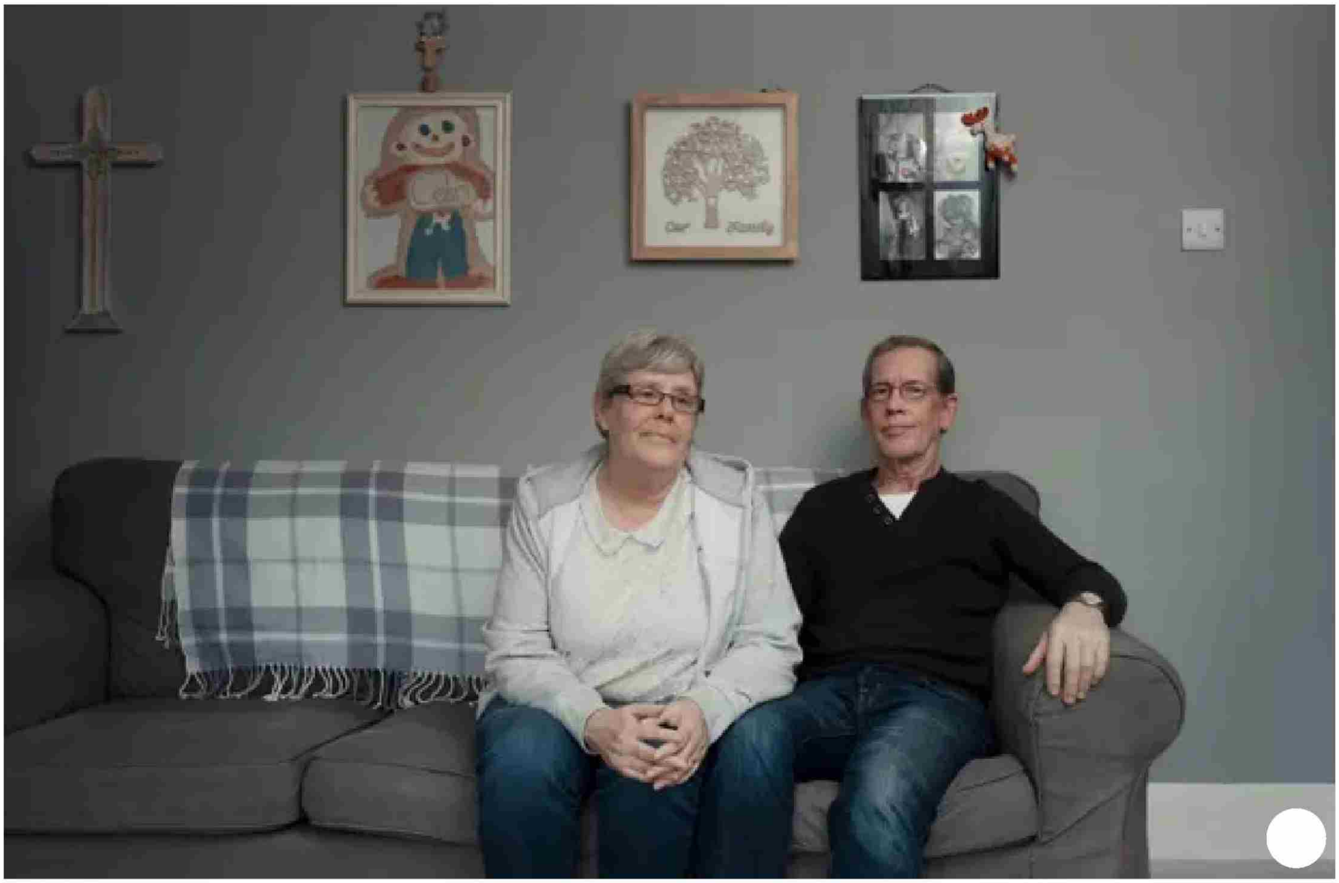


Health

Britain's contaminated blood scandal: 'I need them to admit they killed our son'

Simon Hattenstone

Sat 3 Mar 2018 09.00 GMT

It has been called the biggest treatment disaster in the history of the NHS, and a "horrific human tragedy". But Su Gorman, whose husband has endured years of ill health as a result of haemophilia treatment, does not believe this adequately describes Britain's contaminated blood scandal. As far as she is concerned, it is simply a crime.

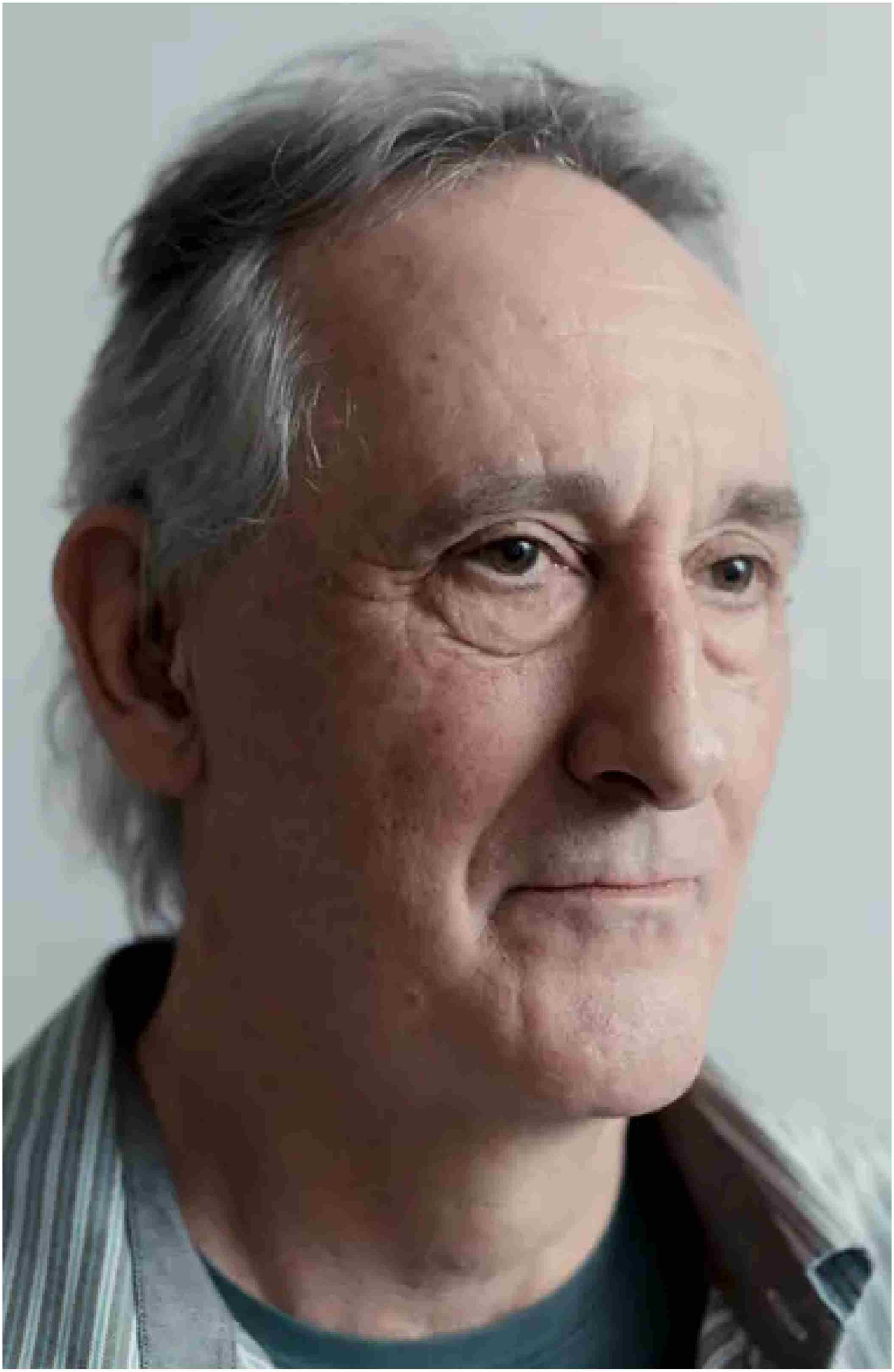
In the 1970s and 80s, 4,689 haemophiliacs became infected with hepatitis C and HIV after they were treated with contaminated blood products supplied by the NHS. Of those infected, 2,883 have since died.

Gorman, who works with Tainted Blood, the national campaigning group for infected haemophiliacs, refers to the Nuremberg Code created at the end of the second world war. "It states that nobody will be experimented on medically without their consent." She believes what happened with haemophiliacs given contaminated blood products was experimentation.

Haemophilia is a genetic condition that causes a lack of the essential blood-clotting protein known as factor VIII, so even a small injury can result in dramatic blood loss. In the 60s, a frozen blood product called cryoprecipitate was introduced, which could stop bleeding. But this could be administered only via transfusion, in hospital, and because it was produced from a small number of donors, it was always in short supply.

But in the 70s, a major breakthrough in the mass production of freeze-dried factor concentrates, made by distilling the plasma of large groups of donors, meant haemophiliacs could now live normal lives. When a cut or bruising led to bleeding, they could simply take a bottle containing factor VIII out of the fridge, inject themselves, and their blood would start clotting.

But the miraculous new treatment carried hidden dangers. British laboratories were unable to keep up with demand and in 1973 the government started buying cheap blood products from American drug companies. Much of the blood sold to British hospitals came from prisons in Arkansas, where a high number of inmates were infected with hepatitis and HIV. Whereas in Britain blood was given on a voluntary basis, in the US donors were paid for it - including prisoners. Many of those who most needed the money led chaotic lives and were likely to have infected blood - drug addicts, sex workers or alcoholics, all of whom were at risk of contracting blood-borne diseases. A single batch of factor VIII would include blood from up to 20,000 donors. If only one donor was infected, the whole batch could be contaminated. After Britain started importing blood products from America, there was an outbreak of hepatitis B in haemophiliacs. A 1975 World In Action TV report exposed the fact that the contaminated products had been harvested on "skid row" in America, and asked why Britain was putting its haemophiliacs at risk by not producing enough of its own factor VIII concentrate. But even after the programme aired, most haemophiliacs remained oblivious to the dangers. A few doctors explained the risk to their patients; many didn't.



▲ Steve Dymond, who contracted hepatitis C from contaminated blood. Photograph: Francesca Jones/The Guardian

To call the use of contaminated blood a "tragedy" suggests nothing could have been done to prevent it, Su Gorman says - and that could not be further from the truth. At best, the government, medical experts and drug companies were reckless and incompetent. At worst, they treated patients as unwitting guinea pigs and for the past 40 years have continued to cover it up.

Su Gorman's husband, Steve Dymond, 61, is a haemophiliac whose mild symptoms allowed him to lead a full life until he was infected with hepatitis C. He played school rugby, studied Russian at university and worked as a teacher before joining Cambridge University Press in France. He looked after himself, and rarely needed treatment.

By 1983, government experts knew that those receiving clotting factor concentrates were at risk of Aids (this was revealed in minutes from a meeting of the Committee on the Safety of Medicines in July 1983, obtained by the Guardian in 2007). Medical experts recommended that factor concentrates undergo heat treatment to kill infection-causing viruses, but implementation was delayed because of the expense. After a British haemophiliac who had contracted HIV from blood products died of Aids in August 1983, the government still refused to accept HIV was blood-borne. Even though heat treatment was widely introduced in Britain over the next few years, drug companies were treating the concentrates at different temperatures and older, untreated ones were retained to save money. It wasn't just haemophiliacs who were at risk: contaminated blood was also used in transfusions for the general population. About 35,000 people in Britain are believed to have contracted hepatitis C from contaminated blood, including GRO-A, who was infected by a transfusion of British blood after the birth of her daughter in 1971 and died in 2007.

In 1984, the US Food and Drug Administration banned medical use of blood from high-risk groups including prisoners. But the British Department of Health continued to import blood from US prisons, as Steve Dymond was to find out to his cost.

In the mid-80s, Dymond bashed his hand in the garden and it bruised. There was no bleeding and he was tempted to leave it. "It was fairly minor, so I was going to wait till the next day," he says. "Su was more worried, so we erred on the side of caution."

"Some stupid A&E registrar panicked, took a bottle of factor VIII off the shelf and treated him," Gorman says. The next day Dymond went to the haemophilia centre at

St Thomas' hospital and was told he should not have been given factor VIII for such an inconsequential injury. He was also told that the factor VIII had not been heat-treated, so he may have been exposed to HIV.

"That was another cost-cutting measure," Gorman says. "The untreated stuff was put in the A&E departments of non-specialist hospitals for use in life-saving emergencies. If there was, say, a haemophiliac in a car crash who'd die anyway, they thought it was worth the risk of giving them this factor VIII. It should never have been given to a mild haemophiliac or to treat a bruise."

> **" Waiting for the result, I lived in fear. We had friends dying of Aids, so no illusions about what the endgame would be**

Shortly after this, Dymond fell ill. The change was dramatic, physically and mentally. His muscles were sore, his joints ached, he was permanently exhausted. He would fall asleep anywhere. "Ten o'clock on the dot, he would always fall asleep. It was so regular it became known as 'doing a Steve'," Gorman says.

His memory deterioriated. He would be on the motorway in France, travelling for work, and could not remember where he was going. Not surprisingly, he lost his job.

In the early days, Dymond and Gorman had so much fun. They went to the theatre, travelled widely, laughed all the time. Back then, Gorman says, they could even laugh about his haemophilia. She regarded it as exotic. "When he told me he was haemophiliac, I was totally impressed. Queen Victoria passed it on to most of the royal families in Europe. The son of the last tsar was a haemophiliac!"

Haemophilia didn't seem so exotic now. Dymond was tested for HIV - which back then took 18 months. He became withdrawn. "I thought for a while he was being unfaithful because he had no time for me at all. The minute they told him he might have HIV, he took the most basic step to avoid infecting me. I had decided if it was confirmed he was HIV positive, I'd get myself infected, too, so he couldn't shut me out and we would go together."

She gave up her job as a social worker to look after him. "During the 18 months waiting for the result, I lived in fear," she says. "We had friends who were dying of Aids, so we had no illusions about what the endgame would be."

Eventually Dymond was told he was not HIV positive. That was in 1985. His symptoms persisted but it was not until 1997 that he was diagnosed with hepatitis C. Two days later he was seeing a liver specialist. "I said, 'Have I got cirrhosis?' And the doctor said, 'Of course you do.' It's almost a straight line. You get cirrhosis, liver cancer, you'll probably need a transplant."

"His liver is like a bunch of grapes," Gorman says. "The medical term is nodular. Each nodule is a breeding ground for cancer."

▲ Su Gorman: 'Untreated factor VIII should never have been given for a bruise.' Photograph: Francesca Jones/The Guardian

Gorman is a small woman with piercing eyes and a fierce intellect. Dymond is a big, handsome man with a quiet voice and understated eloquence. Today, after punishing treatments, he is clear of hepatitis C (though it was a close-run thing: in 2016 he had a near-fatal stomach bleed). He is still suffering side-effects, including hearing loss, from the drugs he was given. But for the first time in decades he has the energy to discuss the scandal at length without falling asleep or losing focus. It is August 2017 and we are sitting outside a pub that looks over Pegwell Bay in Kent. The weather changes by the minute from sunny to thunderous. A little like Gorman. Forty years on, she is still seething.

Dymond's fury is more contained. He believed he had been desperately unlucky to be infected and that nobody was to blame. But over the years, documents have emerged that show the government was aware that there were risks with this treatment.

Factor VIII concentrate was initially produced in 1966, more than a decade before the first Aids case was diagnosed, but as early as the 50s, experts had warned of the risk of hepatitis from mass-produced blood products. In 1974, American scientist Judith Graham Pool - who had discovered cryoprecipitate - described the payment of blood donors as "dangerous" and "unethical". The World Health Organisation warned the UK not to import blood from countries that paid donors and had a high incidence of hepatitis, such as the US.

America was not alone in exporting bad blood. Following an investigation, the Canadian company Continental Pharma Cryosan pleaded guilty in 1980 to falsely labelling blood intended for human beings as coming from donors in Sweden when in fact it came from cadavers in Russia. The blood was then repackaged and exported to Europe to be made into factor VIII concentrate.

" At every single stage, the truth has been there and people have evaded it, and that must carry a penalty

The danger of pooled blood products from abroad was acknowledged by British politicians as early as the 70s. In 1975, health secretary David Owen promised a £500,000 programme to boost plasma collection. He pledged Britain would be self-sufficient in factor VIII by 1977. But when he moved to the Foreign Office, the decision was reversed. By 1980, Britain was importing twice the amount of blood products it produced.

In September 2016, Lord Owen addressed an audience of campaigners and victims of the contaminated blood scandal, referring to a "cover-up" and saying "incriminating evidence" had been suppressed by the government. "At every single stage, the truth has been there and people have evaded it, and that must carry a penalty." Lord Owen was visibly distressed as he said: "I have failed and I feel very miserable about it."

Perhaps the most serious warning came in May 1983 from Dr NS Galbraith, founding director of the Communicable Disease Surveillance Centre in England and Wales. After hearing of the first death of a haemophiliac from Aids in the UK, he wrote a paper for the Department of Health and Social Security, saying: "All blood products made from blood donated in the US after 1978 should be withdrawn from use until the risk of Aids transmission by these products has been clarified." But they were not withdrawn. The Department of Health considered his advice "premature".

Six months later, the then minister of state for health, Kenneth Clarke, told the House of Commons: "There is no conclusive evidence that Aids is transmitted by blood products."

In 2007, after a freedom of information request, Tainted Blood received hundreds of documents relating to the scandal. In one, dated 22 January 1985, Clarke had written: "Before we all panic further, it is presumably the case that the ending of the collection of blood from homosexuals greatly reduces the risk from blood collected in this country. Also, as only haemophiliacs have died and they may have had factor VIII from American blood, is it the case that we have not had one Aids fatality from blood donated in this country yet? Do we need this *and* heat treatment of the blood?" The suggestion seemed to be that heat treatment may be one expensive precaution too many. Not surprisingly, the discovery of this letter many years later caused great hurt in the haemophilia community. Gorman spits out the phrase: "*Only* haemophiliacs."

Between 1988 and 1990, Clarke was secretary of state for health. In 1990, he was advised by the then chief medical officer, Sir Donald Acheson, to settle claims with those affected out of court, to prevent the government being forced to hand over sensitive documents. It was reported at the time that Clarke was reluctant to settle, insisting haemophiliacs had to prove their case in court.

In the early 90s, pharmaceutical companies began to produce synthesised factor products in labs, which prevented nearly all forms of disease transmission. But by then the damage had been done.

The blood scandal was not confined to Britain. But in other countries officials and drug companies were held to account. In France, which was self-sufficient in blood, about 4,000 people, many of them haemophiliacs, were infected with HIV and hepatitis C through contaminated blood. France's former health secretary was found guilty of manslaughter but not jailed; the former head and deputy head of the blood transfusion service were sent to prison. In America, the companies that supplied infected products paid out millions in out-of-court settlements. Japan continued to import untreated blood factor products from the US until 1985. Of about 4,500 haemophiliacs there, an estimated 2,000 contracted HIV and hepatitis C. Renzo Matsushita, former head of the Ministry of Health and Welfare's Pharmaceutical Affairs Bureau, and two colleagues were found guilty of professional negligence resulting in death.

But in Britain, nobody was made liable. In 2007, Labour peer Lord Archer of Sandwell launched a privately funded inquiry, but it held no official status and was unable to subpoena witnesses or demand the disclosure of documents. In 2009, Archer concluded that the government was slow to react to the crisis but no one was to blame, except the US suppliers of contaminated blood. In 2008, the Scottish government announced a public inquiry into the scandal there, to be chaired by Lord Penrose. It lasted seven years, cost £13m, made just one recommendation and failed to apportion any blame. Campaign groups called it a whitewash.

On 26 April 2017, Andy Burnham used his last speech in the House of Commons to demand a Hillsborough-style inquiry into the contaminated blood scandal. Burnham, a former health secretary, said "all of us here are collectively culpable" for failing thousands of victims. He called the use of contaminated blood a "criminal cover-up on an industrial scale" and threatened to pass his evidence to the police if the government did not act. Three months later, in July 2017, a public inquiry was announced.

Campaigners such as Tainted Blood had spent decades fighting for this, but the news was met with suspicion. The government initially said the inquiry would be managed by the Department of Health, which Tainted Blood denounced as a conflict of interest (how could the department investigate its own failings?) and called for an independent judge to handle the inquiry. Last November, it was announced that the inquiry would move from the health department to the Cabinet Office, and would be led by a judge.

Lauren Palmer radiates optimism. Her sentences are punctuated with laughter and the walls of her Bristol flat are papered in feel-good sayings - Believe in your Dreams, Dream Big, Love Always, Shine Bright. It is this positivity that has helped her cope with a shocking childhood trauma. In August 1994, her mother and father died within eight days of each other.

▲ Lauren Palmer with her parents, Stephen and Barbara

Her father was a severe haemophiliac. With hindsight, she thinks that is why they never had a close bond - young Lauren was a handful and one friendly knock could have made him bleed. But she was extremely close to her mother and her two older half-brothers, and life was fun.

Then one day her mother called a family meeting. Palmer was nine, and she knew it was serious by the expression on her mother's face. "Dad was living back with his parents because he was quite ill. Mum sat us down and said she had this disease, HIV. I burst into tears. I didn't know what it was, but I knew that she was going into hospital and she wouldn't be getting better. That was in our summer holidays." Within weeks both her parents were dead.

Her father had been infected after receiving contaminated factor VIII and had unknowingly passed it to his wife. It is only recently that Lauren learned her parents also had hepatitis C, which is much more contagious than HIV.

Palmer, now 34, heard talk of contaminated blood, but she did not want to know more. On the other hand, she could not totally avoid the consequences of what happened: as the daughter of a haemophiliac, she would be a carrier of the gene. As a young girl she was told this meant that if she had children, there was a high chance any boys would be infected.

Her parents' deaths tore her life apart. Palmer's half-brothers went to live with their father in Wiltshire, while she moved in with her mother's sister and her family in

West Sussex. She couldn't sleep, struggled with eating and started to wet the bed. She never spoke about how her parents had died because her aunt told her she shouldn't mention it. "She said we couldn't talk about HIV with anybody because it wouldn't be accepted, so I never did."

▲ Lauren Palmer, whose parents died within eight days of each other in 1994. Photograph: Francesca Jones/The Guardian

Last year, she was forced to confront the horror of what happened when she found herself watching a Panorama documentary about the contaminated blood scandal. Palmer had no idea that thousands of haemophiliacs lost their lives in a similar way to her father. She decided she could not stay silent any more. After her parents died, she found letters her mother had written to MPs and celebrities, trying to draw attention to the scandal. Now, 24 years after her parents died, it is time for Palmer to fight for them. "I couldn't believe so many people had died and so many were still suffering. It's ripped apart the lives of every single family I've spoken to." Palmer recently took a less demanding job, so she can devote more time to campaigning.

It is not simply what happened that is so shocking, but the scale of it.

Treloar College was a boarding school for disabled children with a specialist haemophilia centre. Ade Goodyear joined the school at the age of 10. He adored his time at Treloar, a former stately home in Hampshire. After a lifetime wrapped in cotton wool, he now felt he could live independently - the teachers were supportive, the new revolutionary clotting factors meant there was no cause for panic if he bled, and he made many wonderful friends there. Goodyear says it was like being at Hogwarts.

Ten other haemophiliacs arrived at Treloar at the same time, in September 1980. They were called the "golden boys" and treated with great love, he says.

Of 89 haemophiliac children who attended Treloar from 1975 onwards, all were infected with hepatitis B and C, and 64 contracted HIV. Only 16 are alive today. Goodyear, aged 47, had three brothers who were also haemophiliac, although they did not attend Treloar. Two of them died after treatment with factor VIII - Jason from Aids, aged 28, in 1997; Gary from complications related to hepatitis C, aged 53, in 2015. While at Treloar, Goodyear was infected with both HIV and hepatitis C. He became a tour manager in the music industry, but had to quit because of the stigma attached to HIV - nobody would insure him.

▲ Ade Goodyear, who was infected with both HIV and hepatitis C: 'They gave us two years to live.' Photograph: courtesy of Ade Goodyear

Back in the early days at Treloar, the "golden boys" were laden with gifts from drug companies. "We were given watches, stationery kits, backpacks and so on, branded with American pharmaceutical company logos by the very conglomerates that ended up killing us," Goodyear says. "Looking back, it was a little like being groomed by pedlars of death, but at the time we were happy with the freebies. Little did we know what was to come."

Goodyear talks heartbreakingly of the day he was told he was HIV positive. "The haemophilia team just didn't know how to tell us nor where to begin. We were summoned to the clinic one bright spring day in 1985. They said, 'You've probably heard that factor VIII isn't as healthy as it should be.' They talked to us about hepatitis and HIV. Me and a mate looked at each other. Although there was this comfortable atmosphere, we knew the doctors weren't messing around. They were talking about Aids. They went around the room and said, 'You have, you haven't, you have, you have, you haven't,' in that order. They gave us about two to three years to live and said they would do their best as always for us, but to make the most of our lives. I remember walking through the office and the sun was beating through the blinds, and I thought, 'How many days will I be seeing the sunshine for?'" Of the five boys in the room that day, Goodyear is the only survivor.

▲ The haemophilia awareness ribbon: red for blood, yellow for hepatitis C, black for those who have died

Documents obtained by campaigners through freedom of information requests have since revealed that government officials were wondering exactly the same thing. In one particularly callous memo, written in March 1985, an official discusses data suggesting that 40% of those infected with HIV by contaminated blood products will go on to develop Aids and die (a vast underestimate, as it turned out). While acknowledging the "strong cost-benefit plus", in terms of lives saved, of taking steps to prevent the remainder of the haemophiliac population becoming infected with Aids, the memo points out that if the anticipated number of infected haemophiliacs' deaths is reached, this will be financially advantageous. "Of course, the maintenance of the life of a haemophiliac is itself expensive, and I am very much afraid that those who are already doomed will generate savings which more than cover the cost of testing blood donations."

That document does not surprise Goodyear. "We were constantly reminded how much we cost. As a child I knew how much factor VIII cost because I was always reminded by doctors. It was around £7,000 a year at the time, about £20,000 today. It was drummed into us how much we cost the state, and how much could be saved if we weren't here." Goodyear says many doctors made it clear they believed haemophiliacs were not worth the money spent on them. "A doctor in the 70s once said to my dad, 'The best thing for haemophiliacs would be to let them all go because it's a terrible condition.'"

At home in Newport, Colin and Jan Smith are surrounded by reminders of their son, also called Colin - framed photos of their beautiful blond boy, pictures he painted, toy cars. On Jan's arm is a tattoo of a witch framed by neat handwriting which reads: My Witch By Colin. The picture is the last one Colin drew. "He was a cheeky little boy," Jan says.

When he was a baby, Colin woke up one day and couldn’t move his legs. His nappy had been wrapped too tightly, giving him internal bleeding in his groin. At the age of 10 months, he was diagnosed with haemophilia and treated with cryoprecipitate, administered in the form of a transfusion. It was time-consuming and had to be given at the hospital, 11 miles away in Cardiff: “We could be up and down to Cardiff three times a day,” Jan says.

But then they were introduced to the miraculous factor VIII concentrate. If Colin hurt himself, instead of rushing to the hospital, his parents could inject him at home.

> **“ They told us in the hospital corridor, with kids running past. Just, ‘Oh, by the way, Colin has tested positive for HIV'**

At the age of two, their son was diagnosed as HIV positive. “When they told us, we didn’t realise it could be a death sentence. We were just told it’s another problem we’ve got to cope with, and he can be treated for it,” his father says.

“They told us in the hospital corridor, with kids running past,” Jan says. “They didn’t take us to a room, just said, ‘Oh, by the way, Colin has tested positive for HIV.’”

If there was a stigma attached to hepatitis C (people made connections with drug addiction or alcoholism because of the liver damage), it was nothing compared with the prejudice the Smith family faced. HIV was regarded as the “gay plague” and sufferers were demonised. “It was a bloody nightmare. Friends stopped coming to the house,” Colin says. “I got up to let the dog out one morning and there was AIDS written across the side of the house in six-foot letters. Another day there was a scratch across the bonnet of my car - AIDS DEAD scraped into the paintwork. Anonymous callers rang four or five times in the middle of the night, saying, ‘How can you have him in the house? He should be locked away somewhere safe where he can’t cause trouble.’” Few friends stood by them. “They didn’t know what to say to us, so they’d walk across the road.” The Smiths ended up moving away.

Colin had a tremendous zest for life. But the last months were torture, Jan says. In December 1989, they were told he was not going to get better. He was in hospital and the medical team were performing test after test on him. His parents did not understand what the point was if he was dying. They told the hospital they were taking him home to die but were refused permission by the head of the haemophilia department, Professor Arthur Bloom; he said haemophiliacs had to die in hospital. They ignored him and on 19 December 1989, Colin came home. He died a month later, at the age of seven, weighing 6kg (13lb).

“Towards the end we had to pick him up in two big sheepskins because if we picked him up in our hands it would hurt him so much,” Jan says.

▲ Jan Smith's tattoo of Colin's last drawing. Photograph: Francesca Jones/The Guardian

Bit by bit, over the past 28 years, Colin's parents have been piecing together the full story. Three years after his death they discovered he had hepatitis C as well as Aids. Documents have since been disclosed that show Professor Bloom, who died in 1992, had been fully aware all along of the risk of hepatitis from contaminated factor products. In January 1982, more than a year before Bloom treated Colin, he and his then boss at the Oxford haemophilia centre wrote to all the centres in the country, telling them new preparations of factor VIII were going to be processed through heat treatment, "to reduce the risk of transmitting hepatitis B and non-A non-B". (Seven years later, hepatitis non-A non-B became known as hepatitis C.) They explained that initial batches had been tested on chimpanzees but "it is unlikely the manufacturers will be able to guarantee this form of quality control for future batches… It is therefore very important to find out by studies in human beings to what extent the infectivity of the various concentrates has been reduced. The most clear-cut way of doing this is by administering those concentrates to patients requiring treatment who have not been previously exposed to large pool concentrates."

The acronym used was Pups - previously untreated patients. They were in effect being experimented on. A year after writing this letter, Bloom became director of the Cardiff haemophilia centre, where Colin was one of his pups.

Another document about the factor VIII concentrates was recently discovered in Colin's notes, written by Bloom in August 1983, shortly after he had started treating Colin. "All these materials carry the risk of hepatitis… but this is something haemophiliacs have to accept." His parents were never told of this risk. The more the Smiths discovered, the more outraged they became. One internal document revealed Colin had been given factor VIII concentrate after he had fallen and hit his head "without any evidence of intracranial bleeding".

"We then found out he had a treatment for a swollen finger," Jan says. "He had a bruise on his bum and they gave him a treatment." The Smiths believe Colin was a guinea pig; that he was often given factor VIII when he did not need it, simply to advance the study into the toxicity of the products.

Six years after Bloom wrote the initial note saying Colin's treatment carried a risk, the Smiths took him out of hospital to die at home. Bloom wrote to pharmaceutical companies saying that he was unable to provide more "samples" because Colin had been withdrawn from his facility.

The Smiths are distraught when they talk about it. Colin is purple with rage, Jan so upset she can barely speak. "We now know they used factor VIII on new patients to see if they would get infected," Colin says. "They weren't heat-treating it long enough. So for the sake of a couple of pence a unit they killed thousands of people in this country. We don't think the batch that killed Colin was heat-treated at all."

At the moment, the government insists on dealing with haemophiliacs and those who were infected by whole blood transfusions in a single inquiry. Many of those affected believe they should be scrutinised separately, as conflating the two will make it harder for both parties to achieve justice. But the main reason haemophiliacs demand a separate inquiry is that they believe they were deliberately targeted and experimented on without their consent. They were never told of the risks involved, so they couldn't make an informed decision: "A small community was targeted and betrayed. We were experimented on, then systematically abused by the government through silence about diagnoses, testing and monitoring," Steve Dymond says.

The Arthur Bloom haemophilia centre, which is part of the University Hospital of Wales, was named in honour of Bloom after he died. The Smiths are now trying to get his name removed from the centre. A spokesperson for Cardiff & Vale University Health Board said: "We have not been made aware of a petition to change the name, but would be very open to discussions with patients and their relatives about this issue."

▲ Colin Smith (second from left) with his older brothers

In 1991, a year after Colin died, the government made ex gratia payments to haemophiliacs infected with HIV, averaging £60,000 each. Stringent conditions were attached: everybody had to accept the deal for it to go through, victims could not take the government to court for any subsequent infections discovered and the government accepted no liability. It was not then public knowledge that the factor concentrates were contaminated with hepatitis C, though Department of Health officials knew.

"It was a one-off payment," Colin says. "A non-discretionary payment, they called it. We all had to sign a disclaimer or nobody would get anything. Men had died, wives were losing their homes and were desperate. We didn't want to do it, but we couldn't do that to them, so we signed. As it turns out it's illegal because they didn't give us the full information at the time." In 2004, a further payment of up to £45,000 was made to those infected with hepatitis C. Again the government accepted no liability.

Last year, Kenneth Clarke was forced to retract claims that victims of the contaminated blood scandal had been compensated. The word "compensation" was removed from his autobiography, Kind Of Blue, and replaced with "ex gratia payment". Like Gorman and Dymond, the Smiths believe the Department of Health knew the risks and ignored them because they were determined to treat haemophiliacs on the cheap.

For the Smiths, the forthcoming public inquiry is not so much about financial compensation but liability. What would justice look like?

"I would need them to admit they killed Colin," Jan says.

When asked to respond to the allegations made in this article, a government spokesperson said: "The infected blood scandal of the 1970s and 80s is an appalling tragedy which should simply never have happened, which is why this government committed to a full inquiry to ensure that victims and their families finally get the answers they have spent decades waiting for."

Kenneth Clarke told the Guardian: "The allegations made by the victims of the blood products tragedy are completely inaccurate. I was not the secretary of state for health at the relevant time. I was a junior minister, as minister for health, and blood products were not one of my responsibilities.

"In my opinion, victims have made attempts in recent years to bring me into their campaigns because I am the only person left who was at the Department of Health at the time and who is a minor celebrity still, so they could obtain more publicity for their complaints if they associated me with them. The two public inquiries that have been held so far have never seen the need to call me to give evidence because I have no close connection with the subject. I am of course waiting to see whether the new public inquiry that has been announced will wish to hear me, but I really do not think I will be able to tell them anything particularly relevant to the subject from my own first-hand experience."

n response to a freedom of information request, the Department of Health and Social Care revealed on 7 February that since the public inquiry into the scandal was

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announced in July 2017, 60 more victims have died in Britain.

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