

Commemorative & impact statement of Julia Hopper mother of Christopher Samson Nota (DOB: 30/12 /2000 - DOD: 08/ 07/2020)

My son Chris Nota must be dead because I am sat here.

And I still just can't accept it.

Thank you to my great friend Melanie Leahy who I found about five and a half years ago on social media when I was beginning to advocate on behalf of large numbers of children with additional needs as well as my own children in Southend on Sea.

In the town where I live - Southend - the majority of our disabled children were attending mainstream education with inadequate and inappropriate assessment or support. Over the years we have seen, for example, 8 year old children within this group, with suicidal ideation who can access nothing. It is my belief that this sets the scene for their suffering to escalate.

1. CHRIS

Chris was born on 30 December 2000 the eldest of 3 autistic boys all approximately 2 years apart and when he was a year old we moved from Chelmsford to Southend because it was once a great place for a child to grow up. Chris had classic autism and was assessed at Great Ormond St for this and an IQ of 58 which put him well within the threshold for Learning Disability. He later also developed epilepsy.

As a baby Chris was extremely demanding. He screamed a lot and I could never put him down without him screaming like a fire alarm. When he was small he would play Thomas The Tank Engine over and over again repeating the script. It was so comforting to him. It was how he learned to speak. There were so many things that he did not yet do, but he could sing. He could not hold a conversation with me but if I sang a song to him while he bathed and I stopped mid line, he could complete it in perfect pitch. His voice was heavenly. We would laugh together with such joy over that. He would later go on to say that music was his therapy. He mostly ate yellow food as a small child.

It was extremely challenging looking after him and ensuring that he was safe. I would have to be very, very organised, careful and safety conscious for he knew no fear. He had no patience and he was impulsive. He would climb out of a window on a hot day and serenely walk on a slanted conservatory roof or take off on one of his beloved scooters to explore the neighbourhood. I would have to chase and catch him. He would run into a busy road if his

hand were not held at all times. I knew that he loved me. We were very close because of his disability.

As a small child he would weep if I drove home from school taking a slightly different route or if the lamp posts along the street had missing bulbs. He looked for patterns and connections in a deeply confusing world.

When he was very little he would walk up to other children in the park and say “cashier number 3 please’ (a phrase that he had heard at the bank) because he had no idea what else to say in order to make their acquaintance. If he got carried away and lost for words he might bite them - but children never seemed to mind that.

Chris struggled to sleep so for the first 8 years of his life I went up to sleep beside him at 8pm every night holding his hand. It was nothing to ask of me since he so obviously deserved this. It also meant that I could be up and have a clear and focussed head from 6am and keep him safe and occupied. I very rarely left him. It would have disrupted his routine and upset him.

After 2 scary burglary attempts I sold our house when Chris was 10 and we moved into a large house with my parents and Chris’s two younger autistic siblings. We are mostly an autistic family. A very independent one. I had lost my own brother (also named Chris) when he too was 19. He had ended his life with his own hand unexpectedly. I now suspect that he was autistic too. My big brother’s loss was devastating. It made me feel very protective of the boys.

Chris was determined to attend mainstream school but he had to have a 1 to 1 helper with him to be able to cope and to manage his day. As he grew into his teens he would stop at the park on his way home and would sometimes return bruised. He would always refuse to say how it happened.

Sadly, one or 2 teachers at school and college also made it their mission to “sort him out” because he looked so normal physically that they didn’t believe that he was genuinely disabled.

In the evenings after school he was always exhausted. Sometimes he would lie on the pavement and people would ring me to ask if he needed an ambulance. I wanted to wrap him in cotton wool but he refused to let me.

Chris did not wish to look or feel different. He became increasingly skilled at masking who he really was and concealing his feelings. He often pretended to be someone he was not. All the while I think his anxiety and depression were building up inside.

I remember once driving him along the beach before school and chatting to him to reassure him about the world. As I drove, he nodded away. I remember feeling that we had made progress in our communication. As I pulled up I said something along the lines of “so do you agree?” He turned and looked at me and removed his earphones. He had been listening to music and nodding away to the beat. He had not heard a word.

Chris was slowly becoming able to be more independent relishing every part of that sense of freedom. Using the school bus and developing a great passion for walking. Being with friends at the park. We felt so totally blessed. We travelled and spoiled the boys. We never expected life to be easy. Our lives were good enough.

Very sadly, my late mother was diagnosed with advanced ovarian cancer in 2014 when Chris was almost 14. She fought against it for 2 years with our help. We all pulled together and our home remained a very happy place.

However her death (and that of my 2 aunts at roughly the same time also from cancer) was enough, combined with being bullied and dealing with school, to completely break Chris’s spirit overnight. He could not reconcile the brutality of it all, and it became too much for him to bear. Outwardly, he claimed to be absolutely fine but events were to prove otherwise.

In 2016 on a rainy Monday morning Chris left for school but never made it there. Instead, [Chris attempted to end his life] He hesitated and was saved by a heroic guard who took him to our GP opposite and I rushed to collect him and take him to A&E where he was briefly spoken to by a mental health nurse and released to me with a EWMHS (children’s mental health team) Mental Health Assessment with a psychiatrist organised for 2 weeks later. He was 16.

During that 2 week wait he developed a plan not to eat and to reach a target weight of 11lb. He began to cut his arms and legs. For reasons that are not clear EWMHS cancelled his psychiatrist assessment appointment by leaving an answerphone message. In desperation I went to our GP for help. None was forthcoming.

We provided scaffolding to his life as best we could thereafter with the help of the good friends that he made and loved. Time passed. He began to really improve. He had a short period of happiness at college but he'd been introduced to cannabis.

Chris became acutely psychotic and suicidal again in April 2020. I think a significant causative factor was the global pandemic which led to very restricted living conditions. We had all been told that we could not leave the home. This terrified Chris. He went missing and was found on [a] Bridge many miles from home. His life was saved but he was not sectioned. He was sent home in a taxi while in what was clearly a psychotic episode with no notice and immediately went missing again...From this time onwards Chris ricocheted in and out of hospital multiple suicide attempts both in and outside with a revolving door. It was absolute chaos.

My grandfather spent 4 years in a concentration camp. He never ever spoke of it. I now understand why. The mention of some things pollutes and toxifies the earth because it is so wrong and so ugly. I can't bring myself to deal with too much detail of what went wrong today. The time will come shortly when I will ensure that every single horrific issue is addressed.

What I knew was that our beautiful glorious boy desperately needed help and did not get it. He died on 8 July 2020 after falling from a height in Southend. He was under the care of Essex Mental Health Services and Southend City Council at the time because I had demanded he be in a place of safety having been discharged while still unwell. He was in their care because he was not safe at home and EPUT kept discharging him regardless. I was told that he would be safe. The coroner ruled that EPUT, South Essex ICB and Southend City Council had contributed to his death together. EPUT apologised in a letter. I have asked repeatedly but no apology has been forthcoming from the other 2.

2. IMPACT

When Chris died in public one of the most beautiful days of the year, people were going about their day and were forced to witness it. They have suffered beyond measure. I think of them always. My heart is with them. He would have hated the impact of this upon them. He was too ill to notice.

I am autistic and I sometimes struggle to show emotions. Most of my emotions are masked to spare others. It has become my way. So sometimes I appear unemotional. I may appear to be fine. But often this could not be further to the reality.

I've had to take Chris's death and place it in a sealed box mostly like I had to do with my brother. This is how we survive. If I were not to do this I would be paralysed. I am very aware of the need of those around me for stability. I don't get to indulge in screaming and collapsing. It serves no purpose and makes others fearful.

I have been devastated by the loss of my son and severely traumatised by the circumstances in which it took place. My suffering continues. I have terrible panic attacks if I have to go out even shopping and leave my children. It is something I do rarely.

I am now diabetic and have been diagnosed with PTSD. My blood pressure at one point became so high that I had to be admitted to hospital. I don't really sleep. I am so tormented that the only thing I feel I am fit for is supporting my community who understand me. That might take me to Westminster with a banner in the rain or to the cells of a police station to support a vulnerable young person suffering with untreated mental illness on Boxing Day or a comprehensive school where a mentally ill child is being treated as if he were a truant and his distraught mother wrongly threatened with a fine for his non-attendance. My hair comes out in clumps. It keeps me busy and stops me dwelling on what was and what should have been.

I try to speak generally and not to speak about my family. My boys. Because if I allow myself to feel anything I will hit the floor and never get up. I know that nobody has our back.

Perhaps my emotions are masked. Perhaps I have simply just become mostly totally numb because of what I have seen and in the knowledge that it still goes on and threatens many openly, including my own family.

Our home is on the market at a very reduced price and we wish to leave the UK quickly and forever. We do not feel safe. I can't leave soon enough. Nothing has been done to protect or reassure us.

Just after Chris's inquest ended in early 2023 the police contacted me to collect his effects from the day of his death. They refused to drop them to me at home, explaining that I was not feeling strong enough to attend the station to collect them. They coldly said they were busy. I had to force myself to go there and stand in a queue in reception whereby a transparent carrier bag containing my son's shoes, wallet and mobile phone I had not seen for 3 years were coldly tipped out onto the public reception desk in a busy room and I was asked to confirm them as being his. It took my breath away to see them again. They were so much a part of him. It was

deeply painful and dehumanising that nobody could see my need for dignity and privacy and a little empathy. There have been many such times at the hands of other local agencies since Chris died.

I can confirm that both of Chris's brothers, who showed great academic and sporting promise and achievement despite their own challenges and worked very hard, have not been in education since his death. After we lost Chris the two of them became unwell with one of them unable to access appropriate basic statutory support while the other was subject to virtually identical systemic negligence to that suffered by Chris. They are not remotely recovered.

We feel entirely instinctively unable to ever trust anyone. I have been forced to drag myself to court on my own bereaved and traumatised to fight the same agencies for other members of our family and "win" standing against their paid barristers for those rulings to be effectively ignored by them openly. The judge said that the case should never have had to come to court so why did it?

Somehow I have to attempt to live with the knowledge that, the majority of people paid to keep our incredible Chris along with so many others safe, knew that he was at great risk and did not act as they should have done.

In internal emails sent during that very short 11 week fight when Chris became unwell in 2020 and needed to be safe but was repeatedly discharged - clinicians wrote in their internal emails "No amount of expertise and/or intensive monitoring can safeguard someone who will act in this way without any trigger or warning."

'Plans have failed too many times in the last few weeks. Chris can't keep himself safe. We are not able to help him remain safe either.....God forbid we are going to the coroners court....'

'There were no contingency plans in place to meet Chris's needs in the community.'

The coroner concluded that I had "fought ferociously" for my son's life.

They had each other. Chris and I were alone. I was left to try to hold on to my son. I fought ferociously. I'm still fighting. My body is still full of adrenalin. Those who loved Chris Nota get no breaks. No closure.

I remember having to fly my 2 surviving children abroad to my elderly father since no support was offered to us in order for me to attend a 3 weeks inquest and leave them and travel 40 miles a day.

That inquest had to be adjourned because it came to light that thousands of pages of critical evidence had not been given to independent investigators by EPUT. I had to fly over there and tell my family that the inquest was adjourned for months and we had to try to have some kind of a Christmas with it all hanging over us. I remember going to the bathroom and vomiting blood then just washing it away as if it had not happened. I was so numb. I brought one of my sons back after the inquest and left one with dad. I miss him very badly. We will join him as soon as possible.

I have lost all faith, hope and trust in this broken nation. It would take the second coming of Christ now to convince me otherwise. What we need is a broad and uncompromising inquiry that encompasses every issue, every agency.

From all of the unitary local authorities in the geographical Essex area, the integrated commissioning boards, EPUT and NELFT, the friendly quangos that bolster them, Essex Police. The LGO and the PHSO. Ofsted. The CQC. NHS England. And more.....Potential frauds and the like need exploring. People like me are told that we are greedy in attempting to address these issues and wanting to establish basic safety. Told that money is limited. But is it? Or is someone diverting it before it gets to where the taxpayer in good faith wishes it to go?

This present system is rotten, poisonous, radioactive and corrupt, crude and medieval, toxic and hellish to its absolute stinking core.