

William Murphy - deceased Hepatitis C haemophiliac

Background facts; some sentiments and soundbites

- Health Secretary John Reid announced on Friday 23 January 2004, that UK haemophiliacs infected with the Hepatitis C virus, through contaminated NHS blood products, who then went on to die from this disease prior to August 29th 2003, were not to receive compensation. He believes this to be 'fair and reasonable'. Here's why it's not. (Note: John Reid HAS read this briefing sheet).

- William Murphy died on September 3 1994, aged 59, at Royal Liverpool University Hospital (RLUH).

- Causes of death: hepatocellular carcinoma; cirrhosis; Hepatitis C; Haemophilia A.

- One of three haemophilic brothers (among five siblings). His two other haemophilic brothers (brother A and B for anonymity) died of AIDS related illnesses in 1989 and 1990 following diagnosis as +HIV in the mid 1980s as a result of infected NHS blood products.

- William campaigned vigourously for justice for the families of his two brothers as financial recompense for HIV haemophiliacs was sought.

- He was actually diagnosed as -HIV in 1987 but refused to believe the accuracy of this as ill-health persisted (gastro problems, severe fatigue, irritability, nausea, general malaise). 'Something's up,' he kept emphasising.

- He was finally diagnosed with Hepatitis C in January 1992, after complications had arisen following a knee replacement operation at the RLUH.

- Prognosis was that he had approx. 2.5 years left to live.

- Medical opinion was that his infection with Hepatitis C was most likely to have occurred as a result of the NHS blood products that were administered to him during an operation to repair a duodenal ulcer at the RLUH in November 1981.

- His first attack of 'varices' (major oesophageal haemorrhaging) surfaced in April 1992; close to death over Easter weekend.

- Varices reparation treatment then ensued episodically at RLUH for remainder of his life.

- He was recommended for liver transplant in July 1994 by RLUH; plans for transfer to Newcastle Freeman Hospital (NFH) were underway.

- An episode of extreme encephalopathy was experienced in early August 1994; so plans for transfer to NFH were hastened.

- He was transferred to NFH in mid-August 1994 for liver work-ups ahead of prospective transplant.

- All plans were heartbreakingly put on hold as the NFH discovered a tumour, then some 7 cms in diameter, growing on his liver. He was discharged back to RLUH.

- A chemotherapy course was agreed to, although positive prospects were described as remote, and the first treatment was arranged to be administered on September 5th 1994.
- A massive and fatal burst tumour haemorrhage occurred on September 3rd 1994, just 48 hours before chemotherapy was to start.
- He had been married for 35 years to Maureen; he left two children, Anne, then 34, and Greg, then 27, and three grandsons (the youngest a severe haemophiliac) then aged nine, seven and three.
- His mother, then aged 89, survived him and had witnessed the death of a third haemophiliac son to blood infections within the space of five years. She later died in 1997, aged 92, knowing, and being acutely distressed about, the likelihood that a callous distinction was to be drawn between her two sons who had earlier died of AIDS related illnesses and William who drew the short-straw in the great blood infection lottery.
- An accountant by trade, he had been employed by the Roman Catholic Archdiocese of Liverpool until he was forced to retire in 1991, when complications set in following the knee replacement operation at RLUH, which eventually led to the discovery of his +HCV status.
- In the two and a half years that he knowingly suffered HCV, he endured a painful life. Aside from the attacks of varices and encephalopathy (on one occasion he had to return early from a family meal out due to an embarrassing and overwhelmingly spontaneous oral haemorrhage) he competed with a vile array of conditions. Putrid looking leg ulcers forced the constant wearing of special bandages and the persistence of these eventually led to the indignity of adapted footwear and later the necessity to wear a slipper and a shoe, such was his disfiguration.
- He was regularly beset by styes and digestive chaos. His dietary requirements were unpredictable and one foodstuff after another was gradually removed from the 'agreeable' list. Pathetically, he reached a point where, for example, milk could no longer be 'tolerated' with corn flakes.
- One of the more desperate and heart-rending manifestations was the severe psoriasis he experienced across his body and the relentless itchiness, related to his liver failure, that plagued and tormented his body and refused to yield to cooling creams.
- However, the most indignity was endured through his bodily appearance. Always a slim man and an ultra-smart dresser, the unsightly and extreme presence of fluid ascites gave a pear-like shape to his abdominal region so ridiculously out of proportion to his otherwise slight build. This alone would have prevented him from wearing anything other than jogging bottoms - and eventually only loose-fitting pyjama trousers - but allied to the presence of an umbilical hernia, which sat atop the ascites balloon, it lent him an utterly undignified profile, resembling a cherry-topped dessert, and he was simply unable to dress properly. He tearfully lamented and despised the indignity of this.
- His social life between 1992 and 1994 was almost nil and from early 1994 he was effectively housebound, save for the odd, almost militarily planned, excursion, such was the unreliability of his condition. Perhaps most poignantly he had to sacrifice a once-in-a-lifetime opportunity to fly on Concorde with his wife. A newspaper competition had been won by her and it seemed a perfect way for them to celebrate their 35th wedding anniversary. He was forced to stay at home but insisted his wife and his daughter enjoy the experience

nonetheless. Ironically, he watched and waved from his front porch as the plane performed a scheduled by-pass over the city of Liverpool on Grand National day 1994.

- Although he was not diagnosed with HCV until January 1992, he had always insisted that he could not possibly have escaped the chilling blight of the blood infections, such was the way he was continuously feeling. In fact, he maintained that medics had made an extreme error and he would soon be told that he was +HIV after all. This pessimism, which eventually proved to be justified, led to very dark times domestically as he refused to accept his 'good fortune'. Indeed, his gradually deteriorating condition, without adequate explanation, was such that it forced him to stop going on holiday from 1990. The pressure on his loved ones was intense and immense.

- He always had an instinct that his liver was the root of his malaise, given that he had contracted bouts of Hepatitis A and B in the late 1970s. Based on the likelihood that he was infected with HCV in 1981, it underlines how rapidly the effects of the disease accelerated within him that he was already experiencing the symptoms of cirrhosis by 1992, accompanied by life-threatening bouts of varices.

- The deleterious and acutely stressful effects on his wife were such that she was forced to retire from a supervisory position at Marks & Spencer, aged 53, in 1991, thus depriving the home of two regular salaries. In any case, it was rapidly obvious that such were the incessant demands of her husband's condition that she would have had no alternative but to resign from her employment to become a full-time carer for him.

- Earlier, in 1988, the precarious financial standing of their marriage was starkly brought to the fore. Like many haemophiliacs at the time, William thought it prudent, in the light of HIV and haemophilia related circumstances and stigma, to cash-in, well before maturity, his pension from a former long-standing employer. He feared that the certified causes of his eventual death would prevent or seriously affect payments to his wife. This was a drastic, and seemingly rash, course of action, given that his status at the time was recorded as -HIV. Naturally this increased pressures domestically, however it was eventually proved to be a wise and pragmatic decision when unwelcome vindication arrived in the shape of his HCV diagnosis. Nevertheless, only a modest 'rainy day' savings pot was realised.

- No other life assurance policies were ever taken out by him, as it was plainly obvious, from literature encountered over the years, that it was not even worth the effort filling out application forms. Similarly so regarding mortgage protection policies, the absence of which left the couple dangerously exposed should early death occur to either of them.

- By retiring through ill-health, both had also lost any entitlement to death-in-service benefits.

- At the time of his death in 1994, five years remained on the mortgage, the payments for which would then have to be met by his widow, without the aid of either a pension lump-sum, mortgage protection or indeed a regular salary. The meagre savings pot that had been created from that earlier cashed-in pension was therefore drained and, by 1999, was almost obliterated.

- Now 65, Maureen's gross income is a little over £7,000 per year comprising, among other things, a drastically reduced personal pension because of her own ill-health retirement and a paltry nominal pension from her husband's employment of just £250 per year. After overheads, Maureen is left with some £2,000 a year to survive and she counts the cost, not only of lost entitlements but also five years' loss of salary from her husband and seven

years' loss of her own salary had she retired aged 60.

- Unlike widows of HIV victims, who were rightly compensated - even for funeral expenses - Maureen has never received a penny in recompense for so much emotional and financial injury and it would now appear that she never will.

- The viewpoint of Maureen and her children, Anne and Greg, is that this is an iniquitous and indefensible injustice, devoid of any moral justification and inexplicable beyond the reaches of even the slickest spin.

- They can see no distinction between their father and his two other haemophilic brothers, aside from the lottery of NHS blood infection, which dealt out two cases of HIV and one case of HCV. They all ended up as ashes.

- Ironically, William was a late convert to the supposed 'benefits' of blood products for haemophiliacs, always believing them to be suspect, a view which seemed to be borne out by the ITV World in Action documentary, first screened in 1975, which more than exposed the scandal of the tainted materials. Incredibly though, such materials continued to be liberally administered in the UK with catastrophic, yet thoroughly avoidable, consequences.

- Repeatedly assured though of the 'safety' of such materials - and in any case left with Hobson's Choice given the excruciating pain from his knee and elbow joints as he entered his 40s - he underwent treatment with both Cryoprecipitate and Factor VIII believing they would help him. Instead, they were slowly killing him.

- Prior to his death, and sensing it was near, William instinctively predicted that a distinction would be drawn between his wife and the widows of HIV haemophiliac victims. Fearing this, he expressed a wish, in August 1994, that he utilise whatever time he had left to prepare a published account of his experiences. Unfortunately he died one month later before he could even start.

- After an initial round of publicity, in the immediate aftermath of his death, William's children have struggled to gain any continuous momentum in publicising this injustice, and have experienced widespread ignorance of the realities of Hepatitis C.

- They now firmly believe that the lack of concerted publicity has allowed the present government - who they hold as the latest in a long-line of culpable or morally tainted parties tangential to this bloody scandal - to create a deplorable caveat within the proposed financial recompense scheme for HCV victims. To exclude widows or bereaved relatives from this scheme on the grounds that their cases are too long ago - and the injury has therefore presumably subsided - is heinous and morally reprehensible.

- William's case is now so relatively long ago - but actually only 10 years - because it has taken that long for Westminster to accept this injustice.

- Whilst perhaps distasteful to say so, it is nonetheless the belief of William's family that it would have been emotionally and financially preferable for him to have contracted AIDS. This is a hideous circumstance. Medical opinion will assert that the clinical manifestations of HCV are every bit as disgusting as those of HIV - and in some cases moreso. Had William died from an AIDS related illness, like his two brothers, his immediate family would have been spared an even more prolonged illness and almost a decade's heartache brought on

by the prevailing injustices they have had to endure.

- As it was, William died a truly disgusting and highly prejudiced death and his widow has been left emotionally and financially battered by the whole experience.
- His family hold that he was the victim of avoidable manslaughter and have no hesitation in using such an emotive term.
- His family also deeply resent having to lay themselves so open and reveal so much personal and deeply distressing information but feel that the heartless intransigence of this present government has backed them into a corner, leaving them with little option if justice is seen to be served.

Gregory Murphy can be contacted on 0151 521 1799 / 07742-109910

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