

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MRS TRACEY PRICE

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Tracey Price, will say as follows:

1. Introduction

1. My name is Tracey Clare Price. My date of birth is GRO-C 1972 and my address is known to the Inquiry.

2. How Affected

1. My husband, Martin Price, is a severe haemophiliac and was diagnosed in 1965 when he was two years old. He was told in 1985 that he had HIV and told in 1993 that he had Hepatitis C. He no longer has Hepatitis C.
2. I have worked as a Civil Servant for 28 years and my current role is a supervising data analyst. I work full time and I am the sole provider for my husband and me. My husband is unable to work.
3. I met my husband in 1999 and we married on the 24th December 2004. He has two sons from a previous marriage. I was therefore not with him when he

started receiving treatment and not around when he was diagnosed with HIV and Hepatitis C.

4. He told me of his diagnosis two months after we met but I already loved him and it didn't change my mind of how I felt about him. When I initially found out I was really annoyed that this had happened to him and the impact this has had on his quality of life. I had only known him for two months when I found out so my emotions were not as strong as they are now. Over the years I have become more upset as it has completely changed our lives as a married couple.
5. My husband has much greater knowledge in relation to his treatment and diagnosis and he will submit his own evidence regarding this to the Inquiry.

3. Other infections

1. When I met my husband in 1999 he was already aware that he had HIV and Hepatitis C.
2. My husband recently found out, through looking at his haemophilia database records, that he was exposed to Variant Creutzfeldt-Jakob Disease through the Factor VIII. He was incredibly frustrated and felt as if it was just "another thing to add to the list".

4. Consent

1. As mentioned above, I was not around when my husband was being tested for HIV.
2. From what my husband has told me, he believes that he was tested for HIV without his knowledge and he was never told what he was being tested for.

5. Impact

1. The impact of what has happened to my husband has been extremely stressful at times. It certainly has not been easy but it's important that I stay strong for my husband and for myself.
2. I have always suffered with my nerves but I'm not entirely sure why. I was adopted as a small child so it might be something that runs in the family. I had a nervous breakdown in 2001 with Martin being ill and all the pressure of that was the straw that broke the camel's back.
3. As a result of the stress I was off work for 6 months. I received 6 sessions of counselling from a psychiatric nurse which I found helpful. As I work for the civil service, I had the benefit of having a welfare officer who would be in the same building; she was very approachable and really helped me out through the difficult times.
4. I sadly lost my father 7 years ago and my mother is not a very well woman. I am the sole carer for Martin and my mother and this can cause me a lot of stress and anxiety due to the pressure of caring for two people who are very unwell. It can sometimes be a lot to deal with. I take medication to assist with the anxiety such as beta blockers which I find helpful.
5. We are quite guarded about the situation as we want to protect the children, we didn't want them to be bullied at school. I was aware that this had happened to other children and did not want the same for them.
6. My husband's youngest son who is 26 is aware that he's ill but does not know to what extent. He doesn't know that he has HIV. He is extremely sensitive and very young for his age. He can get quite stressed about the smallest of things, he like things regimented. It would simply worry him too much if he knew the full extent of Martin's illness.

7. The eldest son is 33 and he found out when he was 11 whilst on a family holiday with his mother. They had gone away for a holiday with some friends, some of whom were haemophiliacs and had HIV, and she told him because it was being openly discussed. As far as I'm aware, the eldest does not talk about it to his dad but may talk to his mum.
8. Our closest friends and family are aware of what my husband has gone through but they never discuss it with him. When Martin was diagnosed with HIV in 1985 he told his parents straight away and told his fiancée at the time as they were about to get married, despite being advised by Professor Bloom not to tell anyone. Family and friends would ask me how Martin is rather than ask him directly - I think they bury their heads in the sand.
9. It has had an impact on the intimate aspect of our relationship. In the early years we had to be very careful with protection and that takes the spontaneity out of a relationship. Now that it is undetectable I'm not so nervous. It has also stopped us from considering the possibility of having a child together.
10. I always had an aspiration to become a solicitor as I found law really interesting. Whilst still working full time as a civil servant, I completed a Law degree with the Open University in 2009 and I also completed the Legal Practice Course.
11. As a result of the Interferon treatment Martin received in 1994 he could no longer work. I am therefore the only breadwinner and have been since we met in 1999.
12. It was very difficult studying and working full time but it was not possible for me to go part-time, I simply couldn't afford to take the pay cut. I still had the mortgage and bills to pay. Martin's youngest son was also starting University just as I was coming to the end of my studies. Money was therefore tight as the youngest also needed financial assistance.

13. I really enjoyed studying both courses but the salary of a trainee solicitor at the time was very low compared to my salary I was earning with the civil service. I took the difficult decision to not pursue my legal career and I am really gutted I couldn't do that. However, I could not take the risk of not being able to provide for me and my husband. I therefore stayed with the civil service and will have to work there until I'm at least 68 to get my state pension.
14. I am very lucky that I have very supportive employers. My bosses are aware of my home life and they are very understandable. There may be times where my husband will need to call me at work because he is unwell mainly if he's had a bleed. He can be in so much pain and agony if he suffers from a bleed. I have to give him morphine to calm him down. He has also been diagnosed with Crohn's disease. He can become really dehydrated and starts to become disorientated – I therefore can't be in work when he's like this. I can just go with no questions asked. He doesn't often call but it's comforting to know that my bosses won't make it an issue if I do have to leave work immediately.
15. I have remained within the same department for 28 years. If I were to move to a different department or wanted to apply for a promotion I may not get the same treatment and the flexibility that I currently have. It has limited my progression within the civil service.
16. I work full time. I wish I could work part-time so I can spend more time with my husband but I simply can't afford to do it. I am not eligible for income support even if I went part-time. I wish we could spend more time together.
17. As previously mentioned, my office used to have a welfare worker but that facility is no longer there. They now have occupational health assist which is a service that you can call if you have any issues. It's good that we have this facility but you can only phone them and sometimes it can be difficult to engage with someone on the phone.

18. Work is currently in the process of arranging a type of passport for carers which are only for civil servants, this is written document written with the help of an occupational therapist. It sets out the caring aspects expected. If you move jobs or departments this document can be passed to the manager instead of having a conversation each time a new person becomes involved. It also enables the holder to apply for special leave if the need arises.

6. **Treatment/Care Support**

1. My husband will submit his own evidence to the Inquiry in relation to the treatment he has received.
2. I support my husband financially, emotionally and physically. The HIV has a negative effect on his mental wellbeing and I am the one he talks to and leans on for support. As I have said above, I am the main breadwinner for the family. Physically I support him as much as I can in whatever he needs. I cook, clean and manage the household. I drive if he is unable and attend hospital appointments with him. I help with bathing etc. when needed. When the children were younger I did a great deal of the childcare as the HIV leaves him tired and fatigued easily.
3. I can sometimes get worked up if we go for scans and hospital appointments as it's a constant worry.
4. We are no longer as sociable as we use to be. My husband was heavily involved with the Birchgrove group. Around 10-12 couples would meet up twice a year in Swindon as it was in the middle for everybody, there is also a woodland memorial. There are 1,200 trees at Stratton Wood, the number of trees represents those with haemophilia who were infected with HIV.
5. We haven't met up with the other couples for around 5 years. As the years have gone on people have unfortunately passed away or some aren't well enough to travel anymore.

7. Financial Assistance

1. I attended a Macfarlane AGM in 2001 and I was chatting to Anne Hithersay, who was the CEO at the time. I explained to her I was studying law and was interested in helping the HIV community and she suggested that I apply for a position as user trustee of the Macfarlane trust – I applied and was interviewed and was successful.
2. I was a trustee between 2002-04 and I would attend board meetings every three months. There were 12 trustees in total. We would discuss the business of the trust and the financial applications that had been submitted. Part of my role was to review anonymous applications and to review the requests for payments. There was a strict criteria and decisions were made on a case by case basis. We would normally consider around 10 applications at a time and a decision would be made based on a majority.
3. It was sometimes difficult having first hand experience of how difficult it can be. I wanted to give everybody everything they requested. I understood that despite being ill people have their pride and asking for handouts is not a nice thing to do.
4. In terms of financial restraints, we are happy as we are. The worst thing is not being able to spend enough time together as I have to work full-time.
5. We are not able to obtain insurance and that can be a worry, particularly if something were to happen and I need to sell the house. I do not have any savings or a fall back which is a big worry.
6. When I first joined the civil service the pension contribution from my employer would have been roughly half my salary but due to government cuts it's now roughly worth a third of my salary and now I will need to work until I'm 68 get a state pension rather than 60.

8. Other Issues

1. I am annoyed and upset that this has happened to my husband. I wish that I didn't have to work as much so I could spend more time with him. I am upset that my soulmate has had to deal with this suffering inflicted by something that was supposed to ease his pain. We are extremely happy and I am very thankful that I married my best friend but there is always the threat that our happiness will be cut short due to these cruel diseases.
2. I wanted to be part of the inquiry because I want someone to be held accountable. We have been involved for so long and campaigning to get here and all I want is for someone to admit that it's their fault.

Statement of Truth

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

Signed GRO-C

Tracey Price

Dated...15/3/19.....