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FAX

FAQ: SUNDAY TELEGRAPH FEATURES

MESSAGE

Please consider for publication on Sunday 3.9.95
Nine (9) pages including this.

Contact : Greg Murphy (0181 256 6555 work)
(0191 524 2922 home)

Would be grateful if you could let me know either way. As you
see from the piece, publicity is paramount for us.

Regards,



Greg Murphy

FEATURES

HEP C 1

Greg Murphy

AT precisely 20 minutes to five this afternoon it will be a year since I watched my father, ravaged by haemophilia and its attendant virus, give up his battle for life.

A victim of Hepatitis C, haemophilia was the virus that led me to AIDS / HIV in the 1980s was too close to home for me to write about. I am 39, so that I was plain old beetle haemophilia.

FAX

FAO: SUNDAY TELEGRAPH FEATURES

That's putting it simply about the virus that led me to AIDS / HIV. I am 39, so that I was plain old beetle haemophilia. I am 39, so that I was plain old beetle haemophilia.

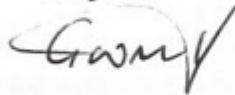
MESSAGE:

but eventually Please consider for publication on Sunday 3.9.95
Nine (9) pages including this.

Since that the silence has been broken by
Contact : Greg Murphy (0161 236 8856 work)
(0151 524 2929 home)

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Regards,



Greg Murphy

At precisely 20 minutes to five this afternoon it will be a year since I watched my father, ravaged by haemophilia and its attendant debris, give up his battle for life.

HIV, his condition deteriorates markedly and it is discovered that he has cirrhosis of the liver. A victim of Hepatitis C, haemophilia's Second World War (the contest against AIDS / HIV in the 1980s was the Great War), the irony of my father's death, at 59, is that it was plain old basic haemophilia that defeated him.

Then, last summer, it was discovered that the cirrhosis had worsened, cancer had developed. That's putting it simply of course - he did have cirrhosis of the liver, which led to cancer, the same inevitable course of events which Larry Hagman has contested - but eventually it was a haemorrhagic denouement.

Once the funeral was over, the letters to MPs began. After all, this was a repeat of the events of 1982. Since that desperate Saturday afternoon at Liverpool's Royal University Hospital the silence has been deafening.

The silence of the government, the legal fraternity, the media et al, has confirmed what the family always feared - it's nobody's problem but ours.

Since the full horror of Hepatitis C was realised, there was a brief flurry of activity. The events that led up to my father's escape from his bloody hell on earth can be bizarrely followed like one of those early computer-age flow charts.

In 1969, after working as a travelling accountant, the stress of the B&B, 'A' Road and on-the-hoof, six days a week lifestyle culminated in a duodenal ulcer - a dangerous thing for a haemophiliac.

Kept under control for eight years, a dispute with a neighbour over fencing arrangements, which almost ended up in court, produced enough stress to force the ulcer into severe haemorrhage.

Eventually an operation becomes an inevitability - again, a highly dangerous thing for a haemophiliac to undergo - and huge doses of Factor VIII clotting agent and transfused blood are administered.

More...

Eight years later, after learning he had miraculously escaped the death claws of HIV, his condition deteriorates markedly and it is discovered that he has cirrhosis of the liver, caused by Hepatitis C, which was an unwelcome passenger of ~~repeating~~ transfusions.

Then, last summer, it was discovered that the cirrhosis had worsened, cancer had formed. A year ago today the tumour burst causing a massive internal abdominal bleed and it was the end.

Once the funeral was over, the letters to MPs began. After all, this was a repeat of the fight against AIDS - which incidentally stripped my grandmother (still alive) of two other sons - and we surely had a case ? Haven't we ? Didn't we ?

It seems not.

Once the full horror of Hepatitis 'C' was realised, there was a brief flurry of newspaper activity last November. A bit of local newspaper interest about my Dad, one or two indentations on the national broadsheets even. The justice bandwagon was up-and running, or so we thought. Even *Panorama* did its bit.

Of course, the Government refused to even consider the remotest possibility that there may be one or two things for the Department of Health to answer. You see, we were all assured after the 'settlement' of the HIV debacle that this type of thing would never happen again.

Hepatitis 'C' - though sad and highly dangerous - just isn't the same.

The media, as could only be expected, had run out of stories and angles. There was a complaint against the government, we were told - there are plenty we were told - and the government has refused to play ball. End of story in news terms.

More...

The newsdesks inform us that we need a development or a new angle. But there isn't one. The families of the HIV victims were addressed and compensated and the government has told the Hepatitis C victims that there is no intention of repeating the show.

The irony here is that my father is one of three haemophiliac brothers. If he'd had the foresight to have contracted HIV instead of Hepatitis C (he'd be dead either way) then the government would have admitted responsibility. This way round and it's no can do. And you're meant to accept that ?

The Haemophilia Society believes there is very little that can be done, though it will fight but in vain, one suspects. In fact, the society of haemophiliac families is somewhat divided on the matter. To bring 'the plight' back onto the newspapers will only recreate the stigma of the HIV era according to some.

People don't understand about haemophilia, goes the understandable cry. A recent episode of Casualty didn't help either. NB - Haemophiliacs who slice themselves on a bread knife are about as likely to die from an ensuing Niagara of blood as the officials in the Department of Health are to accept that the Hepatitis C tragedy is just what it is - a bloody tragedy.

For God's sake, my four-year-old haemophilic nephew starts school later this month. The teachers are terrified. They'll have to keep him away from the playground. 'What if he falls over ?' Then you put a plaster on him and ring his Mum, same as any other kid. I hope.

No - it simply wouldn't do to have haemophilia dominating the headlines again, say the HIV families and other families within the circle. To a certain extent, under the 'once-bitten' mentality, that's understandable but effectively it creates a class structure of haemophiliacs. Hepatitis C families are firmly in the Second Class carriages having to make do with a buffet car that is stocked with nothing but a limp: 'We're sorry but there's nothing we can do'.

More...

Surely that in itself is a manifest example of the disastrous circumstances which have besieged the haemophiliac community for almost two decades ?

Cliché: it isn't about money *per se*. But there are hidden financial injustices striking straight at the heart of the stigma problem. Once the words 'haemophilia' and 'AIDS' were first connected in a news story the writing was on the wall.

My father could see it coming. Insurance policies and pension documents suddenly started mentioning HIV. There had never been any need to let his employers or insurance agents know about his condition when he started work in the 1950s. Taking good care of himself also helped and he didn't miss a day's work for almost 12 years. Sheer bravado maybe but his secret was safe.

Why a secret ? Because he had a highly honed sense of cynicism about the general public's attitude toward haemophilia (and this was long before HIV) which was eventually proved accurate. I'm pretty certain that the state's insistence that he be sent a special needs school had something to with it. But that was in the 1930s - people are much more educated now I told him.

When he went into hospital for his ulcer operation he was asked by his employers to join the firm's BUPA plan. He told them he couldn't because of his condition. This was fine until the HIV era was up-and-devastating just two years later and then, mysteriously, redundancy followed.

Haemophilia was AIDS. AIDS was filth and that was that.

Pensions were cashed in, as were insurance policies, just to be on the safe side and any plans for a seaside retirement cottage were filed under fantasy. He did get another job but eventually his condition got so bad that he had to retire because he'd had nearly a year off. If he'd died during that year, i.e. 'in service' my mother would have got a lump sum. Because he died after retirement she gets less than £200 per year.

More...

Of course, she'll qualify for Legal Aid if the Hepatitis C case ever gets underway but she's not holding her breath.

So a year has gone by and I smell a distinct case of legal and media fatigue about the plight of haemophiliacs. There are no fresh news angles - only anniversaries. Like today's.

And the silence will continue. Like tomorrow's.

ENDS (1,282)