

Witness Statement for the Penrose inquiry

Geraldine Brown

D.O.B. [REDACTED]

The events under consideration by the Inquiry began to unfold twenty years ago. While I recall quite clearly the general atmosphere, and the great efforts made to meet the needs of patients infected with HTLVIII, my memory of specifics is not always so sharp. I have now been retired for five years and out of touch with the issues that were so important then and are important now. In recalling the sequence of events which began in December 1984, when I took up the post of social worker in the Haemophilia Centre at the Royal Infirmary, I have refreshed my memory by consulting papers I deposited in the Lothian Health Board Archives when I retired, and reading the thesis of Helen Coyle, partly based on these papers.

My academic qualifications and professional training are as follows: in 1969 I graduated with an Honours History degree at Edinburgh University and immediately afterwards did a Diploma in Social Administration, followed by a year's work in a community based team as an unqualified social worker; I then took a Diploma in Social Work and the associated professional qualification.

After a five year break to care for my children I took up a part-time post as a social worker in a community team providing a range of social work services. In September 1980 I took up a part-time post at the Royal Infirmary and for the next four years covered a variety of units in the hospital.

In December 1984 I was asked to take up the post of social worker at the Haemophilia Centre as the current social worker was leaving. Historically the allocation of social work time to the Haemophilia Centre was nine hours a week. At around the time I took up my post this was increased to eighteen hours per week in acknowledgement of the extra needs created by HTLVIII infection.

As a hospital based social worker I was a member of a large team, employed initially by the Lothian Regional Council and latterly, after local government reorganisation in the late 1990s, by the City of Edinburgh Council.

At the time of my appointment I had discussions with Dr Ludlam about Haemophilia and the challenges facing patients. I was also made aware that some of the patients had been exposed to HTLVIII as a result of using blood products. I spoke too to colleagues who had experience of working with haemophiliacs. I was made aware of the existence of the Haemophilia Society and the British Association of Social Workers special interest group for Haemophilia workers. My understanding at that time was that I would be offering a social work service for patients and their families to support them in dealing with a chronic illness with implications for physical disability and its attendant emotional, employment and financial difficulties. I understood that for those infected with HTLVIII there would be even greater difficulties and uncertainties, and that they would require counselling and extra support.

My first contact with the patients was at a meeting called by Dr Ludlam in December 1984. My understanding was that the purpose of the meeting was to share with patients up-to-date knowledge about HTLVIII infection.

At the meeting there was a discussion about the testing which had taken place to establish whether patients had been exposed to the virus. There was also discussion of current scientific knowledge and about the routes through which the virus could be spread. Patients were made aware that a number of them had tested positive for exposure to the virus, and that all patients could have their test results if they wished. It was emphasised that the virus was blood borne and was also sexually transmitted. Patients were advised that as a precaution they should all treat themselves as though they were infected; they should observe safe sex practices and barrier methods of contraception; they should exercise caution if a cut or a wound bled to avoid putting others at risk.

Detailed written advice about the risks of transmission and keeping safe was sent out shortly after this meeting to all patients.

At this time there was increasing discussion of the HTLVIII virus and AIDS in the press and other media. I think the meeting was seen as a way of giving patients more accurate information than might be presented in the media. It was well attended. It is difficult to be precise about numbers. Perhaps around a hundred were there. There was plenty of opportunity for questions and discussion. There may have been some other doctors than Dr Ludlam present - my memory about this is hazy. Among the patients there was dismay and anger, and also frustration, over the relative lack of knowledge and the uncertainty of the future.

The Haemophilia Centre in Edinburgh is a Reference Centre with a large geographical area of responsibility - the whole of the east of Scotland. I do not know whether all the east of Scotland patients were invited to the meeting. I do know that Dr Ludlam was very concerned about confidentiality for his patients and made great efforts to ensure the press did not get wind of the meeting. To my knowledge no media representative did attend.

I do not know exactly when Dr Ludlam decided not to tell patients automatically what their antibody status was, but only to give this information if requested. Considered in the context of the time there were several factors which might have influenced this decision. There was uncertainty about how the virus would progress and whether it would be fatal in every case. There was no vaccine available or other treatments that would halt the progress of the virus. Among the professional agencies there was a great concern that patients would be stigmatised and discriminated against if they were antibody positive, both in their day to day dealings in the community and also in relation to things like life insurance and mortgages. There was concern that they might be denied services, including medical and nursing care. There was a suggestion at one point that surgeons were reluctant to operate on patients with the virus.

After consideration of their position, patients began to ask Dr Ludlam to tell them their antibody status. This happened gradually. My recollection is that I was present on three occasions when patients were told their status. One had been infected through IV drug use. The second was a young African student about to return home. Both had presented as haematology patients. There was no suggestion that they had been infected by blood products. The third was a haemophiliac in his teens who had become very ill and died soon afterwards. My feeling was that although Dr Ludlam clearly explained what was causing his symptoms and described HTLVIII infection, he was at that point too ill to grasp fully the implications or to take the opportunity to ask questions.

My memory is that a few patients declined to be told their antibody status for some time. I remember one young man in particular who resisted being told for a long time and maintained only limited contact with the Haemophilia Centre. As knowledge of the virus grew and treatments were developed it became clear to patients that it was in their best interests to have clarity about their status, regular planned assessment and treatment if necessary. There was concern that the young man referred to above was not having appropriate monitoring and care. The decision was made by medical staff that it was in his best interests to know that he had been exposed to the virus. With some difficulty contact was made with him and he was told.

I was always available to see patients who had been told they were infected, immediately or later if that was their preference. Although patients were given information and guidance when they were told they were infected, many had difficulty in immediately absorbing the full implications of their situation. The initial discussion with the doctor was in fact the beginning of a process of reflection and adjustment to new difficult circumstances.

Following the December 1984 meeting I began to get to know haemophilia patients, both affected and unaffected by the virus. Some I met when they were inpatients on the ward, others when they were attending as outpatients. Some were referred directly to me by medical and nursing staff. Sometimes patients introduced themselves by telephone to arrange an appointment to see me. Latterly this was in my own office which was adjacent to the Haemophilia Centre. I often visited patients at home and met other family members. I was able to respond quickly to requests for appointments.

Over time I got to know many of the patients and their families very well. There was distress and anger among affected patients and their families and a feeling of being let down by the very treatment that had transformed their lives. There was a feeling that they had done nothing to deserve this and a desire not to be associated with other groups whose behaviour had been instrumental in their becoming infected. In many patients these feelings changed over time as they moved to a less judgemental position.

Patients faced a very uncertain future. They worried about a long decline and death and the impact of this on their families. They were very concerned not to infect other people. They were worried about finances and in the case of single men about who would care for them if they became ill. There was an overwhelming concern about confidentiality and about protecting themselves and their families from discrimination. Many lived in small communities. They were known to be Haemophiliacs and were quickly identified in the public mind as a risk group. There were concerns about confidentiality even in G.P. practices where, for example, a receptionist might know the family personally. They were anxious to be kept up to date with improving knowledge and potential treatments.

I spent a lot of time talking to patients and their families about their feelings. On a practical level I gave them advice about welfare benefits and helped with applications for allowances. There was a particular emphasis in treatment on the need for a healthy diet. I spent a lot of time working to ensure that patients got their full entitlement to dietary allowances. I liaised with and made referrals to local agencies, for example to

occupational therapy services. I had close contact with the MacFarlane Trust and made applications for grants on patients' behalf. I was also in regular contact with the Haemophilia Society.

As well as one-to-one and family contact, patients were also offered support in a group led by Dr Alison Richardson, clinical psychologist, and me in the Haemophilia Centre. A small number of patients and their wives attended.

I maintained contact with many patients and their families for a long time, continuing to see the families of some of the patients who died for some time after their bereavement.

My memory is that during the period I worked in the Haemophilia Centre staffing levels improved in response to increased need. There was a staff nurse as well as a sister. There was more social work time. The Clinical Psychology Service was involved as was the Department of Psychiatry. There were regular weekly multi-disciplinary meetings where individual patients were discussed. Staff could raise general issues of concern and seek advice from colleagues. For example, the psychiatrist might comment on an individual patient or more generally. The meetings were also a means of sharing developing knowledge of the virus and the treatments becoming available.

My impression in general was that patients were up to date with developments through discussion with the doctors. There was also a good deal of information available in the media. Most importantly the Haemophilia Society was active in keeping its members informed and in working on their behalf.

My work was supported in a variety of ways, through attendance at conferences and study days, through membership of the Haemophilia Social Workers Special Interest Group, and through links within the Social Work Department and with voluntary agencies. I attended a major international conference in Newcastle in 1986. It was very useful as there were presentations from workers from the United States who had been dealing with the virus for some time and whose knowledge and experience were more advanced. I attended a second conference in Bradford in 1987. These conferences were medically and scientifically led and were multi-disciplinary.

The Haemophilia Social Workers Special Interest Group met twice yearly. The focus of discussion was the social work task, the support of individuals and their families, addressing bereavement and loss and ensuring appropriate financial and material provision.

With what has been described as 'the AIDS epidemic' in Lothian developing over the 1980s and 1990s, the Social Work Department was involved with other agencies in developing strategies to meet the needs of those affected and their families. The vast majority had become infected through intravenous drug use and the development of most services reflected this. However, the emphasis in policy development was on meeting the needs of all affected groups and some of the services made available were used by a number of Haemophiliacs. For example, Milestone House, the hospice which was set up by the Waverley Care Trust, was used by three patients that I can remember and possibly more. Milestone House also offered support to their families. SOLAS, a community based organisation which offered counselling, complementary and alternative therapies to people affected by the virus, was used by the mother of one patient, who also offered her services as a volunteer.

My impression in talking to patients was that they were aware that there was an ongoing programme of research in Haemophilia. The older generation, who had very limited treatments available to them in early life, were particularly aware that research had led to better treatments that had significantly improved their quality of life. I remember one patient who was affected saying that the benefits of treatment had been worth the risks. I think the nurses when they took blood would say they would like a little more for research purposes. I do not remember when this was made explicit.

Details of my contact with patients were recorded in individual case files, not in the medical files. My files were kept in my room and were not available to medical staff. Social work files are kept only for a limited period, except in the case of looked after or adopted children. Given the time scale, the files will have been destroyed.

When I retired I gave a miscellaneous collection of papers to the Health Services Archive. They are held in Edinburgh University Library. The collection includes advice and fact sheets from a variety of sources, some for workers, such as a format for counselling referring specifically to drug users but largely applicable to all affected groups, others for a general audience. What is striking are the regular information bulletins from the Haemophilia Society, painstakingly updating patients about scientific advances, welfare benefits, general finance, insurance, mortgages and travel. There is a substantial booklet, *Aids and the Blood*, by the Dr Peter Jones, published in 1985 and distributed by the Haemophilia Society. The MacFarlane Trust sent out regular newsletters and an annual statement of accounts and expenditure. The papers also include an Advice Sheet for Adult Patients and Partners. It is undated but I think it is the advice sheet sent out after the December 1984

4

meeting.

The development of HIV/AIDS policy is the subject of an Edinburgh University Ph.D. thesis by Helen Coyle, completed in 2008, 'A Tale of One City - the History of HIV/AIDS policy in Edinburgh, 1982-1994.'

I worked in the Royal Infirmary until my retirement. From 1985 I worked full time - half my time in the Haemophilia Centre and the other half initially at the City Hospital but latterly in the Royal Infirmary. In 1989 I was promoted and gradually over a period of time moved to specialise in children's services. I was still involved in working with Haemophiliacs until well into the 1990s. I cannot be exact about the date I stopped.

Geraldine M. Brown

Geraldine M. Brown

15 April 2011