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INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CHRIS CUNNINGHAM

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22nd May 2019.

I, Chris Cunningham, will say as follows: -

Section 1: Introduction

1. I have been asked to provide a paper setting out my knowledge of the developments in dental care, treatment and cross infection control since 1980, as a response to the HIV epidemic and associated blood borne viruses. The following report is based largely on the personal experience of the author and backed up by references where relevant.

2. I graduated as a dentist in 1979 and started working in a hospital environment in 1981 just as the HIV epidemic was about to become a major health issue. I moved to Edinburgh in 1990 as a Senior Dental Officer with the Community Dental Service (CDS) specialising in Special Care Dentistry particularly related to dental care for people with blood borne viruses (BBV).

3. I retired as Assistant Clinical Director and Specialist in Special Care Dentistry in 2018.

Section 2: Background

4. The first reports of what was to become known as AIDS were published in 1981 reporting a cluster of cases of a rare

pneumonia in gay men in the USA. Later that year the first cases were reported in people who inject drugs.

5. In 1982 the first cases of AIDS in haemophiliacs were reported and also in that year the first case associated with blood transfusion. Heterosexual transmission was implicated in 1983.

6. Initially the causative agent was unclear but in 1983 French investigators isolated a virus they called LAV; later that year HTLV was isolated and named in the USA and in 1986 it was agreed that the AIDS retroviruses be officially designated Human Immunodeficiency Virus (HIV).

Section 3: Cross Infection Control Procedures in dentistry

7. In the early 1980s many of the procedures and materials now deemed appropriate for adequate cross infection control were not in common usage. Hand instruments were sterilised in autoclaves between patients but not the handpieces (dental drills). The use of "single use items" was rare with the exception of disposable hypodermic needles, and the use of Personal Protective Equipment (PPE) was not mandatory. It was common for dental staff not to routinely wear gloves and if used they were not always single use. Eye protection and masks were rarely used.

8. Additional special precautions were used when treating patients who were deemed to be "high risk". For example, in 1982 I saw a patient who was known to be HBV and HCV positive. His General Dental Practitioner had referred him to the dental hospital for a routine dental extraction. He was treated in a side room and my dental nurse and I wore surgical gowns and hats, double gloves and shoe covers and after his straightforward treatment was complete the walls and surfaces of the room were washed down and not used for the rest of the day.

9. This process was in line with published guidance at the time [1,2] which recommended the following procedures when treating carriers of viral hepatitis:

    - All personnel in clinical contact with the patient should use full barrier technique, including masks, gloves, glasses or eye shields, and disposable gowns

- Use as many disposable covers as possible, covering light handles, drawer handles, and bracket trays. Headrest covers should also be used
- All disposable items (e.g., gauze, floss, saliva ejectors, masks, gowns, gloves) should be placed in a lined wastebasket. After treatment, these items and all disposable covers should be bagged, labelled, and disposed of, following proper guidelines for bio-hazardous waste
- Aseptic techniques should be followed at all times. Minimise aerosol production by *not using ultrasonic instrumentation, air syringe, or high-speed handpieces*. (Author's italics). Remember that saliva contains a distillate of the virus. Pre-rinsing with chlorhexidine gluconate for 30 s is highly recommended
- When the procedure is complete, all equipment should be scrubbed and sterilised. If an item cannot be sterilised or disposed of, it should not be used
- All working surfaces and environmental surfaces should be wiped with 2% activated glutaraldehyde

10. This degree of infection control was considered impractical and financially unrealistic for General Dental Practitioners (GDP) at the time and so patients who knew and shared their diagnosis were referred to specialist centres for even routine treatment. Naturally the consequence was that the majority of carriers who did not know their status, or those that did but did not share that knowledge, were treated differently than those who were open about their status.

11. As the extent and spread of AIDS diagnoses grew this approach was considered to be inadequate and in 1987 the Centres for Disease Control (CDC) the main public health institute in the USA, published **Recommendations for Prevention of HIV Transmission in Health-Care Settings** [3] which described what has now come to be called "Universal Precautions". This is based on the premise that…

"Because all infected patients cannot be identified by history, physical examination, or readily available laboratory tests, the

following recommendations should be used routinely in the care of all patients in health care settings."

12. Interestingly the previous year the CDC had published "*Recommended infection control practices for dentistry*"[4] which had suggested this approach but it was the 1987 paper that is widely seen as the launch of this change in advice.

13. The CDC guidelines additionally emphasised that HBV is the more resistant and infective virus and suitable precautions against HBV will therefore be more than adequate for other BBVs:

"A common set of infection-control strategies should be effective for preventing hepatitis B, acquired immunodeficiency syndrome, and other infectious diseases caused by blood borne viruses. The ability of hepatitis B virus to survive in the environment and the high titres of virus in blood, make this virus a good model for infection-control practices to prevent transmission of a large number of other infectious agents by blood or saliva."

14. Following the CDC adoption of Universal precautions this guidance was generally taken up in other countries including the UK where the advice was reported in the medical and dental press and led to the publication in 1991 of the British Dental Association (BDA) guidance document "*A12 Infection Control in Dentistry*"[5] which has been updated regularly and is still the official guidance today. This document details the concept and practical aspects of Universal Precautions and specifically emphasises;

"Those with human immunodeficiency viruses (HIV), who are otherwise well, and carriers of the hepatitis viruses may be treated routinely in a primary care setting (general dental practice, community dental service, for example)."

15. Furthermore the advice goes on to say;

"It is unethical to refuse dental care to those patients with a potentially infectious disease on the grounds that it could expose the dental clinician to personal risk. It is also illogical as many undiagnosed carriers of infectious diseases pass undetected through practices and clinics every day. If patients are refused

treatment because they are known carriers of an infectious disease, they may not report their conditions honestly or abandon seeking treatment; both results are unacceptable."

16. Despite this being the stated policy of the dental professional body as well as the regulatory body the General Dental Council (GDC), the experience of those clinicians working in the secondary care services in the early 1990s was that many GDPs, while eventually accepting the guidance on PPE and single use items, were less willing to accept patients who were carriers of BBVs.

17. The only additional development that has affected cross infection control guidance in Dentistry since the introduction of Universal Precautions is the development on variant CJD in humans in 1994 as a result of cross species transmission of Bovine Spongiform Encephalopathy. As the vector of transmission, known as prions, are found in neural tissue the risk of transmission from dental treatment is very low but there is a theoretical risk of certain instruments being contaminated during root canal therapy. Guidance was published in 1999 and 2002 which emphasised that risks of transmission of infection from dental instruments are thought to be very low provided optimal standards of infection control and decontamination are met and further emphasised that all root canal files and instruments such as matrix bands should be considered single use.

Section 4: Community Dental Service (CDS)

18. The CDS was formed in 1974 and later renamed the Public Dental Service in Scotland (PDS) in 2014. It is an NHS salaried dental service with the remit to treat groups of individuals who find difficulty accessing routine dental care from the General Dental Service (GDS) due to a range of issues including learning difficulties, or medical, psychiatric or psychological issues.

19. Clinicians from the CDS in Lothian work in all of the region's hospitals providing routine care for people with medical issues which complicated their dental treatment. These include severe kidney or heart disease, haemophilia, patients undergoing treatment for cancer, and the elderly. In addition, in the early 1990s we were increasingly treating people with AIDS, or liver disease due to late stage hepatitis C infection. However, at this

time we were also receiving regular referrals from Consultant Medical Physicians for people they were seeing as outpatients who were HIV or HCV positive but asymptomatic yet were unable to find a GDP willing to take them on for routine dental care. Occasional referrals were also received from GDPs for people who were asymptomatic carriers of BBVs for treatment which, the guidance suggested, could be carried out in general dental practice.

20. The reasons for this were not always clear. At the time many dental practices were not taking on new patients due to issues relating to NHS funding. Some dentists, anecdotally, were not prepared to take on people with BBVs by suggesting they needed specialist care in a hospital or secondary care environment and many times patients reported that the dentist had said that they "couldn't afford the extra time, equipment and materials needed to treat them" which would suggest that the dentist in question was not up to date with the Universal Precautions philosophy.

21. In addition, many patients were not willing to approach a GDP and be open about their condition because of concerns about rejection, perceived judgmental attitudes and worries about confidentiality within their community setting. Many patients actively preferred being seen in a secondary or specialist setting for their dental care because they felt that their condition was better understood, and they had less concerns about confidentiality. Because of these reasons through the 1990s increasing numbers of asymptomatic carriers of BBVs were seen at clinics and hospitals in Lothian in addition to those who had developed AIDS or Liver Disease.

Section 5: Stigma in Health Care

22. In Scotland as in every country in the world, stigma can create barriers to testing and uptake of HIV services whether perceived, anticipated or directly experienced. Studies examining the dental perspective have suggested that some dentists were reluctant to treat patients with HIV due to concerns about how this would be perceived by other patients at the practice and studies assessing patients' perceptions highlighted apparent stigma and actual discrimination in some cases. A study we carried out in Edinburgh showed that people with HIV were less likely to be registered with a dentist, more likely to have difficulties accessing dental care

and more likely to have recently undergone emergency dental care when compared with a matched cohort of non HIV+ individuals.[6] A previous London based study of over 1600 people with HIV reported that 15% felt discriminated against by health care workers and a quarter of these responders named dental care as being a particular issue. [7]

Section 6: Developments in anti-viral treatment

23. Since the emergence of HIV many anti-viral drugs were developed. Many of these were effective initially but soon patients developed resistance and the side effects could be debilitating. In 1996 a new family of anti-virals were developed called protease inhibitors which when combined with other related drugs and taken as a "cocktail" proved to be effective in controlling the replication of HIV in the body and reducing the viral load to undetectable levels thus allowing people who had access to treatment and were able to cope with the side effects, to live with HIV and significantly reduce the risk of developing AIDS.

24. In the years following this dramatic development, access to dental care in General Dental Practice improved for individuals with HIV as AIDS became less prominent in public discourse as the prognosis for people living with HIV improved and younger dentists graduated who had not lived through the early years of the epidemic and had been trained from the beginning in the concept of universal precautions.

25. A decision was taken in 2006 within Lothian CDS that we would no longer accept referrals for asymptomatic individuals with BBV to allow us to concentrate on treating more individuals with systemic disease. It was agreed that exceptions would be made for those individuals who could demonstrate that they had been refused treatment by the GDS or who had a genuine and well-founded concern that they would suffer stigmatisation. The few who were accepted on this basis usually lived in very small rural or island communities who came to Edinburgh for their medical treatment and whose diagnosis was not known by neighbours and sometimes even family in their communities and were not prepared therefore to attend a local dental practice.

Section 7: Developments in the CDS and patients with haemophilia

26. In 2013 the Scottish Government published a circular which combined the roles of the CDS and the Salaried GDS to create the new Public Dental Service. (PDS). [8]

27. As a result of this change NHS dental charges were introduced for certain patient groups who had previously been treated without charge by the CDS. Only certain, well defined categories of patient continued to be treated without charge. These included hospital in-patients and people who required medical support to allow their dental treatment to be completed safely.

28. Soon after this circular was published I was invited onto a national expert panel[1] to discuss how these changes would be implemented for patients with haemophilia. Evidence based guidance already existed to advise which dental procedures could safely be carried out under Primary Care arrangements by the GDS for patients with milder forms of haemophilia. Similarly, the guidance defined which patients or treatments should always be referred for specialist care in hospital with haematological support and how to obtain referral advice. The panel heard representations from patient support groups and medical specialists and updated guidance and referral pathways were developed which included the information about the changes that the government had introduced regarding NHS dental charges and how this would affect some patients with haemophilia who had not previously been charged if they had been seen by the CDS.

29. During the consultation period further representations were heard from The Haemophilia Society who suggested that haemophilia patients who had been infected with BBVs as part of their treatment should be included in the group who would not be charged for their dental care whether or not they had developed symptoms of Liver Failure or AIDS. This suggestion was not

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[1] Deputy Chief Dental Officer's Working Group on Dental Charges for People with Haemophilia. 2015

agreed to as it would have gone against the guidance that was in place for all other medical conditions whereby dental treatment was only free if it was carried out in a Secondary care setting as part of the patient's treatment or in order to allow the treatment to be carried out safely. It was not considered ethically appropriate to adjust the NHS charging regulations based on the route by which the patient was infected.

Section 8: Conclusion

30. In this paper I have attempted to summarise the developments in dental care, treatment and cross infection control since 1980 as a response to the HIV epidemic and associated blood borne viruses. I have noted how improved knowledge of the infective agents and the risks of transmission alongside the developments of new modes of treatment have been reflected by changes both in the approaches of those in the medical professions but also the social attitudes of the wider community towards people infected with BBVs. However, significant barriers to care still exist especially to certain subgroups of people infected with BBV and, specifically, HIV infection still carries a marked level of self-perceived and expressed social stigma when compared with other chronic medical conditions.

Statement of Truth

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

Signed GRO-C

Dated 18 August 2021

Table of exhibits:

Date	Notes/ Description	Exhibit number
	1. Withers AJ. Hepatitis: A review of the disease and significance to dentistry. J Periodontol. 1980;51:162–6	WITN4440002

	2. Dinsdale R.C.W. Viral Hepatitis, AIDS and Dental Treatment. London. Pub. British Dental Association, 1985.	WITN4440003
	3. CDC. Recommendations for prevention of HIV transmission in health-care settings. MMWR Suppl. 1987 Aug 21;36(2):1S-18S	WITN4440004
	4. CDC. Recommended infection control practices for dentistry. MMWR 1986;35:237-42.	WITN4440005
	5. Bimbaum W, Dinsdale R., Dowell T., Howard C., Scully C. and Shovelton D. (1991) The Control of Cross infection in Dentistry, BDA Advice Sheet A12. London, British Dental Association	WITN4440006
	6. Steedman, NM and Cunningham CJ. Is being HIV+ a barrier to accessing dental care (poster) BASCD Conference 2008	WITN4440007
	7. Elford, J., Ibrahim, F., Bukutu, C. and Anderson, J. (2008). HIV-related discrimination reported by people living with HIV in London, UK. AIDS and Behavior, 12(2), pp. 255-264.	WITN4440008