

Witness Name: Margaret Cooper

Statement No: **WITN0306001**

Exhibits: None

Dated: 5 December 2018

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARGARET COOPER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29th November 2018.

I, MARGARET COOPER, will say as follows: -

Section 1. Introduction

1. My name is Margaret Cooper. My date of birth and address are known to the Inquiry. I am married to Richard (Ricky) Cooper and have had 4 children. I intend to speak about my husband's Hepatitis C Virus (HCV) infection. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it has had on us, my family and our lives together.
2. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

3. I am making this statement due to the fact that Ricky is unable due to his stroke. He is unable to communicate sufficiently as a result of the damage to his speech. He is aware that I am making this statement to the inquiry.

Section 2. How Affected

4. We were married in 1964 and I have had 4 children. Sadly, my third child passed away through Sudden Infant Death Syndrome at 8 months old. That was bad, the worst thing. You never want to have that. We were made to feel like criminals. We have got the 3 children now. My daughter is the oldest, Gary is the middle boy, and my youngest girl stays round the corner; she is 48.
5. Ricky worked and I stayed in the house looking after and caring for the kids. Time rolled on and he had a few injuries at football and things. In 1982 he felt horrific pain in his stomach and we got the emergency GP out. The Doctor thought it was either prostate or appendicitis. This was April 1982; he would have been aged 39 then.
6. We took him in to the Royal Alexander Infirmary (RAI); the old one, not the new one. They kept Ricky in to operate and told me just go home. It was a Sunday in May, and I like to go bingo. The Doctor told us to go home, so my sister in law Janet and I decide to go to the Bingo. I phoned the hospital for an update on Ricky's condition at 6pm, 7pm and 8.30pm. Worryingly, he was still in theatre. I came home and then phoned hourly. He was still in theatre. It was 2am by the time he was brought back into the ward.
7. My son-in-law drove me up to the hospital to see him. At that time the hospital had circular wards. The ward sister said it was horrific. She said Ricky had had a terrible time with the operation itself but that she could not discuss it with me. She said the consultant would come down and speak to me. The consultant came down and said that the appendix had been stuck/ attached to his bowels, which is what caused the extreme

pain. They had to remove half of his bowels and put in a temporary bag. They were in surgery for 8.5 hours. It was during this operation that he was infused with 8 pints of contaminated blood.

8. It was about 6 weeks by the time he came out of the hospital but he was in a mess, an absolute mess. He came out on the Friday and went back on the Sunday because he had a case of pneumonia. He was kept in for another 3 or 4 weeks. He developed abscesses in his back passage. They wanted them to heal up a bit. They then took him back in September and reversed the bag and cleaned out the abscesses and his back passage. It was awful for him.
9. From then on he came out and was weak, a total disaster. He lost a tremendous amount of weight. Before we knew it, we had passed that year and were in to the next year.
10. Then from there he developed diabetes and high blood pressure and we did not have any knowledge about the contaminated blood. We just knew he had got 8 pints previously. Time was going on and he had his diabetes and various things, but there was nothing major at the time. He worked hard and then the building firm he worked for went down and that was Ricky unemployed.
11. We went into January 2007 and then Ricky started to feel really unwell. He could not get himself off the carpet while he was watching TV. He complained that he was so tired, I gave it a week or so and then said to him that this is ridiculous and told him that he needed to get down to a doctor.
12. We got an appointment with Dr McLaren. The doctor did blood tests and they all came back fine. But then this went on from about January to June. One blood test was taking 3 weeks to come through and showed something in the liver. We said we did not understand. Then another test was done and it went onto another month waiting on this one to come

back for the liver – still enzymes were showing up in the liver and each time the results were showing more enzymes than the last one. We were asked to repeat it again and again. This went on until the end of May 2007.

13. They did not tell us what the last blood test was, but when it came back Dr McLaren phoned and asked for Ricky. This was in the June. He spoke to him and I remember Ricky came off the phone and said, "I've got Hepatitis C". He was in shock. That was the start of the disastrous year.
14. Dr McLaren asked us to attend the surgery. We attended a couple of days later. He told us that he was shocked to hear that Ricky had HCV. Ricky was his first patient to be infected. In fairness Dr McLaren treated us very well. We were referred to the specialist unit at Gart Navel, a hospital in Glasgow.
15. Within 8 to 10 days we had our appointment. I asked about the virus and its implications, they told me to read a book and that will tell me all I needed to know. I thought is that it?
16. My brother stays up in Glasgow so offered to go in to a 'drop in centre' that did Hepatitis C talks. He spoke to the guy at the desk and explained that his brother had just been diagnosed and could he have some information. They gave him a bunch of stuff. I got more out of them than I did my own doctors. I was given a sterile box, which the needles used for his treatment, had to go after they had been used. He injected his treatment himself in the stomach. We just got on with it. We just had to see how he was on a daily basis.
17. When Ricky was diagnosed I saw our doctor who had retired. (Dr Aitchison) I told him Ricky had Hepatitis C and he said, "I am not surprised Margaret. Sue the NHS. He got that through the operation."

18. The information about the blood Ricky received is currently contained within his medical file. There was a letter sent to his GP after the operation in which the batch numbers of the blood he received were supplied. (Strathgryffe Surgery, Kilmacolm Road, Bridge of Weir)

Section 3. Other Infections

19. I do not believe that Ricky received any infection other than HCV as a result of being given infected blood products.

Section 4. Consent

20. Ricky received 8 pints of blood during his operation and so it was not possible to obtain his consent. That said Ricky would have signed a consent form for the actual operation.

Section 5. Impact

21. Dr McLaren thought it was necessary for me to be tested for the HCV. My test came back negative. He said he had to get us to a specialist clinic, which is when we went up to Professor Mills. I did not like him at all.
22. He was nasty and rude. He had a bad attitude. My husband was born in India and is sallow skinned. His father was in the British army and his mother was Greek. The doctor asked where Ricky was born. I answered and the doctor said he was not talking to me. He asked whether Ricky got it in India and whether he brought it over here. I told him that Ricky had been here since he was 6 years old. Professor Mills was just trying not to blame the NHS.
23. When we were waiting to see Professor Mills we were waiting in the waiting room. NOT RELEVANT

NOT RELEVANT

The nurse took a load of bloods and asked Ricky again where he was born. He said India. She asked if he was sure he did not get it over there and brought it over when he arrived in the UK. I said he did not get anything over there. He had been here since he was 6 years old. I felt terrible for him.

NOT RELEVANT

I did not like the feeling. You can get a feeling about a place and I just did not like it.

24. The nurse said she was going to get blood tests done. I did not take up Ricky's full list of medication he was on at the time. Professor Mills asked what tablets he was on and I answered. Professor Mills again said that he was not talking to me. I explained that it was me who made up his tablets. Then Professor Mills just said Ricky had got HCV Type 1, that he was in a mess and it was not going to get much better. Type 1 is the worst type.
25. I just thought where do we go from here? We got a liver biopsy done and it came back Type 1. Professor Mills said we needed to consider what medication he should be going on. Ricky said, "I don't know you tell me". I really did not like their attitude at that hospital.
26. During that time I went to play Bingo. I recognised a nurse from the HCV clinic and we started chatting. I told her that I was not impressed with Professor Mills; she informed me that a new clinic was opening up in Paisley and was being run by Dr McPeake. She told me that she would have a word with him to see if Ricky could attend his clinic.
27. Dr McLaren agreed with this and organised the transfer.
28. Ricky was Dr McPeake's first patient. That was in the July or August 2007. Because of all the previous tests and blood results Ricky was able to commence his treatment straight away, this gave him head start.

29. I was glad that we got transferred to Dr McPeake. He is just an every day guy who would sit there and talk normally to you, tell you how it is and explain.
30. Ricky started his treatment with Ribavirin and Interferon in September 2007. From then on life was just shattered. It was horrendous. A horrendous medicine. One was an injection every Thursday and I think he was on 8 tablets per day. So between the injection and the tablets, he was just a wreck. Dr McPeake and Audrey, his nurse explained a lot, the medication, how Ricky would feel, how I should never hesitate to phone up. If I got Dr McPeake's secretary he would always phone back. Dr McLaren was also very good, our local GP. He is retired now but he was very good too.
31. We would go up for the blood count to Dr McPeake every month. Then Audrey would phone and say everything is fine. The time would come when his bloods dropped drastically and so we would have to get his bloods counted again. We had to reduce Ricky's tablets to get the blood cells back up again. That was stopped and started a number of times. They monitored it very carefully and they were very good.
32. I had some painters and decorators in one day and Ricky was sitting there and I just knew he was not right. He said he felt funny and did not feel good. Dr McLaren came straight up and said his blood pulse and pressure was too low. I had already phoned Audrey and she was coming up too. She said he needed to come in straight away for a blood transfusion.
33. His blood count was so low they said he was dying in front of us. We took him to see Dr McPeak. We laughed about it. The irony. He had Hepatitis C from a transfusion, and now he was getting a blood transfusion again. He was taken into the Royal Alexander Hospital

(RAH), the new one. Dr McPeake was waiting on him. We got him blood tested. They did a few tests on him before they got started. They realised he was really ill and he got 3 or 4 pints of blood. They dropped the tablets down to two to let the blood get through his system.

34. We plodded on throughout that year. We went for monthly blood tests. At week 52 of the treatment we went to see Dr McPeake. He told us that the treatment was not working at all and that he would have to withdraw it. The treatment was supposed to last 72 weeks, but we only got to 52. It finished in 2008.
35. Ricky always suffered from cluster headaches but they got really bad. He took a stroke about 9 years ago. It was Hogmanay. We were here at home and he fell out of bed in the morning. His speech had completely gone. That was New Years Eve of 2009. He fell out of bed that morning and I told him to get up. It was 2.30am. I saw he was ill so I phoned 999, and my son and daughter. They met us up at the hospital. The ambulance man came in and said he had a stroke and that it was a bad one. He got rushed straight through. I could not give them the definite time of his stroke because I had been asleep. Because of that they could not give him the drug that could have helped.
36. He got rushed in for a brain scan. They said it was a bad one and would probably affect his speech. Now he does not read, he does not write. His speech is bad. He has had a speech and language therapist. The girls come to the house to help him. It just was not to be. We have struggled with that on top of everything else.
37. Driving got taken away from him. His car had to be taken away. His independence went. We then got sent up to the renal unit because Dr McLaren thought his kidneys might be failing through tests for diabetes. I am sure within 6 months of him being up there for

treatment, his kidneys were failing very quickly. Then before we knew it in the February he had to start dialysis.

38. The nurse came down, spoke to us about it and asked if we wanted to have dialysis in the house. She showed us pictures and I said no. I did not want that in the house. I said I am not going to be tied any more than what I am – putting needles in him, being responsible for the machine and being sure he is ok. No I said. I am not doing that in the house.
39. We got given the choice of hospitals. I said leave him to Greenock. Because Ricky had the HCV he could not go into a ward where other people were in with dialysis. So we had to wait until he got a room. He was in isolation. He is isolated from all the other patients. There are sometimes no conversations because of his speech. The nurses came in with masks and gowns on and that makes him feel terrible. It is hellish. Through no fault of his own he is completely segregated.
40. He started the dialysis in 2013 and has been on it for 5 years. He has to go 3 times a week – 6.30am he goes out and he is done at 12.45-1.45pm. Patient transport takes him. I cannot do it and I do not want my family to have to deal with it.
41. His speech was affected. His right side was affected. He has lost movement in his arms. He can hardly cut his meat. He cannot walk to the kettle or to the table for a cup of tea. Just the tiny things he cannot do. He cannot zip up his jacket. If you have not got the power in that hand then the other hand doesn't seem much good.
42. That has been my life. My whole family has been affected and Ricky is still infected because the medication did not work. Ricky felt so stigmatised when people got wind of his infection. I am a truthful person but I told him to say it was cancer treatment because this is a

nosy place. Even my family ask how the hell he got it and I just say we do not know.

43. I do not think Ricky's kidney problems are linked to his HCV infection. I think his kidney failure came in with his diabetes. However, they cannot give him a kidney transplant because his heart is weak and he has liver failure due to the HCV infection.
44. Ricky worked as a builder for many years. He did slating but he fell off the roof while working for a company that did not give him any safety harnesses. He landed on his feet, and did not break anything but he did damage the ligaments. That was about 30 years ago. He got taken in and they just checked him out and told him to go to the local hospital. They said it just needed to be plastered up and that it was just badly torn ligaments. He was out for a good 6-9 months. He went back to work and then the company went bust. His boss told him to put in a claim and get a lawyer because of health and safety. He did and they paid him out a lump sum.
45. He then worked with my brother who has a building business. Ricky helped him out for a couple of years but slowly he was not feeling great. He started feeling tired. Really feeling tired. That all started about 24-25 years ago. Ricky has been dubbed with illness most of my married life through one thing or another.
46. He started complaining about fatigue before he was diagnosed. He was infected for about 27 years before he was diagnosed in 2007. Leading up to that he was an active man who did manual work, loved his garden and sport and had it fine. He did all that. He just seemed to have started losing it quite a bit. He was not fit to get up and go. He could not. This was all before the diagnosis. Ricky does not complain and it was me who said that we should go and see a doctor.

47. When Ricky started treatment he was getting terrible sickness, feeling really tired, and we had to get a bigger TV in the room so he could see more there. We just made everything as comfortable as we could at that time. He could not continue to work because he was too tired. He could not maintain a full week's work. He did not know why he was so tired all the time; we never considered the fact that he had been infected with something. Why would we?
48. He could not get down to the local pub and back unless someone would give him a lift up the road. Ricky could take a good drink like everybody else. Then gradually he did not go out. It became worse when he had the stroke.
49. The minute he got diagnosed with that it was a shock and he cleaned the house obsessively. I spoke to the doctor about it. I would just tell him to get a rest and walk away. It makes me feel angry to see how he is. It makes the family angry because they have missed out on their dad, grandfather. It is hard because you just don't know where you are turning some days. His obsession with cleaning lasted about a month. If he cut himself he would get a plaster quick, get the wipes quick. If the cat is on him we have got stuff that is easy to get on, his wipes and plasters. I have got rubber gloves but sometimes I forget and just scrub myself after. Because sometimes you have just got to be quick. If his skin bursts we need to get bandages on it so fast and conceal it so fast and put the pressure on it and get him to the hospital.
50. In between this time I fostered children. I have fostered about 30-40 children, mainly long term but sometimes they would just be in for 2-3 weeks.

51. In the past couple of years another member of my family has been diagnosed with a severe illness and Ricky finds that very difficult to manage.
52. We have nine grandchildren and he was going through this treatment at the same time as they were growing up. He missed out on a lot with them. An awful lot. My grandchildren are always up visiting. They are good with him. My youngest is eleven and knows nothing else but his grandpa being sick. He has never known his papa not to be sick. He helps him get into the ambulance, takes his hand, and takes his boots off, takes his jacket off. The wee man does all of that. It is heart breaking to see. He has never known papa to go out with him and watch football. Nine grandchildren, six great grandchildren – Ricky cannot hold any of the babies. When he does he is frightened in case they fall.
53. We have not had a holiday in years because it is too much for him. The trouble is finding a hospital with an isolation room. Also he would have to be in a strange place among strange people. They know him here. So if something goes wrong we feel better if we stay at home.
54. As a result of Ricky's illness my own social life is severely curtailed. I would love to go out with friends for lunch etc., as normal people do. My life is, I go out on the mornings Ricky has his dialysis and do my shopping. If my grandchildren are around they will tell me to stay out and they will go and get Papa.
55. I do not normally go out the times that Ricky is in the house. Yesterday we went to the dentist. But that is as far as we can go because he is exhausted. We are so limited. It has all been taken away from us, from me. I have got nothing except to sit in here.

56. I have put my Christmas decorations up and I am putting up a surprise birthday tea for him on his birthday. He is turning 75 soon. I am hoping the weather is good so the kids and grandkids can get here. But I know that Ricky will be exhausted, maybe sleeping. He can sleep all night, come down in the morning and then sleep all day. And that is because of the HCV.
57. Ricky's whole body cramps and he is up screaming during the night. The doctor gave him 2mg of diazepam, which helps his spasms a little. His potassium is through the limit. His heart is in failure. Two years ago they told me to get everything in order because he has not got long. I called the undertaker, the lawyer, the doctor to take the Do not Resuscitate (DNR). We have all planned his death. Ricky has had an input into that. In the meantime I'm trying to plan his 75th and keep that quiet as a surprise for him.

Section 6. Treatment/Care/Support

58. I have already detailed the treatment Rick received for the HCV.
59. The doctor pointed us to a social worker to see if I could get respite. We were put in touch with St Vincent's Hospice. Home support came out to us. They managed to get Ricky 2 weeks respite but it was not very good. It lasted a week. Ricky told me to just put him in a home because he was getting too much. I said he did not have to be in a home but that it was a lot. I would never let him go to a care home unless it was really desperate. I would not give the government the money to put him in a care home. I want to look after him. I do not get any money for looking after him. I do not claim attendance allowance because they will stop his disability living allowance.
60. I go for counselling but Ricky will not go because of his speech and he does not like to speak in front of strangers.

Section 7. Financial Assistance

61. Financially things were not that difficult because we had the fostering money and his disability money. He started getting a disability living allowance about 18 years ago because of his diabetes and his legs because he cannot walk well. We also got the private payout after he fell off the roof.
62. We receive payments every quarter from Scottish Government, previously via the Skipton Fund. It was a straightforward process. We just filled out some forms and posted it off. Audrey helped us. One phone call to the bank and the money was in. We never had any problems.
63. I think in all we have had about £75,000. I get a heating allowance of £200 from the government and sometimes get a £10 bonus at Christmas time. We are comfortable. I think I might get £10,000 when Ricky passes but I am not greedy for anything.
64. Audrey says there are new things coming out that we should be entitled to but you cannot put a price on this. What is the price for his health? What is the price for everything I have done? What is the price of any of it? Ricky at least deserves enough for a good quality of life but he will never get it now.

Section 8. Other Issues

65. I have previously given a statement to the Penrose Inquiry; I do not have a copy of this.
66. I give permission for the Infected Blood Inquiry team to speak to our doctors about Ricky's medical history and also the Skipton fund if required.

67. I do not seek any form of anonymity; we want our story to be heard.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed

GRO-C

Dated 5th December 2018