

**TOPIC B6****The effects of infection with HIV, including the effects of treatment, on patients and their families.**

## INTRODUCTION

The exploration by the Inquiry of this topic goes far beyond the powerful testimonies of the patient witnesses<sup>1</sup> who gave evidence at the public hearings in June 2011. The results of investigation before the commencement of the public hearings are contained in Chapter 4 of the Preliminary Report. On behalf of the patient and relative core participants and the Haemophilia Society it is submitted that what is contained in Chapter 4 is accurate. The submissions made here are intended to draw together some of the threads from those testimonies but anyone interested in this story must read those testimonies in full to begin to appreciate the full impact of infection with HIV, including the effects of treatment on patients and their families.

**1. The physical and mental effects of HIV infection on patients.**

**and**

**2. The physical and mental effects of treatment for HIV.**

A useful summary of the symptoms and pathology, testing and treatment is set out in the Preliminary Report at paragraphs 2.56 to 2.65

It is reasonable to think that most patients infected through blood or blood products would not have been aware of infection during the primary HIV infection stage or the asymptomatic phase unless informed of the result of a test. No doubt the initial flu like symptoms or fever would have been attributed to other things.

Those that lost their lives did so as a result of the various conditions described at paragraph 2.58 of the Preliminary Report. Those that survived could develop significant complications connected to HIV. Mark suffers from Progressive Multifocal Leukoencephalopathy - a virus of the nervous system. The effect upon his eyesight resulted in a serious accident at work involving machining wood and he is now registered blind and has paralysis of the right side.

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<sup>1</sup> Amy, Christine, David, Elaine, Frances, Mark. At the public hearing in December the Inquiry heard from co-infected patient Stephen

If that was not enough as a result of HIV he has suffered from bowel cancer requiring chemotherapy and radiotherapy and a full colostomy.

Apart from the direct experiences of the witnesses themselves the Inquiry heard from Professor Leen<sup>2</sup>. He described the difficulties experienced in the early years due to the lack of knowledge and available treatment. Those infected that survived were those whose asymptomatic stage lasted sufficiently long for effective treatment to arrive. Many of those infected reached the AIDS phase of the disease and so succumbed before treatment became available. In the early years patients with advanced HIV disease were treated with whatever drug was available. He described the changes in treatment for HIV and AIDs over the years. In the mid 1980s treatment would have been by the physician who made the initial diagnosis. Later on HIV infected patients were referred to the Infectious Diseases Unit or to the Genito-urinary Medicine Department nearest to them. Before guidelines were devised clinicians would treat patients with zidovudine or any licensed drug that was available. It was up to the prescribing physician and much depended on their knowledge and experience. When and what treatment should be initiated in asymptomatic patients was controversial. It was a case of trial and error and only after observation over many years did a consensus emerge.

Drugs such as zidovudine lost their efficacy because of the emergence of drug resistance, patients became symptomatic and developed further opportunistic infections. Professor Leen described how patients were desperate to try anything to keep them alive. He explained that now treatment for HIV is started when patients have symptomatic HIV disease and if asymptomatic treatment will be started according to their CD4 cell count and based on the treatment guidelines.

The drugs used had significant side effects and sometimes the decision was taken to preserve what was left of quality of life by stopping treatment. Agonising decisions had to be made by patients and their loved ones.

In 1996 marked a turning point when new drugs led to a marked improvement in outcomes and in 1998 the HAART (Highly Active Anti-Retroviral Treatment) era began.

Although treatment has improved enormously it is complex, permanent, expensive, and constant. Patients must continue to take all of the drugs without missing doses in the prescribed combination or they will risk developing a drug-resistant virus. So patient compliance is absolutely essential otherwise treatment will fail. Severe side effects can

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<sup>2</sup> Day 33 15 June 2011 His report is PEN0121044

accompany treatment<sup>3</sup> and lead to a patient stopping the medication. There are many side effects reported by patients using HIV medication but they are too many and too diverse to describe. Body shape changes appear to be the most prominent side effect of treatment and can lead to stigmatising, low self esteem, isolation and depression. There is no cure. It is thought that most HIV sufferers have a slightly lower than normal life expectancy. It is a chronic condition with long term morbidity requiring careful monitoring.

Professor Leen described in detail the difficulties for patients in taking treatments throughout the reference until the present. Treatment intervals are disruptive and the fact that some drugs need to be taken with food and others on an empty stomach a significant barrier to good adherence. The side-effects are also a barrier. Taking HIV treatment can be very stressful and can cause a lot of anxiety. Some physicians prescribe additional medication to counter act the side effects adding to the pill burden; these include anti-sickness medication, antidiarrhoeal agents and painkillers for headaches. The difficult decisions facing patients deciding when to start treatment are well described in David's evidence<sup>4</sup>. The need to keep the condition confidential can be a serious impediment to beginning treatment and continuing medication appropriately.

**3. The personal and social consequences of HIV for patients and the stigma associated with it.**

and

**4. The personal and social consequences of HIV for patients' families and the stigma associated with it.**

The news that an individual had been infected with HIV invariably had a devastating impact on the person and his family. Where the person infected was a child as was frequently the case where blood products were concerned almost unimaginably difficult questions arose for parents. Apart from having to digest the situation for themselves it was necessary to agonise over what to tell the child, how to tell the child and when. Parents had to come to terms with the fact that they had administered the treatment that had resulted in the

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<sup>3</sup> The side effects of the earlier drugs included headache, nausea, vomiting, diarrhoea, flatulence, skin rashes, liver inflammation, kidney stones, dysphoria, weird and frightening dreams, depressive symptoms, tiredness, poor sleep and body shape changes

<sup>4</sup> Day 30 9/06/11 140 (17) et seq.

infection. The climate of the period was one of public hysteria<sup>5</sup>, fear and mistrust. The uncertainties created by a positive diagnosis meant that planning for the future was meaningless. Someone who was HIV positive could only watch as others developed symptoms and deteriorated and wonder whether he would be next. The courses of the lives of spouses and siblings as well as parents and children were changed forever. Christine spoke about how her husband drowned out the bad news by drinking too much alcohol. This was a response that occurred in others. One response was to be reckless for personal safety by riding a motor cycle "like a lunatic"<sup>6</sup>. Intimate relations between spouses were destroyed by the fear of cross infection. One of the most difficult problems was the inability to share information about the diagnosis with friends and colleagues or in the wider community. The prevailing atmosphere in the community did not encourage openness with others. Elaine's husband was told by a good friend with whom information had been shared not to go near his grandchildren. Such an attitude was common making social isolation inevitable.

It is impossible to over-estimate the stigma attached to HIV and AIDs particularly in the earlier years but which carries on until the present. As lepers were regarded in biblical times or plague victims in the Middle Ages so the HIV positive were viewed by the rest of society in the late 1980s and early 1990s. Public Health campaigns designed to protect against the spread of the disease intensified the fear and stigma attached to those with the condition. Mark described the appalling effect such campaigns had upon him during his teenage years and graphically described the social exclusion and stigma. The stigma continued after death affecting certification of the cause of death, funeral arrangements and the ability to talk openly about the person's life. This was and remains a source of great pain. Of course the stigma was considerably heightened by the fact that AIDs was seen by many as the consequence of "misconduct" such as sexual promiscuity homosexual or heterosexual and intravenous drug use. Attitudes to homosexuality have changed only relatively recently.

Those starting out in life and forming relationships had considerable difficulty because of their HIV status. Family planning is complicated by the risk of cross infection. One method used was donor insemination which is an extremely difficult decision which involves important complications of its own. Assisted conception increases the risk of ectopic pregnancy. Attempts at donor conception sometimes had to be paid for privately.

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<sup>5</sup> See the selected press material produced [DHF 0017443 DHF0017744 DHF0017790 DHF001815 DHF0018091 DHF0019316 DHF 0019322 DHF 0019348 DHF 0024628]

<sup>6</sup> See Mark

Professor Leen described the huge physical and psychosocial impact on HIV infected individuals and their families. It is an enormous strain living with someone with HIV. The individual stories heard in the public hearings bear this out. Frances described the impact of her father's illness and death on her family and in particular upon her mother and brothers. Her mother became an alcoholic and survived her husband by only ten years. One of her brothers has been unemployed for sixteen years and her younger brother was orphaned at quite a young age having to be supported by his siblings in young adult life. Her own academic performance was seriously affected and she required treatment for depression that involved a lengthy period of absence from work.

**The financial consequences of HIV infection and treatment for patients and their families.**

Despite the financial consequences of HIV being quite well understood and appreciated only very limited assistance from the McFarlane Trust is available.

A positive HIV status often had far reaching consequences in employment prospects and in other financial contexts. Investigations, treatment, stress and poor health affect the ability to work. Constant treatment interrupts and affects employment and the side-effects of medication can hamper the ability to earn a living. It is almost certainly impossible to obtain life cover or any other form of insurance. Mortgage protection and other products taken for granted by most people cannot be obtained or are prohibitively expensive. There is a significant impact on employment mobility<sup>7</sup>.

The impact of a positive result or development of the condition and death has had far financial consequences for family members. The significant side-effects of treatment mean that financial problems are common. Someone like Mark is completely unfit for any form of employment permanently. Widows without dependants receive limited assistance. It is uncertain for how long this will continue. There are miscellaneous and consequential financial consequences – one example is the cost of privately funding assisted conception another is supporting siblings through University.

It is very hard for relatives to cope with the loss of a loved one. Depression, alcoholism and dysfunction occurred in families devastated by the events described in the Inquiry and this all had a significant financial impact.

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<sup>7</sup> See Stephens evidence [Day 75 8/12/11 pp90-92]

## 5. **The effects of co-infection with HIV and Hepatitis C.**

All of those infected with HIV through blood products were also infected with Hepatitis C. Often patients were not informed of their hepatitis C infection until many years after it had occurred and certainly many years after clinicians appreciated that it would have occurred. In some cases it is doubtful whether they were told at all. It is noteworthy that many patients cannot recall being told about hepatitis C despite there being indications in medical records that such information was provided. David, Mark and Stephen are examples of co-infected patients and provide a detailed insight into some of the issues arising.

Professor Leen was asked to explain the effect of co-infection with Hepatitis C and HIV.<sup>8</sup> He made it clear that it is something that is difficult to study but there is evidence that HCV has a deleterious effect on HIV progression. In HIV an individual's progress of HCV is likely to occur more frequently and at a faster rate<sup>9</sup>. There is a proportional increase in deaths from end stage liver disease throughout the HIV-infected population such that HCV infection is one of the major causes of death in people with HIV. It is possible that co-infected patients with suppressed HIV infection do better than those with poorer HIV control. Hepato-cellular carcinoma in co-infected patients occurs at a younger age and within a shorter time period. Response to HCV treatment is also impaired in the co-infected patient. As a result co-infected patients<sup>10</sup> have deferred treatment until better options become available.

## 6. **The level of information, support and counselling previously and currently available to patients infected with HIV through blood and blood products, and their families and the differences between centres.**

Professor Leen has told the Inquiry that support and counselling for patients and their families is widely available across Scotland and that standards of psychological care are currently being developed. In the early stages the amount and availability of support was at best patchy.

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<sup>8</sup> Day 33 15/06/11 66 (13) – 75 (5)]

<sup>9</sup> Stephen who is co-infected experienced a rapid progression in his HCV leading to the requirement for a liver transplant at a relatively early stage.

<sup>10</sup> Such as Mark

**7. The effect that the level of information, support and counselling has had on the ability of patients and their families to cope with HIV infection and its consequences**

There is evidence that support has helped patients and their families to cope better with HIV infection and its consequences than they would have done otherwise. Some declined the offer help. It would be useful to have more information in relation to the value of counselling and an outline of the best methods of supporting patients and their families.