

Lesley from Lancashire had “No paediatrician ever contacted us even though my husband is a GP and knew them all.”

“There were some aspects that were dealt with sensitively and very well after Jessica died. My GP was very good – he stayed with me for hours and did not rush me at all. In other ways I felt ignored by the professionals. No paediatrician ever contacted us even though my husband is a GP and knew them all. No-one ever explained the results of Jessica’s post mortem to me. One time I was in the supermarket with my husband Mike. The pathologist who examined Jessica said ‘hello’ to him and ignored me. This hurt a lot. I would have done anything for Jessica to have been examined by a paediatric pathologist. I feel cheated that she only had a twenty minute post mortem. This wasn’t enough and I do not feel that every stone was turned to find the cause of her death. If a child is in hospital with a broken arm, you don’t expect them to be seen by an obstetrician.

Even if the post mortem examination didn’t show why Jessica died it might help with a future understanding of why apparently health babies go on to die suddenly and unexpectedly, it might help with research in the future. This might help provide some insurance for the future with my children and the next generations.”

Susan from Kent “I felt ignored and abandoned. No-one like my health visitor or GP visited me.”

“When Edward died, aged only 10 weeks, I was devastated and confused. I couldn’t understand why he died. We were rushed to A&E and the staff there were fantastic, really supportive. However in the awful days and weeks that followed, I felt ignored and abandoned. “No-one like my health visitor or GP visited me. No-one asked how I was doing. I started to fall into depression. I went to my GP regularly with my symptoms. Less than five months after Edward’s death my doctor told me to “pull myself together and get over it”. My reply, when I walked out of the office crying, was “you haven’t a clue”.”

“On Edward’s death certificate it said broncho pneumonia but doctors seemed to be saying he died as a cot death. What did this mean? Why did my baby die? No-one properly explained the post-mortem findings to me and it was only when I approached a doctor at one of FSID’s conferences that I got the answers I had been needing for months. I was told that there was evidence of broncho pneumonia but this was not enough to kill Edward and really he died as a cot death.

“This is really confusing and unfair. Different pathologists work to different standards. What I want to see is a clear way of working for all professionals so that all bereaved parents and their babies get treated equally.”

Anonymous: “FSIDs suggested guidelines for professionals involved with a SIDS death would have made our experience of losing our daughter quite a different one.

Our daughter, our only child, was only three weeks old when she stopped breathing one night. We awoke to find her cold. The emergency services tried to instruct us over the phone on resuscitation but it was clear she was already dead. We are both grateful that the ambulance staff, when they arrived, gave my husband an opportunity to try to resuscitate her himself under their instruction.

Although the ambulance staff and team at A+E were sensitive, there were a number of things I would have preferred to be done differently. I was given the opportunity to hold her for a short time in the corner of the A+E ward, and would have preferred more time with her. There wasn’t any opportunity for my husband and I to sit together with her in a private place. I really wanted to sing to her and found myself doing this quietly and hurriedly under my breath in a public place. We were then told that we should call some friends or family when we got home, and the next thing I knew (less than two hours after we had woken up) we were outside the hospital

and walking home without our daughter.

We had no idea the police would come round until they arrived an hour after we got home. We were obliged to re-enter our bedroom in which she had died, which I was not keen to do so soon after her death. No clear explanation was ever given as to why my pyjamas, bedding and baby’s blanket were “arrested” and removed for tests. It would have been extremely helpful to have been told at the hospital what we should expect over the next few days – police visit, negotiating funeral dates with the coroner etc. We were allowed to go back to view our baby’s body in the evening but nobody had warned us that she would be looking blue and strangely bruised at this time.

From the moment we left the hospital, we seemed to fall off the healthcare radar. I was breastfeeding when our baby died, and found myself in considerable pain as the hours went by after her death. I called my GP for advice, and of course she was shocked to find out what had happened. I also called the midwife for advice, and she informed the hospital at which our daughter had been born. At no point did any healthcare professional take any information on the baby’s health prior to death, or our family history. At no time did the hospital to which she had been taken when she died call any of my healthcare professionals - my GP or consultant obstetrician. It would have been invaluable to give a case history to a paediatrician, because it would have given us a sense of doing something, of someone - anyone - being concerned about what had happened.

Our daughter died at the end of October 2000. In mid-January 2001, on a bright sunny Saturday morning, when I was feeling cheerful for the first time that winter, we received a plain envelope in the post which contained our daughter’s post-mortem report. There was a compliment slip attached. I don’t know how many people have read the clinical report of the dissection of their child, but take it from me it is immensely distressing. I read it carefully, desperate to find an explanation for her death. Cause of death was recorded as para-influenza 3. I rang the FSID helpline and it was only when I spoke to somebody there who was shocked that we had received the post-mortem in this way that I realised it was not common practice. I rang the person detailed on the compliment slip and was told you shouldn’t have got a copy. I asked why we had been sent it and was told by the woman on the end of the phone that she didn’t know, she had been away for Christmas etc. This event triggered a bad bout of depression.

Worse was to come. Ours was the only copy of the post-mortem that had ever been sent out. The paediatric department of the hospital never received one, nor did my GP. It took three further months of phone calls to find a paediatrician who would go through the post-mortem report with us. A colleague of the obstetrician who had overseen our baby’s birth agreed to talk to us. Several months later - five months after her death - I received a letter from the hospital to which she had been taken when she died extending condolences. I spoke to the consultant paediatrician there who agreed to meet me, and he informed me that the coroner’s office had consistently refused to give him a copy of the post-mortem, even on the day of our meeting. Mine remains the only copy ever released.

It seems a shame that the coroner saw the purpose of the post-mortem as simply a police investigation into mode of death - presumably to establish there was no foul play. The information was not made available for any kind of medical examination of the death, or to enable health professionals to answer our questions about our daughter’s death. I am still unclear whether my baby died of infection, or whether her extremely small adrenal glands (which the post-mortem revealed but did not note clearly) had an effect on this. Both my GP and the hospital made a complaint to the coroner’s officer, but to this day I have never had an apology nor found out if the matter was ever looked into in order to avoid such a mistake being repeated. I cannot overemphasise how much this action delayed our emotional recovery.”