Witness Name: Pat Latimer
Statement No.: WITN4091001
Exhibits:
Dated: 19th August 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PAT LATIMER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25th June 2020.

I, Pat Latimer, will say as follows: -

SECTION 1 INTRODUCTION

1 DOB GRO-C 1942

1984 Certificate of Qualification in Social Work:
Newcastle upon Tyne Polytechnic,
1994 Certificate in Counselling:
Newcastle University
1997 Master of Arts in Counselling:
Durham University
1999 Accredited Counsellor: British Association for Counselling

2 1984 – 1988 Gateshead Social Services Department
Social worker – statutory child care/child protection/ supervision of fostering placements, adoption assessments

1988 – 2002 Newcastle Social Services Department
Social worker Regional Haemophilia Centre
Royal Victoria Infirmary, providing emotional, practical, and social support to families living with Haemophilia, HIV, and Associated Blood Disorders

2000 – 2002 MacFarlane Trust Trustee
Voluntary position. Attendance at 4 formal meetings a year and a limited number of other meetings when requested. I also provided support to staff if/when appropriate.

3 1988 – 2002 Haemophilia Society [general member]
1989 - ? BASW Special Interest Group [haemophilia/HIV]
1999 - ? British Association for Counselling [member]

4 No involvement in any other Inquiries etc

SECTION 2 ROLE AS HAEMOPHILIA SOCIAL WORKER

Written without the benefit of casework/meeting notes etc

5 The Regional Haemophilia Centre at the Royal Victoria Infirmary was set up in 1974. A multidisciplinary team was formed consisting of the Director, a nursing sister, physiotherapist, social worker, and secretary. I was appointed as a second social worker in 1988 and was in post until I retired in 2002. There were always two social workers in post providing a service to families who regularly attended the Centre from 1988 until the date of my retirement.
When I joined the multidisciplinary team the staff members were Director Dr Peter Jones, Co-director Dr Peter Hamilton, Clinical nurse specialist Maureen Fearns, Senior staff nurse Julie Vowles, Senior physiotherapist Brenda Buzzard, Social worker Jean Lovie. General haematology social work was undertaken by a separate worker within the RVI social work team.

6 I understand I was funded by the Haemophilia Commissioners, but contracted directly to Newcastle City Council as part of the hospital social work team. I was line managed by the hospital social work team manager.
I was appointed as a second social worker as the workload had increased considerably due to the overwhelming impact HIV had on patients and families attending the Centre.

7 As stated previously my role was within the Haemophilia Centre and not general haematology. The social work role was:
To be an integral member of the multidisciplinary team
To carry out social assessments either by self referral or from other team members and external professionals.
To provide ongoing emotional, practical, social support to patients and their families

8 Practical - liaison with and applications to Newcastle and regional authorities to provide aids, adaptations, and support with personal needs.
Welfare Rights advice and information
Liaison with DSS throughout the region on behalf of patients.
Completion of application forms for numerous welfare benefits on behalf of patients
Attendance at tribunals when necessary.
Due to the increase in welfare rights/benefit work, the Director then approved the appointment of a specialist welfare rights officer to help cope with the volume of work. Martyn Leates was then appointed to this post. He attended the Centre on clinic days and made home visits when necessary. This ensured that any patient who wished could have a comprehensive assessment and then be supported through the process to receive their full benefit entitlement.
Applications for grants on behalf of patients to The Haemophilia Society, The MacFarlane Trust, and other charities where made where appropriate.
Liaison with Northern Haemophilia Group Society Committee who also provided information and support to the patient group.
Worked closely with regional HIV co-ordinators and specialist HIV social workers in order to provide a comprehensive equitable service to patients/families in the areas covered by the Haemophilia Centre.
School visits with parents when requested.
Home visits to patients/families throughout the region
Joint home visits with other team members e.g. nursing / physiotherapy

Emotional support to infected, affected adults and families. Use of active listening and counselling skills.
Bereavement Counselling [supervised by an independent supervisor]
Direct work with children and parents and children independently. Use of life story material, ecomaps, games, books, drawings etc.
Involvement with families was for the most part long term less intense continuing support with periods of task centred involvement either emotional and or practical.

Groupwork co-facilitated initially with social worker Jean Lovie and then from 1990 to1995 with Jeannie Fraser
Bereavement Group
Mother's Group
Carer's Weekends [Newcastle and Cumbria]

Provision of supervision during a period of that time was undertaken by
John Hodge, Independent Trainer and Consultant in Groupwork

Ushaw College Durham Volunteer Befriending Project
Training and supervision of students
Matching students with individuals/families
Monitoring of placements
This project was developed to help meet the needs of extremely isolated patients. It provided a highly confidential volunteer support service.
Haemophilia Patient Weekends
Weekend information, support, and social weekends were arranged for patients and families who regularly attended the Newcastle Centre.
Social workers were available throughout the weekend to provide information, support and advice.

9 The "Why did my daddy die" publication was produced in response to the individual work I was involved in supporting a young widow and her small child. I had been working with this family for several years. The young child was very angry, having nightmares and destroying work at school. The mother asked me to visit the school with her and explain the situation. I then agreed to do some direct work with the child to help him express some of the feelings he was experiencing. He asked the direct question to his mother "why did my daddy die." I suggested to the mother that we write a story about a small boy whose father had died from a blood disorder. Initially it was a "homemade book." I discussed this work with the multidisciplinary team and then Maureen Fearns, clinical nurse specialist provided the written explanation of the blood factory. I supported the mother to write the story. The Director then supported the publication of the book. The "blood factory" information proved to be helpful and the book in general helped children coping with bereavement and loss in various haematological settings.

10 Psychological support at some level was undertaken by most members of the multidisciplinary team. The nursing staff provided informal psychological support by using active listening skills when treating patients. The senior staff nurse and the clinical nurse specialist provided a considerable amount of psychological support to patients and their families attending clinics and during home visits. Both social workers had a caseload and provided psychological support using a range of counselling skills, more formal counselling sessions, and through groupwork. The team had access to psychologists based in the RVI, Newcastle University, and a psychologist at Newcastle General Hospital who had an HIV remit. The medical staff could also refer to a consultant psychiatrist if necessary.

11 The individual services stated above {10} were available where appropriate
12 In my opinion the arrangements for social work support were more than adequate. There was a continuity of information, knowledge, and experience. Social workers were well supported by the Director to engage with patients in whatever way the patient's chose. We were also supported to develop specific skills [counselling/groupwork] to meet individual/families needs. Referrals to the social workers were either made by the patients/families themselves, other members of the multidisciplinary team, or external professionals/agencies.
13 In my experience Dr Peter Jones and the senior doctors were very professional, caring, and always accessible to the patient group, and to team members. I was not involved in clinical policies or practices whilst working in the Centre. I was not employed as a social worker when patients were informed about their HIV diagnosis. Dr Peter Jones was instrumental in setting up the multidisciplinary team to provide comprehensive care for the patient group. This meant clinics, treatment, nursing care, physiotherapy, social work and secretarial support were all accessible in one department.
Doctor Jones encouraged and supported patient group activities e.g. Bereavement Group, Mother's Group, Carer's Groups and the Volunteer Befriending Project. He instigated many residential patient weekends which provided information, advice and support to patients and families. All the multidisciplinary team members attended these meetings and were able to respond to patients either individually or in a group setting. There was also time built into the programme for socialising. These meetings provided a safe environment for individuals/family members to talk together, share information, and experiences and offer support to each other.

14 I did not contribute directly to Dr Peter Jones' book "Living with Haemophilia." The acknowledgement related to my work in the Haemophilia Centre.

SECTION 3 Your role within the MacFarlane Trust

I provide the following information without the benefit of meeting minutes etc.
I was a Trustee from 2000 until 2002. I can recall that a social worker based in Scotland was appointed as a Trustee when the Trust was set up. Therefore having a social worker as a Trustee was established at the outset.
Trustees in 2000 were Peter Stevens, Nicholas Lawson, Tony Yeaman, Elizabeth Boyd, Mark Winter, Chris Hodgson, Patricia Winterton, Pat Latimer.
Staff - Ann (Chief Executive), Fran (Social Worker), Jenny (Benefits Advisor), Rodney (Finance officer), Roz (Admin secretary). I cannot remember their surnames.
15 I was appointed by the Haemophilia Society.
16 I acted as a Trustee in a voluntary capacity. I did not have a direct role within the Trust as a social worker. However, I did bring to the Trust many years of social work experience working within a well established multidisciplinary regional haemophilia team. This Regional Centre provided care for patients/families from North Yorkshire, Teesside, Co Durham, Northumberland, Cumbria and Tyne and Wear.
During the two years I was a Trustee I attended four formal meetings a year. I also attended a limited number of other meetings when requested. Travelling time, distance, and my social work responsibilities in Newcastle prevented more frequent attendance. I also provided informal advice/support to staff when appropriate.
17 I cannot recall having specific responsibilities in the Trust's bereavement project. However I can recall a weekend meeting for the bereaved. I was there as a Trustee and acted as a facilitator and provided one to one support. A clinical nurse specialist and another experienced social worker were also there to facilitate and provide one to one support.
There was a lack of specialist support services for those who had lost loved ones through infected blood products. There was an understandable reluctance to access local voluntary bereavement services because of fears regarding secrecy and stigma. The bereavement project enabled people to access information safely and gain support. Those accessing services via the project were confident of confidentiality. Meetings provided the opportunity for participants to talk openly about their experiences and feelings. Sharing experiences with others coping in similar circumstances was extremely valuable to participants.

18 My understanding of the Partnership Group was it provided the opportunity for registrants to inform, have representation, and make recommendations to the Trust.

I had no involvement in the Payments Review Group

19/20 The personal contact with registrants [other than Newcastle patients] occurred when I attended meetings organised by the MacFarlane Trust and the Haemophilia Society. Support included;
Practical:
Benefit information and advice
Information/advice re voluntary sector services
Information/advice re local authority services
Advice on how to access the above services. Protection of personal health information and establishing a "who needs to know" policy.

Emotional support in group and one to one sessions

In the formal Trust meetings I attended a number of registrant's applications for financial help were considered and processed. Although these applications were presented anonymously I was at times able to advocate on behalf of registrants by providing additional supportive information that was gained from my social work experience.

22 As a haemophilia social worker I cannot recall ever having made an application for independent counselling/psychological support on behalf of a registrant. I cannot recall an application for financial help for independent psychological support/ counselling being made at any of the Trustee meetings I attended.
Social work staff resources at the Trust as far as I can recall were one social worker and one benefits adviser in post. To my knowledge their role was to provide a service to all those registered with the Trust. My experience of these workers was that they provided the best service they could with the resources available.

21 As previously stated I was able to provide emotional support when I attended Haemophilia /MacFarlane Trust meetings. At these registrant/family meetings other professionals would be present as facilitators and provide psychological support on a

one to one basis and in a group setting. During the period 2000 – 2002, Trust staff would also provide emotional support at the registrant meetings I attended.

23/24 i I was not involved in the establishing of the MacFarlane Trust and therefore have no knowledge of how it originally reached registrants. Most families were members of the Haemophilia Society and would be aware of the Trust from the information in the Society's Bulletins. Haemophilia staff were aware of the Trust's existence and in the Newcastle Centre staff actively promoted the Trust and information was displayed on the Centre's notice board.
ii No knowledge of this
iii Not to my knowledge
iv All applications were treated anonymously. In the Trustee meetings I attended [2000 -2002] I felt applications were decided in a consistent way and applicants were treated equally
v I have no knowledge of haemophilia centres undertaking screening for eligibility for payments. However, haemophilia centre staff often made or supported applications on registrant's behalf. In Newcastle this was with the patient's consent. I am unable to comment on the procedure of other haemophilia centres.
vi I have no knowledge of how payment levels were set. As a social worker applying for financial help related to specific health/social care needs the cost of these was usually approved.
vii I have no knowledge of there being a medically led and beneficiary informed analysis of payment levels. I have no knowledge of life expectancy influencing the amounts individuals received. However, in my experience as a social worker and my limited time as a trustee if an urgent grant application was made or if the registrant was seriously/terminally ill then this would be dealt with sympathetically and speedily.

Section 4 Impact on people infected and affected

23 It is impossible to quantify the devastating impact on the quality of life of those who were infected/affected by HIV. All areas of life were severely affected.
b. Relationships
men were fearful of infecting wives/partners, other family members, friends
marital/partnership relationships became strained, difficult and in some cases broke down
wives and partners became carers. Parents became carers again supporting adult children
damaging effect on children within a family
infected children struggled to develop and maintain relationships apart from close family members
feelings of guilt from siblings who were not infected
Mother's guilt because of being a carrier of haemophilia
parents feeling of guilt because they had administered the treatment
fear of stigma prevented infected/affected sharing health information even with extended family and close friends. This led to feelings of isolation.
Living a life of secrecy had a profound effect on families
Coping with uncertainty, fear of the future regarding medication, treatment, and money etc, and feelings of loss impacted on all areas of family life
c. Living a life of secrecy and fear of discrimination impacted considerably on those infected and affected to live a full life as a member of society.
d. Coping with fluctuating, debilitating, and deteriorating health had a considerable impact on access to education, work, insurance, and pension funds. In my experience often those infected chose not to reveal health status to schools, colleges, universities, and work places.
e. Many individuals experienced stigma and discrimination e.g. "Aids in here" daubed on walls.
Individuals /families were hounded by press. Local newspaper reporters would follow up death notices particularly of young men and ask the cause of death.
Individuals shunned by neighbours, friends
Some children with haemophilia were requested to be excluded from school by parents of other children
Fear of some funeral directors led to them refusing to arrange funerals
Fear of infection by some church officials led to some patients feeling rejected and unwelcome in their local church. This was devastating for those whose faith was such an important part of their life.

.f I can only comment on the MacFarlane Trust as I had no contact with the other trusts listed.
Registrants inexperienced in making applications may have found the process daunting. Some patients had minimal literacy skills as their education was limited due to the long periods of hospital admissions they experienced because of bleeding

episodes. Health issues could also impact e.g. severe fatigue on the registrant's ability to make applications. The Trust did try to make the application procedure straightforward and encouraged telephone contact for support and advice.

As a haemophilia centre social worker I made numerous applications to the Trust on behalf of patients and did not encounter any difficulties. However, I was a professional used to making such applications.

g. My experience of the benefit system was it was extremely complex, time consuming and often inconsistent. A Disability Living Allowance form had approx forty pages. Registrants suffering from fluctuating health and often severe fatigue found the forms overwhelming and very difficult to complete. It was so daunting for some registrants that they gave the up on the task. As stated previously the Newcastle Centre appointed a specialist welfare rights worker to help cope with the overwhelming volume of work.

Section 5 Trusts and schemes established to provide financial support

25 Newcastle Haemophilia Staff members advised patients to apply to the MacFarlane Trust for grants following a medical, nursing, physiotherapy, or social assessment

26 Written applications to the MacFarlane Trust were usually made by the social workers when patients requested this.

27 Information supporting the application was included if appropriate with patient's consent.

28

a As a social worker I found the application process to the MacFarlane Trust straightforward. For registrants coping with health issues, fatigue, or literacy difficulties then this process would be more difficult. However, the Trust did encourage telephone contact in order to make the process easier.

b The MacFarlane Trust published a Handbook which included information regarding the provision of financial support

c In my experience as a social worker the MacFarlane Trust did not require repeat applications to be made. They may have at times requested further information before making a decision.

d Patients attending the Newcastle haemophilia centre were given practical support and assistance in making applications. In most instances the patient requested the social worker to complete the application on their behalf. To my knowledge every request was undertaken. I have no knowledge of the practice carried out in other haemophilia centres.

e My experience of the decision-making process of the MacFarlane Trust was that applications were considered sympathetically and appropriately.

f In my experience the MacFarlane Trust treated applicants with respect during the decision-making process.

g At the limited number of Trustee meetings I attended where applications were considered decisions were usually made on the same day unless further information was required.

h In my experience decisions made by the MacFarlane Trust were made in a consistent way.

i I have no personal recollection of an application being refused, but I can recall the Trust had a system in place to review decisions where appropriate.

Section 6 Effect on Clinical Staff

31 As a social worker in the Newcastle Haemophilia Centre I can recall the work was daunting, demanding, complicated, and often overwhelming. The contrast of work undertaken was quite stark. Supporting newly diagnosed children and their families and encouraging living a life as normal as possible at one level, to supporting families living with life threatening conditions, and also providing emotional support for the bereaved through their complicated mourning process was extremely challenging.

Accessing any external service provision for patients/families [apart from the MacFarlane Trust and Haemophilia Society] was complicated and time consuming. Issues related to confidentiality were paramount. There was a continual need to confirm with agencies/services which needed to know certain health information and also who would have access to it. New systems and working relationships needed to be established to ensure patients were confident about the security of their personal information.

To work more effectively with the patient group I was funded to undertake a four year part-time course in counselling. This training provided me with additional skills and enabled the provision of more formal counselling sessions. Supervision during this time was carried out by Maureen Leyland an Independent Counselling Supervisor.

When the groupwork undertaken became more challenging e.g.

Mothers' Group - some of their children died and this affected the group dynamics. Mothers coping with bereavement felt unable to express their feelings of guilt and loss, and mothers whose children were well felt unable to talk about their child's

achievements. Similarly, challenges in the Carer's Group and the Bereavement Group resulted from the diversity of roles and expectations. Some people were able to move forward and others could not.
To help work more effectively with the groups my social work colleague [Jeannie Fraser} in the Centre was funded to undertake an Extended Groupwork Course. I was her co-worker and supervision of this training was facilitated by John Hodge, Independent Trainer and Consultant in Groupwork.

Recalling my social work role has brought back many vivid memories. Many of the feelings experienced by myself were some way similar to those of the patient group. Work was a "secret" not to be shared unless within the multidisciplinary team.
Normal support systems i.e. other hospital social work colleagues, family, friends were unaware of the work I was involved in. Therefore, the multidisciplinary team support was vital. I was very fortunate to work within a caring, supportive team environment as at times stress and distress levels could be extremely high.
I attended with another staff member as many funerals as possible. Families valued our attendance and support. Sometimes the family explained why we were there, and at other times families would "invent" a reason for our presence. Complicated grief for the families could also be a complicated process for their professional carers.

32 My limited time as a Trustee of the MacFarlane Trust highlighted the varied resources, responses, and support available to registrants in their local care systems. Being made aware of the differences and variable level of support and care available was distressing and difficult to accept on both a professional and personal level. I resigned from my Trustee appointment after two years when I retired from my social work post in the Newcastle haemophilia centre. I felt it was important that the position should be held by someone actively working in haemophilia care..

Section 7 Other Issues

33 I have not had any significant discussions or conversations or interactions with senior clinicians in the Haemophilia Centre.

34 The provision of counselling today is much more acceptable than it was when I worked as a social worker. Mental health issues are now discussed much more openly. Men attending the Newcastle haemophilia centre were often manual workers living in heavy industrial or mining communities. These men's experiences of living with haemophilia had an impact on how they lived with HIV. For many it was one secret added to another. They were unlikely to admit to needing psychological support. Therefore, emotional support was often intermittent, informal, and ongoing at clinic attendances and home visits. The men were much more likely to accept emotional support when they became very ill and had more hospital contact. Wives/partners, mothers, carers, daughters, sisters, and girlfriends were much more likely to admit to coping difficulties and seek help.

Statement of Truth

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

Signed GRO-C

Dated 28.09.20