House of Commons: Justice Committee inquiry
The Coroner Service: follow-up

Submission of Dorit Young

Introduction

My daughter Gaia Young died shortly after admission to hospital of an unexplained brain condition. Her death was the subject of an inquest. This took place on 14 February 2022. Information including medical records, hospital investigation reports, and inquest papers are published on the website:

> www.truthforgaia.com

The Committee asks:

> "What progress has been made towards the goal of placing bereaved families at the heart of the Coroner Service."

My experience of the inquest was the opposite. It was wholly unsatisfactory. This is my story.

Facts

1. On 17 July 2021 previously well Gaia (born 4 March 1996) aged 25 was admitted to hospital. Her symptoms included headache, vomiting, and behaving and speaking strangely. This suggested raised intracranial pressure due to an unexplained brain condition, a possible encephalopathy. She was assessed. The examination did not include fundoscopy. The tests did not include blood ammonia.

2. On 18 July 2021 her condition suddenly and catastrophically deteriorated neurologically. Her brain was pushed through the hole at the base of the skull because of raised intracranial pressure ("coning"). There was no prospect of recovery; she was brain dead.

3. Gaia was a registered organ donor. When Gaia was still alive the coroner indicated "no heart donation"; her liver and kidneys were retrieved. Gaia had no history of heart disease, whether personal or family. Her death did not suggest a cardiac cause. The post-mortem report did not identify heart disease. The inquest evidence and findings did not refer to heart disease. Gaia's heart was cremated with her body. The coroner has refused to explain why her healthy heart was not retrieved for donation.

4. The Trust prepared its investigation report (dated 9 December 2021; updated 7 February 2022). It was superficial and unsatisfactory. It did not construct any differential diagnosis; it did not consider any primary encephalopathy. It was much concerned with low blood sodium.

5. On 13 December 2021, I wrote to the court with submissions based on my overview of the evidence and with proposals as to the direction, scope, and evidence. There was a differential diagnosis; I suggested that Gaia died of metabolic encephalopathy, and that there should be an independent neurologist expert in court. I considered the low blood sodium was incidental rather than causal.

6. On 10 January 2022 I was advised by the court that Gaia's file "had been reviewed". I had not been invited to participate in the review, and my submissions to the court were disregarded without reason. This does not comply with The Coroners (Inquests) Rules 2013, and the Chief Coroner's Guidance number 22.

7. On 28 January 2022 the court held a pre-inquest review. The directions order included the following:

   > "[The Trust] will ensure the attendance at the inquest of such medical witness or witnesses to give oral evidence as are best able to assist HMC with the likely cause of the deceased's cerebral oedema and thus her death." (paragraph 9)

8. The court again disregarded my submission dated 13 December 2021. It did not provide reasons for doing so.

9. On 11 February 2022 late afternoon I received from the Trust's solicitors a copy of a letter dated 9 February 2022 from the neurologist involved in Gaia's care as documentary evidence for the inquest - less than one working day before the hearing. The neurologist's statement did not contain any differential diagnosis of Gaia's illness or attempt to explore the aetiology.

10. Gaia died of an unexplained brain condition and there were issues concerning her clinical care. The inquest hearing took place on 14 February 2022. There was no neurologist in court. There was no independent clinician in court. My questions on fundoscopy and coning due to raised intracranial pressure could not be answered properly because there was no neurologist in court. The witness from the Trust "best able to assist HMC" was unable to answer many of my questions. There was no exploration of metabolic encephalopathy or raised blood ammonia by the court. Instead, the court was much concerned with low blood sodium.

11. The court again disregarded my submission dated 13 December 2021.

12. The inquest was emotionally draining and concerned complex medical issues. There was a 10-minute lunch break (this was with my agreement). The inquest lasted under one day.

13. The court returned a narrative conclusion. The cause of death was "unclear".

14. After the inquest I received a letter dated 7 March 2022 from a senior physician at the Trust. He stated:

> "…a metabolic diseases specialist at the [Trust]… did suggest that a rare metabolic condition called ornithine transcarbamylase (OTC) deficiency could have been a cause of the symptoms seen in Gaia…"

Such expert evidence had always been accessible to the Trust but was not made available to the court. This did not accord with the court order. The Trust includes the nation's leading specialist neurological hospital.

15. I have researched OTC deficiency. I believe Gaia died from catastrophic raised intracranial pressure due to fulminant high blood ammonia crisis, a form of metabolic encephalopathy: (1) Gaia's case conforms with published case reports; (2) the evidence is consistent with this diagnosis; (3) there is no evidence which refutes this diagnosis; (4) there is no plausible alternative diagnosis. OTC deficiency provides a complete, coherent, clear, robust explanation for her death.

16. The Trust has agreed to instruct (at its expense) jointly with me expert reports in the following disciplines: neuroradiology, neuro-ophthalmology, neurology, neuro-intensivist.

17. The coroner opposed my publication of the approved transcript of the inquest, suggesting that it represented contempt of court. The coroner did not provide any appropriate legal authority. The coroner erroneously conflated publication of the recording with publication of a transcript of the recording. The Chief Coroner has confirmed that there is no "general prohibition" against publication of an approved transcript. It accords with the well-established principle of open justice.

18. The Trust opposed my publication of Gaia's medical records.

19. I have been in correspondence with the Attorney General. The Attorney General by letter dated 6 October 2023 has stated:

    > "The circumstances you have described… may amount to a reason to seek a fresh inquest."

20. I am willing to provide any materials on request. I am willing to attend to give oral evidence to the Committee,

<u>Comment and conclusion</u>

My experience of the inquest was unsatisfactory. It was uninformed and uninformative: a waste of time and money.

The non-retrieval of Gaia's healthy heart for donation (without the coroner's explanation) has added to my sense of loss.

The court did not act in accordance with the legislation. There was material procedural irregularity. The first pre-inquest review did not comply with the statutory scheme.

The court repeatedly disregarded without adequate explanation my submissions proposing the scope, direction, and evidence for its inquiry. The scope of the evidence was decided by the

Trust. Was this fair and in accordance with natural justice? Why accept the Trust's evidence but not my proposals for independent expert neurological evidence in court?

The provision by the Trust of an important (neurologist) statement less that one working day before the inquest hearing was unacceptable. It showed disrespect for the court, for Gaia, and for her relatives. Did the court comment on this discourteous conduct?

There was insufficient inquiry. The evidence before the court was not capable of addressing the issue of how Gaia died: the aetiology of her fatal illness. Such evidence was always available to the Trust but was not provided to the court by the Trust.

The court's inquiry was based mainly on the Trust's evidence, particularly its superficial, unsatisfactory investigation report. It was rambling and muddled. It was preoccupied with low blood sodium and did not consider any primary encephalopathy. The clinical reasoning was unsound, the diagnostic analysis was chaotic: the causal and the incidental were conflated. My submission proposed an inquiry that was informed, focused, and proportionate.

The time management of the inquest was not appropriate: less than one day with a 10-minute lunch break for medically complex death. It was my first attendance at an inquest. Was it reasonable for the coroner to suggest a 10-minute break to a traumatised, bereaved mother?

The Trust has agreed to fund independent expert reports under joint instruction (thereby impliedly accepting its investigation was deficient). Why were such expert reports not provided to the inquest in the first place in accordance with the court order?

I do not understand the coroner's and the Trust's opposition to my publication of papers relating to Gaia to promote patient safety. It is contrary to transparency and accountability.

The NHS cannot be trusted to investigate itself. The inquest provides an opportunity for independent clinical scrutiny. In Gaia's case there were concerns about medical care but there were no independent clinician expert witnesses.

I was in no way placed "at the heart of the Coroner Service"; my experience was the very opposite. It has added to the pain of my grief.

Dorit Young
12 December 2023

Gaia Young

Born 4 March 1996 Died 21 July 2021