Q. So you put him to bed with your mum.

17 A. Mm-hm.

18 Q. And then your mum was watching him while you briefly
19 went out.

20 A. I did.

21 Q. And while you were out you just had a sense that you
22 needed to go back.

23 A. Yes.

24 Q. And what happened when you got back?

25 A. Just not responsive at all, and I contacted Dr Heelis

81

1 A. Well, just before that headline there was an article
2 in the paper where the local council -- the local
3 health authority were aware of this person with AIDS
4 and they were giving him all the help and support they
5 could. They didn't realise actually my husband had
6 already passed.

7 Q. And at that stage you weren't receiving any help from
8 the local health authority.

9 A. No.

10 Q. And they hadn't even picked up the yellow plastic bags
11 of medical items from outside your door.

12 A. They had actually made quite a fuss about any medical
13 waste that Keith had in the house and they provided
14 the very luminous yellow plastic huge bags to put
15 everything in and three weeks after he died they were
16 still outside the front door -- outside the back
17 door -- sorry -- but people could see, and it was --
18 it was so stigmatising and so uncaring, and no
19 actually the health authority or the local authority
20 didn't -- weren't able to help, didn't help at all
21 and, yes, there was a headline in the paper, "Local
22 man days of AIDS", and a few innuendos and wonder what
23 type of lifestyle they had.

24 Q. And that article arose because the day before the
25 funeral a journalist had come to your door.

83

1 and he came straightaway. I mean, Keith had had
2 a little packet of jelly babies. He had eaten some,
3 but he wasn't -- he wasn't well at all.

4 Q. Dr Heelis said that he thought that Keith had had
5 a stroke.

6 A. Yes.

7 Q. And so he referred Keith to the hospital, to
8 Addenbrooke's.

9 A. He did.

10 Q. And it was the same ambulance crew that came --

11 A. Yes.

12 Q. -- for him.

13 A. Yes. They took him to Addenbrooke's. I think that
14 was the next -- the next day. He hadn't moved
15 position in bed. Sorry. I'm trying to think of -- he
16 hadn't moved at all in bed, but he was still
17 breathing, because I felt his breath and then, of
18 course, Dr Heelis came and ordered for the ambulance
19 and it was the same ambulancemen again.

20 Q. And Keith never regained consciousness.

21 A. He didn't.

22 Q. And died on 6 March 1987.

23 A. Yes, he did.

24 Q. After Keith died there was a headline in the paper
25 about his death. Can you tell us about that?

82

1 A. Yes, wanting some no doubt salacious titbits for
2 a newspaper, again thinking or wondering did we have
3 parties -- well, they didn't say that, but, you know,
4 this is my mind thinking, oh, they wanted to dig and
5 find out the truth about this person who died of AIDS.

6 Q. After Keith died, you described immersing yourself in
7 lots of activities to try to cope with being a young
8 widow. One of those was to get involved in a local
9 AIDS helpline. What was the reaction you got when you
10 asked to be a volunteer?

11 A. They knew I was a Christian and I think some expected
12 me to judge perhaps, to condemn, and actually when
13 I told them my story and how my thinking had changed
14 and that this wasn't a punishment, these people,
15 anybody who was sick would need help, would need
16 support and we had lack of support from the
17 authorities, so anybody in that position of need
18 really needed people on their side.

19 Q. And subsequently you have said that the helpline made
20 a significant difference.

21 A. They did. They were there for people who needed to
22 call and talk to people, who could give them contacts,
23 who could point them in directions where they would
24 find help. It became Stevenage AIDS helpline became
25 quite a thing in the area, a novel idea really at the

84

1 time, and there was quite a drug community in
 2 Stevenage itself who needed support.
 3 **Q.** And also in doing battle with the local authority you
 4 have described getting people the help they needed.
 5 **A.** Yes, absolutely.
 6 **Q.** Can you tell us what the financial impact was on you
 7 prior to Keith's death and after he died?
 8 **A.** Well, when we first got married, we were -- we had
 9 both been students. So we didn't have a great lot of
 10 money. However, when we got married, moved down south
 11 and Keith was a lecturer. I did some too and I also
 12 worked in a local day centre. So we had double income
 13 and no kids and so we went on little trips abroad here
 14 and there.
 15 In the next year, as his health declined, it
 16 meant he had to cut work hours. He couldn't manage as
 17 much. So I worked a little more to help make up any
 18 shortfalls. We didn't have any financial commitments
 19 anywhere really, other than weekly food and living
 20 costs and as he became more poorly, he had to leave
 21 his job altogether because of the ongoing sickness and
 22 diarrhoea. Eventually my job came to an end and there
 23 was a job going to replace my job, which I applied
 24 for, but I prayed to God, "Lord, I don't know what the
 25 answer is, whether I should be at home all the time,

85

1 I could through an attorney in America just filling
 2 out paperwork. I couldn't get medical records, but
 3 Skipton, the team there were very helpful and, yes,
 4 I was awarded a payment.
 5 **Q.** Now, as far as you are aware Keith wasn't offered any
 6 counselling or psychological support throughout his
 7 illness and neither were you until about six months
 8 after Keith's death.
 9 **A.** Uh-huh.
 10 **Q.** It's right that about six months after his death your
 11 widow's allowance had come to an end?
 12 **A.** It did.
 13 **Q.** And you were, you have described it as being wiped out
 14 and very distraught and it was only that point that
 15 you were offered some counselling?
 16 **A.** Yes, it was, yes. I had had friends in church, but as
 17 far as sort of professional help and counselling that
 18 didn't come until much later at that time.
 19 **Q.** And it was only because you sought it out and your GP
 20 was proactive?
 21 **A.** Yes. I actually collapsed. A nurse friend -- we sat
 22 and talked a little bit and I broke down.
 23 **Q.** And you have described that process as feeling like
 24 walking through a blackberry bush and being torn?
 25 **A.** It was, yes.

87

1 whether I should have money to look after Keith", so
 2 it was in his hands. I didn't get the job. My
 3 colleagues were amazed I didn't get the job, but
 4 I knew that I needed to be home with Keith, so then we
 5 were on benefits.
 6 **Q.** And it was a struggle?
 7 **A.** It was definitely a struggle. Absolutely.
 8 **Q.** You received a payment from the MacFarlane Trust some
 9 time after Keith died. Did you have to sign anything
 10 before receiving that?
 11 **A.** I did. I had to sign a statement that said I wouldn't
 12 be involved in any future -- I don't know what the
 13 wording was -- but I wouldn't be involved in any
 14 litigation, yes. That was back in '91 I think it was,
 15 1991.
 16 **Q.** And you also received a payment from the Skipton Fund
 17 in 2010 or 2011?
 18 **A.** I did.
 19 **Q.** How did you come to hear about them?
 20 **A.** Keith's brother -- I was living in America at the time
 21 and Keith's brother had contacted my dad and mentioned
 22 this Skipton Fund and if I needed help, financial
 23 help, then I could apply for it, but I was living in
 24 America at the time, so I appointed my dad as the
 25 person to handle that affair and legally did what

86

1 **Q.** Those are the questions I have for you. Is there
 2 anything else you would like to say?
 3 **A.** Well, we did have an awful lot of support in other
 4 ways, day-to-day support, for which I am extremely
 5 grateful, especially to Dr Heelis, who still is
 6 practising in Letchworth. He is a very caring doctor.
 7 I saw him cry at Keith's demise, especially when he
 8 said Keith had had a stroke. He cried.
 9 The ambulance station which was about half
 10 a mile from where we lived and the people who came to
 11 take Keith to hospital various times, our friends in
 12 church, it is [redacted] and [redacted] were there on
 13 the phone, at the end of the phone, or even in the
 14 house, the prayer team, [redacted], our pastor, a very
 15 caring man and the church body really.
 16 Had it not been for those people I think Keith's
 17 care would have -- would have suffered, because
 18 I wouldn't have been upheld myself. I wouldn't have
 19 been supported as well. I'm very grateful to those
 20 people.
 21 **Q.** I am just going to turn and ask Mr Snowden, who, as
 22 you know, represents you, if there's any points he
 23 wishes for me to raise. He has nothing else.
 24 **SIR BRIAN LANGSTAFF:** Well, there is something I'd like to
 25 ask. Did you write a book?

88

1 A. I did.
 2 **SIR BRIAN LANGSTAFF:** What was it called?
 3 A. "Stigma: an AIDS widow's story".
 4 **SIR BRIAN LANGSTAFF:** In 1989 was that?
 5 A. It was.
 6 **SIR BRIAN LANGSTAFF:** What were you wanting to say in that
 7 book?
 8 A. It was really to say that people going through this
 9 situation there was hope and there is hope. There's
 10 a God who cares. So it was very much from our
 11 Christian point of view and he is a compassionate God
 12 and we had to have hope and we do have hope -- we did
 13 have hope and I did too and I still do, and it was to
 14 help other people in a similar situation who might not
 15 have had a faith, but who might have reached out to
 16 people of a faith in God to find support in people, in
 17 a caring community.
 18 **SIR BRIAN LANGSTAFF:** And when you called it "Stigma:
 19 an AIDS widow's story", what was the stigma that you
 20 had in mind particularly?
 21 A. Collectively I think you could put it all in a big
 22 yellow plastic medical refuse bag. That was the
 23 stigma.
 24 **SIR BRIAN LANGSTAFF:** Thank you very much indeed.
 25 A. Thank you.

1 **SIR BRIAN LANGSTAFF:** Thank you for your quiet and calm
 2 courage.
 3 A. Thank you.
 4 **SIR BRIAN LANGSTAFF:** There's no rush. You can stay there
 5 or sit back where you came from, as you wish.
 6 Well, Ms Fraser Butlin, that's the end of the
 7 witness evidence that we have for today.
 8 **MS FRASER BUTLIN:** It is.
 9 **SIR BRIAN LANGSTAFF:** And tomorrow we start at 10.30 and
 10 who are we due to hear from? There is a change, is
 11 there not, to tomorrow's published programme.
 12 **MS FRASER BUTLIN:** There is.
 13 **SIR BRIAN LANGSTAFF:** For reasons I spoke about briefly
 14 this morning.
 15 **MS FRASER BUTLIN:** The witnesses we will be hearing from
 16 are Martin Beard, David Gort and Darren Rawson.
 17 **SIR BRIAN LANGSTAFF:** So was David Gort who is taking what
 18 had been the time in which we had hoped to hear from
 19 Mr Ahearn?
 20 **MS FRASER BUTLIN:** That's correct, sir.
 21 **SIR BRIAN LANGSTAFF:** I am sure everyone here will
 22 understand the reason for the change and sympathise
 23 with Mr Ahearn at this moment. It just remains for me
 24 to say thank you and I look to forward as many of you
 25 as wish to come tomorrow, 10.30.

1 (2.59 pm)
 2 (Adjourned until 10.30 am the following day)
 3

4 **I N D E X**

5	Opening statement by SIR BRIAN LANGSTAFF	1
6	JOHN CORNES, sworn	10
7	Questioned by MS RICHARDS	10
8	GRAHAM BINKS, sworn	46
9	Questioned by MS FRASER BUTLIN	46
10	JO-ANNE COHRS, sworn	67
11	Questioned by MS FRASER BUTLIN	67

12
 13
 14
 15
 16
 17
 18
 19
 20
 21
 22
 23
 24
 25

<p>MS FRASER BUTLIN: [10] 46/9 61/2 61/9 66/19 67/1 67/6 90/8 90/12 90/15 90/20</p> <p>MS RICHARDS: [3] 10/9 10/21 46/2</p> <p>SIR BRIAN LANGSTAFF: [32] 1/4 10/10 10/15 45/16 45/24 46/3 46/7 46/10 61/1 61/3 61/6 61/8 65/7 65/9 65/13 66/4 66/17 66/20 66/24 67/2 88/24 89/2 89/4 89/6 89/18 89/24 90/1 90/4 90/9 90/13 90/17 90/21</p> <p>'</p> <p>'60s [1] 11/23</p> <p>'70s [1] 12/11</p> <p>'80s [1] 36/7</p> <p>'86 [1] 78/1</p> <p>'90s [2] 36/6 36/7</p> <p>'91 [1] 86/14</p> <p>'95 [1] 28/7</p> <p>'Hurray [1] 24/8</p> <p>'s [1] 73/9</p> <p>'shit' [1] 24/7</p> <p>.</p> <p>... [1] 72/6</p> <p>... as [1] 72/6</p> <p>0</p> <p>006 [1] 20/4</p> <p>0288003 [1] 62/19</p> <p>0288005 [1] 60/9</p> <p>1</p> <p>10.30 [3] 90/9 90/25 91/2</p> <p>10.31 [1] 1/2</p> <p>11 [2] 1/1 49/19</p> <p>11.41 [1] 46/4</p> <p>1170002 [1] 13/17</p> <p>1170003 [1] 37/20</p> <p>117002 [1] 15/13</p> <p>117006 [1] 20/3</p> <p>12 [3] 33/17 43/3 49/1</p> <p>12.10 [2] 45/25 46/3</p> <p>12.16 [1] 46/6</p> <p>12.49 [1] 66/21</p> <p>120 miles [1] 31/9</p> <p>13 May [1] 63/11</p> <p>14 [1] 78/2</p> <p>15 [2] 12/21 28/18</p> <p>15 years [2] 46/25 47/10</p> <p>17 [1] 41/21</p> <p>18 [3] 23/7 23/10</p>	<p>46/22</p> <p>18th [1] 47/11</p> <p>1912 [1] 11/17</p> <p>1934 [1] 11/22</p> <p>1970s [1] 68/2</p> <p>1970s/1980s [1] 15/17</p> <p>1972 [2] 47/23 48/5</p> <p>1974 [2] 41/20 48/14</p> <p>1975 [2] 49/18 50/5</p> <p>1978-79 [1] 13/5</p> <p>1979 [3] 13/3 13/20 50/11</p> <p>1980 [4] 13/20 53/12 55/6 67/9</p> <p>1980s [2] 15/17 45/21</p> <p>1983 [1] 67/9</p> <p>1984 [2] 68/15 68/17</p> <p>1985 [1] 72/12</p> <p>1985/1986 [1] 71/11</p> <p>1986 [7] 71/11 75/1 75/18 76/15 77/24 78/14 79/22</p> <p>1987 [4] 79/22 79/23 80/11 82/22</p> <p>1989 [1] 89/4</p> <p>1990 [1] 14/4</p> <p>1990s [3] 15/18 26/25 44/1</p> <p>1991 [1] 86/15</p> <p>1992 [2] 17/2 23/9</p> <p>1994 [5] 20/6 20/10 22/5 22/22 23/9</p> <p>1995 [1] 23/10</p> <p>1996 [1] 38/5</p> <p>1997 [1] 38/6</p> <p>2</p> <p>2.05 [2] 66/18 66/20</p> <p>2.10 [1] 66/23</p> <p>2.59 [1] 91/1</p> <p>20 [2] 18/9 48/24</p> <p>20 years [1] 28/18</p> <p>20-month [1] 60/21</p> <p>2000 [1] 24/14</p> <p>2001 [1] 37/21</p> <p>2004 [1] 38/23</p> <p>2010 [1] 86/17</p> <p>2011 [3] 39/23 43/25 86/17</p> <p>2017 [2] 36/11 36/22</p> <p>2019 [2] 1/1 62/18</p> <p>21 [3] 7/4 8/13 18/9</p> <p>23 [2] 47/1 59/5</p> <p>24 [2] 29/20 29/21</p> <p>24-hour [1] 79/25</p> <p>25 January [1] 55/5</p> <p>25 mile [1] 76/14</p> <p>26 [1] 17/12</p> <p>26 years [1] 20/9</p> <p>27 May [1] 20/16</p> <p>28 [1] 46/23</p> <p>29 January 2001 [1]</p>	<p>37/21</p> <p>3</p> <p>30 [1] 25/3</p> <p>30 minutes [1] 81/9</p> <p>30 years [1] 57/21</p> <p>33 [3] 47/1 55/10 57/19</p> <p>36 [1] 48/21</p> <p>36 hours [1] 54/15</p> <p>37 [1] 48/22</p> <p>39 [1] 40/19</p> <p>39 years [1] 57/21</p> <p>4</p> <p>40 [1] 40/20</p> <p>40 years [2] 63/16 64/23</p> <p>41 [1] 40/20</p> <p>43 [2] 55/8 55/9</p> <p>5</p> <p>5 year [2] 56/8 56/13</p> <p>50 [3] 16/23 21/12 23/24</p> <p>50/50 [2] 16/23 21/12</p> <p>6</p> <p>6 March 1987 [1] 82/22</p> <p>7</p> <p>7 pounds [1] 48/12</p> <p>7 year [1] 56/12</p> <p>79 [1] 13/5</p> <p>8</p> <p>8.45 [1] 32/15</p> <p>81 [1] 14/9</p> <p>82 [1] 14/9</p> <p>83 [1] 14/9</p> <p>84 [1] 14/9</p> <p>85 [1] 26/21</p> <p>8Y [1] 14/5</p> <p>9</p> <p>9 May 2019 [1] 62/18</p> <p>999 [1] 80/23</p> <p>A</p> <p>abide [1] 53/21</p> <p>abiding [1] 54/1</p> <p>ability [1] 42/12</p> <p>able [12] 8/21 9/5 16/4 53/15 56/12 75/13 76/22 76/24 77/1 78/22 79/17 83/20</p> <p>about [118]</p> <p>above [1] 9/12</p> <p>abroad [1] 85/13</p> <p>absolutely [7] 27/14</p>	<p>47/10 49/6 49/23</p> <p>50/24 85/5 86/7</p> <p>accessible [1] 1/24</p> <p>accessing [1] 4/12</p> <p>accident [2] 75/24 76/2</p> <p>accommodate [1] 59/14</p> <p>accommodation [1] 73/22</p> <p>accusations [1] 6/13</p> <p>accused [1] 20/7</p> <p>accusing [1] 7/9</p> <p>acknowledged [1] 62/12</p> <p>across [1] 68/10</p> <p>acting [1] 43/7</p> <p>actions [1] 6/2</p> <p>active [4] 33/8 33/9 60/12 69/23</p> <p>activities [2] 43/6 84/7</p> <p>actual [2] 23/17 28/2</p> <p>actually [23] 16/6 22/10 23/10 24/10 27/11 27/12 30/12 30/15 30/18 40/1 43/16 43/18 43/19 44/12 70/10 70/12 73/5 73/14 83/5 83/12 83/19 84/12 87/21</p> <p>adamant [1] 71/4</p> <p>add [3] 44/17 65/13 65/13</p> <p>Addenbrooke's [6] 68/23 69/8 76/6 76/14 82/8 82/13</p> <p>addressed [1] 66/5</p> <p>Adjourned [1] 91/2</p> <p>adjournment [1] 66/22</p> <p>admiration [1] 64/25</p> <p>admired [1] 25/6</p> <p>admit [2] 76/4 81/3</p> <p>admitted [2] 76/7 76/12</p> <p>admitting [1] 40/18</p> <p>advanced [1] 51/16</p> <p>advantage [1] 2/16</p> <p>advertised [1] 58/2</p> <p>advice [3] 14/11 14/13 15/1</p> <p>advised [3] 48/17 48/18 61/16</p> <p>advising [1] 21/7</p> <p>aeroplane [2] 51/24 52/1</p> <p>affair [1] 86/25</p> <p>affect [9] 14/14 14/19 19/22 28/20 28/21 39/11 39/23 40/9 72/22</p>	<p>affected [8] 1/10 24/21 25/2 25/4 31/22 42/6 64/12 71/9</p> <p>affording [1] 64/18</p> <p>after [44] 1/18 13/12 18/10 18/11 22/7 22/9 22/10 25/20 25/24 26/10 28/11 31/11 39/18 48/5 48/13 48/14 48/17 49/1 49/7 49/10 50/5 52/14 57/24 58/15 60/21 61/20 65/19 66/6 68/15 69/5 69/10 72/25 73/12 73/24 75/14 75/15 82/24 83/15 84/6 85/7 86/1 86/9 87/8 87/10</p> <p>after-effects [1] 1/18</p> <p>aftermath [1] 41/15</p> <p>afternoon [1] 51/8</p> <p>again [20] 14/2 29/12 29/14 30/6 33/23 37/8 38/23 41/6 48/15 48/25 49/10 51/11 54/4 62/18 62/20 73/25 74/1 80/15 82/19 84/2</p> <p>age [4] 12/21 48/21 57/19 59/12</p> <p>aged [1] 52/25</p> <p>aggressive [2] 49/16 50/19</p> <p>ago [11] 2/13 9/20 13/11 19/3 20/11 21/9 30/5 31/18 45/1 63/17 77/2</p> <p>ahead [2] 75/13 75/15</p> <p>Ahearn [2] 90/19 90/23</p> <p>AIDS [21] 17/8 17/9 18/22 19/4 20/8 20/10 22/21 24/3 40/25 42/4 45/20 68/21 69/6 70/24 83/3 83/22 84/5 84/9 84/24 89/3 89/19</p> <p>AIDSelwell [1] 19/1</p> <p>Alan [7] 35/24 36/1 36/2 36/2 36/4 36/11 36/19</p> <p>Albert [1] 43/9</p> <p>alcoholics [1] 56/10</p> <p>alive [3] 20/21 26/20 26/22</p> <p>all [77] 3/3 3/14 5/14 6/9 6/9 6/10 6/23 7/1 9/12 9/15 11/7 11/19 12/8 15/22 16/3 16/5 16/9 19/4 19/5 19/15 19/17 19/24 20/20 21/10 22/25 23/2 23/4 23/7 23/10 23/25 24/2</p>	<p>24/17 25/7 26/11 27/14 28/21 29/11 30/14 30/16 31/15 35/11 35/12 36/15 38/14 39/12 39/15 40/10 43/6 43/9 43/10 44/11 44/14 45/17 45/19 46/16 47/5 51/3 51/19 56/6 56/6 58/21 64/17 64/25 70/2 70/9 74/23 74/23 75/12 76/19 79/6 81/25 82/3 82/16 83/4 83/20 85/25 89/21</p> <p>allegations [1] 20/19</p> <p>alleging [1] 64/1</p> <p>allow [4] 8/13 29/2 30/20 76/12</p> <p>allowance [4] 78/17 79/12 79/15 87/11</p> <p>allowed [4] 24/12 72/17 74/24 74/24</p> <p>along [1] 35/21</p> <p>already [7] 2/23 2/25 5/10 58/5 68/22 75/5 83/6</p> <p>also [16] 9/23 25/4 29/22 34/14 36/17 41/10 44/20 58/17 58/25 59/21 63/5 71/11 77/3 85/3 85/11 86/16</p> <p>although [5] 15/17 27/17 35/11 59/23 71/8</p> <p>altogether [2] 33/17 85/21</p> <p>always [21] 11/25 17/18 25/21 25/22 26/12 26/13 28/24 29/18 30/7 35/9 35/10 35/16 36/9 37/17 39/4 42/14 42/16 56/21 69/20 78/8 78/9</p> <p>am [40] 1/2 2/21 9/5 9/6 9/14 9/21 18/9 20/20 25/3 28/23 29/15 29/20 30/6 30/22 32/18 33/6 33/15 33/24 35/3 38/7 42/21 43/2 43/9 44/22 44/23 45/12 46/4 56/16 57/22 60/19 61/13 63/25 64/1 64/10 67/8 67/23 88/4 88/21 90/21 91/2</p> <p>amazement [2] 54/11 86/3</p> <p>ambulance [6] 32/21 54/1 76/13 82/10 82/18 88/9</p> <p>ambulancemen [3] 80/24 81/15 82/19</p>
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<p>A</p> <p>America [3] 86/20 86/24 87/1</p> <p>amount [1] 53/16</p> <p>amounts [1] 53/8</p> <p>an accident [1] 75/24</p> <p>an aeroplane [1] 51/24</p> <p>an AIDS [2] 89/3 89/19</p> <p>an AIDS-related [2] 17/8 20/10</p> <p>an ambulance [3] 32/21 54/1 76/13</p> <p>an ancillary [1] 46/22</p> <p>an appointment [1] 78/7</p> <p>an arrangement [1] 46/19</p> <p>an article [1] 83/1</p> <p>an attorney [1] 87/1</p> <p>an attractive [1] 47/5</p> <p>an authority [1] 60/1</p> <p>an awful [2] 68/18 88/3</p> <p>an emergency [1] 76/9</p> <p>an end [3] 51/20 85/22 87/11</p> <p>an evening [1] 32/16</p> <p>an example [1] 8/18</p> <p>an exceptional [1] 47/4</p> <p>an explanation [1] 6/2</p> <p>an extremely [1] 53/20</p> <p>an hour [1] 31/9</p> <p>an idiot [1] 59/7</p> <p>an important [1] 9/25</p> <p>an increasing [1] 53/16</p> <p>an Inquiry [2] 1/21 1/22</p> <p>an oath [1] 56/6</p> <p>an officer [1] 78/19</p> <p>an ongoing [1] 66/7</p> <p>an opinion [1] 76/24</p> <p>an ordinary [2] 23/19 23/22</p> <p>analysing [1] 61/25</p> <p>analysis [1] 64/8</p> <p>ancillary [1] 46/22</p> <p>angry [2] 76/5 77/10</p> <p>ankle [1] 11/12</p> <p>ankles [1] 13/12</p> <p>Anne [8] 67/1 67/2 67/2 67/4 67/6 67/13 67/23 91/10</p> <p>anonymous [1] 7/7</p> <p>another [8] 6/9 13/24 28/2 33/16 37/9 38/22</p>	<p>73/7 81/5</p> <p>answer [6] 1/6 56/17 56/19 70/3 78/22 85/25</p> <p>answered [1] 9/9</p> <p>anti [1] 72/22</p> <p>anti-fungals [1] 72/22</p> <p>antiseptic [1] 81/13</p> <p>anxiety [2] 37/2 38/13</p> <p>any [40] 6/19 7/10 8/1 8/11 9/8 14/11 15/1 21/13 38/18 40/16 41/6 41/11 42/14 43/13 44/1 44/1 44/2 44/5 49/5 49/25 56/9 56/16 63/2 63/8 64/8 66/14 71/5 74/11 75/11 75/16 78/5 78/7 83/7 83/12 85/17 85/18 86/12 86/13 87/5 88/22</p> <p>anybody [8] 12/4 12/7 32/5 50/21 52/14 54/13 84/15 84/17</p> <p>anymore [1] 27/18</p> <p>anyone [5] 4/4 8/4 47/12 47/13 65/19</p> <p>anything [24] 13/6 14/11 14/15 14/16 17/20 21/12 24/2 27/11 33/21 43/15 44/17 45/13 50/2 50/17 61/19 63/22 66/4 70/8 71/6 77/17 78/8 79/4 86/9 88/2</p> <p>anyway [1] 52/7</p> <p>anywhere [1] 85/19</p> <p>apart [4] 18/19 23/7 23/11 30/21</p> <p>apartment [1] 73/8</p> <p>apparently [3] 25/23 32/25 33/20</p> <p>appear [1] 38/9</p> <p>appearing [1] 33/1</p> <p>appears [1] 6/18</p> <p>application [2] 62/12 78/20</p> <p>applications [2] 43/12 43/14</p> <p>applied [5] 61/3 61/12 73/3 78/17 85/23</p> <p>apply [1] 86/23</p> <p>appointed [2] 9/19 86/24</p> <p>appointment [1] 78/7</p> <p>appreciate [3] 44/18 44/19 44/25</p> <p>appreciative [3] 6/7 6/9 9/6</p> <p>approach [1] 61/16</p> <p>approached [2] 61/13 62/7</p>	<p>appropriate [1] 6/16</p> <p>approximate [1] 15/15</p> <p>approximately [1] 49/21</p> <p>April [2] 32/12 32/15</p> <p>April 3 [1] 32/15</p> <p>are [79] 1/25 1/25 2/5 2/22 3/6 3/14 3/14 3/18 3/19 4/4 4/6 4/25 5/5 6/6 6/9 6/10 7/8 7/25 8/5 8/10 9/10 10/24 11/6 13/20 14/2 14/4 16/1 16/18 23/19 23/20 23/21 23/21 23/25 24/11 24/17 29/11 34/11 35/5 35/8 35/8 35/11 35/12 35/19 35/21 37/1 37/15 37/23 38/14 39/10 40/21 44/15 45/5 45/7 45/25 46/13 51/9 51/24 59/12 60/1 61/14 61/21 61/25 62/1 62/15 63/15 63/16 63/21 65/9 65/22 67/15 67/23 67/24 76/2 77/13 79/2 87/5 88/1 90/10 90/16</p> <p>area [5] 40/24 40/25 41/19 73/15 84/25</p> <p>aren't [1] 47/14</p> <p>arose [1] 83/24</p> <p>around [4] 23/13 31/16 47/14 69/16</p> <p>arrange [1] 6/23</p> <p>arranged [1] 76/13</p> <p>arrangement [1] 46/19</p> <p>arrangements [1] 4/15</p> <p>arrival [1] 49/7</p> <p>arthritis [1] 34/15</p> <p>article [3] 22/3 83/1 83/24</p> <p>as [120]</p> <p>Asda [1] 60/2</p> <p>ask [20] 1/5 6/10 7/23 8/2 14/17 14/18 15/22 24/1 27/14 27/22 31/24 37/5 39/16 45/12 65/25 79/1 79/5 79/5 88/21 88/25</p> <p>asked [6] 19/2 28/15 34/6 56/15 74/17 84/10</p> <p>asking [2] 8/4 8/10</p> <p>assist [1] 4/6</p> <p>assistance [1] 34/18</p> <p>assume [1] 64/14</p> <p>assumed [3] 48/20 59/7 59/11</p>	<p>atmosphere [2] 41/22 42/1</p> <p>attack [2] 25/20 26/3</p> <p>attempts [1] 62/13</p> <p>attended [1] 12/22</p> <p>attention [3] 9/14 23/14 23/17</p> <p>attitude [1] 11/18</p> <p>attorney [1] 87/1</p> <p>attracted [1] 2/2</p> <p>attractive [1] 47/5</p> <p>attribute [1] 5/24</p> <p>attributed [1] 50/19</p> <p>aunty [1] 26/1</p> <p>authorities [1] 84/17</p> <p>authority [9] 60/1 60/20 73/6 73/20 83/3 83/8 83/19 83/19 85/3</p> <p>autumn [2] 75/18 79/22</p> <p>available [9] 15/17 39/13 50/23 51/1 51/3 52/17 58/10 61/22 63/13</p> <p>avoid [1] 14/24</p> <p>awarded [1] 87/4</p> <p>aware [12] 15/4 27/25 28/9 37/14 37/23 49/5 50/4 50/21 62/11 76/21 83/3 87/5</p> <p>awareness [1] 53/9</p> <p>away [12] 10/4 17/20 17/22 19/10 51/8 51/9 55/18 55/18 65/8 76/11 76/14 81/7</p> <p>awful [2] 68/18 88/3</p> <p>AWOL [2] 17/15 17/17</p>	<p>bags [3] 18/21 83/10 83/14</p> <p>balloon [2] 54/23 55/3</p> <p>bank [1] 59/6</p> <p>barrier [1] 74/18</p> <p>basically [4] 48/20 54/20 57/12 58/1</p> <p>batch [2] 14/3 14/9</p> <p>batches [3] 38/4 38/10 38/24</p> <p>battle [1] 85/3</p> <p>be [109]</p> <p>bear [3] 3/4 9/10 62/14</p> <p>Beard [1] 90/16</p> <p>beaten [1] 41/24</p> <p>became [13] 17/17 17/19 26/9 26/14 26/19 48/7 49/8 50/8 51/13 59/25 84/24 84/24 85/20</p> <p>because [84] 1/10 5/18 7/8 9/11 10/4 11/19 12/15 16/8 16/22 19/1 19/11 21/1 21/10 21/17 22/8 22/13 22/20 23/16 24/22 25/21 26/22 28/3 28/14 29/18 29/20 30/15 30/19 30/20 31/8 32/5 33/6 33/10 33/15 33/25 34/21 37/2 40/2 40/23 41/4 41/20 41/23 42/19 42/19 42/23 43/2 43/4 43/10 44/13 45/6 45/18 47/4 48/21 48/21 49/22 51/13 51/14 53/5 53/20 54/6 58/2 58/9 58/17 61/20 62/9 62/20 64/10 65/16 69/15 70/23 73/14 74/9 74/15 75/6 75/15 76/9 76/19 77/7 78/25 79/12 82/17 83/24 85/21 87/19 88/17</p> <p>become [2] 19/12 56/10</p> <p>becoming [1] 79/6</p> <p>bed [10] 13/9 14/24 25/25 52/20 52/22 53/8 80/6 81/16 82/15 82/16</p> <p>bedrooms [1] 59/15</p> <p>been [63] 1/13 2/3 7/4 9/4 10/3 16/12 16/13 16/16 16/17 20/20 23/17 25/7 25/8 26/6 27/1 28/1 29/18 30/7 31/18 32/16 33/14 34/22 34/23 35/10</p>	<p>36/5 36/13 37/17 38/3 39/4 39/4 39/12 40/21 42/10 42/14 42/16 42/18 45/3 45/18 45/20 49/1 51/1 51/2 56/21 57/2 58/3 58/6 59/16 63/2 64/12 64/20 66/6 68/14 70/11 70/12 72/21 75/18 78/11 78/25 85/9 88/16 88/18 88/19 90/18</p> <p>before [29] 7/4 7/22 8/13 13/13 18/16 21/2 21/4 25/17 26/6 26/10 27/11 27/15 28/2 34/10 46/20 51/3 52/19 53/2 61/24 62/24 68/7 76/15 77/6 77/12 78/24 79/15 83/1 83/24 86/10</p> <p>beforehand [1] 13/4</p> <p>began [2] 3/7 53/23</p> <p>beginning [1] 34/23</p> <p>behalf [1] 10/25</p> <p>behind [1] 17/3</p> <p>being [40] 2/16 3/8 3/10 3/11 6/13 7/20 9/11 11/13 14/24 15/15 23/18 23/21 24/8 27/19 28/9 28/25 29/19 29/21 30/10 33/5 33/8 33/22 47/19 54/9 54/12 60/22 60/22 62/2 63/6 70/5 73/19 76/21 76/21 76/22 76/24 77/1 79/2 84/7 87/13 87/24</p> <p>Belfast [2] 4/22 4/25</p> <p>believe [5] 39/25 47/9 54/13 71/13 73/9</p> <p>believed [1] 72/6</p> <p>beneficial [1] 80/9</p> <p>benefits [1] 86/5</p> <p>beside [1] 3/25</p> <p>besides [2] 17/10 47/4</p> <p>best [6] 7/24 40/21 42/21 52/14 60/17 61/14</p> <p>between [2] 17/16 54/9</p> <p>big [8] 11/6 12/1 25/15 25/16 28/4 58/8 73/7 89/21</p> <p>bigger [1] 18/7</p> <p>binding [1] 10/17</p> <p>Binks [3] 46/1 46/11 91/8</p> <p>bio [1] 38/4</p> <p>bio-products [1] 38/4</p> <p>biopsy [5] 27/13 28/2</p>
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(25) America - biopsy

<p>B</p> <p>biopsy... [3] 28/12 49/14 49/14</p> <p>Birmingham [10] 2/20 18/21 18/24 31/12 31/16 37/21 41/15 41/22 41/25 42/2</p> <p>birth [5] 48/5 48/14 48/17 49/10 64/5</p> <p>birthday [1] 47/11</p> <p>bit [17] 2/18 3/16 12/13 25/14 32/23 34/9 37/17 39/5 47/2 47/18 52/19 52/21 57/14 67/14 68/24 81/13 87/22</p> <p>bits [1] 81/8</p> <p>blackberry [1] 87/24</p> <p>blacked [1] 6/16</p> <p>blah [13] 27/25 27/25 27/25 29/22 29/22 29/22 29/22 40/25 40/25 40/25 43/20 43/20 43/20</p> <p>blame [2] 5/25 5/25</p> <p>bleed [1] 39/6</p> <p>bleeding [2] 13/10 60/11</p> <p>bleeds [5] 11/11 11/12 11/12 13/11 28/24</p> <p>blood [28] 1/10 1/11 6/3 6/4 13/12 13/13 25/7 30/17 32/20 32/24 38/6 45/2 48/6 48/11 48/15 48/25 53/21 53/24 54/11 54/24 54/24 60/4 62/4 64/3 64/6 75/20 75/24 76/3</p> <p>blush [1] 6/19</p> <p>body [1] 88/15</p> <p>bombings [3] 41/16 41/20 42/6</p> <p>book [3] 33/7 88/25 89/7</p> <p>books [1] 70/23</p> <p>boost [1] 75/9</p> <p>boot [1] 69/18</p> <p>bore [1] 70/10</p> <p>born [3] 11/17 11/22 48/10</p> <p>boss [1] 34/24</p> <p>both [16] 7/14 12/25 48/10 48/12 51/21 57/4 57/7 64/18 64/19 69/12 69/25 72/4 75/23 75/24 78/11 85/9</p> <p>bottom [1] 22/3</p> <p>bought [1] 54/7</p>	<p>boxes [1] 70/9</p> <p>boys [1] 48/1</p> <p>BPL [1] 13/21</p> <p>brain [2] 36/16 37/25</p> <p>brave [2] 51/19 52/12</p> <p>bravery [1] 45/22</p> <p>break [5] 45/24 46/5 58/23 66/18 77/12</p> <p>breakdown [4] 17/15 30/3 39/21 43/24</p> <p>breakfast [1] 65/5</p> <p>breakthrough [1] 14/22</p> <p>breath [1] 82/17</p> <p>breathing [1] 82/17</p> <p>BRIAN [3] 1/3 64/16 91/5</p> <p>brief [2] 63/23 63/24</p> <p>briefly [2] 81/18 90/13</p> <p>brilliant [1] 43/8</p> <p>bring [6] 5/24 19/20 32/18 70/15 71/8 81/15</p> <p>bringing [3] 32/24 78/6 78/8</p> <p>broke [2] 39/19 87/22</p> <p>bronchopneumonia [1] 60/11</p> <p>brother [16] 12/9 14/23 15/24 17/12 18/5 22/4 22/14 31/5 35/24 36/2 36/4 36/18 47/8 54/8 86/20 86/21</p> <p>brother's [3] 18/18 39/19 40/13</p> <p>brothers [13] 4/2 12/22 15/23 16/20 18/8 23/2 24/23 25/1 27/4 29/10 35/18 35/20 44/5</p> <p>brought [4] 2/8 11/18 26/23 43/19</p> <p>buds [1] 72/23</p> <p>bugger [1] 44/24</p> <p>building [1] 8/3</p> <p>built [1] 58/13</p> <p>bungalow [1] 73/7</p> <p>burst [1] 33/16</p> <p>bush [1] 87/24</p> <p>bushes [2] 23/23 23/24</p> <p>business [1] 53/20</p> <p>busy [1] 69/23</p> <p>but [138]</p> <p>Butlin [8] 46/7 46/12 66/17 66/24 67/5 90/6 91/9 91/11</p> <p>buying [1] 42/18</p> <p>by [45] 1/3 1/10 1/13 2/24 5/11 5/17 6/24 7/3 7/9 7/11 9/4 10/12 14/10 18/25 19/14</p>	<p>20/24 27/18 38/3 38/5 42/6 46/12 49/13 49/14 49/19 53/22 54/25 57/7 60/14 62/20 62/22 63/11 67/5 69/18 70/5 74/17 74/22 78/14 78/19 80/4 80/24 81/8 91/5 91/7 91/9 91/11</p> <p>C</p> <p>call [9] 18/25 18/25 31/7 44/9 61/18 71/24 78/4 80/23 84/22</p> <p>called [8] 1/13 32/21 54/1 54/21 58/4 62/21 89/2 89/18</p> <p>calling [1] 78/8</p> <p>calls [1] 76/6</p> <p>calm [1] 90/1</p> <p>came [24] 1/8 12/19 16/5 18/17 24/6 28/6 29/13 31/4 32/19 44/11 52/21 68/10 68/13 72/3 72/19 75/25 76/3 80/24 82/1 82/10 82/18 85/22 88/10 90/5</p> <p>cameras [1] 8/1</p> <p>camping [1] 68/5</p> <p>can [71] 3/23 4/5 5/19 5/20 6/24 7/24 11/1 11/4 11/16 12/9 13/6 13/19 13/22 14/1 14/2 14/11 15/14 15/25 16/4 20/22 22/16 28/15 28/19 29/4 30/5 30/24 31/24 33/18 33/20 33/22 34/6 34/10 37/6 39/16 41/21 42/2 42/4 42/5 46/16 47/2 47/14 49/8 51/4 52/9 52/15 53/12 56/9 58/25 59/13 60/9 61/11 65/8 65/18 67/11 67/15 67/25 68/12 68/12 70/15 70/15 71/2 72/13 75/25 76/16 77/25 78/18 79/12 80/14 82/25 85/6 90/4</p> <p>can't [14] 5/2 8/22 27/5 28/1 30/19 30/19 31/17 34/8 43/5 43/5 45/18 49/11 50/17 60/3</p> <p>cancer [4] 16/3 34/4 34/5 34/9</p> <p>candidate [1] 51/2</p> <p>Cannock [3] 31/5 31/6 31/10</p> <p>canteen [1] 65/5</p>	<p>capable [2] 12/2 76/21</p> <p>capital [3] 2/6 2/10 4/24</p> <p>car [1] 30/9</p> <p>Cardiff [2] 4/23 5/1</p> <p>care [9] 12/17 12/19 53/22 61/17 72/16 74/16 79/3 79/25 88/17</p> <p>cared [3] 74/3 74/9 79/2</p> <p>careers [1] 57/5</p> <p>careful [1] 8/7</p> <p>carer's [1] 78/17</p> <p>cares [1] 89/10</p> <p>caress [1] 74/12</p> <p>caring [5] 20/18 70/25 88/6 88/15 89/17</p> <p>carpet [1] 53/23</p> <p>carried [2] 29/17 34/16</p> <p>carry [5] 16/10 29/18 33/18 35/6 77/12</p> <p>case [4] 12/19 12/25 66/13 81/4</p> <p>cases [2] 7/1 7/2</p> <p>cast [1] 64/9</p> <p>cat [2] 78/8 80/5</p> <p>cause [2] 50/20 60/9</p> <p>caused [4] 1/11 29/23 60/18 63/18</p> <p>causes [2] 11/12 34/15</p> <p>cautious [1] 67/16</p> <p>ceased [1] 58/15</p> <p>celebrities [1] 23/20</p> <p>celebrity [1] 23/21</p> <p>cells [3] 75/7 75/10 75/17</p> <p>cemetery [1] 24/6</p> <p>central [3] 2/16 2/20 3/1</p> <p>centre [4] 3/19 23/17 38/21 85/12</p> <p>centres [1] 5/6</p> <p>cerebral [1] 76/2</p> <p>certain [4] 41/17 52/8 61/21 62/16</p> <p>certainly [2] 57/2 60/20</p> <p>certificate [3] 17/9 36/24 60/7</p> <p>chair [1] 73/13</p> <p>change [5] 8/17 41/3 58/8 90/10 90/22</p> <p>changed [9] 19/11 40/15 40/17 41/3 41/8 41/10 77/11 79/1 84/13</p> <p>changes [1] 77/3</p> <p>changing [1] 64/7</p>	<p>chap [1] 37/14</p> <p>Chapman [1] 58/4</p> <p>character [2] 12/14 25/14</p> <p>chase [1] 62/13</p> <p>checked [1] 38/8</p> <p>checks [1] 32/10</p> <p>cheerful [1] 78/23</p> <p>child [5] 11/7 11/15 16/22 48/22 71/8</p> <p>childhood [1] 13/5</p> <p>children [13] 12/17 35/5 36/23 40/7 40/9 40/11 43/10 47/17 48/19 51/18 51/22 54/2 57/15</p> <p>children's [2] 11/8 12/18</p> <p>chill [1] 33/7</p> <p>choice [1] 2/12</p> <p>chosen [1] 57/6</p> <p>Chris [1] 56/19</p> <p>Christ [1] 45/7</p> <p>Christian [3] 78/10 84/11 89/11</p> <p>Christmas [5] 16/24 22/22 69/1 69/5 69/11</p> <p>chronic [3] 49/16 50/19 60/12</p> <p>chronically [1] 60/23</p> <p>chuffed [1] 32/4</p> <p>church [6] 69/23 77/24 78/1 87/16 88/12 88/15</p> <p>circumstances [4] 10/19 15/11 64/12 76/21</p> <p>cirrhosis [2] 32/8 43/17</p> <p>city [4] 2/5 2/5 2/6 2/12</p> <p>CJD [3] 37/15 37/23 38/7</p> <p>claim [2] 43/15 43/17</p> <p>classed [1] 11/3</p> <p>cleaning [2] 58/12 80/7</p> <p>clear [5] 51/13 62/14 62/25 63/25 65/18</p> <p>cleared [5] 10/4 32/4 32/7 36/3 36/4</p> <p>clearing [1] 32/2</p> <p>clever [1] 76/20</p> <p>clip [1] 12/10</p> <p>close [2] 1/20 58/5</p> <p>closeness [1] 42/4</p> <p>closer [1] 67/14</p> <p>clothing [1] 58/7</p> <p>coaster [1] 62/2</p> <p>cognitive [1] 76/16</p> <p>COHRS [2] 67/4 91/10</p> <p>coin [1] 7/15</p>	<p>cold [1] 13/10</p> <p>collapsed [3] 36/15 36/21 87/21</p> <p>colleagues [2] 62/10 86/3</p> <p>collect [1] 58/11</p> <p>Collectively [1] 89/21</p> <p>college [1] 69/19</p> <p>coma [1] 54/9</p> <p>come [32] 1/5 1/21 7/2 8/20 10/10 10/21 13/16 14/18 15/11 19/9 25/5 26/8 27/23 30/22 31/3 33/19 37/9 37/11 44/20 52/5 57/8 58/17 67/2 69/7 71/12 76/13 80/25 83/25 86/19 87/11 87/18 90/25</p> <p>comes [5] 6/25 7/22 8/14 23/20 65/19</p> <p>comfortable [2] 10/18 57/3</p> <p>coming [11] 12/2 12/5 21/5 21/19 25/8 31/13 45/17 51/17 54/24 67/14 68/25</p> <p>comment [3] 24/8 24/10 24/11</p> <p>commitments [1] 85/18</p> <p>committed [1] 2/21</p> <p>communicated [1] 28/7</p> <p>community [5] 42/6 67/19 77/24 85/1 89/17</p> <p>companies [2] 42/17 42/17</p> <p>compassionate [1] 89/11</p> <p>complaints [1] 39/3</p> <p>complement [1] 69/22</p> <p>complete [1] 5/19</p> <p>completely [2] 11/25 35/12</p> <p>complicated [1] 64/15</p> <p>complimented [1] 69/25</p> <p>concentrate [1] 38/5</p> <p>concentrates [3] 13/1 14/4 51/20</p> <p>concern [1] 63/18</p> <p>concerned [1] 72/8</p> <p>concerning [1] 72/6</p> <p>concluded [1] 5/12</p> <p>conclusion [3] 3/12 45/10 63/24</p> <p>conclusions [1] 9/11</p> <p>concrete [1] 63/2</p> <p>condemn [1] 84/12</p> <p>condition [4] 50/16</p>
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(26) biopsy... - condition

<p>C</p> <p>condition... [3] 51/13 78/25 79/24</p> <p>confirmed [2] 49/14 61/18</p> <p>confused [5] 69/16 70/1 79/6 80/1 80/15</p> <p>connected [1] 68/22</p> <p>conscious [1] 67/23</p> <p>consciousness [1] 82/20</p> <p>consequence [3] 15/6 23/3 40/13</p> <p>consequences [2] 9/7 20/25</p> <p>consequently [1] 56/25</p> <p>conservative [4] 67/12 67/16 69/24 77/8</p> <p>considerably [1] 74/4</p> <p>considerate [1] 77/8</p> <p>consultant [2] 68/25 74/17</p> <p>consultants [1] 65/3</p> <p>consultation [1] 71/13</p> <p>consultations [1] 70/19</p> <p>contact [1] 38/20</p> <p>contacted [5] 61/22 61/23 73/23 81/25 86/21</p> <p>contacts [1] 84/22</p> <p>contained [1] 38/6</p> <p>contaminated [2] 75/5 75/9</p> <p>content [1] 80/5</p> <p>continue [2] 5/4 5/4</p> <p>continued [1] 50/11</p> <p>contract [1] 60/18</p> <p>contracted [4] 20/12 24/13 60/15 73/24</p> <p>contrasting [1] 26/6</p> <p>contribute [1] 64/14</p> <p>contribution [1] 36/25</p> <p>control [1] 21/17</p> <p>controlled [1] 77/9</p> <p>conversation [2] 76/22 77/16</p> <p>convinced [2] 20/21 37/1</p> <p>cope [1] 84/7</p> <p>coped [1] 51/4</p> <p>copy [2] 27/17 62/19</p> <p>core [1] 2/12</p> <p>Cornes [5] 10/3 10/11 41/5 42/4 91/6</p> <p>correct [16] 10/23 11/2 12/21 12/24 13/2 14/6 14/25 15/8 15/21</p>	<p>16/15 18/1 22/2 27/22 28/13 46/9 90/20</p> <p>correctly [1] 48/20</p> <p>costs [1] 85/20</p> <p>coughing [1] 32/17</p> <p>could [32] 9/2 12/11 13/17 14/14 14/19 21/8 21/11 21/23 22/15 25/18 27/22 34/4 34/5 37/11 43/15 43/17 54/13 61/16 67/2 71/25 72/18 77/5 77/11 80/5 81/9 83/5 83/17 84/22 84/23 86/23 87/1 89/21</p> <p>couldn't [4] 39/25 56/14 85/16 87/2</p> <p>council [2] 73/10 83/2</p> <p>counselling [5] 43/23 44/2 87/6 87/15 87/17</p> <p>country [3] 2/10 52/8 70/24</p> <p>couple [8] 13/24 19/3 19/15 31/19 37/19 56/23 71/4 75/14</p> <p>courage [1] 90/2</p> <p>course [8] 9/8 29/25 32/2 39/22 51/23 53/11 61/2 82/18</p> <p>crash [2] 51/25 52/1</p> <p>crew [1] 82/10</p> <p>cricket [1] 67/21</p> <p>cried [2] 69/14 88/8</p> <p>crier [2] 33/24 33/24</p> <p>crimson [1] 53/23</p> <p>criticise [3] 6/6 6/8 6/20</p> <p>criticised [1] 6/21</p> <p>criticising [1] 64/1</p> <p>criticism [5] 7/3 7/5 7/6 7/17 9/8</p> <p>Cross [3] 4/6 4/11 4/12</p> <p>crumbled [1] 26/9</p> <p>cry [4] 33/23 33/24 44/21 88/7</p> <p>crying [2] 16/9 30/5</p> <p>Cryo [1] 13/22</p> <p>cryoprecipitate [3] 13/1 13/13 14/2</p> <p>cuddle [1] 74/12</p> <p>cultures [1] 68/9</p> <p>cure [1] 16/4</p> <p>cures [1] 22/21</p> <p>cut [1] 85/16</p>	<p>dare [1] 74/14</p> <p>Darren [1] 90/16</p> <p>date [4] 15/15 49/12 51/20 63/2</p> <p>dates [1] 13/23</p> <p>daughter [3] 32/21 40/19 43/6</p> <p>daughter's [1] 36/14</p> <p>daughters [1] 40/10</p> <p>David [2] 90/16 90/17</p> <p>Dawson [1] 25/14</p> <p>Dawson's [1] 12/13</p> <p>day [29] 16/4 16/8 19/16 26/15 26/16 29/21 30/12 31/18 31/18 33/18 34/4 34/20 36/17 36/18 36/19 42/22 42/22 43/17 52/20 56/22 78/3 78/4 78/24 82/14 83/24 85/12 88/4 88/4 91/2</p> <p>day-to-day [1] 88/4</p> <p>daylights [1] 12/15</p> <p>days [14] 7/4 8/13 13/9 19/7 28/3 33/3 33/12 49/1 50/22 54/7 56/23 60/1 62/22 83/22</p> <p>dead [1] 58/3</p> <p>dead' [1] 24/8</p> <p>deal [2] 1/8 53/20</p> <p>dealt [2] 4/11 64/20</p> <p>death [19] 17/8 17/13 20/15 22/4 26/5 36/23 37/1 39/19 39/19 47/11 52/10 56/13 57/21 60/7 60/10 82/25 85/7 87/8 87/10</p> <p>deaths [1] 23/13</p> <p>debilitating [1] 72/15</p> <p>deceased [1] 62/16</p> <p>December [1] 23/10</p> <p>December 1995 [1] 23/10</p> <p>decent [1] 59/25</p> <p>decided [1] 75/14</p> <p>decision [3] 53/22 54/5 54/6</p> <p>declined [1] 85/15</p> <p>decorated [1] 73/13</p> <p>deeply [3] 6/6 6/9 9/5</p> <p>definitely [2] 37/4 86/7</p> <p>degree [1] 67/18</p> <p>delay [1] 63/18</p> <p>delivered [1] 49/2</p> <p>delivery [3] 48/13 62/23 63/12</p> <p>demands [1] 6/15</p> <p>demise [1] 88/7</p> <p>deny [1] 22/11</p>	<p>department [1] 81/13</p> <p>departments [1] 44/10</p> <p>depressing [1] 52/2</p> <p>depression [2] 29/23 30/22</p> <p>deprived [1] 56/24</p> <p>descending [1] 51/25</p> <p>describe [1] 42/2</p> <p>described [20] 12/1 12/18 17/14 23/12 27/19 30/1 34/14 39/18 39/21 41/13 42/10 49/15 55/16 73/19 77/3 77/19 84/6 85/4 87/13 87/23</p> <p>deserve [1] 35/2</p> <p>deserves [1] 1/14</p> <p>desk [1] 71/15</p> <p>desperate [1] 75/12</p> <p>despite [5] 2/11 51/17 62/11 62/13 68/6</p> <p>detached [2] 17/25 27/20</p> <p>detail [1] 14/8</p> <p>details [2] 30/25 56/22</p> <p>deteriorated [1] 53/14</p> <p>deterioration [1] 50/7</p> <p>determined [1] 35/6</p> <p>devastated [1] 22/25</p> <p>devastating [1] 59/3</p> <p>develop [1] 64/6</p> <p>developed [1] 38/7</p> <p>devoted [1] 47/15</p> <p>diabetes [1] 34/14</p> <p>diabetic [1] 29/20</p> <p>diagnosed [1] 49/13</p> <p>diagnosis [4] 27/17 28/6 49/13 49/24</p> <p>diarrhoea [1] 85/22</p> <p>did [80] 2/11 3/3 6/2 6/7 9/16 9/17 19/6 19/19 19/21 21/1 21/2 21/22 21/25 22/10 22/25 24/12 24/19 28/21 30/21 30/22 31/3 32/2 32/22 33/23 33/24 39/23 40/9 41/7 46/24 52/16 54/10 54/14 55/25 58/12 59/24 61/3 61/15 67/10 68/4 68/7 69/2 69/4 69/12 70/1 70/19 70/21 71/3 71/12 71/18 73/23 74/16 76/9 77/4 78/4 78/4 78/5 78/6 78/7 79/5 79/5 79/8 79/21 80/13 81/20 82/9 82/23 84/2 84/21 85/11 86/9 86/11 86/18 86/19</p>	<p>86/25 87/12 88/3 88/25 89/1 89/12 89/13</p> <p>didn't [60] 14/15 14/17 14/18 14/18 17/24 20/24 21/12 24/1 24/17 25/4 25/5 26/15 28/15 28/17 29/8 29/11 29/24 36/20 37/9 37/9 40/2 43/15 44/18 45/1 45/16 53/22 54/12 57/12 61/6 62/16 68/21 69/2 69/14 70/7 70/7 71/8 71/20 72/4 72/23 73/11 75/11 75/11 75/11 75/15 75/16 77/11 79/7 79/25 80/2 80/18 82/21 83/5 83/20 83/20 84/3 85/9 85/18 86/2 86/3 87/18</p> <p>die [11] 5/4 16/7 18/8 21/2 22/16 24/17 31/8 35/17 53/19 55/2 69/6</p> <p>died [42] 1/9 16/24 17/1 17/9 17/11 18/10 18/15 18/16 20/9 21/2 22/22 23/4 23/10 24/4 24/14 25/1 25/17 25/21 26/2 26/10 35/25 36/18 36/18 36/19 36/22 36/24 37/14 37/15 53/1 53/3 54/18 55/4 55/14 76/16 79/20 82/22 82/24 83/15 84/5 84/6 85/7 86/9</p> <p>dies [1] 20/8</p> <p>difference [5] 52/2 56/12 75/12 75/16 84/20</p> <p>different [9] 5/12 5/23 19/12 35/11 35/12 52/11 72/22 73/3 79/9</p> <p>differently [2] 71/5 74/11</p> <p>difficult [10] 4/7 6/12 47/9 58/25 60/1 76/18 77/15 77/16 77/18 78/15</p> <p>difficulty [1] 4/12</p> <p>dig [1] 84/4</p> <p>digs [1] 67/21</p> <p>directions [1] 84/23</p> <p>director [1] 76/23</p> <p>dirty [1] 26/2</p> <p>disaster [1] 1/15</p> <p>discharge [1] 50/12</p> <p>discharged [4] 48/13 49/1 50/5 75/18</p> <p>discussions [1] 78/10</p>	<p>disease [2] 20/13 22/1</p> <p>dishes [3] 77/10 77/20 80/16</p> <p>dislike [1] 31/2</p> <p>disorder [1] 37/24</p> <p>disrespectfully [1] 27/9</p> <p>distance [1] 68/21</p> <p>distraught [1] 87/14</p> <p>do [40] 1/18 2/21 4/23 6/24 7/11 8/6 8/11 11/21 16/9 17/20 25/5 27/12 28/5 28/6 29/16 31/17 32/6 32/14 33/6 33/8 33/25 38/19 43/18 43/18 44/7 44/19 55/17 55/19 57/10 58/23 59/11 64/4 70/5 70/18 70/18 70/18 71/2 80/2 89/12 89/13</p> <p>doctor [14] 6/8 7/2 7/4 8/13 39/1 39/1 39/2 70/20 72/5 75/25 76/3 76/5 76/12 88/6</p> <p>doctor's [1] 30/11</p> <p>doctors [6] 6/5 6/6 6/7 39/3 65/3 72/7</p> <p>document [5] 13/15 13/18 15/13 38/16 60/8</p> <p>documents [1] 9/16</p> <p>does [5] 8/25 31/22 46/8 66/24 70/17</p> <p>doesn't [4] 36/24 66/2 79/10 79/12</p> <p>dog [1] 78/7</p> <p>doing [12] 11/20 25/7 29/9 33/10 34/1 34/2 35/8 35/8 67/18 80/7 80/16 85/3</p> <p>don't [46] 5/3 8/9 14/8 18/25 22/24 25/15 27/8 27/17 28/5 28/14 28/17 29/2 31/7 32/11 33/25 35/2 35/10 36/13 37/8 37/16 37/18 37/18 39/13 40/18 42/17 43/2 44/8 44/23 51/8 53/9 56/19 57/11 62/3 64/9 64/16 66/6 66/15 69/1 69/6 71/18 71/24 73/11 75/22 79/4 85/24 86/12</p> <p>donate [1] 34/12</p> <p>donating [1] 34/12</p> <p>done [8] 27/12 31/9 31/19 33/22 43/10 66/13 80/8 81/13</p> <p>donor [1] 38/6</p>
--	--	--	--	--	---

(27) condition... - donor

<p>D</p> <p>door [7] 80/12 80/17 80/22 83/11 83/16 83/17 83/25</p> <p>double [2] 59/10 85/12</p> <p>doubt [1] 84/1</p> <p>down [21] 10/13 14/1 18/17 29/13 30/14 32/11 32/15 33/2 34/18 38/1 43/7 53/15 54/3 55/3 58/20 67/21 68/16 78/18 80/16 85/10 87/22</p> <p>downstairs [3] 80/7 80/20 81/8</p> <p>downturn [1] 77/16</p> <p>dozen [1] 26/16</p> <p>Dr [8] 65/3 70/25 73/9 76/12 81/25 82/4 82/18 88/5</p> <p>Dr Heelis [5] 76/12 81/25 82/4 82/18 88/5</p> <p>Dr Lawson [1] 65/3</p> <p>drawing [2] 9/11 47/16</p> <p>draws [1] 3/13</p> <p>dreadful [1] 76/19</p> <p>dreamed [3] 69/21 69/21 69/21</p> <p>dressed [1] 80/25</p> <p>drive [2] 31/2 51/9</p> <p>driving [1] 31/23</p> <p>drug [1] 85/1</p> <p>drugs [1] 11/24</p> <p>due [5] 33/15 45/25 59/4 62/9 90/10</p> <p>during [8] 4/5 5/8 49/17 50/14 51/14 68/15 71/13 72/16</p> <p>dyed [1] 53/23</p> <p>dying [4] 17/16 18/11 20/14 31/5</p>	<p>easy [1] 45/19</p> <p>eat [1] 80/2</p> <p>eaten [1] 82/2</p> <p>echo [1] 64/22</p> <p>Edinburgh [1] 4/22</p> <p>education [2] 9/22 67/17</p> <p>educational [1] 57/1</p> <p>effect [5] 37/17 38/23 51/12 57/14 57/18</p> <p>effective [1] 52/10</p> <p>effectively [1] 54/6</p> <p>effects [5] 1/18 22/15 30/1 31/24 33/21</p> <p>EIBSS [1] 43/13</p> <p>eight [2] 30/4 33/2</p> <p>either [1] 38/20</p> <p>ejected [1] 53/21</p> <p>elapsed [1] 63/6</p> <p>eligible [1] 79/15</p> <p>Elizabeth [2] 12/20 20/15</p> <p>else [15] 8/4 8/7 21/18 34/2 43/11 45/13 50/15 63/22 66/4 66/6 67/14 71/6 72/1 88/2 88/23</p> <p>embarrass [1] 12/7</p> <p>embarrassing [1] 12/2</p> <p>emergency [2] 76/9 81/12</p> <p>emotional [1] 16/8</p> <p>employee [1] 35/3</p> <p>employees [1] 35/2</p> <p>employer [2] 34/19 34/20</p> <p>employment [2] 48/4 59/17</p> <p>enable [1] 39/13</p> <p>encephalopathy [1] 60/11</p> <p>end [20] 5/8 11/14 24/16 24/20 32/22 36/21 42/23 43/1 51/20 52/5 52/6 53/25 54/15 54/19 55/1 68/17 85/22 87/11 88/13 90/6</p> <p>ended [13] 16/25 17/17 24/20 25/18 25/19 29/19 29/20 30/5 30/10 30/13 31/15 32/23 32/24</p> <p>ends [1] 75/24</p> <p>energy [1] 52/17</p> <p>engaged [1] 58/3</p> <p>England [3] 2/9 2/15 61/17</p> <p>enjoy [2] 57/5 72/24</p> <p>enjoyed [1] 51/11</p> <p>enjoying [1] 68/9</p>	<p>enough [3] 10/1 22/25 34/11</p> <p>enter [1] 2/11</p> <p>entirely [3] 59/4 65/9 65/23</p> <p>entitled [3] 6/10 7/8 38/14</p> <p>entitlement [1] 6/11</p> <p>entries [2] 13/19 14/2</p> <p>envelope [3] 69/7 69/9 69/13</p> <p>envy [1] 64/16</p> <p>equation [1] 21/4</p> <p>erratic [1] 77/14</p> <p>escape [1] 5/25</p> <p>especially [7] 21/22 22/25 64/19 69/17 70/3 88/5 88/7</p> <p>Europe [1] 68/7</p> <p>even [15] 8/20 24/7 26/14 42/17 43/15 56/8 57/21 62/4 62/15 65/4 73/16 79/17 81/14 83/10 88/13</p> <p>evening [1] 32/16</p> <p>event [1] 64/23</p> <p>events [3] 23/13 39/17 63/15</p> <p>Eventually [1] 85/22</p> <p>ever [8] 31/16 33/4 43/25 47/7 50/19 55/17 55/18 57/20</p> <p>every [12] 3/9 5/9 5/11 19/16 32/10 32/11 34/20 42/22 42/22 58/22 65/6 78/4</p> <p>everybody [5] 30/8 32/16 35/4 39/1 62/6</p> <p>everyone [5] 4/19 5/3 66/6 67/14 90/21</p> <p>everything [14] 11/24 11/25 21/16 21/18 25/22 29/13 30/18 34/2 36/10 36/21 40/9 43/11 60/2 83/15</p> <p>everything's [2] 79/3 79/3</p> <p>evidence [26] 3/22 4/2 4/7 4/8 4/21 5/13 6/17 6/25 7/5 7/14 7/20 7/23 8/14 8/21 8/22 9/2 9/24 10/2 10/5 46/13 62/21 63/25 65/15 65/19 67/6 90/7</p> <p>ex [1] 41/2</p> <p>ex-wife [1] 41/2</p> <p>exact [1] 49/12</p> <p>exactly [3] 36/13 40/6 42/3</p> <p>example [1] 8/18</p> <p>exceptional [1] 47/4</p>	<p>excited [1] 67/18</p> <p>excuse [2] 76/11 76/22</p> <p>exhausted [1] 50/10</p> <p>expectation [1] 59/16</p> <p>expected [3] 57/18 70/8 84/11</p> <p>expecting [1] 56/14</p> <p>expenses [1] 59/20</p> <p>expensive [1] 59/22</p> <p>experiences [2] 10/25 61/25</p> <p>experiencing [1] 62/1</p> <p>experimental [1] 75/2</p> <p>explained [4] 21/24 26/5 53/19 62/8</p> <p>explanation [1] 6/2</p> <p>explanations [1] 6/13</p> <p>exploded [1] 54/20</p> <p>expressed [3] 6/13 20/24 53/18</p> <p>extended [2] 58/18 59/13</p> <p>extent [2] 29/24 52/8</p> <p>extra [1] 54/7</p> <p>extremely [4] 47/19 53/20 57/5 88/4</p> <p>eyes [1] 50/8</p>	<p>face [4] 25/19 70/6 70/6 79/9</p> <p>face-to-face [1] 70/6</p> <p>Facebook [1] 45/2</p> <p>faced [1] 59/19</p> <p>fact [11] 5/2 9/6 11/8 25/17 27/3 27/20 37/19 39/12 51/17 63/15 79/20</p> <p>factor [10] 13/1 13/14 13/21 13/22 14/3 38/4 38/5 39/7 39/7 68/3</p> <p>factors [3] 50/20 60/14 60/21</p> <p>facts [2] 38/15 64/13</p> <p>fair [2] 7/14 9/12</p> <p>fairness [1] 6/17</p> <p>faith [5] 47/7 52/12 78/10 89/15 89/16</p> <p>fall [1] 80/18</p> <p>families [3] 30/17 43/3 78/2</p> <p>family [36] 3/24 4/1 10/21 11/1 11/6 17/21 17/22 18/17 18/19 19/4 19/7 19/24 23/15 23/19 23/22 24/3 24/17 25/3 30/15 31/2 36/5 36/7 39/17 40/12 40/15 41/14 42/3 42/4 44/5 44/20 45/20 45/20 51/22 52/17</p>	<p>58/10 58/18</p> <p>fantastic [2] 45/9 73/14</p> <p>far [8] 2/8 15/4 33/17 50/4 55/18 55/18 87/5 87/17</p> <p>fast [1] 78/3</p> <p>fat [1] 25/15</p> <p>fatal [1] 37/24</p> <p>father [3] 2/7 11/17 25/2</p> <p>fatigue [1] 52/16</p> <p>fault [2] 42/7 42/7</p> <p>favour [1] 12/6</p> <p>feed [1] 58/12</p> <p>feel [9] 4/11 19/24 38/13 42/5 64/10 66/6 69/12 70/5 74/11</p> <p>feeling [3] 30/6 81/1 87/23</p> <p>feelings [1] 2/11</p> <p>fell [2] 80/11 80/22</p> <p>felt [9] 17/24 19/22 22/23 30/9 31/14 36/14 41/22 44/13 82/17</p> <p>few [12] 13/11 13/16 21/9 30/14 31/9 54/7 58/9 62/22 64/21 79/9 81/7 83/22</p> <p>fields [1] 57/6</p> <p>fight [1] 75/10</p> <p>fighting [3] 75/6 75/10 75/16</p> <p>figure [1] 59/10</p> <p>figured [1] 80/19</p> <p>filled [1] 78/20</p> <p>filling [1] 87/1</p> <p>film [1] 76/23</p> <p>filming [1] 8/1</p> <p>final [1] 56/23</p> <p>finality [1] 56/13</p> <p>Finally [2] 9/13 64/23</p> <p>financial [4] 42/10 85/6 85/18 86/22</p> <p>financially [6] 42/20 43/22 58/25 59/2 59/3 78/14</p> <p>find [16] 4/5 4/6 6/12 10/18 42/20 47/9 56/18 56/20 57/18 61/16 68/13 70/15 75/20 84/5 84/24 89/16</p> <p>fine [1] 70/9</p> <p>finished [1] 46/21</p> <p>finishes [1] 66/8</p> <p>firms [1] 58/7</p> <p>first [27] 1/7 1/23 2/24 3/17 4/14 6/19 8/10 10/3 13/19 15/22 20/19 22/8 27/14 28/7</p> <p>28/21 29/5 31/4 33/4 33/23 36/3 39/18 46/16 47/22 48/5 48/17 48/22 85/8</p> <p>five [1] 46/25</p> <p>flat [1] 73/1</p> <p>flighty [2] 69/23 77/9</p> <p>flings [1] 18/15</p> <p>floated [1] 2/14</p> <p>floor [4] 73/1 73/8 77/10 77/20</p> <p>focused [1] 3/22</p> <p>following [4] 54/18 69/3 75/19 91/2</p> <p>food [4] 72/24 77/20 78/8 85/19</p> <p>forefront [1] 36/9</p> <p>forever [1] 59/12</p> <p>feeling [1] 66/11</p> <p>forgetful [1] 33/21</p> <p>forgetting [1] 65/4</p> <p>forgive [3] 2/6 3/4 51/6</p> <p>forgot [1] 51/10</p> <p>forgotten [1] 65/21</p> <p>form [1] 62/13</p> <p>forms [3] 43/19 43/20 78/20</p> <p>fortunate [2] 59/23 61/13</p> <p>fortunately [2] 53/14 57/4</p> <p>forward [8] 10/10 14/19 19/9 21/20 25/8 34/3 67/3 90/24</p> <p>fought [1] 24/15</p> <p>found [7] 18/22 25/24 27/1 33/16 49/24 59/23 71/11</p> <p>four [6] 3/14 9/13 13/19 23/6 33/14 33/16</p> <p>fourth [2] 9/13 13/18</p> <p>frail [2] 25/18 26/19</p> <p>framed [2] 9/18 68/18</p> <p>franked [1] 69/6</p> <p>Fraser [8] 46/7 46/12 66/17 66/24 67/5 90/6 91/9 91/11</p> <p>fraught [2] 25/19 26/19</p> <p>free [2] 65/10 65/23</p> <p>Friday [5] 34/21 34/21 43/1 54/18 55/4</p> <p>friend [2] 8/24 87/21</p> <p>friends [7] 3/23 40/21 41/23 68/6 78/3 87/16 88/11</p> <p>frightened [3] 3/12 51/13 52/12</p> <p>from [74] 1/17 2/8 2/13 4/19 9/15 10/21</p>
--	---	---	---	---	--

<p>F</p> <p>from... [68] 11/6 12/10 12/12 13/3 13/19 14/3 17/21 17/22 18/2 18/4 19/10 21/5 21/6 22/13 24/11 24/25 27/4 27/12 30/14 30/15 30/19 31/10 32/7 33/2 34/23 35/14 37/8 37/21 38/6 38/9 38/17 41/4 45/14 45/25 47/5 47/11 50/5 54/17 57/20 58/6 58/11 58/17 60/4 60/22 64/23 66/4 66/15 68/2 69/8 73/5 73/17 75/19 77/1 77/23 77/24 78/10 79/22 83/7 83/11 84/16 86/8 86/16 88/10 89/10 90/5 90/10 90/15 90/18</p> <p>front [9] 3/20 3/24 19/16 47/8 52/22 54/8 69/6 79/7 83/16</p> <p>froze [1] 31/13</p> <p>fully [1] 57/20</p> <p>fun [1] 57/10</p> <p>Fund [3] 61/4 86/16 86/22</p> <p>funeral [7] 22/17 22/18 23/16 23/18 23/19 59/19 83/25</p> <p>funerals [1] 23/14</p> <p>fungals [1] 72/22</p> <p>funny [1] 36/15</p> <p>furnish [1] 64/12</p> <p>further [4] 2/18 38/18 48/15 72/5</p> <p>fuss [1] 83/12</p> <p>future [3] 10/15 14/20 86/12</p>	<p>Germany [1] 68/8</p> <p>get [24] 2/19 14/23 17/20 24/2 24/3 29/1 30/23 31/8 32/7 34/10 43/21 45/10 48/19 52/18 56/17 57/22 69/2 76/15 77/10 79/17 84/8 86/2 86/3 87/2</p> <p>gets [1] 10/4</p> <p>getting [8] 21/16 26/11 30/9 33/9 44/7 66/14 67/17 85/4</p> <p>giddy [1] 77/9</p> <p>girl [3] 18/15 21/2 21/19</p> <p>girlfriends [1] 18/14</p> <p>give [22] 3/23 4/2 4/10 5/15 6/25 7/20 7/22 8/14 8/22 9/2 17/24 26/13 39/6 46/13 52/24 58/23 62/9 62/21 65/19 67/6 73/22 84/22</p> <p>given [17] 7/5 7/13 9/22 13/7 14/12 14/13 16/17 21/13 27/16 45/19 47/17 49/4 50/12 66/7 73/12 75/1 78/14</p> <p>gives [1] 6/17</p> <p>giving [2] 4/16 83/4</p> <p>glass [1] 56/7</p> <p>gloves [3] 71/6 74/5 74/19</p> <p>go [31] 8/21 12/14 13/17 15/25 26/13 27/12 30/11 33/15 34/1 34/18 38/1 39/6 42/23 42/24 42/25 44/24 51/8 52/20 53/25 54/5 55/13 57/10 62/24 63/3 65/10 66/2 69/1 75/15 78/6 80/20 81/22</p> <p>God [4] 85/24 89/10 89/11 89/16</p> <p>Godsend [1] 58/9</p> <p>goes [1] 30/8</p> <p>going [49] 11/13 12/10 16/7 21/17 22/18 22/20 26/25 27/9 27/14 29/12 29/16 30/13 31/8 31/10 31/15 32/18 35/21 37/17 39/8 39/11 39/25 40/3 40/6 41/1 41/2 42/22 44/23 44/25 45/12 52/4 54/14 56/16 57/9 61/25 67/13 68/6 69/17 71/5 71/6 71/7</p>	<p>71/9 72/1 74/10 74/13 74/14 81/2 85/23 88/21 89/8</p> <p>gone [6] 4/9 31/19 32/11 42/19 80/17 80/21</p> <p>good [12] 11/18 18/13 19/17 35/2 35/3 35/3 47/6 47/19 51/11 54/6 66/14 67/25</p> <p>Gordon [12] 22/4 22/6 22/7 22/9 22/10 22/17 22/18 22/22 23/2 23/9 25/20 26/10</p> <p>Gort [2] 90/16 90/17</p> <p>gory [1] 56/22</p> <p>gossip [2] 20/20 25/15</p> <p>got [55] 12/9 15/25 17/9 18/12 18/16 20/1 22/11 22/21 24/16 24/21 24/22 24/23 24/25 25/1 25/2 25/6 25/9 28/13 31/13 31/20 32/8 32/25 33/25 34/9 34/10 34/20 34/24 35/13 36/22 37/19 38/25 39/2 39/6 40/7 41/23 42/15 42/20 42/24 42/25 43/1 43/6 44/21 44/22 50/10 51/7 62/19 68/8 69/18 69/19 69/19 81/8 81/24 84/9 85/8 85/10</p> <p>government [5] 3/12 21/6 21/7 44/9 44/10</p> <p>GP [8] 48/18 49/13 53/19 53/24 61/13 65/2 76/7 87/19</p> <p>graduate [1] 57/4</p> <p>graffiti [1] 19/6</p> <p>Graham [8] 45/25 46/8 46/10 46/11 46/13 65/7 65/13 91/8</p> <p>grandmother [1] 58/5</p> <p>grasp [1] 56/13</p> <p>grateful [3] 9/21 88/5 88/19</p> <p>grave [1] 24/7</p> <p>great [9] 24/15 34/20 39/2 39/4 43/19 45/3 53/20 54/10 85/9</p> <p>greatest [1] 1/15</p> <p>grieving [1] 24/3</p> <p>ground [1] 73/8</p> <p>group [5] 25/7 45/2 45/5 61/14 68/23</p> <p>grow [1] 51/18</p> <p>growing [1] 11/5</p> <p>guaranteed [2] 51/24 52/1</p>	<p>H</p> <p>had [169]</p> <p>hadn't [6] 20/20 57/18 77/6 82/14 82/16 83/10</p> <p>haematologists [1] 71/14</p> <p>haematology [1] 68/23</p> <p>haemophilia [9] 11/3 11/20 16/17 23/4 38/17 68/2 68/6 68/23 71/21</p> <p>haemophiliac [3] 20/7 28/23 42/15</p> <p>haemophiliacs [4] 10/22 11/6 21/8 29/10</p> <p>haemorrhage [1] 36/16</p> <p>haemorrhaged [1] 53/12</p> <p>half [7] 26/16 28/25 30/4 60/10 76/11 81/7 88/9</p> <p>halfway [1] 14/1</p> <p>Hall [1] 43/9</p> <p>hallway [3] 67/21 80/17 80/20</p> <p>hand [1] 4/6</p> <p>handle [1] 86/25</p> <p>hands [2] 74/12 86/2</p> <p>happen [3] 21/8 34/5 70/1</p> <p>happened [27] 6/1 15/23 16/21 18/5 18/16 22/6 23/13 23/15 26/22 30/15 31/1 32/12 36/1 36/6 36/7 42/3 42/7 44/12 45/8 49/9 53/24 61/11 75/20 75/25 78/18 80/14 81/24</p> <p>happening [1] 45/10</p> <p>happens [1] 37/18</p> <p>happy [1] 78/21</p> <p>hard [2] 25/9 56/20</p> <p>hardest [2] 55/16 55/18</p> <p>hardly [2] 2/1 63/14</p> <p>has [33] 1/5 1/13 2/3 2/15 4/9 6/21 7/13 8/19 10/3 19/11 22/5 24/21 26/23 31/18 32/16 33/8 33/14 36/22 37/14 37/15 38/6 39/12 42/16 45/3 45/20 58/3 63/2 63/18 66/6 66/13 71/25 78/10 88/23</p> <p>have [228]</p> <p>haven't [3] 22/12 25/2</p>	<p>44/22</p> <p>having [12] 25/19 27/13 32/17 38/8 49/5 52/9 54/22 59/20 64/21 71/10 76/25 78/21</p> <p>Hazelwell [1] 19/1</p> <p>he [177]</p> <p>he'd [3] 71/15 77/15 80/17</p> <p>he'll [1] 74/22</p> <p>he's [4] 15/25 16/7 21/14 79/6</p> <p>head [4] 35/13 70/2 80/23 81/14</p> <p>headline [4] 19/15 82/24 83/1 83/21</p> <p>headline there [1] 83/1</p> <p>health [9] 31/25 34/13 50/6 51/11 64/25 83/3 83/8 83/19 85/15</p> <p>healthy [4] 48/11 48/24 49/10 60/22</p> <p>hear [14] 4/19 5/2 7/19 10/5 26/17 45/25 56/11 66/9 67/15 67/24 80/18 86/19 90/10 90/18</p> <p>heard [13] 2/21 2/25 3/10 4/20 5/5 5/6 5/7 5/21 6/10 9/24 47/12 47/13 80/18</p> <p>hearing [2] 65/24 90/15</p> <p>hearings [2] 3/2 4/5</p> <p>heart [7] 3/6 3/18 5/22 16/6 25/20 26/3 26/24</p> <p>heartfelt [1] 64/24</p> <p>heat [1] 39/7</p> <p>Heath [1] 18/24</p> <p>heaven [1] 56/17</p> <p>Heelis [5] 76/12 81/25 82/4 82/18 88/5</p> <p>help [18] 5/19 43/25 58/3 59/22 70/13 75/9 83/4 83/7 83/20 83/20 84/15 84/24 85/4 85/17 86/22 86/23 87/17 89/14</p> <p>helped [2] 14/23 30/21</p> <p>helpful [6] 43/22 58/21 58/24 70/11 71/1 87/3</p> <p>helpline [3] 84/9 84/19 84/24</p> <p>helpline became [1] 84/24</p> <p>helpline made [1] 84/19</p> <p>hep [9] 21/4 27/7</p>	<p>27/25 28/3 28/13 28/19 36/3 36/24 42/15</p> <p>hep C [1] 28/3</p> <p>hepatic [1] 60/11</p> <p>hepatitis [28] 15/7 15/16 16/14 27/1 28/6 28/21 29/2 31/25 35/20 39/23 49/13 49/15 49/16 49/22 50/19 60/4 60/12 60/15 60/18 68/11 68/11 71/12 71/20 71/23 71/23 71/24 71/25 72/8</p> <p>Hepworth's [1] 58/7</p> <p>her [45] 12/1 12/5 25/10 25/17 25/19 25/24 26/3 26/5 26/6 26/7 26/15 26/24 43/7 47/8 47/11 47/12 47/13 47/25 48/21 49/4 50/8 50/9 50/16 51/12 51/12 51/14 51/18 52/7 52/9 53/22 53/25 54/7 54/8 54/9 54/19 54/20 56/14 58/6 58/8 60/7 60/18 60/25 61/9 61/12 74/21</p> <p>here [30] 1/4 1/25 2/8 2/22 4/17 4/23 4/25 7/21 9/5 9/14 9/24 10/24 11/1 19/5 25/3 29/24 30/16 33/1 34/1 39/12 44/23 44/23 45/17 46/13 57/12 64/10 67/6 79/6 85/13 90/21</p> <p>herself [1] 24/13</p> <p>hesitate [2] 5/16 38/19</p> <p>hid [1] 22/13</p> <p>hide [2] 30/18 44/12</p> <p>hiding [2] 23/23 30/14</p> <p>him [38] 4/11 8/21 19/21 19/22 20/17 21/18 21/18 22/16 22/24 36/21 43/4 44/12 67/9 67/12 67/20 69/10 71/5 72/18 74/3 74/14 74/16 75/20 76/4 76/7 76/12 76/13 78/24 80/6 80/18 81/3 81/6 81/15 81/16 81/18 82/12 82/13 83/4 88/7</p> <p>himself [7] 67/17 69/10 69/18 69/18 69/19 69/19 79/17</p> <p>his [48] 8/21 9/2 10/5 16/6 16/17 16/22 17/3</p>
---	---	---	--	---	---

<p>H</p> <p>his... [41] 17/4 17/5 17/5 17/8 18/4 19/20 19/23 20/16 20/25 21/15 21/16 22/19 24/7 36/12 36/13 36/23 37/1 39/20 47/8 64/16 65/5 67/17 69/9 72/22 72/23 72/23 75/10 75/16 76/21 77/14 78/25 80/8 81/14 81/14 82/17 82/25 85/15 85/21 86/2 87/6 87/10</p> <p>history [2] 1/15 70/24</p> <p>hit [1] 12/11</p> <p>HIV [24] 16/2 16/2 16/12 18/11 18/12 18/15 21/3 21/16 22/5 22/11 23/3 24/13 27/8 35/19 40/14 42/15 44/7 68/12 68/12 68/14 68/21 72/8 72/11 75/5</p> <p>HIV/AIDS [1] 68/21</p> <p>hm [1] 81/17</p> <p>hmm [1] 43/21</p> <p>hold [1] 18/16</p> <p>hole [3] 12/10 12/12 12/12</p> <p>holiday [1] 58/22</p> <p>Holland [1] 68/8</p> <p>home [11] 8/21 16/5 43/2 53/19 55/13 72/21 74/9 78/19 81/9 85/25 86/4</p> <p>homes [1] 73/15</p> <p>honest [3] 34/23 56/21 71/21</p> <p>hope [11] 2/6 3/18 45/10 47/17 51/6 66/8 89/9 89/9 89/12 89/12 89/13</p> <p>hoped [1] 90/18</p> <p>hoping [1] 57/22</p> <p>horrendous [1] 75/21</p> <p>horror [2] 75/21 75/22</p> <p>Horsforth [1] 61/15</p> <p>hospital [42] 11/7 11/9 11/13 11/14 11/15 12/18 12/20 16/1 20/15 27/12 27/23 32/22 32/23 33/3 33/12 33/22 33/24 34/3 37/11 37/21 39/4 48/8 48/16 50/5 53/25 54/5 54/9 54/16 61/22 62/7 68/24 72/16 73/25 74/3 75/19 76/8 76/10 76/11 81/1 81/6 82/7</p>	<p>88/11</p> <p>hospitalisation [2] 50/14 51/15</p> <p>hospitalised [3] 49/17 49/20 50/11</p> <p>hospitals [2] 21/6 21/7</p> <p>hotels [1] 44/12</p> <p>hour [3] 31/9 65/20 79/25</p> <p>hours [7] 9/3 31/9 54/15 54/18 55/4 79/10 85/16</p> <p>house [11] 12/5 16/5 18/18 18/19 53/17 54/3 59/13 59/22 73/13 83/13 88/14</p> <p>houses [1] 18/19</p> <p>housing [2] 73/3 73/6</p> <p>how [37] 1/8 2/2 9/2 11/4 14/14 14/19 17/11 19/23 21/22 24/11 26/6 28/6 28/19 28/21 31/3 37/16 39/11 39/18 39/23 44/23 46/16 51/4 55/4 55/20 56/18 59/12 64/5 66/24 68/13 69/4 69/12 70/5 70/15 71/12 79/2 84/13 86/19</p> <p>however [3] 6/11 65/20 85/10</p> <p>huge [2] 5/10 83/14</p> <p>huh [3] 57/16 73/2 87/9</p> <p>Hull [2] 2/13 2/18</p> <p>human [1] 47/19</p> <p>humane [1] 64/20</p> <p>humble [1] 58/18</p> <p>hurt [1] 33/9</p> <p>husband [7] 4/1 58/6 67/7 71/5 74/10 74/25 83/5</p> <p>Hyde [3] 48/9 64/3 77/5</p> <p>I</p> <p>I actually [1] 87/21</p> <p>I advertised [1] 58/2</p> <p>I also [3] 9/23 63/5 85/11</p> <p>I always [1] 26/13</p> <p>I am [36] 2/21 9/5 9/6 9/14 9/21 18/9 20/20 25/3 28/23 29/15 29/20 30/6 30/22 32/18 33/6 33/15 33/24 35/3 38/7 42/21 43/2 43/9 44/22 44/23 45/12 57/22 60/19 61/13 63/25 64/1</p>	<p>64/10 67/8 67/23 88/4 88/21 90/21</p> <p>I applied [1] 85/23</p> <p>I appointed [1] 86/24</p> <p>I appreciate [2] 44/18 44/19</p> <p>I approached [2] 61/13 62/7</p> <p>I ask [1] 31/24</p> <p>I asked [1] 28/15</p> <p>I assume [1] 64/14</p> <p>I assumed [1] 59/11</p> <p>I became [3] 17/17 17/19 59/25</p> <p>I began [1] 3/7</p> <p>I believe [2] 71/13 73/9</p> <p>I broke [1] 87/22</p> <p>I can [14] 12/9 15/25 16/4 22/16 29/4 30/5 30/24 33/22 41/21 42/2 42/4 42/5 52/9 79/12</p> <p>I can't [8] 5/2 27/5 28/1 31/17 43/5 43/5 49/11 50/17</p> <p>I cared [1] 74/9</p> <p>I carried [1] 29/17</p> <p>I come [1] 58/17</p> <p>I confirmed [1] 61/18</p> <p>I contacted [3] 61/22 61/23 81/25</p> <p>I could [7] 34/4 34/5 43/15 43/17 81/9 86/23 87/1</p> <p>I couldn't [2] 39/25 87/2</p> <p>I cry [1] 44/21</p> <p>I did [16] 9/16 9/17 30/22 33/23 33/24 59/24 71/18 74/16 79/5 79/8 81/20 85/11 86/11 86/18 89/1 89/13</p> <p>I didn't [18] 25/4 25/5 29/24 40/2 43/15 44/18 45/1 53/22 54/12 57/12 62/16 70/7 71/20 73/11 79/7 80/18 86/2 86/3</p> <p>I do [3] 33/6 33/8 43/18</p> <p>I don't [25] 22/24 25/15 27/8 28/14 28/17 29/2 32/11 33/25 35/10 36/13 37/8 37/18 43/2 44/8 44/23 51/8 53/9 64/9 64/16 66/15 71/18 73/11 75/22 85/24 86/12</p> <p>I dreamed [1] 69/21</p>	<p>I ended [6] 17/17 29/19 29/20 30/5 30/10 30/13</p> <p>I ever [1] 55/18</p> <p>I explained [1] 62/8</p> <p>I feel [1] 64/10</p> <p>I felt [4] 19/22 31/14 41/22 82/17</p> <p>I find [1] 56/18</p> <p>I finished [1] 46/21</p> <p>I floated [1] 2/14</p> <p>I froze [1] 31/13</p> <p>I gathered [1] 80/19</p> <p>I get [3] 14/23 29/1 30/23</p> <p>I go [3] 42/23 42/24 42/25</p> <p>I going [1] 56/16</p> <p>I got [3] 25/6 31/13 81/8</p> <p>I had [15] 17/20 27/3 27/13 28/2 28/3 28/13 31/7 33/2 43/17 46/20 57/23 59/24 77/6 86/11 87/16</p> <p>I hadn't [2] 57/18 77/6</p> <p>I have [65] 2/23 5/10 8/23 9/16 16/19 17/18 18/7 18/22 22/12 24/21 24/22 24/25 25/1 25/8 25/22 28/10 28/24 29/18 29/23 30/7 31/17 31/19 31/19 32/8 32/25 33/19 33/25 34/6 34/6 34/20 34/22 35/9 35/10 35/12 35/16 37/17 38/25 39/2 39/6 40/7 40/20 41/23 42/18 42/19 42/19 42/20 42/24 42/25 43/1 43/3 43/6 44/15 44/18 44/21 47/7 47/17 51/7 56/21 56/22 60/19 63/7 63/21 64/1 64/20 88/1</p> <p>I haven't [1] 22/12</p> <p>I heard [1] 80/18</p> <p>I hope [6] 2/6 3/18 45/10 47/17 51/6 66/8</p> <p>I imagine [1] 51/1</p> <p>I just [8] 3/5 7/23 10/15 22/23 37/5 39/16 40/8 44/25</p> <p>I keep [1] 35/16</p> <p>I kept [2] 19/22 30/5</p> <p>I knew [5] 9/17 9/18 9/19 69/7 86/4</p> <p>I know [8] 9/16 35/12 40/5 45/2 45/16 64/4 70/25 78/10</p> <p>I left [1] 69/8</p>	<p>I like [1] 35/9</p> <p>I listened [1] 2/21</p> <p>I live [1] 18/23</p> <p>I lived [1] 54/16</p> <p>I look [1] 90/24</p> <p>I love [3] 26/13 40/11 42/22</p> <p>I loved [2] 59/7 76/20</p> <p>I made [1] 63/7</p> <p>I make [1] 65/18</p> <p>I managed [1] 29/18</p> <p>I mean [6] 37/17 40/10 52/9 58/21 63/14 82/1</p> <p>I mentioned [1] 8/12</p> <p>I met [1] 67/12</p> <p>I might [1] 33/7</p> <p>I must [4] 2/19 8/2 31/9 57/7</p> <p>I naively [1] 59/7</p> <p>I need [2] 79/5 79/8</p> <p>I needed [4] 40/7 40/8 86/4 86/22</p> <p>I never [2] 47/11 47/12</p> <p>I owe [1] 56/19</p> <p>I owed [1] 64/10</p> <p>I peered [1] 71/16</p> <p>I perhaps [1] 71/17</p> <p>I persuaded [1] 57/8</p> <p>I possess [1] 64/13</p> <p>I prayed [1] 85/24</p> <p>I probably [1] 61/24</p> <p>I promised [1] 3/17</p> <p>I pushed [1] 36/8</p> <p>I rather [1] 2/8</p> <p>I realise [1] 51/7</p> <p>I really [1] 30/9</p> <p>I reassure [1] 56/9</p> <p>I received [1] 62/22</p> <p>I recognise [1] 66/10</p> <p>I refused [1] 74/9</p> <p>I remember [2] 24/7 44/8</p> <p>I repeat [1] 5/20</p> <p>I run [1] 65/8</p> <p>I rushed [1] 81/3</p> <p>I said [15] 5/20 13/11 19/14 21/9 21/13 25/13 26/10 40/3 42/22 43/18 44/19 56/4 69/24 74/10 77/7</p> <p>I sat [1] 56/5</p> <p>I saw [2] 71/18 88/7</p> <p>I say [7] 19/6 19/18 55/19 58/20 59/23 60/21 66/8</p> <p>I see [3] 40/9 54/8 61/8</p> <p>I seem [1] 33/9</p> <p>I separate [1] 9/14</p> <p>I shall [2] 7/2 7/22</p>	<p>I should [5] 48/23 65/13 65/13 85/25 86/1</p> <p>I sit [1] 43/4</p> <p>I speak [1] 5/17</p> <p>I spent [2] 17/19 17/21</p> <p>I spoke [1] 90/13</p> <p>I started [1] 45/1</p> <p>I still [2] 39/7 89/13</p> <p>I suppose [1] 62/5</p> <p>I suspect [1] 45/18</p> <p>I take [1] 43/4</p> <p>I think [26] 4/9 16/25 18/8 21/15 26/20 26/21 28/1 30/7 30/16 35/3 36/3 38/22 41/21 43/12 44/21 45/9 45/25 59/2 64/21 75/6 79/11 82/13 84/11 86/14 88/16 89/21</p> <p>I thought [8] 24/11 25/8 27/7 27/9 29/15 33/25 43/21 79/4</p> <p>I told [3] 56/1 56/4 84/13</p> <p>I took [2] 57/24 59/5</p> <p>I understand [1] 10/7</p> <p>I used [2] 59/2 71/22</p> <p>I want [3] 15/22 34/1 66/9</p> <p>I wanted [2] 44/19 53/21</p> <p>I was [45] 9/19 27/14 31/5 31/6 31/10 31/14 32/4 32/7 32/15 32/21 33/4 33/12 36/3 38/25 39/25 40/2 41/21 46/22 47/1 54/11 58/2 58/17 59/5 59/19 59/23 61/16 62/8 62/9 62/21 69/9 69/16 69/23 69/25 71/2 71/4 71/20 72/17 74/13 74/24 80/6 80/15 84/11 86/20 86/23 87/4</p> <p>I wasn't [5] 71/5 71/6 74/10 74/13 74/14</p> <p>I went [5] 17/16 32/19 33/11 33/14 46/20</p> <p>I will [5] 3/16 5/11 33/7 44/24 68/1</p> <p>I wish [2] 51/9 63/25</p> <p>I work [1] 34/21</p> <p>I worked [1] 85/17</p> <p>I would [2] 6/10 64/17</p> <p>I wouldn't [4] 86/11 86/13 88/18 88/18</p> <p>I wrote [1] 62/20</p> <p>I'd [5] 17/20 51/9 63/23 64/24 88/24</p>
--	---	--	--	---	--

<p>I</p> <p>I'm [8] 27/9 45/5 50/4 57/22 67/13 77/14 82/15 88/19</p> <p>I've [2] 24/16 33/17</p> <p>ice [1] 13/10</p> <p>idea [6] 28/10 48/2 51/23 53/10 54/3 84/25</p> <p>ideas [1] 6/13</p> <p>identifiable [1] 8/9</p> <p>identities [1] 7/20</p> <p>idiot [1] 59/7</p> <p>if [63] 3/24 4/12 4/21 5/8 6/18 7/10 7/11 8/5 8/25 10/13 12/4 13/5 13/15 13/17 13/24 14/10 15/12 15/23 16/7 16/11 16/18 16/19 18/9 20/19 21/8 22/24 25/16 25/17 26/15 26/22 31/7 32/12 34/24 36/16 38/1 39/1 41/4 41/16 41/24 45/13 48/18 51/23 52/2 53/22 53/25 57/9 60/7 62/24 63/3 64/5 65/18 65/23 66/4 67/25 70/11 71/25 72/6 74/12 75/8 78/24 80/6 86/22 88/22</p> <p>ignorance [1] 69/6</p> <p>ill [9] 8/19 8/20 29/17 29/22 50/18 53/10 55/20 60/24 79/14</p> <p>illness [7] 1/18 1/18 17/8 20/10 55/21 64/7 87/7</p> <p>imagine [2] 51/1 51/23</p> <p>immediately [1] 8/3</p> <p>immersing [1] 84/6</p> <p>immortal [1] 59/8</p> <p>immune [2] 75/7 75/17</p> <p>impact [6] 11/11 17/13 21/22 25/10 39/16 85/6</p> <p>impacted [1] 11/5</p> <p>impacts [1] 42/11</p> <p>implicated [1] 38/10</p> <p>importance [2] 3/15 8/24</p> <p>important [5] 3/14 5/13 9/25 10/17 78/11</p> <p>importantly [1] 58/13</p> <p>inability [1] 31/2</p> <p>incidentally [1] 54/16</p> <p>income [2] 59/21 85/12</p>	<p>increasing [2] 53/8 53/16</p> <p>increasingly [1] 50/8</p> <p>indeed [8] 1/7 4/7 4/8 4/18 4/23 65/7 65/11 89/24</p> <p>independent [2] 3/11 20/5</p> <p>indicated [1] 33/1</p> <p>indicating [1] 63/12</p> <p>individual's [1] 7/17</p> <p>indulgence [1] 63/24</p> <p>inevitably [1] 5/13</p> <p>infect [1] 21/1</p> <p>infected [21] 1/9 6/4 15/7 15/16 15/20 16/16 16/22 16/24 18/15 23/3 25/4 27/1 35/19 35/20 37/16 52/3 60/4 62/4 64/2 68/11 68/14</p> <p>infecting [2] 20/7 21/19</p> <p>infection [8] 1/20 15/2 20/25 40/14 42/11 49/25 50/3 72/19</p> <p>infections [4] 1/11 1/17 23/5 75/10</p> <p>inflated [1] 54/23</p> <p>info [1] 21/13</p> <p>inform [1] 38/8</p> <p>information [14] 14/11 15/19 19/10 21/5 21/19 27/16 27/21 28/18 38/18 39/13 66/15 69/15 70/5 70/22</p> <p>informed [4] 18/11 22/10 38/3 38/14</p> <p>informing [1] 27/20</p> <p>infuriated [1] 23/25</p> <p>initially [2] 60/23 61/23</p> <p>inkling [1] 55/20</p> <p>innuendos [1] 83/22</p> <p>inquiry [30] 1/5 1/7 1/8 1/21 1/22 1/23 2/14 2/24 3/7 3/15 3/17 3/21 3/21 4/17 5/9 5/12 5/18 5/22 5/24 8/20 8/20 9/12 9/20 20/2 62/11 64/13 64/17 65/23 65/24 66/7</p> <p>inside [2] 28/4 31/14</p> <p>instance [1] 7/3</p> <p>instead [4] 23/18 59/19 76/14 80/21</p> <p>insulin [1] 29/21</p> <p>insurance [2] 42/12 42/17</p> <p>Insurances [1] 42/14</p>	<p>insured [1] 59/10</p> <p>interest [2] 2/2 59/10 29/8</p> <p>interferon [2] 29/7 29/8</p> <p>interval [1] 54/13</p> <p>interviewed [1] 78/19</p> <p>interviews [1] 19/19</p> <p>into [14] 2/11 11/13 19/23 27/23 41/2 52/4 52/8 52/22 53/25 54/5 65/25 71/8 73/25 80/17</p> <p>introduced [1] 75/8</p> <p>involved [5] 49/5 71/14 84/8 86/12 86/13</p> <p>involves [1] 54/22</p> <p>Irish [4] 41/16 41/23 41/24 42/5</p> <p>ironing [1] 58/12</p> <p>issues [1] 31/1</p> <p>it's [20] 1/4 1/6 16/19 19/7 22/20 25/2 28/24 30/20 32/11 34/9 39/4 51/24 51/25 52/1 52/6 55/2 57/11 61/18 76/18 87/10</p> <p>items [1] 83/11</p> <p>its [3] 2/10 3/18 64/17</p> <p>itself [3] 1/24 22/1 85/2</p> <p>IX [1] 38/5</p>	<p>J</p> <p>Jack [1] 18/13</p> <p>James's [2] 49/20 65/4</p> <p>January [3] 37/21 53/12 55/5</p> <p>January 1980 [1] 53/12</p> <p>jaundiced [1] 48/7</p> <p>Jean [2] 58/4 58/4</p> <p>Jekyll [1] 77/5</p> <p>jelly [1] 82/2</p> <p>jigsaw [1] 64/15</p> <p>Jo [8] 67/1 67/2 67/2 67/4 67/6 67/13 67/23 91/10</p> <p>Jo-Anne [8] 67/1 67/2 67/2 67/4 67/6 67/13 67/23 91/10</p> <p>job [11] 57/24 59/25 66/14 68/16 69/20 85/21 85/22 85/23 85/23 86/2 86/3</p> <p>John [22] 10/3 10/8 10/10 10/11 10/13 10/21 11/3 13/20 14/21 15/22 24/5 27/1 27/15 31/1 35/18 37/22 41/13 43/23</p>	<p>44/15 45/12 45/16 91/6</p> <p>joined [1] 78/1</p> <p>joke [1] 12/6</p> <p>jokes [1] 26/2</p> <p>joking [1] 24/18</p> <p>journalist [1] 83/25</p> <p>judge [1] 84/12</p> <p>junction [4] 31/11 31/11 31/20 31/20</p> <p>June [2] 1/1 20/6</p> <p>June 1994 [1] 20/6</p> <p>just [86] 3/5 4/8 4/14 4/21 7/13 7/17 7/23 8/7 9/20 10/15 11/19 13/4 13/15 14/1 14/7 15/12 16/11 17/20 18/17 18/22 19/18 19/21 19/22 20/9 20/22 22/23 23/19 23/22 24/2 24/22 25/4 26/17 27/4 27/14 27/24 28/24 30/1 30/4 30/9 31/7 31/22 36/12 36/20 37/5 37/13 38/1 38/25 39/16 40/6 40/8 41/1 44/20 44/25 45/8 45/12 47/2 53/15 57/11 58/6 58/20 60/8 60/10 61/1 61/23 62/1 62/24 62/24 63/23 67/13 69/5 69/10 70/8 71/17 74/23 76/3 77/9 77/11 80/3 80/4 80/5 81/21 81/25 83/1 87/1 88/21 90/23</p>	<p>30/5 33/3 40/3 40/6 48/8 56/14</p> <p>kids [6] 12/2 12/11 12/16 13/8 26/12 85/13</p> <p>killed [2] 26/3 33/5</p> <p>kind [9] 13/6 17/15 20/18 47/6 52/10 54/25 58/18 63/2 63/8</p> <p>kindness [1] 65/2</p> <p>Kings [1] 18/24</p> <p>kiss [1] 26/14</p> <p>kisses [1] 26/15</p> <p>kitten [1] 80/3</p> <p>knee [2] 11/12 56/5</p> <p>knees [1] 13/11</p> <p>knew [20] 9/17 9/18 9/19 16/2 26/7 28/14 51/18 52/3 52/6 53/5 53/6 53/10 55/19 68/24 69/7 70/11 74/22 80/24 84/11 86/4</p> <p>knocked [1] 12/14</p> <p>know [67] 4/17 4/20 7/6 7/8 8/9 9/16 9/23 14/15 14/17 19/22 20/24 21/6 21/22 21/25 22/24 22/25 23/21 26/12 27/9 28/6 29/1 31/7 32/6 32/11 32/17 34/10 34/22 35/9 35/12 35/15 36/13 37/16 37/18 37/18 40/2 40/5 42/17 43/11 44/9 44/23 45/2 45/5 45/16 51/3 51/19 51/24 51/25 52/6 52/10 56/16 62/3 62/5 64/4 64/9 68/21 69/14 70/25 71/2 71/18 71/20 73/11 78/10 80/2 84/3 85/24 86/12 88/22</p> <p>knowing [2] 23/25 70/17</p> <p>knowledge [1] 64/2</p> <p>known [8] 7/21 10/8 18/21 40/24 46/8 61/10 66/25 67/1</p> <p>knows [1] 22/20</p>	<p>LANGSTAFF [2] 1/3 91/5</p> <p>large [3] 10/21 58/18 64/15</p> <p>last [13] 3/2 4/9 5/20 9/17 15/14 25/25 28/18 33/9 54/15 61/23 62/7 63/3 66/8</p> <p>lasted [2] 36/16 36/17</p> <p>late [9] 5/17 9/7 15/17 36/6 46/13 64/11 65/2 67/7 76/15</p> <p>later [16] 7/10 15/9 18/10 20/12 22/9 27/5 27/6 45/11 47/1 48/24 52/18 61/3 65/22 79/20 81/9 87/18</p> <p>laughing [2] 24/18 26/3</p> <p>laundry [1] 80/7</p> <p>law [1] 56/15</p> <p>Lawson [1] 65/3</p> <p>Lawyers [1] 3/20</p> <p>lead [1] 9/19</p> <p>leading [1] 72/21</p> <p>leads [1] 11/13</p> <p>leaflets [1] 70/23</p> <p>learn [2] 9/22 9/24</p> <p>learned [1] 15/9</p> <p>learning [2] 71/21 71/22</p> <p>learnt [1] 15/12</p> <p>least [6] 5/11 23/24 25/3 27/8 51/14 78/2</p> <p>leave [3] 20/22 56/3 85/20</p> <p>leaving [1] 24/21</p> <p>lecturer [3] 68/17 69/20 85/11</p> <p>led [1] 57/3</p> <p>Lee [4] 17/4 21/11 24/15 24/20</p> <p>Leeds [14] 1/5 1/22 2/10 2/15 4/24 9/24 46/18 48/9 58/8 58/18 61/15 61/22 62/7 64/3</p> <p>left [4] 17/3 69/8 71/15 73/16</p> <p>legal [1] 62/14</p> <p>legally [2] 3/11 86/25</p> <p>Les [2] 12/13 25/14</p> <p>less [7] 21/10 24/20 33/9 35/5 57/1 57/2 57/3</p> <p>let [2] 69/10 74/23</p> <p>Letchworth [1] 88/6</p> <p>letter [17] 15/14 27/3 27/18 27/18 27/22 28/11 37/8 37/9 37/13 37/20 38/22 62/19 62/25 63/9 69/5 69/10 73/11</p>
--	---	--	---	---	---	--

L	53/15 59/12 lived [8] 25/23 37/3 54/16 58/5 58/20 67/19 73/1 88/10 liver [12] 27/13 28/2 28/4 32/8 33/2 34/7 34/8 43/16 49/14 50/22 51/1 51/15 livers [2] 34/12 34/12 lives [6] 2/24 20/18 24/19 30/9 40/10 69/17 living [6] 12/14 68/5 80/10 85/19 86/20 86/23 load [1] 24/25 local [15] 18/23 73/5 73/10 73/15 73/20 76/7 81/6 83/2 83/2 83/8 83/19 83/21 84/8 85/3 85/12 locally [1] 76/4 London [5] 1/22 3/2 4/9 43/7 62/10 long [10] 19/8 31/18 33/23 43/5 44/23 65/20 73/7 73/24 76/25 81/5 long-term [1] 81/5 longer [4] 11/1 31/25 48/16 61/21 look [13] 13/15 14/3 25/16 25/21 45/7 45/8 52/14 57/24 62/24 74/13 76/24 86/1 90/24 looked [3] 25/22 72/25 78/20 looking [9] 8/16 18/14 22/17 22/18 25/24 39/9 45/1 45/4 62/8 looks [1] 16/7 Lord [1] 85/24 lose [1] 68/19 losing [2] 25/10 77/1 loss [2] 68/25 76/16 lost [4] 26/7 58/6 68/17 72/24 lot [17] 9/16 9/18 17/19 22/10 29/6 30/5 30/16 57/9 68/18 68/19 68/22 69/15 71/22 77/23 80/1 85/9 88/3 lots [10] 11/11 19/19 22/21 23/24 33/25 40/22 41/23 59/11 67/24 84/7 love [6] 12/5 12/7 24/17 26/13 40/11 42/22 loved [6] 17/18 25/14	56/2 59/7 76/19 76/20 lovely [3] 1/4 20/18 47/15 loving [2] 56/24 58/14 low [2] 30/23 75/7 lower [1] 33/1 lucid [1] 54/13 lucidity [1] 54/10 luckily [3] 22/20 30/21 44/22 lucky [3] 42/18 58/2 58/17 luminous [1] 83/14 Luncheon [1] 66/22 luxury [1] 5/3 lynch [1] 44/14	M MacFarlane [2] 61/4 86/8 mad [1] 37/18 made [21] 5/14 7/6 20/17 20/19 22/12 23/24 29/12 29/17 29/22 38/5 38/11 43/12 49/5 58/6 62/25 63/1 63/7 73/17 76/5 83/12 84/19 mail [3] 62/17 63/9 69/9 main [4] 11/12 13/8 13/11 36/25 mainly [1] 11/11 make [13] 1/23 3/3 4/16 5/14 5/18 7/18 33/21 63/23 63/25 65/18 75/11 75/16 85/17 makes [2] 9/8 52/10 making [2] 4/15 7/6 man [11] 2/7 14/10 20/18 65/5 68/19 69/22 71/7 76/20 76/20 83/22 88/15 manage [1] 85/16 managed [4] 29/18 36/20 42/9 59/24 managing [1] 50/2 Manchester [1] 2/17 manner [2] 6/20 64/19 many [13] 1/9 1/9 1/10 1/13 1/17 16/1 37/3 47/14 58/15 63/6 64/5 76/25 90/24 March [6] 36/11 36/17 79/22 79/23 80/11 82/22 March 1987 [3] 79/22 79/23 80/11 Margaret [14] 46/14 46/17 47/1 47/2 47/4 48/5 51/4 52/5 53/3	53/12 53/18 59/16 60/14 65/1 marriage [2] 17/17 39/19 married [13] 40/21 46/25 46/25 59/5 67/9 68/8 68/15 69/19 71/4 71/10 76/20 85/8 85/10 marry [1] 46/24 Martin [1] 90/16 masked [1] 74/5 masks [1] 74/19 massive [1] 25/20 Maternity [2] 48/9 64/3 matter [8] 1/6 27/3 27/20 39/12 62/13 62/22 64/9 65/19 mature [1] 67/22 may [31] 1/5 2/25 3/3 4/18 4/24 5/16 6/12 6/14 6/20 7/23 8/6 8/15 10/15 15/24 20/16 23/8 23/9 27/25 27/25 37/14 38/13 50/11 60/7 62/18 63/11 64/11 64/11 64/13 64/14 66/11 71/9 May 1979 [1] 50/11 May 1994 [1] 23/9 maybe [1] 79/9 McDonald's [2] 39/5 39/9 me [66] 1/4 2/6 2/13 2/25 3/4 3/20 3/22 9/22 9/23 10/1 10/2 16/9 18/23 19/3 21/14 22/13 24/22 24/23 27/4 27/13 29/1 29/5 29/9 29/17 29/22 30/12 30/14 30/22 30/25 31/22 32/12 33/3 33/5 33/10 33/11 33/11 34/3 34/4 36/3 40/3 40/6 40/11 41/13 42/21 43/17 44/20 45/6 51/6 57/8 57/11 57/18 58/23 62/3 64/18 66/15 69/22 71/22 74/22 76/11 76/23 78/4 79/5 79/5 84/12 88/23 90/23 mean [13] 8/25 25/15 27/8 37/17 40/10 52/9 58/21 63/14 70/1 70/4 70/17 77/11 82/1 meaningful [2] 77/17 80/10 means [1] 7/11 meant [3] 69/15 80/20	85/16 media [1] 4/9 medical [8] 60/19 60/25 61/9 70/14 83/11 83/12 87/2 89/22 medicine [1] 52/14 member [1] 3/24 members [4] 11/1 40/15 44/5 51/22 memories [2] 4/7 54/2 memory [1] 77/1 mend [1] 70/16 mental [1] 22/19 mentally [5] 17/21 17/24 18/20 40/2 80/2 mention [4] 40/16 41/4 41/6 71/3 mentioned [7] 2/23 8/12 18/5 43/23 51/10 80/19 86/21 mentioning [1] 41/11 mess [2] 81/10 81/11 message [1] 56/2 messy [1] 53/20 met [7] 46/16 46/17 47/7 67/9 67/12 69/25 79/3 mic [1] 67/14 mid [2] 12/19 26/25 mid-teens [1] 12/19 might [14] 1/19 2/14 8/12 26/8 28/1 33/7 51/2 56/17 60/14 65/16 75/9 78/24 89/14 89/15 mile [4] 76/10 76/14 81/7 88/10 miles [1] 31/9 mind [11] 9/10 21/15 21/16 22/19 40/18 51/21 62/14 67/13 81/2 84/4 89/20 minutes [4] 13/11 21/9 77/2 81/9 miracle [1] 73/14 miss [1] 65/17 mistake [1] 22/12 Mm [1] 81/17 Mm-hm [1] 81/17 moment [3] 20/23 61/1 90/23 moments [1] 13/16 Monday [2] 34/21 42/24 money [3] 1/19 85/10 86/1 monster [1] 20/17 month [9] 18/10 22/8 32/11 33/5 33/13 43/4 49/12 60/21 63/18 months [19] 2/13	11/15 22/7 22/9 23/7 23/10 30/13 30/14 32/10 48/24 49/19 50/13 50/15 63/6 72/16 79/14 79/20 87/7 87/10 mood [3] 77/3 77/14 77/19 morals [1] 19/12 more [41] 1/10 1/24 3/16 4/22 7/4 7/22 8/13 9/16 9/17 9/19 9/23 11/9 11/22 11/23 17/17 17/19 19/13 21/10 24/19 26/8 26/14 32/24 34/3 39/16 45/18 48/19 50/9 50/9 50/10 50/10 51/16 57/10 58/13 63/19 71/22 72/8 72/10 72/24 75/8 85/17 85/20 morning [8] 3/8 30/12 30/25 31/21 41/13 52/18 65/6 90/14 mortal [1] 51/20 mortgage [3] 59/6 59/9 59/14 mortgages [1] 42/12 most [6] 6/25 7/2 10/18 17/21 47/6 56/22 mother [11] 11/22 18/4 23/1 25/2 39/20 47/16 53/7 53/10 54/4 56/2 56/25 mothers [1] 64/5 motorway [2] 31/10 31/15 motorways [2] 31/3 31/17 mouth [1] 72/23 move [2] 70/9 73/24 moved [6] 52/22 68/15 71/17 82/14 82/16 85/10 movie [2] 75/22 75/23 movies [1] 75/22 Mr [5] 45/12 45/14 88/21 90/19 90/23 Mr Ahearn [2] 90/19 90/23 Mr Snowden [3] 45/12 45/14 88/21 Ms [11] 10/7 10/12 46/7 46/12 66/17 66/24 67/5 90/6 91/7 91/9 91/11 Ms Fraser [4] 46/7 66/17 66/24 90/6 Ms Richards [1] 10/7 much [21] 4/21 9/23
----------	--	---	--	--	--	--

(32) letters - much

<p>M</p> <p>much... [19] 10/6 15/19 21/25 30/24 45/15 45/17 45/23 53/9 58/13 65/7 65/10 66/13 70/22 71/20 75/21 85/17 87/18 89/10 89/24</p> <p>mum [12] 12/13 25/12 25/13 25/23 25/24 26/14 55/14 55/19 59/6 80/16 81/16 81/18</p> <p>mum's [2] 18/18 26/1</p> <p>mummy [1] 56/16</p> <p>musketeers [1] 56/5</p> <p>must [7] 2/19 5/22 8/2 9/12 31/9 57/7 79/11</p> <p>my [94]</p> <p>myself [9] 17/22 19/23 31/17 38/20 56/15 57/19 59/8 65/1 88/18</p>	<p>new [4] 12/4 38/7 38/19 68/21</p> <p>Newcastle [2] 2/18 2/19</p> <p>newly [1] 73/12</p> <p>news [5] 19/15 38/13 51/5 68/20 70/10</p> <p>newspaper [2] 20/5 84/2</p> <p>newspapers [1] 24/10</p> <p>newspapers' [1] 23/17</p> <p>next [13] 14/8 31/9 31/11 31/20 33/15 38/1 38/11 43/4 46/7 66/24 82/14 82/14 85/15</p> <p>NHS [1] 1/16</p> <p>nice [3] 32/5 32/6 48/24</p> <p>nieces [2] 24/25 44/22</p> <p>night [1] 65/22</p> <p>nine [1] 30/4</p> <p>no [63] 3/12 4/11 4/12 5/7 11/1 14/13 15/1 15/3 20/3 21/3 21/5 21/19 27/22 28/8 28/10 28/10 28/10 28/17 31/21 32/11 36/13 39/2 39/15 43/15 44/7 44/7 45/14 46/25 50/1 50/4 50/19 50/20 50/24 50/25 51/23 53/10 54/3 55/20 57/22 59/6 60/6 60/6 60/14 60/19 60/20 61/5 61/7 61/16 61/21 63/2 63/12 64/2 66/3 70/17 70/23 70/23 77/14 79/19 83/9 83/18 84/1 85/13 90/4</p> <p>no-one [2] 3/12 50/19</p> <p>nobody [2] 64/1 70/3</p> <p>non [4] 71/18 71/18 71/23 71/24</p> <p>non-A [2] 71/18 71/23</p> <p>non-B [2] 71/18 71/24</p> <p>none [7] 14/13 15/5 16/2 44/4 44/8 56/10 60/16</p> <p>nooses [1] 44/13</p> <p>nor [2] 59/9 64/7</p> <p>normal [10] 11/9 11/19 29/1 48/16 52/24 68/5 71/10 74/15 74/15 74/25</p> <p>normality [1] 69/21</p> <p>north [4] 2/9 2/15 2/18 4/24</p> <p>northern [2] 68/7 68/7</p>	<p>nostrils [1] 54/23</p> <p>not [101]</p> <p>note [1] 2/7</p> <p>notes [2] 51/7 65/16</p> <p>nothing [9] 13/4 14/16 19/17 23/21 29/3 29/4 45/14 64/1 88/23</p> <p>notice [2] 4/24 8/18</p> <p>noticed [2] 2/4 8/16</p> <p>notifications [1] 37/5</p> <p>Notwithstanding [1] 34/13</p> <p>novel [1] 84/25</p> <p>November [2] 17/1 23/8</p> <p>now [34] 4/16 5/8 7/21 7/23 10/2 10/7 12/17 15/22 17/13 18/5 26/21 28/5 30/23 31/2 32/11 33/14 34/7 37/23 42/19 43/8 43/13 45/10 45/19 45/24 46/20 47/13 58/4 60/3 63/17 65/8 66/18 73/1 80/24 87/5</p> <p>nowadays [1] 22/20</p> <p>number [8] 5/10 10/25 13/1 13/21 14/9 15/9 17/10 61/21</p> <p>numbers [3] 1/25 14/3 14/9</p> <p>nurse [2] 74/18 87/21</p> <p>nurses [3] 38/20 39/3 65/3</p> <p>nursing [1] 74/18</p>	<p>offered [5] 44/1 44/6 57/7 87/5 87/15</p> <p>officer [2] 78/19 79/1</p> <p>often [1] 80/6</p> <p>oh [8] 22/11 27/7 32/18 49/23 73/6 74/22 79/10 84/4</p> <p>okay [4] 27/10 59/24 77/13 77/14</p> <p>old [7] 17/11 20/9 49/20 56/8 56/12 56/13 80/4</p> <p>older [3] 22/14 35/7 67/22</p> <p>oldest [2] 12/9 40/19</p> <p>once [6] 5/11 10/3 33/20 40/21 47/25 48/2</p> <p>one [55] 3/12 4/8 5/1 5/11 6/8 7/15 8/19 9/7 20/1 20/14 21/1 24/9 24/9 24/22 30/25 31/18 31/18 31/19 33/18 34/4 35/20 36/12 38/9 38/20 38/24 40/10 43/6 44/10 47/6 48/23 48/23 50/19 51/2 51/7 54/1 55/2 56/5 56/6 56/7 58/7 58/9 59/21 61/14 63/5 65/14 65/17 67/22 71/13 71/17 73/15 74/17 75/23 76/19 78/3 84/8</p> <p>ones [2] 30/23 35/7</p> <p>ongoing [2] 66/7 85/21</p> <p>only [20] 2/4 2/5 4/3 4/17 4/18 7/14 10/24 13/8 18/22 19/3 40/3 40/20 42/2 51/7 71/21 73/15 76/10 81/12 87/14 87/19</p> <p>onwards [1] 13/4</p> <p>open [4] 3/10 34/23 69/8 69/10</p> <p>opened [2] 69/12 80/17</p> <p>Opening [2] 1/3 91/5</p> <p>openness [2] 6/15 6/18</p> <p>opinion [1] 76/24</p> <p>opportune [1] 72/19</p> <p>opportunities [1] 9/21</p> <p>opportunity [6] 6/22 9/9 54/7 64/18 65/12 65/17</p> <p>opposite [1] 71/16</p> <p>options [1] 50/25</p> <p>or [91] 1/12 1/12 1/18 1/20 2/19 3/19 3/25 4/1 4/1 4/7 4/12 4/15</p>	<p>4/22 4/22 4/23 5/8 5/14 5/15 6/2 6/12 6/13 6/13 7/4 7/7 7/7 7/9 8/3 8/13 9/3 10/16 11/12 13/9 14/12 14/16 15/1 16/18 16/24 21/10 22/1 23/6 24/1 24/20 24/22 25/2 26/17 26/21 31/2 32/18 32/19 33/7 33/8 36/24 36/25 38/20 42/15 42/15 43/25 44/2 44/5 48/23 49/4 49/12 62/17 64/2 64/11 64/13 65/18 65/20 65/22 71/6 71/17 73/7 75/22 76/2 76/23 77/1 77/9 77/10 77/12 77/20 77/20 78/7 80/2 80/7 80/7 83/19 84/2 86/17 87/6 88/13 90/5</p> <p>oral [3] 6/17 9/24 72/13</p> <p>orally [5] 4/19 5/5 5/7 5/8 5/15</p> <p>ordered [1] 82/18</p> <p>ordinary [2] 23/19 23/22</p> <p>other [37] 5/6 13/23 16/20 17/10 19/1 19/9 22/4 23/6 27/4 27/21 29/10 36/2 36/4 40/22 44/5 50/20 51/15 51/21 52/5 53/8 55/1 58/24 60/10 60/14 60/20 64/5 64/21 67/20 68/9 69/25 75/10 76/5 78/3 80/1 85/19 88/3 89/14</p> <p>others [3] 1/18 3/1 64/11</p> <p>otherwise [2] 9/4 64/2</p> <p>our [26] 8/19 8/24 10/2 19/7 20/18 30/15 36/7 38/8 38/14 42/3 42/7 45/7 48/18 52/23 53/19 59/9 59/14 65/2 66/24 69/17 78/10 78/19 78/20 88/11 88/14 89/10</p> <p>out [46] 2/15 3/1 6/16 9/14 11/7 12/3 12/15 16/6 18/22 20/17 21/5 21/17 26/24 27/1 30/22 33/10 33/11 33/11 34/1 43/2 44/11 44/20 49/24 52/5 54/5 54/12 54/25 59/5 60/10 60/23 61/10 68/6 68/13 70/15 71/11 78/6 78/20</p>	<p>80/17 80/22 81/19 81/21 84/5 87/2 87/13 87/19 89/15</p> <p>outside [4] 8/3 83/11 83/16 83/16</p> <p>over [16] 9/20 14/1 14/7 16/5 19/11 19/20 33/9 48/12 63/6 63/16 65/20 68/19 71/17 79/14 80/11 80/22</p> <p>overtake [1] 30/20</p> <p>overwhelming [1] 72/10</p> <p>owe [1] 56/19</p> <p>owed [1] 64/10</p> <p>own [11] 4/7 10/24 12/25 20/15 39/17 40/9 43/24 45/6 45/7 52/9 59/4</p>
					<p>P</p> <p>packed [1] 81/7</p> <p>packet [1] 82/2</p> <p>packs [1] 13/10</p> <p>page [4] 13/18 14/1 14/7 15/13</p> <p>page we [1] 14/1</p> <p>pages [2] 13/25 19/16</p> <p>pages of [1] 19/16</p> <p>pain [3] 28/25 28/25 34/15</p> <p>paint [1] 5/19</p> <p>pamphlets [1] 70/23</p> <p>panic [1] 80/23</p> <p>paper [4] 5/9 82/24 83/2 83/21</p> <p>papers [2] 19/17 71/15</p> <p>paperwork [1] 87/2</p> <p>paragraph [4] 38/2 38/11 63/1 63/3</p> <p>paragraph 2 [1] 63/1</p> <p>paragraph it [1] 38/2</p> <p>paragraph to [1] 38/11</p> <p>parents [4] 11/16 53/15 56/9 58/20</p> <p>parents' [2] 53/17 54/3</p> <p>part [14] 8/14 9/25 15/14 28/24 33/1 34/18 42/20 45/5 47/25 48/3 58/3 59/17 67/18 76/18</p> <p>part-time [6] 34/18 42/20 47/25 48/3 58/3 59/17</p> <p>participant [1] 2/13</p> <p>participants [1] 6/11</p> <p>particular [10] 3/15 4/10 13/13 16/8 21/1 28/19 30/11 32/5</p>

<p>P</p> <p>particular... [2] 41/25 45/4</p> <p>particularly [4] 45/21 49/8 77/24 89/20</p> <p>parties [1] 84/3</p> <p>partner [4] 21/9 40/7 47/6 57/21</p> <p>parts [1] 44/9</p> <p>party [1] 16/25</p> <p>passed [3] 21/23 28/15 83/6</p> <p>pastor [1] 88/14</p> <p>patients [4] 6/5 38/14 51/16 61/14</p> <p>Paul [7] 13/17 13/24 14/7 15/13 20/3 20/23 37/20</p> <p>pause [1] 16/11</p> <p>pay [1] 59/22</p> <p>payable [1] 14/8</p> <p>paying [3] 3/9 5/21 7/16</p> <p>payment [3] 86/8 86/16 87/4</p> <p>pays [1] 7/17</p> <p>peered [1] 71/16</p> <p>peers [1] 57/3</p> <p>penny [1] 29/15</p> <p>people [47] 1/23 2/24 3/6 3/18 4/14 4/16 5/4 5/4 5/22 5/23 6/9 10/16 10/18 19/9 20/17 24/6 24/18 25/7 30/16 31/7 34/11 35/11 35/13 40/23 44/13 47/7 47/14 51/6 58/10 62/15 66/10 66/10 67/24 74/15 83/17 84/14 84/18 84/21 84/22 85/4 88/10 88/16 88/20 89/8 89/14 89/16 89/16</p> <p>people's [2] 8/8 19/13</p> <p>perfectly [1] 60/22</p> <p>perhaps [2] 71/17 84/12</p> <p>period [3] 13/5 58/11 60/21</p> <p>periods [2] 54/10 64/4</p> <p>permission [3] 8/4 8/6 24/1</p> <p>permits [1] 3/9</p> <p>person [22] 1/21 6/8 6/14 6/21 6/25 25/25 30/7 47/4 47/7 47/15 51/19 52/3 52/11 52/13 59/24 60/19 67/16 70/25 77/8 83/3 84/5 86/25</p> <p>person's [3] 3/9 5/21 7/16</p> <p>personal [2] 2/7 2/11</p> <p>perspectives [1] 5/23</p> <p>persuaded [3] 30/11 53/25 57/8</p> <p>pestering [1] 73/20</p> <p>phlegm [1] 32/18</p> <p>phone [10] 25/25 26/2 26/16 26/17 31/7 39/5 61/18 76/6 88/13 88/13</p> <p>phoning [1] 26/15</p> <p>photographs [5] 8/3 8/5 8/11 25/17 76/23</p> <p>phrase [2] 1/13 59/2</p> <p>physical [3] 4/15 31/24 34/13</p> <p>physically [2] 28/22 28/23</p> <p>piano [1] 80/16</p> <p>pick [1] 72/1</p> <p>picked [1] 83/10</p> <p>picture [3] 5/19 18/7 47/18</p> <p>pictures [2] 8/1 24/1</p> <p>piece [2] 25/9 64/14</p> <p>pieces [2] 20/1 81/8</p> <p>pints [1] 32/20</p> <p>place [3] 9/2 19/23 28/7</p> <p>plan [1] 47/25</p> <p>plasma [3] 38/6 75/5 75/9</p> <p>plastic [3] 83/10 83/14 89/22</p> <p>played [2] 62/4 67/21</p> <p>playing [3] 12/3 24/18 80/15</p> <p>playroom [1] 59/15</p> <p>please [18] 3/4 8/2 8/7 8/11 9/10 10/10 13/18 13/24 14/7 15/12 20/3 20/23 32/14 34/12 37/20 38/19 46/10 67/2</p> <p>pm [4] 46/6 66/21 66/23 91/1</p> <p>pneumonia [5] 72/12 72/15 73/25 75/19 79/23</p> <p>point [7] 15/14 30/3 62/21 79/17 84/23 87/14 89/11</p> <p>pointed [1] 2/15</p> <p>points [1] 88/22</p> <p>policy [2] 61/17 61/20</p> <p>poorly [1] 85/20</p> <p>port [1] 56/7</p> <p>position [2] 82/15 84/17</p> <p>positions [1] 57/6</p> <p>positive [2] 22/5 30/7</p> <p>positives [2] 25/21 25/22</p> <p>possess [1] 64/13</p> <p>possibilities [2] 14/14 14/19</p> <p>possibility [1] 62/4</p> <p>possible [9] 3/11 4/19 6/23 7/1 8/13 8/25 11/19 52/24 64/8</p> <p>post [2] 64/5 70/6</p> <p>post-birth [1] 64/5</p> <p>pound [1] 29/15</p> <p>pounds [2] 48/12 48/24</p> <p>practical [1] 4/15</p> <p>practices [1] 61/14</p> <p>practising [1] 88/6</p> <p>praise [1] 4/10</p> <p>pray [1] 78/2</p> <p>prayed [1] 85/24</p> <p>prayer [1] 88/14</p> <p>precautions [1] 71/3</p> <p>precise [1] 60/1</p> <p>preference [1] 53/18</p> <p>preferred [1] 53/18</p> <p>preliminary [1] 3/2</p> <p>presence [1] 64/2</p> <p>present [1] 53/24</p> <p>press [13] 2/1 8/10 18/16 19/10 19/11 19/14 19/18 19/18 20/1 21/17 23/14 25/16 44/11</p> <p>pressure [1] 54/24</p> <p>prevented [2] 1/12 1/12</p> <p>previous [1] 73/17</p> <p>previously [1] 74/10</p> <p>price [1] 60/2</p> <p>primary [7] 46/17 46/18 46/21 47/20 48/4 56/25 61/17</p> <p>principle [3] 1/6 2/3 3/7</p> <p>principles [4] 2/23 3/1 3/4 9/13</p> <p>prior [4] 21/18 26/5 44/2 85/7</p> <p>private [1] 23/18</p> <p>proactive [1] 87/20</p> <p>probably [13] 21/2 30/8 32/16 36/4 37/23 40/2 48/4 48/20 54/15 57/1 59/11 61/24 65/25</p> <p>problem [3] 24/23 35/14 43/13</p> <p>problems [3] 24/22 30/17 34/13</p> <p>procedure [1] 54/21</p> <p>proceedings [1] 7/25</p> <p>process [2] 39/14 87/23</p> <p>product [2] 14/8 38/9</p> <p>products [7] 1/11 6/3 13/12 13/13 13/21 16/16 38/4</p> <p>profession [1] 70/14</p> <p>professional [2] 64/19 87/17</p> <p>professionally [1] 37/10</p> <p>programme [2] 8/16 90/11</p> <p>progressive [2] 37/24 50/7</p> <p>project [1] 71/14</p> <p>promised [1] 3/17</p> <p>promptly [2] 63/19 64/6</p> <p>proper [3] 3/9 48/2 73/22</p> <p>properties [1] 42/18</p> <p>protect [2] 41/4 52/23</p> <p>protected [1] 53/5</p> <p>protective [2] 12/8 12/16</p> <p>proud [1] 43/9</p> <p>prove [2] 28/3 64/8</p> <p>proven [1] 8/19</p> <p>provide [2] 38/16 62/15</p> <p>provided [5] 9/23 20/2 27/21 70/22 83/13</p> <p>psychological [2] 44/2 87/6</p> <p>psychologist [1] 30/13</p> <p>pub [6] 18/23 18/23 18/24 18/25 41/15 41/20</p> <p>public [6] 1/8 1/24 3/20 7/8 7/21 45/19</p> <p>published [3] 6/16 7/12 90/11</p> <p>pull [3] 28/4 31/15 36/20</p> <p>Pulled [1] 69/18</p> <p>pumped [1] 54/12</p> <p>punishment [1] 84/14</p> <p>puppy [1] 80/3</p> <p>pursue [1] 61/19</p> <p>push [1] 31/17</p> <p>pushed [3] 36/8 43/11 54/22</p> <p>put [19] 3/17 11/13 17/23 19/23 24/10 24/12 28/4 29/9 33/19 33/20 54/23 60/8 64/24 65/25 81/3 81/13 81/16 83/14 89/21</p> <p>puts [1] 1/23</p> <p>putting [5] 2/24 3/6 4/14 5/22 29/5</p> <p>puzzle [1] 64/15</p>	<p>Q</p> <p>QE [10] 12/21 16/19 16/19 27/4 27/12 32/22 33/15 37/8 39/3 43/16</p> <p>quality [1] 80/8</p> <p>Queen [2] 12/20 20/15</p> <p>question [7] 14/18 19/2 34/6 56/18 64/4 64/24 72/4</p> <p>Questioned [6] 10/12 46/12 67/5 91/7 91/9 91/11</p> <p>questions [5] 44/15 56/15 63/21 78/23 88/1</p> <p>quick [1] 3/8</p> <p>quicker [1] 39/8</p> <p>quickly [2] 1/12 60/23</p> <p>quiet [3] 70/16 70/16 90/1</p> <p>quietly [1] 69/9</p> <p>quite [13] 16/8 24/9 32/9 52/9 59/22 67/16 68/19 72/18 80/6 80/15 83/12 84/25 85/1</p> <p>R</p> <p>raise [1] 88/23</p> <p>rapidly [1] 53/14</p> <p>rate [1] 6/19</p> <p>rates [1] 59/10</p> <p>rather [6] 1/14 1/22 2/8 2/12 10/4 70/6</p> <p>Rawson [1] 90/16</p> <p>reached [1] 89/15</p> <p>reaction [3] 73/4 74/8 84/9</p> <p>read [6] 5/10 5/10 5/11 6/19 33/7 66/1</p> <p>readily [1] 8/8</p> <p>reading [3] 9/15 39/2 47/16</p> <p>ready [2] 44/14 72/20</p> <p>real [2] 5/15 42/1</p> <p>realise [4] 43/15 45/1 51/7 83/5</p> <p>realised [1] 75/16</p> <p>realising [2] 22/14 22/15</p> <p>really [34] 23/25 25/5 29/23 30/9 32/9 34/10 37/10 43/21 45/3 47/18 52/23 54/12 56/19 58/19 60/17 66/5 70/3 70/7 70/17 71/21 72/18 73/18</p> <p>74/1 76/18 77/10 79/7 80/8 80/10 80/23 84/18 84/25 85/19 88/15 89/8</p> <p>reason [4] 5/2 8/15 62/8 90/22</p> <p>reasonable [2] 3/8 66/9</p> <p>reasons [2] 7/1 90/13</p> <p>reassurance [1] 38/16</p> <p>reassure [1] 56/9</p> <p>recall [5] 13/6 14/11 27/18 37/7 68/5</p> <p>recalled [1] 30/25</p> <p>receipt [1] 62/12</p> <p>receive [3] 62/17 63/7 69/4</p> <p>received [26] 6/3 13/22 15/6 23/4 27/24 32/1 37/6 37/20 38/9 38/22 38/24 40/13 48/6 48/10 48/15 48/25 60/5 62/22 63/3 63/11 64/5 68/3 69/5 73/4 86/8 86/16</p> <p>receiving [4] 13/21 14/4 83/7 86/10</p> <p>recently [2] 38/3 38/7</p> <p>recognise [2] 5/23 66/10</p> <p>recognition [1] 38/12</p> <p>recollection [1] 28/11</p> <p>record [1] 64/24</p> <p>recorded [1] 14/4</p> <p>records [13] 13/3 13/20 20/9 38/8 60/25 61/10 61/12 61/16 61/21 62/9 62/15 63/12 87/2</p> <p>recover [1] 57/20</p> <p>Red [3] 4/6 4/11 4/12</p> <p>redacted [15] 6/16 10/22 11/6 24/24 35/7 35/7 40/18 40/19 40/25 48/12 70/25 73/9 88/12 88/12 88/14</p> <p>redundant [1] 58/6</p> <p>reference [4] 9/18 10/15 22/3 38/11</p> <p>referred [1] 82/7</p> <p>referring [2] 51/6 76/2</p> <p>refers [5] 20/10 20/14 20/14 20/16 38/2</p> <p>refuse [1] 89/22</p> <p>refused [2] 74/9 76/4</p> <p>regained [1] 82/20</p> <p>regard [1] 15/15</p> <p>region [1] 2/16</p> <p>regularly [1] 74/4</p> <p>related [2] 17/8 20/10</p> <p>relating [1] 31/1</p>
---	---

(34) particular... - relating

<p>R</p> <p>relation [5] 16/11 18/6 37/6 68/12 76/1</p> <p>relationship [3] 39/24 58/14 71/7</p> <p>relevant [2] 38/24 64/14</p> <p>remains [1] 90/23</p> <p>remember [21] 8/5 12/9 15/25 16/4 21/3 22/16 23/19 24/7 27/5 28/1 28/23 29/4 30/6 33/22 41/22 44/8 49/11 50/17 76/25 77/1 79/12</p> <p>remembrance [6] 17/1 23/8 36/17 36/18 36/19 36/22</p> <p>repeat [2] 3/5 5/20</p> <p>repeating [2] 1/14 3/4</p> <p>replace [1] 85/23</p> <p>replacement [1] 9/7</p> <p>reply [1] 63/19</p> <p>report [1] 64/16</p> <p>reported [1] 68/25</p> <p>reporters [2] 19/6 23/24</p> <p>represent [1] 25/3</p> <p>represents [2] 45/13 88/22</p> <p>request [3] 63/1 63/5 63/7</p> <p>require [1] 38/18</p> <p>requirement [1] 62/15</p> <p>requires [1] 6/18</p> <p>research [1] 71/14</p> <p>reserve [1] 9/1</p> <p>resilient [2] 51/19 52/13</p> <p>resort [1] 54/21</p> <p>respect [9] 3/9 5/21 6/11 6/14 7/16 7/17 7/23 8/8 10/19</p> <p>respectable [1] 19/13</p> <p>respects [1] 52/11</p> <p>respond [4] 6/22 7/9 7/11 7/16</p> <p>response [8] 62/17 62/22 62/24 63/2 63/8 63/11 73/5 74/21</p> <p>responsible [2] 56/24 57/24</p> <p>responsive [1] 81/25</p> <p>rest [4] 18/18 45/6 52/3 72/18</p> <p>restrict [1] 52/16</p> <p>restricted [1] 52/16</p> <p>result [5] 1/17 23/5 32/7 56/10 60/2</p> <p>results [2] 69/2 69/4</p> <p>resume [1] 59/16</p>	<p>return [2] 47/25 48/3</p> <p>revealed [1] 20/11</p> <p>rheumatoid [1] 34/15</p> <p>ribavirin [1] 29/6</p> <p>Richards [3] 10/7 10/12 91/7</p> <p>ride [1] 78/5</p> <p>ridicule [1] 19/21</p> <p>right [25] 2/2 2/19 3/9 4/3 5/21 7/9 7/16 7/18 10/9 15/25 27/7 43/18 46/2 47/24 48/8 49/19 53/25 63/10 63/14 68/1 70/9 74/23 74/23 80/21 87/10</p> <p>rip [1] 30/21</p> <p>ripped [2] 18/19 26/24</p> <p>rising [1] 59/9</p> <p>risk [4] 37/6 39/12 50/20 60/21</p> <p>risks [4] 15/1 22/1 49/5 49/25</p> <p>road [4] 12/13 53/15 54/3 58/20</p> <p>rock [1] 11/24</p> <p>role [1] 62/5</p> <p>roll [1] 11/24</p> <p>roller [1] 62/2</p> <p>room [7] 2/1 3/18 8/1 52/22 56/9 71/15 72/17</p> <p>rooms [1] 4/4</p> <p>round [5] 12/10 12/11 12/12 19/5 70/2</p> <p>row [3] 3/24 47/8 54/8</p> <p>roy [27] 12/22 16/10 17/16 18/5 18/6 18/7 18/8 18/11 18/13 18/15 18/16 18/17 19/14 19/19 20/9 20/17 20/21 21/12 21/22 22/8 22/17 23/2 23/9 23/16 24/3 24/4 44/11</p> <p>Roy's [3] 20/15 20/24 22/18</p> <p>Royal [1] 43/9</p> <p>rubber [2] 54/22 71/6</p> <p>run [2] 65/8 70/2</p> <p>rush [1] 90/4</p> <p>rushed [2] 32/21 81/3</p> <p>Ryan [1] 18/22</p>	<p>S</p> <p>sad [2] 40/5 65/5</p> <p>said [53] 2/13 5/20 8/23 9/11 13/11 14/21 16/6 18/2 19/14 21/9 21/13 21/17 21/21 24/4 24/5 25/13 26/10 28/13 29/14 30/2 33/17 36/14 37/22 39/10 40/3 42/22 43/18 43/20 44/19 47/20 56/1 56/4 57/14 59/17 61/24 63/4 63/6 65/22 66/11 69/1 69/24 71/1 71/1 72/3 73/11 74/10 74/22 77/7 79/11 82/4 84/19 86/11 88/8</p> <p>salacious [1] 84/1</p> <p>same [17] 6/8 7/13 7/15 8/11 9/9 15/13 16/19 21/11 24/4 24/20 24/23 39/25 40/1 42/3 46/21 82/10 82/19</p> <p>sang [1] 43/8</p> <p>Sarah [1] 66/13</p> <p>sat [3] 56/5 71/16 87/21</p> <p>Saturday [1] 54/17</p> <p>saving [1] 78/9</p> <p>saw [3] 51/17 71/18 88/7</p> <p>say [44] 3/16 6/15 7/22 10/15 19/6 19/18 24/13 24/16 25/9 26/12 26/13 28/15 36/24 38/25 39/5 40/5 47/12 47/13 47/14 48/24 55/3 55/19 57/7 58/20 59/23 60/3 60/20 60/21 63/11 63/22 65/11 66/8 66/10 70/12 76/18 78/4 79/3 79/5 79/7 84/3 88/2 89/6 89/8 90/24</p> <p>saying [9] 2/22 15/25 20/16 35/16 37/10 37/11 65/15 67/15 67/24</p> <p>says [2] 8/17 29/11</p> <p>scared [1] 65/16</p> <p>school [15] 11/8 12/23 14/23 41/2 46/17 46/18 46/21 47/20 48/1 48/3 52/20 53/17 56/25 58/12 59/18</p> <p>schools [1] 11/10</p> <p>screen [4] 13/15 15/12 20/22 60/8</p> <p>scum [1] 18/21</p> <p>sealed [1] 56/7</p> <p>seat [1] 2/1</p> <p>second [17] 5/20 15/13 17/12 29/25 32/1 39/22 39/24 40/6 43/7 48/14 48/23 48/23 49/7 49/11 49/19 63/3 73/1</p>	<p>secret [1] 66/2</p> <p>secretary [1] 73/9</p> <p>see [21] 7/14 13/19 13/22 14/1 14/3 15/14 25/19 26/15 30/13 40/9 40/22 51/18 54/4 54/8 56/16 57/23 60/9 61/8 73/11 77/9 83/17</p> <p>seeing [3] 68/5 76/19 76/20</p> <p>seem [1] 33/9</p> <p>seemed [1] 19/21</p> <p>seen [3] 14/22 51/15 77/6</p> <p>Sengstaken [1] 54/21</p> <p>senior [3] 41/1 46/18 57/5</p> <p>seniors [1] 41/2</p> <p>sensation [1] 51/21</p> <p>sense [2] 56/1 81/21</p> <p>sent [4] 30/12 37/10 56/2 62/25</p> <p>sentence [1] 52/10</p> <p>sentiments [1] 64/22</p> <p>separate [2] 2/10 9/14</p> <p>September [4] 3/2 5/20 9/17 16/25</p> <p>series [1] 48/11</p> <p>serious [2] 55/20 64/7</p> <p>seriousness [2] 51/12 53/11</p> <p>served [1] 65/5</p> <p>serves [1] 1/24</p> <p>service [1] 65/1</p> <p>sessions [2] 5/8 9/1</p> <p>set [2] 2/25 60/10</p> <p>seven [1] 73/15</p> <p>several [10] 2/13 18/8 18/14 18/14 20/12 36/23 50/12 62/12 62/13 73/23</p> <p>severe [2] 11/4 68/2</p> <p>sex [3] 11/24 12/6 28/16</p> <p>shaking [1] 31/14</p> <p>shall [5] 7/2 7/22 8/25 10/5 55/2</p> <p>shame [1] 4/11</p> <p>shape [1] 52/5</p> <p>share [2] 20/23 70/18</p> <p>she [132]</p> <p>she'd [8] 11/23 12/4 12/5 12/6 12/7 12/14 48/3 51/18</p> <p>shell [1] 26/9</p> <p>ship [1] 59/4</p> <p>shitty [2] 30/8 34/25</p> <p>shop [2] 36/12 36/14</p> <p>shopping [1] 78/5</p> <p>short [3] 8/18 25/11 46/5</p> <p>shortfalls [1] 85/18</p>	<p>shot [1] 51/7</p> <p>should [19] 4/20 7/14 10/2 13/16 21/7 34/24 35/15 37/11 38/18 48/19 48/23 64/8 65/13 65/13 71/3 74/4 74/5 85/25 86/1</p> <p>shouldn't [3] 11/20 35/1 71/17</p> <p>show [1] 76/16</p> <p>shown [1] 16/19</p> <p>shows [1] 2/2</p> <p>sick [2] 32/18 84/15</p> <p>sickness [1] 85/21</p> <p>side [7] 3/21 4/4 19/20 25/25 33/21 71/16 84/18</p> <p>sides [1] 7/15</p> <p>sign [2] 86/9 86/11</p> <p>signed [1] 43/20</p> <p>significant [2] 6/21 84/20</p> <p>signs [1] 76/16</p> <p>silly [1] 71/22</p> <p>similar [4] 27/5 38/22 64/12 89/14</p> <p>simple [2] 1/6 5/3</p> <p>simply [3] 1/14 6/1 21/23</p> <p>since [2] 31/16 63/7</p> <p>singer [1] 43/8</p> <p>single [4] 5/11 62/17 63/8 63/9</p> <p>sir [8] 1/3 10/9 46/2 46/9 64/16 66/19 90/20 91/5</p> <p>SIR BRIAN [3] 1/3 64/16 91/5</p> <p>sister [3] 25/23 26/1 56/15</p> <p>sisters [1] 4/2</p> <p>sit [10] 2/14 10/13 10/16 33/6 43/2 43/4 79/9 80/3 80/5 90/5</p> <p>sitting [2] 4/25 32/15</p> <p>situation [5] 53/2 53/4 70/12 89/9 89/14</p> <p>situations [1] 19/13</p> <p>six [10] 3/14 49/17 49/21 50/12 50/15 63/6 63/18 79/14 87/7 87/10</p> <p>skin [2] 50/9 72/23</p> <p>skip [1] 13/24</p> <p>Skipton [5] 43/12 61/4 86/16 86/22 87/3</p> <p>sleep [3] 21/9 79/25 80/6</p> <p>slept [3] 20/11 54/16 80/1</p> <p>slightly [1] 52/11</p> <p>slowly [1] 51/25</p>	<p>smack [1] 12/12</p> <p>small [2] 56/7 68/18</p> <p>smashing [1] 30/10</p> <p>Snowden [3] 45/12 45/14 88/21</p> <p>so [133]</p> <p>sobbing [1] 16/6</p> <p>social [3] 4/9 73/10 73/19</p> <p>Society [1] 38/17</p> <p>softly [1] 67/23</p> <p>some [43] 2/25 4/6 6/12 7/19 15/16 16/3 16/14 17/15 23/5 23/12 28/11 32/18 38/4 40/14 42/16 42/16 48/3 52/11 63/18 65/15 66/10 66/11 68/9 70/19 71/15 72/21 73/3 74/12 76/5 76/23 76/23 77/19 78/22 79/8 80/16 81/3 81/4 82/2 84/1 84/11 85/11 86/8 87/15</p> <p>somebody [3] 8/6 9/1 24/11</p> <p>someone [3] 6/20 8/5 70/11</p> <p>something [15] 6/24 8/15 15/9 26/21 30/2 30/10 32/6 32/19 33/7 37/12 65/17 65/21 69/20 77/6 88/24</p> <p>sometimes [6] 6/7 8/12 11/14 30/19 39/8 80/5</p> <p>somewhat [1] 57/3</p> <p>somewhere [1] 78/5</p> <p>son [12] 17/5 17/5 17/5 43/3 47/22 48/5 48/14 48/18 49/7 49/11 49/19 59/18</p> <p>sons [12] 25/10 26/7 36/12 48/10 52/23 53/15 55/13 58/11 58/22 59/14 59/21 64/11</p> <p>soon [1] 45/10</p> <p>sooner [1] 45/11</p> <p>sorry [16] 9/5 18/10 19/22 20/4 22/23 22/24 23/8 41/9 41/22 46/25 53/22 56/3 56/6 81/15 82/15 83/17 34/25 36/21 39/25 40/1 69/10 87/17</p> <p>sorts [1] 58/21</p> <p>sought [2] 43/25 87/19</p> <p>south [3] 2/20 68/16</p>
---	--	---	--	---	--

<p>S</p> <p>south... [1] 85/10</p> <p>space [6] 4/5 4/15 23/5 25/11 40/8 80/25</p> <p>spaceman [1] 74/14</p> <p>Spain [1] 58/22</p> <p>span [1] 27/6</p> <p>spare [1] 2/1</p> <p>spared [1] 56/22</p> <p>speak [5] 3/25 5/7 5/17 10/24 10/25</p> <p>speaking [1] 26/1</p> <p>special [3] 9/14 62/23 63/12</p> <p>specialist [1] 43/16</p> <p>specific [1] 50/17</p> <p>spell [1] 30/8</p> <p>spend [5] 28/25 47/16 52/19 52/20 53/16</p> <p>spending [1] 53/8</p> <p>spent [3] 11/9 17/19 17/21</p> <p>split [1] 18/2</p> <p>spoke [1] 90/13</p> <p>spoken [2] 67/23 72/7</p> <p>spray [1] 81/14</p> <p>St [2] 49/20 65/4</p> <p>St James's [1] 65/4</p> <p>staff [4] 64/18 64/25 65/4 74/18</p> <p>Staffordshire [1] 31/6</p> <p>stage [8] 3/15 3/20 16/14 18/2 52/25 70/22 74/17 83/7</p> <p>stages [4] 29/3 29/4 34/6 52/18</p> <p>stair [1] 73/16</p> <p>stand [3] 10/16 43/5 43/5</p> <p>start [4] 45/4 65/14 68/12 90/9</p> <p>started [13] 21/15 21/16 22/11 22/13 22/14 26/11 29/5 45/1 48/1 48/2 59/18 68/16 76/16</p> <p>starting [1] 15/23</p> <p>starts [1] 37/22</p> <p>state [2] 22/19 51/16</p> <p>statement [22] 1/3 5/9 5/18 6/15 6/19 7/12 7/12 14/21 17/14 17/23 21/21 24/5 27/19 30/2 39/10 59/3 62/10 63/24 66/1 72/3 86/11 91/5</p> <p>statements [3] 5/14 9/15 23/12</p> <p>states [1] 61/18</p> <p>station [1] 88/9</p> <p>statistical [1] 64/8</p> <p>statutory [1] 1/8</p> <p>stay [5] 65/10 66/2 72/17 81/5 90/4</p> <p>stayed [1] 48/15</p> <p>stemmed [1] 30/14</p> <p>stent [2] 33/19 33/20</p> <p>Stevenage [2] 84/24 85/2</p> <p>stigma [7] 36/6 40/14 45/21 89/3 89/18 89/19 89/23</p> <p>stigmatising [1] 83/18</p> <p>still [13] 20/21 26/20 30/22 31/22 39/7 39/11 42/21 44/22 67/22 82/16 83/16 88/5 89/13</p> <p>stone [3] 17/1 25/18 68/19</p> <p>stones [1] 24/6</p> <p>stood [2] 19/8 19/10</p> <p>stop [6] 11/20 13/10 29/2 54/24 67/13 71/10</p> <p>stopped [1] 47/22</p> <p>stopping [1] 35/14</p> <p>stories [1] 68/20</p> <p>story [5] 19/20 50/7 84/13 89/3 89/19</p> <p>straight [1] 30/12</p> <p>straightaway [1] 82/1</p> <p>stranger [1] 57/22</p> <p>straps [1] 69/18</p> <p>streamed [1] 7/25</p> <p>streaming [1] 5/17</p> <p>street [1] 12/3</p> <p>strength [1] 11/18</p> <p>stress [1] 37/2</p> <p>stroke [2] 82/5 88/8</p> <p>strong [4] 12/1 25/16 26/23 58/13</p> <p>struggle [2] 86/6 86/7</p> <p>stuck [2] 36/8 36/9</p> <p>student [3] 67/19 67/21 67/22</p> <p>students [2] 67/20 85/9</p> <p>stupidity [1] 59/5</p> <p>subject [2] 7/3 42/14</p> <p>subsequent [2] 23/15 62/6</p> <p>subsequently [2] 47/21 84/19</p> <p>substantial [1] 59/19</p> <p>substantially [1] 59/14</p> <p>succeed [2] 32/2 32/6</p> <p>successful [1] 57/5</p> <p>such [6] 8/11 25/11 40/14 64/13 65/1 76/9</p> <p>sudden [1] 36/15</p> <p>Sue [2] 45/2 45/3</p>	<p>suffer [4] 1/17 5/4 64/7 76/19</p> <p>suffered [1] 88/17</p> <p>suffering [1] 1/10</p> <p>sufficient [1] 22/24</p> <p>sufficiently [1] 1/12</p> <p>suits [1] 80/25</p> <p>summer [2] 49/17 72/12</p> <p>Sunday [4] 17/2 23/8 31/21 36/22</p> <p>Sunderland [1] 67/19</p> <p>supplementary [2] 66/1 66/15</p> <p>support [17] 44/3 57/1 57/8 57/11 59/20 61/17 70/17 74/13 77/23 83/4 84/16 84/16 85/2 87/6 88/3 88/4 89/16</p> <p>supported [1] 88/19</p> <p>supporter [1] 3/25</p> <p>supporters [1] 3/23</p> <p>supportive [4] 34/19 34/22 58/19 78/2</p> <p>suppose [1] 62/5</p> <p>sure [5] 16/18 18/9 39/11 60/3 90/21</p> <p>surname [2] 41/3 41/3</p> <p>surnames [1] 40/16</p> <p>surprise [2] 57/20 72/4</p> <p>surprised [1] 62/5</p> <p>surprising [1] 63/14</p> <p>survived [1] 22/5</p> <p>survives [1] 35/21</p> <p>suspect [1] 45/18</p> <p>sustained [1] 54/25</p> <p>swings [2] 77/14 77/20</p> <p>swore [1] 56/6</p> <p>sworn [6] 10/11 46/11 67/4 91/6 91/8 91/10</p> <p>symbolises [1] 3/19</p> <p>sympathise [1] 90/22</p> <p>system [2] 75/7 75/17</p>	<p>T</p> <p>tablets [2] 29/21 30/23</p> <p>tabloid [1] 19/14</p> <p>taboo [1] 42/14</p> <p>tainted [3] 25/7 30/17 45/2</p> <p>take [16] 8/1 8/2 8/11 8/21 10/16 43/4 45/24 57/9 58/22 66/17 71/3 76/13 77/12 77/15 81/1 88/11</p> <p>taken [7] 4/21 6/3 9/4 54/17 76/6 79/3 81/6</p> <p>taking [3] 8/5 24/1</p> <p>90/17</p> <p>talk [9] 11/23 12/4 12/5 27/15 27/23 32/12 37/12 37/13 84/22</p> <p>talked [4] 64/21 78/21 78/24 87/22</p> <p>talking [5] 12/6 16/1 45/19 63/15 63/16</p> <p>tangible [1] 63/8</p> <p>taste [1] 72/23</p> <p>teacher [4] 46/18 46/22 47/21 56/25</p> <p>teaching [1] 48/4</p> <p>team [2] 87/3 88/14</p> <p>tears [1] 57/22</p> <p>teatime [1] 58/11</p> <p>technician [1] 47/21</p> <p>teens [1] 12/19</p> <p>tell [25] 11/4 11/16 14/16 46/16 47/2 49/8 51/4 53/12 55/13 55/25 58/25 61/11 67/11 68/13 72/13 74/18 75/25 76/17 77/15 77/25 78/18 80/14 81/10 82/25 85/6</p> <p>telling [2] 18/23 26/2</p> <p>temperament [1] 79/1</p> <p>ten [4] 33/3 33/12 46/17 77/2</p> <p>ten minutes [1] 77/2</p> <p>tennis [1] 43/4</p> <p>term [2] 31/25 81/5</p> <p>terminally [2] 50/18 60/24</p> <p>terms [8] 9/18 13/4 23/14 27/15 31/24 42/12 46/20 46/22</p> <p>Terrace [2] 48/9 64/3</p> <p>test [2] 15/17 69/2</p> <p>tested [2] 28/9 71/2</p> <p>testimony [1] 66/6</p> <p>tests [2] 16/1 75/15</p> <p>than [20] 1/14 1/22 4/22 7/21 9/16 9/17 9/19 11/9 39/8 45/11 48/16 51/16 53/9 57/1 57/2 57/3 57/10 70/6 72/8 85/19</p> <p>thank [27] 10/1 10/5 10/14 10/20 13/18 20/4 44/16 45/15 45/17 45/22 45/23 64/17 65/6 65/7 65/8 65/10 65/12 65/12 66/12 66/13 66/16 66/19 89/24 89/25 90/1 90/3 90/24</p> <p>thanks [2] 45/18 64/25</p>	<p>that [296]</p> <p>that's [42] 10/9 10/23 11/2 12/21 12/24 13/2 14/6 14/25 15/8 15/9 15/19 15/21 16/15 18/1 19/7 20/3 26/20 27/22 28/13 29/10 34/3 34/24 36/16 37/2 40/5 40/5 41/24 46/2 46/9 47/24 48/8 49/19 52/14 63/10 63/14 66/7 66/9 72/10 74/16 75/12 90/6 90/20</p> <p>their [39] 1/10 1/17 4/7 7/20 7/24 8/4 8/9 19/9 23/4 23/13 24/19 27/6 30/9 30/17 34/12 38/15 40/15 41/3 41/3 41/8 41/10 42/7 53/2 53/4 53/7 53/10 54/4 55/13 55/19 56/2 57/1 57/3 57/6 61/17 61/20 61/23 67/21 80/25 84/18</p> <p>them [59] 1/20 1/21 3/5 3/21 3/25 6/7 8/10 10/18 14/18 19/7 20/14 23/23 24/9 24/16 26/14 28/3 29/11 34/23 35/1 36/8 38/5 39/5 41/4 41/23 42/16 44/7 44/9 45/8 49/5 52/19 52/21 52/24 53/5 55/22 55/23 55/25 56/1 56/2 56/3 56/20 56/21 56/22 57/8 57/12 57/23 58/12 58/14 59/15 61/20 61/23 62/18 62/20 73/20 73/23 74/24 84/13 84/22 84/23 86/19</p> <p>themselves [2] 1/20 43/11</p> <p>then [59] 5/9 7/9 9/17 9/19 12/18 13/12 13/22 14/2 14/7 14/23 16/9 22/4 22/8 22/9 22/17 23/9 29/4 29/13 31/10 31/16 31/20 31/24 32/22 33/11 35/19 35/24 38/1 38/19 39/21 46/19 47/21 48/3 48/6 48/14 48/19 48/22 50/12 52/3 52/20 56/18 57/25 60/23 62/16 62/18 70/19 71/25 72/7 72/22 74/22 75/10 75/18 80/4 80/11 80/18 80/23 81/18 82/17 86/4</p>	<p>86/23</p> <p>theory [1] 75/6</p> <p>therapy [3] 29/19 35/16 35/17</p> <p>there [84] 1/25 3/3 3/25 4/4 5/7 8/6 8/18 9/23 10/5 11/9 12/4 13/19 13/23 14/16 16/11 18/23 18/24 19/2 20/23 21/3 21/5 21/19 22/3 23/23 24/7 24/9 25/6 26/8 27/22 29/3 30/16 31/21 33/21 34/11 35/19 42/1 42/1 42/10 43/4 44/17 45/13 45/14 47/13 47/18 50/20 50/25 51/9 59/6 60/9 60/20 62/3 63/19 63/21 64/6 66/4 68/20 69/9 69/15 70/3 70/12 70/13 70/13 70/23 71/25 72/20 74/13 78/9 82/24 83/1 83/21 84/21 85/1 85/14 85/22 87/3 88/1 88/12 88/24 89/9 89/9 90/4 90/10 90/11 90/12</p> <p>there's [8] 19/12 70/2 71/23 73/6 73/7 88/22 89/9 90/4</p> <p>thereabouts [1] 43/25</p> <p>these [9] 13/20 14/12 20/19 21/8 61/25 62/9 70/2 75/14 84/14</p> <p>they [145]</p> <p>they've [1] 22/21</p> <p>thin [1] 26/9</p> <p>thing [11] 12/6 32/17 36/21 40/3 45/9 55/16 55/18 65/14 71/24 81/12 84/25</p> <p>things [17] 17/10 17/24 24/12 33/10 34/11 34/25 43/10 47/5 51/9 57/10 58/24 66/11 69/16 76/25 78/14 79/7 81/3</p> <p>think [42] 2/9 4/9 4/18 4/23 16/25 18/8 19/11 21/15 26/20 26/21 28/1 28/14 28/17 30/7 30/16 32/18 35/3 36/3 38/22 41/21 43/12 44/21 45/7 45/9 45/25 53/9 59/2 64/21 65/21 66/15 70/7 71/22 75/1 75/6 75/13 79/11 82/13 82/15 84/11 86/14 88/16 89/21</p> <p>thinking [8] 1/14 16/3 51/9 60/17 72/2 84/2</p>
---	---	--	---	---

<p>T</p> <p>thinking... [2] 84/4 84/13</p> <p>thinks [3] 16/7 65/19 65/24</p> <p>thinner [2] 26/11 26/11</p> <p>Third [1] 6/14</p> <p>this [106]</p> <p>thorough [1] 61/15</p> <p>thoroughness [1] 3/8</p> <p>those [39] 1/20 2/20 3/1 3/3 3/3 3/14 4/6 4/23 5/5 5/5 5/14 5/16 5/16 5/24 5/25 5/25 6/3 6/3 6/4 6/5 6/5 6/6 7/21 9/3 34/11 34/25 44/15 46/21 49/3 50/22 63/21 64/22 69/4 77/19 79/7 84/8 88/1 88/16 88/19</p> <p>though [2] 3/14 44/13</p> <p>thought [13] 2/9 24/11 25/8 27/7 27/9 29/13 29/15 33/25 43/21 45/6 75/8 79/4 82/4</p> <p>thoughts [1] 70/2</p> <p>Threakall [1] 45/3</p> <p>three [25] 11/14 15/23 22/7 22/9 23/2 23/4 23/6 24/16 25/10 26/7 32/10 35/18 35/19 36/2 40/7 40/13 43/8 48/8 48/13 56/4 59/20 67/20 72/16 79/20 83/15</p> <p>threshold [1] 80/11</p> <p>threw [1] 77/20</p> <p>thrilled [1] 56/11</p> <p>throat [3] 54/20 54/23 55/3</p> <p>through [29] 16/16 22/19 28/15 29/12 30/8 31/4 32/16 36/20 36/23 38/8 40/1 40/6 41/14 45/20 54/2 54/14 54/17 57/10 57/22 58/10 59/4 59/21 61/25 66/5 70/14 75/13 87/1 87/24 89/8</p> <p>throughout [5] 44/1 64/20 77/23 78/12 87/6</p> <p>throw [2] 24/6 77/10</p> <p>thrush [1] 72/13</p> <p>Thursday [1] 42/25</p> <p>tick [4] 70/9 79/10 79/10 79/10</p> <p>tied [2] 33/2 33/17</p>	<p>till [1] 54/17</p> <p>time [90] 4/16 5/3 5/7 5/11 6/24 7/10 7/13 7/15 8/24 9/3 11/9 14/10 15/16 16/2 17/6 17/20 17/21 18/13 19/8 19/21 19/24 19/25 21/1 21/11 22/22 23/13 25/11 25/23 27/6 28/11 28/14 28/19 31/5 31/18 32/5 33/4 33/23 33/23 34/18 40/23 41/21 41/25 42/20 44/1 44/1 47/16 47/25 48/3 49/15 49/19 52/17 52/19 52/21 53/8 53/16 57/9 58/3 59/9 59/17 59/25 61/11 61/19 62/16 62/21 66/9 68/20 69/16 70/7 70/16 72/2 72/9 72/14 72/16 72/24 73/1 75/23 77/23 78/12 78/21 78/22 79/6 79/8 81/8 85/1 85/25 86/9 86/20 86/24 87/18 90/18</p> <p>times [7] 26/16 31/19 43/8 73/23 74/5 80/1 88/11</p> <p>tired [1] 50/10</p> <p>titbits [1] 84/1</p> <p>to [538]</p> <p>today [6] 18/23 19/3 20/21 57/8 64/10 90/7</p> <p>together [5] 3/1 4/2 47/11 57/10 81/4</p> <p>toilet [5] 32/19 79/18 80/19 80/21 81/11</p> <p>toiletries [1] 81/4</p> <p>told [40] 7/4 16/12 16/13 16/23 18/9 19/3 21/10 21/11 21/12 21/15 21/23 22/7 22/8 22/12 27/16 27/18 34/4 35/18 38/23 38/25 39/18 40/12 43/16 45/22 49/25 50/2 50/14 50/15 50/16 50/18 50/18 55/22 55/22 56/1 56/4 56/4 70/5 74/4 79/14 84/13</p> <p>tomorrow [3] 8/19 90/9 90/25</p> <p>tomorrow's [1] 90/11</p> <p>too [8] 5/17 8/19 8/20 16/16 43/5 74/23 85/11 89/13</p> <p>took [6] 19/8 27/11 57/24 59/5 72/15</p>	<p>82/13</p> <p>top [3] 8/17 14/7 70/14</p> <p>torn [1] 87/24</p> <p>torpedo [1] 59/4</p> <p>total [1] 40/8</p> <p>totally [1] 42/5</p> <p>touch [2] 74/12 74/14</p> <p>tour [1] 68/7</p> <p>towards [2] 54/19 68/17</p> <p>track [1] 67/17</p> <p>traffic [1] 31/21</p> <p>tragedy [1] 26/23</p> <p>transfused [1] 6/4</p> <p>transfusion [3] 37/15 37/16 60/4</p> <p>transfusions [10] 13/9 48/6 48/11 48/15 48/25 49/3 49/4 60/17 63/16 64/6</p> <p>transmitting [1] 49/25</p> <p>transparent [1] 3/10</p> <p>transplant [2] 34/7 34/8</p> <p>transplants [2] 50/22 51/1</p> <p>trawl [1] 61/15</p> <p>treat [3] 71/5 72/18 74/11</p> <p>treated [4] 12/25 39/8 41/16 65/1</p> <p>treating [1] 70/19</p> <p>treatment [19] 1/15 13/3 13/8 15/6 16/17 23/3 23/15 29/25 32/1 32/2 38/15 39/22 40/12 41/15 42/11 72/20 75/2 76/1 76/10</p> <p>treatments [7] 13/6 14/12 14/14 14/22 29/5 29/6 75/14</p> <p>Treloar [1] 16/18</p> <p>Treloar's [1] 12/22</p> <p>tribe [1] 58/19</p> <p>tried [5] 19/20 31/17 60/25 61/9 76/7</p> <p>tries [1] 1/23</p> <p>trigger [1] 75/9</p> <p>trips [1] 85/13</p> <p>true [1] 72/10</p> <p>truly [1] 47/15</p> <p>Trust [4] 61/4 61/22 62/7 86/8</p> <p>truth [4] 21/25 47/10 56/1 84/5</p> <p>try [5] 6/23 29/14 61/10 68/1 84/7</p> <p>trying [4] 19/23 61/19 64/16 82/15</p> <p>tube [3] 54/21 54/22 55/1</p>	<p>Tuesday [2] 1/1 42/24</p> <p>tunnel [2] 52/4 52/7</p> <p>turn [2] 56/14 88/21</p> <p>turned [6] 50/9 50/9 54/5 60/23 78/18 80/21</p> <p>turning [2] 53/7 53/7</p> <p>two [24] 2/23 4/17 4/18 4/25 12/22 15/14 20/11 21/2 26/8 27/4 29/8 29/9 29/13 32/20 43/3 46/20 46/21 49/12 52/13 57/23 71/17 73/6 78/3 80/4</p> <p>tying [1] 33/18</p> <p>type [4] 27/3 30/6 33/6 83/23</p> <p>U</p> <p>Uh [3] 57/16 73/2 87/9</p> <p>Uh-huh [3] 57/16 73/2 87/9</p> <p>UK [6] 1/7 1/7 1/23 3/7 19/18 38/3</p> <p>UK-wide [3] 1/7 1/23 3/7</p> <p>ultimately [2] 16/21 37/24</p> <p>uncaring [1] 83/18</p> <p>under [4] 12/17 12/19 12/21 30/4</p> <p>underscores [1] 8/23</p> <p>understand [9] 6/1 10/7 35/9 35/11 42/5 52/9 63/5 68/3 90/22</p> <p>understanding [3] 53/2 53/4 65/2</p> <p>understood [2] 35/13 61/11</p> <p>Unit [2] 48/9 64/3</p> <p>university [3] 37/21 46/20 59/21</p> <p>unpalatable [1] 6/12</p> <p>unpleasant [1] 77/21</p> <p>until [22] 15/18 24/19 34/8 35/16 36/17 37/18 45/1 45/24 47/11 47/22 48/13 49/1 50/11 59/20 66/8 66/18 69/3 79/22 79/23 87/7 87/18 91/2</p> <p>unwell [4] 49/8 53/6 72/13 74/1</p> <p>up [58] 2/8 9/4 11/5 11/14 11/19 12/13 12/14 13/5 13/16 16/25 17/17 18/2 20/22 24/18 24/20 25/6 25/18 25/19 26/17 29/19 29/20 30/5 30/10 30/13 31/13 31/15 32/18</p>	<p>32/19 32/22 32/23 32/24 32/24 33/2 33/17 33/18 39/5 39/6 39/19 41/24 43/5 46/21 51/18 52/18 54/22 56/14 57/8 62/14 65/9 67/25 69/1 69/18 72/1 72/21 78/14 80/20 80/25 83/10 85/17</p> <p>upheld [1] 88/18</p> <p>upon [3] 11/5 30/1 42/11</p> <p>upstairs [2] 75/20 81/3</p> <p>us [55] 11/4 11/13 11/16 11/19 11/20 12/8 14/15 14/17 14/20 16/2 16/5 19/8 22/10 23/25 23/25 29/12 35/18 36/2 37/10 37/17 39/18 40/12 42/8 44/14 45/8 45/19 45/22 46/16 47/2 48/18 49/8 51/4 51/21 52/3 53/13 56/4 56/10 58/15 59/1 59/11 59/20 61/11 67/11 68/13 71/10 72/7 72/14 75/25 76/17 77/25 78/18 80/14 80/24 82/25 85/6</p> <p>used [7] 19/14 23/20 28/3 58/22 58/23 59/2 71/22</p> <p>usual [1] 46/19</p> <p>usually [2] 11/11 31/21</p> <p>V</p> <p>value [1] 5/15</p> <p>variant [2] 37/23 38/7</p> <p>varices [6] 32/25 32/25 33/16 33/18 54/20 60/12</p> <p>various [3] 34/13 48/6 88/11</p> <p>vCJD [2] 37/6 38/19</p> <p>verbally [2] 77/21 79/11</p> <p>very [90] 2/8 9/6 10/6 11/17 12/8 12/16 17/6 19/24 23/16 25/13 27/20 27/21 32/9 39/12 45/15 45/17 45/23 51/19 52/2 54/6 58/2 58/5 58/17 58/17 58/18 58/19 58/21 58/21 58/24 58/25 59/23 60/23 61/13 61/15 64/15 65/5 65/7</p>	<p>65/10 66/13 66/14 67/12 67/18 67/23 68/18 68/20 69/14 69/16 69/23 69/23 69/24 69/25 70/1 70/11 70/11 70/16 70/16 70/25 71/1 72/12 72/15 72/25 73/5 73/5 73/24 74/1 75/21 76/5 76/25 77/7 77/7 77/8 77/14 77/17 77/17 78/1 78/1 78/16 78/21 78/22 78/23 80/1 81/15 83/14 87/3 87/14 88/6 88/14 88/19 89/10 89/24</p> <p>vessels [1] 54/24</p> <p>Victorian [1] 11/17</p> <p>view [2] 63/15 89/11</p> <p>views [1] 20/23</p> <p>VIII [6] 13/14 13/22 38/5 39/7 39/7 68/3</p> <p>vile [1] 19/7</p> <p>virus [3] 27/24 32/3 32/4</p> <p>viruses [1] 14/15</p> <p>visit [2] 54/8 80/16</p> <p>visiting [2] 2/5 68/8</p> <p>voice [2] 26/17 67/25</p> <p>volume [1] 54/11</p> <p>volunteer [1] 84/10</p> <p>vomit [1] 53/23</p> <p>vomited [3] 54/12 75/23 76/3</p> <p>vomiting [1] 75/20</p> <p>vote [1] 4/10</p> <p>W</p> <p>waited [1] 29/8</p> <p>waiting [2] 73/6 73/8</p> <p>walking [4] 36/12 36/14 78/7 87/24</p> <p>wall [1] 52/6</p> <p>walls [1] 40/24</p> <p>Walsall [2] 31/11 31/13</p> <p>want [21] 4/13 10/13 11/21 15/22 16/9 24/17 25/5 25/5 29/24 32/12 34/1 34/1 37/5 44/18 45/16 47/5 51/8 57/12 66/9 67/24 71/8</p> <p>wanted [10] 16/22 24/2 24/19 41/2 44/19 47/16 48/18 53/21 81/11 84/4</p> <p>wanting [2] 84/1 89/6</p> <p>wants [2] 3/24 10/7</p> <p>war [1] 75/22</p> <p>ward [2] 51/15 72/25</p> <p>warnings [1] 15/1</p> <p>was [404]</p>
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(37) thinking... - was

W	67/15 69/1 69/17 72/15 72/25 73/11 74/6 74/22 79/2 79/4 79/5 79/10 79/25 80/3 82/3 83/1 84/3 85/8 88/3 88/19 88/24 90/6 went [25] 11/8 16/5 17/15 17/16 25/18 32/19 33/11 33/14 41/14 41/20 46/20 52/8 52/19 56/10 57/4 58/14 60/22 64/6 68/24 73/25 75/13 75/19 80/22 81/19 85/13 were [121] weren't [6] 14/13 48/12 50/22 53/17 83/7 83/20 west [1] 2/17 what [112] what's [6] 9/11 22/18 42/21 44/25 45/8 71/23 whatever [11] 10/18 13/10 26/18 33/8 36/25 36/25 42/16 52/5 72/1 72/19 80/7 whatsoever [1] 60/16 wheelchair [2] 81/10 81/12 when [80] 2/14 3/4 3/25 4/1 6/17 8/16 9/10 9/17 9/19 12/3 12/11 13/8 15/19 17/11 19/2 19/17 20/19 21/15 22/22 24/4 26/7 26/13 27/6 27/16 31/4 31/21 32/17 33/19 39/22 41/20 43/24 44/10 44/21 45/4 45/25 46/24 47/1 47/10 47/22 48/21 48/22 48/23 49/3 49/3 49/24 50/11 51/12 52/21 53/1 53/16 53/23 54/18 54/19 55/22 56/16 56/17 59/5 59/12 59/17 61/12 61/24 62/7 65/14 65/21 67/12 69/12 71/13 74/3 76/3 76/15 77/15 79/22 80/2 81/24 84/9 84/12 85/8 85/10 88/7 89/18 where [14] 2/14 4/4 6/16 6/23 7/2 19/4 31/19 36/8 40/2 48/10 83/2 84/23 88/10 90/5 whereas [1] 4/25 wherever [1] 4/21	whether [10] 5/15 7/7 10/16 16/23 42/15 64/4 64/7 81/2 85/25 86/1 which [45] 1/11 1/13 2/5 3/22 4/11 6/20 8/15 8/24 9/16 11/18 14/22 15/11 16/3 29/23 31/6 34/15 41/19 42/21 48/9 52/9 54/22 56/19 58/7 58/14 59/22 60/1 60/7 60/14 64/13 64/20 66/1 72/16 72/22 73/13 73/16 75/5 76/14 78/9 79/1 80/18 81/6 85/23 88/4 88/9 90/18 while [10] 11/8 19/16 26/12 26/25 27/11 40/10 54/13 73/12 81/18 81/21 whilst [1] 53/24 white [2] 55/22 56/3 whites [1] 50/8 who [79] 2/7 3/3 4/4 4/6 4/8 4/19 4/23 5/5 5/6 5/14 5/16 5/16 5/25 6/3 6/4 6/4 6/5 6/5 6/6 6/21 7/6 7/8 7/13 9/1 9/4 11/1 20/12 21/2 22/5 23/20 30/13 34/25 35/21 35/21 38/6 39/1 40/7 41/7 41/10 43/6 45/12 46/17 47/8 51/14 51/23 54/8 58/3 58/10 58/20 62/15 64/5 64/11 65/1 65/5 65/19 67/20 67/20 69/22 70/11 70/18 71/9 78/3 78/19 78/21 80/6 84/5 84/15 84/21 84/22 84/23 85/2 88/5 88/10 88/21 89/10 89/14 89/15 90/10 90/17 who's [1] 24/23 whole [2] 40/24 52/20 whom [1] 5/7 whose [1] 8/6 why [10] 1/5 6/1 19/7 35/7 35/8 35/13 35/14 69/1 71/24 75/12 wide [4] 1/7 1/7 1/23 3/7 wider [1] 7/21 widow [1] 84/8 widow's [3] 87/11 89/3 89/19 widower [1] 57/19 wife [18] 4/1 16/22 17/3 17/4 18/3 20/16	20/24 24/13 40/20 41/2 46/14 47/8 47/15 49/24 60/3 64/11 71/8 74/16 wife's [2] 50/6 59/8 will [53] 2/4 2/6 3/16 3/25 4/16 4/18 5/7 5/10 5/11 5/12 5/14 6/8 7/4 7/5 7/6 7/12 7/19 8/1 9/4 9/8 9/25 10/10 10/19 15/11 17/5 26/8 30/21 33/7 33/18 34/5 41/6 43/21 44/24 45/24 47/9 51/6 56/11 56/18 56/20 60/8 65/25 65/25 66/1 66/8 66/17 68/1 70/8 70/9 70/15 74/23 81/1 90/15 90/21 window [1] 54/2 wiped [1] 87/13 wish [12] 4/20 5/25 7/10 7/20 51/9 55/2 63/25 65/10 66/11 66/25 90/5 90/25 wished [1] 8/22 wishes [6] 7/24 8/8 8/10 46/8 67/1 88/23 wishing [2] 5/24 5/25 with [101] within [5] 23/5 49/11 49/12 62/16 66/8 without [5] 7/20 8/4 8/10 41/10 57/23 witness [20] 3/19 3/23 3/24 6/15 6/17 6/18 6/24 7/3 7/7 7/13 8/14 9/1 9/3 9/4 9/15 10/3 10/5 46/7 66/25 90/7 witnesses [6] 3/19 4/8 7/19 8/19 64/21 90/15 woman [8] 12/1 12/12 12/15 24/15 25/15 25/16 26/23 45/4 women [2] 20/7 20/12 won't [4] 8/10 9/6 40/16 66/14 wonder [1] 83/22 wonderful [1] 68/16 wondering [1] 84/2 word [4] 22/24 40/5 47/12 47/13 wording [1] 86/13 words [1] 19/1 work [22] 14/24 17/18 29/8 29/11 29/19 33/4 33/5 34/21 35/3 35/5 35/9 35/10 42/23 47/25 57/9 57/25 58/10 58/15 61/10 75/11 78/14 85/16 workaholic [3] 17/18	17/19 29/19 worked [5] 42/19 47/20 57/25 85/12 85/17 worker [2] 73/10 73/19 working [9] 29/17 31/6 34/16 35/1 35/14 40/4 42/9 42/21 47/22 world [1] 71/9 worldwide [1] 19/19 worried [3] 56/9 68/20 69/14 worriers [1] 36/5 worry [3] 37/2 56/20 81/2 worse [1] 40/1 worst [1] 76/18 worth [2] 65/24 80/10 would [64] 3/17 4/20 5/6 5/18 6/10 8/22 9/3 15/16 16/4 16/23 19/23 20/21 26/16 26/17 26/20 26/20 26/22 29/14 31/4 35/5 38/9 41/5 41/24 44/17 52/18 53/19 55/2 56/15 56/18 57/2 58/11 59/11 59/12 59/16 63/22 64/9 64/17 64/22 65/24 66/11 67/13 67/25 69/22 70/1 70/4 70/10 71/1 72/7 72/22 74/11 77/12 78/2 78/4 79/1 79/2 80/3 80/4 80/6 84/15 84/15 84/23 88/2 88/17 88/17 wouldn't [8] 51/14 52/6 54/4 76/11 86/11 86/13 88/18 88/18 wound [2] 80/23 81/14 wrecked [1] 20/19 wrecking [1] 17/17 write [3] 64/16 65/23 88/25 writing [2] 38/7 40/24 written [3] 5/9 7/11 7/12 wrong [2] 22/13 59/13 wrote [4] 24/7 62/18 62/20 73/10	23/6 26/5 28/18 29/8 29/13 30/5 37/3 45/1 46/18 46/25 47/1 47/10 57/21 57/21 58/4 58/15 61/21 62/6 63/16 64/23 80/4 yellow [7] 50/8 50/9 50/9 53/7 83/10 83/14 89/22 yes [92] yet [2] 63/7 79/13 Yorkshire [1] 2/7 you [455] you'd [2] 13/9 47/5 you're [3] 32/17 61/24 67/6 young [5] 14/10 17/6 21/13 21/14 84/7 younger [2] 36/18 40/15 youngest [4] 17/12 43/3 48/1 59/18 your [91] 10/24 11/1 11/5 11/16 12/19 12/22 12/25 13/3 13/4 14/21 15/23 15/24 17/14 17/23 18/2 18/5 21/21 22/4 23/2 23/12 24/5 25/11 26/12 26/17 27/16 27/19 28/24 28/25 30/2 30/20 31/1 31/2 31/25 32/1 33/2 34/12 34/13 34/14 35/5 35/18 35/20 35/24 39/10 39/17 39/18 39/19 39/22 39/24 40/12 40/13 41/14 42/11 43/24 44/5 44/5 45/5 45/19 45/22 46/13 47/22 48/1 48/1 48/5 48/14 49/7 49/24 50/6 54/22 54/23 55/3 55/13 57/14 60/3 62/10 63/23 65/15 67/7 67/25 70/2 72/3 74/8 76/7 77/24 78/10 81/16 81/18 83/11 83/25 87/10 87/19 90/1 yourself [3] 11/3 35/15 84/6 yourselves [1] 43/13
				Y	
				yeah [2] 31/4 42/18 year [13] 9/20 28/2 32/13 40/19 43/7 56/8 56/12 56/13 58/22 69/3 73/6 76/15 85/15 years [27] 15/9 19/3 19/12 20/9 20/11 21/2	