



The following is a statement from Christopher's Family about the circumstances which led to their request for a Safeguarding Adults Review. The views and opinions expressed in this statement are those of the Family and do not necessarily reflect the view of the Bristol Safeguarding Adult Board. Some of the agencies involved dispute some of the statements made. Their views are reflected in the Safeguarding Adults Review report.

### Christopher's Family Contribution

The circumstances of Christopher's birth and his medical problems that followed have already been documented in the Safeguarding Adult Review, so we shall not repeat them here.

We are encouraged by the SAR report concurring with Christopher's father's submission in the second paragraph of his statement to the Inquest held in respect of Christopher where he says "I believe that there was a systemic failure by those charged with safeguarding Christopher. The SAR report concludes there was "systemic organisational neglect."

What does not come across in the SAR report is the lovely character that was Christopher. He was a loving, funny and life-loving young man who had many friends and acquaintances throughout his life. He was unable to read or write and was unable to make decisions for himself apart from very limited ones based on simple positive choices.

Thanks to the generosity of his wider family Christopher was quite widely travelled, having holidayed in Paris, the US, Jamaica, Spain, Center Parcs on three occasions and Lyme Regis every year for about twenty years. He spent the best part of a week at Claridge's Hotel in London for his 30<sup>th</sup> birthday which he enjoyed immensely.

Christopher's father was his main carer throughout the 30 years of his life prior to moving into supported living. He kept him healthy, well-groomed and happy for most of that time. Christopher could be awkward, stubborn and unhelpful at times but mostly not! And besides who can claim otherwise for their children? Christopher also had a great sense of fun and humour. Christopher attended boarding school for 10 years, 1990-2000 - boarding 4 nights/week, home for 3 nights/week, and home for the holidays and for medical appointments which were in Bristol. Overall during the boarding school years Christopher spent most of his time at home (boarding school holidays are notoriously long!). Christopher also had regular contact through SKYPE with his mother who was based in the USA, his sister and wider family. Christopher loved these contacts with his family and would talk about them for long periods before and after the events.

Christopher and his father were very close, joined at the hip some would say! It was always necessary to maintain a very close dialogue with Christopher to monitor his well-being. We believe the supported living provider did not understand this need, and never understood his serious medical needs. In our view some staff could come across as arrogant. We felt that they considered they knew best and said that they were quite capable of managing Christopher and his needs. In

our opinion this plus miscommunication between the different professionals involved regarding medication and behavioral problems was an accident waiting to happen.

The report very clearly describes the failure to involve family members in meetings and the failure of agencies to pass on information and decisions relating to Christopher. These failures also included not keeping other professionals fully informed.

There are various mentions in the report to Christopher stating that he did not want as much contact with his family. Christopher's mother (who spoke with him on Skype, usually at least twice a week at supported living, and who sat with him in the hospital every day during many of his admissions, including the last one) and his father, never heard Christopher mention anything of the kind and indeed were greeted with open arms by Christopher on arrival at his bedside. His father sat with him every day during every one of his hospital admissions. His wider family are also keen to stress that Christopher loved family contact and really enjoyed big family get-togethers.

Christopher could be quoted saying anything simply by the way the question was put to him. This false understanding that Christopher could make decisions on his own behalf was another failing by involved professionals where again family views were ignored. This led to the almost grotesque series of events where the supported living provider listed 74 occasions when Christopher refused to take his food or medications in the last few months at his placement. He was unable to understand the long-term implications of his decisions and was indeed only ever able to process or analyse very simple information or choices put to him.

The whole process of placement with the supported living provider did not start well. Christopher had had a social worker prior to discussions about moving on. This was for day-service re-assessment as his day-centre was extending to include dementia sufferers. We were then refused a social worker for the move from the family home to the supported living provider. We were refused a nursing care home by the local authority and we were referred to only one facility - the supported living provider.

The SAR report says that respite stays could not describe to Christopher the reality of moving from the family home. We would argue that respite stays, especially the 6 weeks stay where the staff were professionally qualified, following Christopher's father's surgery was the best indicator available as the reality of moving from the family home could only be achieved by doing just that!

Throughout the year of placement no one individual took charge of coordinating the professionals or family and providing a keyworker role. Professionals from many agencies were involved, allegedly assessing Christopher's needs and yet nobody was prepared to lead, make decisions and take appropriate action which could have prevented his death. In fact, in our view it can be said with certainty that there was a withholding of information to Christopher's detriment, especially in regard to the planned hospital admission in November 2015 which we believe could have saved his life. At the same time the family were marginalized by the supported living provider and other agencies involved, told he was now not in our care and blamed for "interfering". Neither was advice sought from those other agencies, especially the respite care facility that had cared for Christopher superbly for many years. We believe that this was negligent with professional arrogance as a contributory factor.

With hindsight, and increasingly throughout the year that Christopher was with the supported living provider, it was clear to us that the staff and management were not sufficiently trained or

qualified to deal with Christopher's needs, medical or social. In our opinion it is also clear that the social work support both in respect of Christopher's placement worker and her management supervision were grossly inadequate, wrongly placing him at the supported living provider and offering no alternative whilst a move would still have been possible. Every agency that was involved with the care of Christopher must accept responsibility for their failings and the SAR report makes this clear.

As his condition worsened, his move to the hospital was seen by family as the best possible outcome that would most probably save Christopher. This was not to be the case, the hospital did very little, except promise us that they would undertake more pro-active measures that evening/the next morning, the next day. This was on a daily basis and nothing happened for 9 days. Once again despite Christopher's inability to make decisions far too much weight was given to his ability to self-determine. We observed that medications were left by staff on his table for him to take – or not as was the case. At the inquest, the hospital doctor repeatedly used “re-feeding syndrome” as an excuse for inactivity, and yet menu cards (which he couldn't read) were issued to Christopher by hospital staff 3 times a day, for him to choose his meals (which he could not do and did not eat in any case).

Christopher's mother is also extremely concerned at the lack of weight and understanding given to her concerns regarding the care and attention Christopher received and her observations to medical professionals about, for instance, other patients taking his food which when reported was greeted with disdain. The family also believe there was a catastrophic failure in hospital records and recording whereby the very difficult decision to DNR which had been painfully taken by the family on medical advice failed for more than a week to appear on the bedside notes. When Christopher died in the hospital on 22nd December, his mother was present and had to scream at the doctors who attempted to resuscitate him 3 times before following instructions from his mother. This is a totally unacceptable failure and one which is having a lasting and distressing impact on family members.

Our sole aim with the report and this contribution is that in future the professionals involved and those involved in similar cases execute their duties based on the individuals needs and to listen more closely to those people equipped with what the Mental Capacity Act describes as “expertise of experience” and thus hopefully prevent this terrible but avoidable outcome from re-occurring.

We would add that as a family we do feel that other families with less financial or social resources may not fare so well in this process. We had the benefits of a barrister to challenge professional accounts at the inquest and the transcript of that inquest which enabled our views to be vindicated.

Perhaps the Safeguarding Board should give thought to this and how they might provide similar support to families who suffer a bereavement of a family member in the care of the local authority.

Christopher's family  
March 2018