



Investigation of Sudden and Unexpected Infant Deaths

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Every year in England and Wales...


- **Around 600 babies die suddenly and unexpectedly in the first year of life**
- **In Lancashire and greater Manchester we see around 90-100 each year**

We have become increasing aware...

- **That we simply cannot distinguish deaths due to some natural cause from those due to asphyxia – the asphyxia can be accidental or in some cases deliberate**
- **We get occasional cases in which a parent confesses to deliberately smothering the child and we know that without the confession we really would not identify these cases**

So for the past 8 years

- We have in this region stopped using the term “SIDS” because this implies a natural disease
- We now use the term “unascertained” for the cause of death and use the term “Sudden Unexpected Death in Infancy” or **SUDI** to describe the typical presentation



Because we give “Unascertained” as the cause of death

- **It means that there will be an inquest**
- **This is because in order to do any investigations such as histology, microbiology, metabolic studies, toxicology the Coroner must open an inquest – this is the Law**



At the Inquest...

- **The Coroner takes evidence from the pathologist(s) and sometimes other clinicians**
- **He/she then gives a decision as to whether the death is natural or not on the balance of probabilities**



The Kennedy Report

- **Published in 2004**
- **Was set up following the release from prison of Sally Clark in Jan 2003**
- **She was convicted of killing her two infant sons who it was claimed had died suddenly and unexpectedly**



The Kennedy Report

- **Suggested a multi-agency approach to the investigation of SUDI**
- **It is suggested that all personnel dealing with the death should have some specialised experience**

It is suggested...

- **That the baby is taken immediately into A&E department**
- **It is suggested that some specimens are taken immediately from the body**



Initially

- **There should be a strategy for investigation decided between the paediatric department and the police**
- **As soon as possible the parental home should be visited**
- **A key part of the Kennedy Report is the instigation of a specialised paediatrician who will visit the parental home in the first 24 hours following the death and investigate such matters as sleeping arrangements**

The paediatrician then...

- **Complies a report for the Coroner and the pathologist**
- **The Coroner orders the post mortem examination usually to take place within 2-3 days of death**
- **This will usually be carried out by a pathologist with a special interest in paediatric examinations, sometimes with a forensic pathologist – who is an expert in injury**

Unless there is an obvious cause...

- **The pathologist(s) must give the cause of death as “Unexplained” or “Unascertained” at this stage**
- **The Coroner will then open an inquest following which the funeral can usually be held (not if any injuries have been found)**

The Post mortem report is confidential until the inquest

- **It must not be disclosed to a third party without Coronial consent (that includes the paediatrician! – however in most cases this is a formality only**
- **As soon as possible it is recommended that the paediatrician goes through the post mortem findings with the family**

The Kennedy report...

- **Recommends that all professionals involved meet 2-3 months after the death (GP, Paediatrician, police, social workers etc) and discuss their findings. The report generated by this meeting should then be made available to the Coroner before the inquest**
- **The paediatrician should also write a detailed letter to the parents explaining all the findings of this report and offer to meet them**

At the inquest...

- **At the inquest (held when all statements and results are available) the Coroner decides the Cause of death and the death certificate is issued**
- **The inquest is public – the press are usually there – (there may issues of interest to the public involved). The Kennedy report recommends that it is held in private if at all possible**

The Kennedy Report ...

- **Recommends that two terms should be used ...**
 - **SIDS** – for those cases that fulfil the criteria exactly
 - **SUDI** for other deaths where there are no post mortem findings and where the police are not conducting an investigation

SIDS - definition

- **An infant dying suddenly and unexpectedly between the age of one month and one year (sometimes two years) in whom no cause of death is found at post mortem and where the clinical circumstances are typical. Usually this means an infant found dead in the cot, often in the morning**



So what is different about the Kennedy protocol?

- **The SUDI paediatrician – this person has a key role in the investigation and the various meetings that are suggested**
- **The multi-agency meetings**

What investigations are suggested? First in A&E

- **Blood gases**
- **Urea and electrolytes**
- **Blood sugar**
- **Blood cultures**
- **Blood and urine samples for metabolic investigations**
- **CSF for culture – also for metabolic investigations**
- **In some cases skin for fibroblast culture and muscle biopsy**
- ***Note the Coroner must give consent for these***

The post mortem

- **The pathologist(s) should have access to the all the information collected by police and SUDI paediatrician including photographs and videos of the scene**

Before starting the PM

- **We get a full skeletal survey. This should be carried out by a department used to doing it and reported by a paediatric radiologist prior to us starting the examination**

We then do a full post mortem

- **That is we look at the body externally, we look at the thoracic, abdominal and cranial cavities**
- **If we find a cause of death – then we can take no further investigations**
- **But in SUDI deaths it is very unlikely that there will be an obvious cause of death on naked eye examination**

Post mortem investigations

- **Any not taken in A&E**
- **Bacteriology**
- **Virology**
- **Metabolic studies –**
 - **Urine,**
 - **blood, bile (for acyl carnitines)**
 - **Frozen tissues (liver, kidney, myocardium, muscle stained with ORO)**
- **Toxicology**

How often do we find something?

- **Well – quite often as far as histology is concerned – in about 10-20% of our cases each year we find that there is evidence that the child had a chest infection at the time of death**
- **This is by far our most common finding**



In the remaining 80-90%...

- **There are usually no positive findings at post mortem**

What about metabolic disease?

- **Well our experience is that there are not a great many cases presenting as sudden unexpected infant death in this group**
- **Over the past 10 years we have only seen 2 such infants and – really- these were not in any sense typical SUDI deaths**

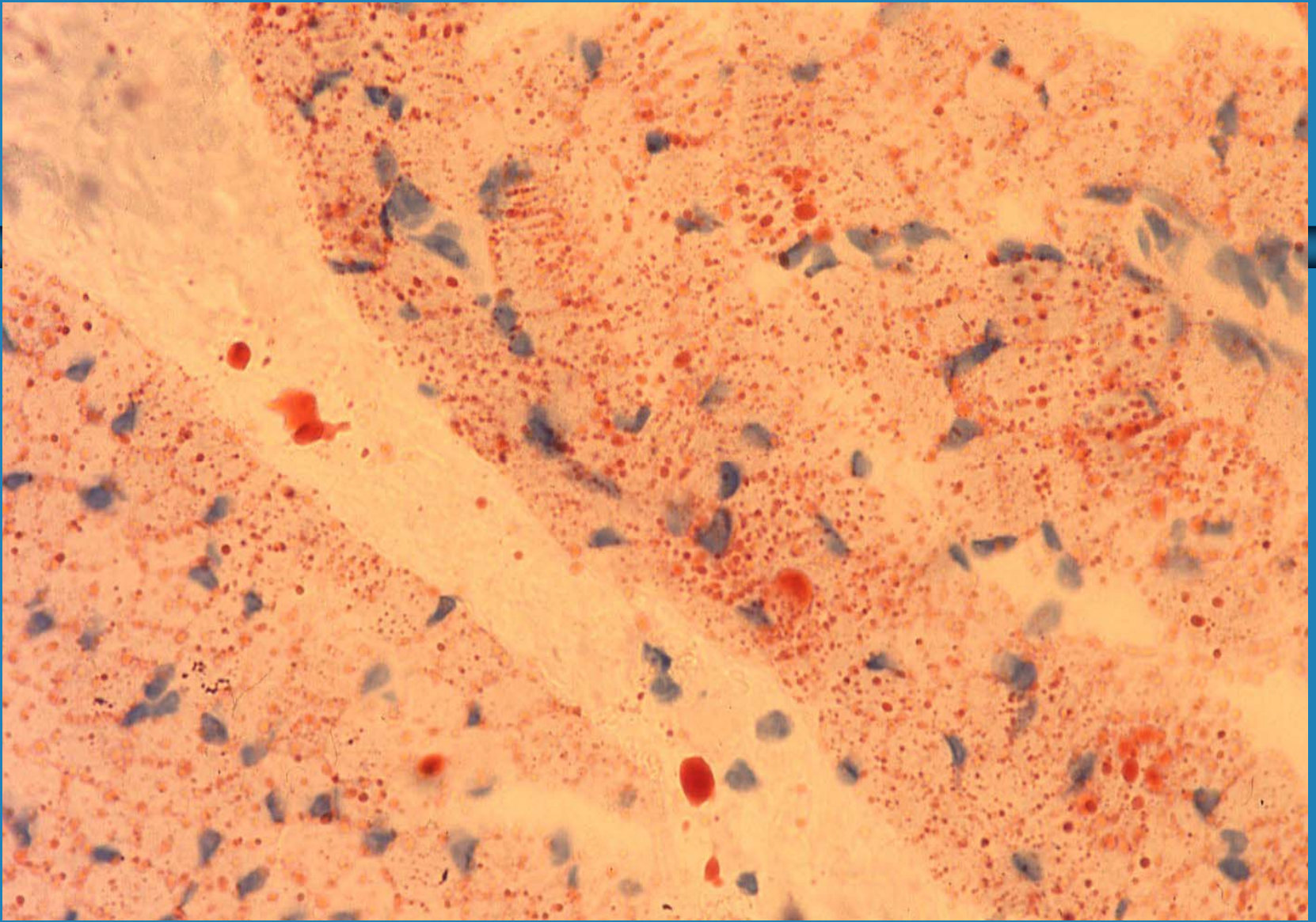


Case1

- **3 month infant found dead in his cot in the afternoon – but in actual fact he had a long history of illness and failure to thrive**
- **Parents first cousins**
- **History of two previous infant deaths – Reye's syndrome diagnosed in both cases**
- **Skeletal survey normal**

Case 1

- **At post mortem – cardiomegaly, hepatomegaly**
- **Frozen sections stained for microscopic fat showed lipid in liver – kidney – myocardium-muscle. All very suggestive of fatty acid oxidation defect**
- **In fact DNA studies later one LCHAD gene showed common mutation.**



Case 2

- **20 month female**
- **Died suddenly – but in fact had been taken to local A&E on several occasions with vague illness (vomiting, lethargy, odd breathing)– especially in week prior to death**
- **Urine sample showed features in keeping with methylmalonic acidaemia**

So my experience is that...

- **Basically deaths due to metabolic causes do not really present like SUDI**
- **It is of course possible that there are metabolic disease that we do not yet recognise – or is it?**

So what do I think?

- **It is becoming increasingly clear that SUDI is essentially a condition that is strongly associated with poor socio-economic conditions**
- **From 1988 onwards the “back to sleep” campaign has been associated with a decrease in the number of infants dying suddenly and unexpectedly**
- **This has led to a particularly marked decrease in such deaths in middle class households**

What factors are associated with SUDI?

- **Several studies in different countries have revealed an association with poverty (Eg unwaged households)**
- **There is also an association with parental smoking**
- **Co-sleeping**

Co-sleeping

- **Up to two thirds of cases in England and Wales are now associated with infants sleeping in the same bed, chair or sofa as a parent**
- **In some of these the position in which the child is found does seem to suggest that asphyxia must be the cause (illustrating how important the history and scene investigations are)**
- **It is possible that they are all caused by asphyxia – but we just do not know**

Co-sleeping

- **There seems to be a clearly increased risk of infant death where A SOFA OR CHAIR IS INVOLVED**
- **But in the case of a conventional double bed it is more complicated Eg the risk is most marked where the parent smokes -**



Co-sleeping

- **There is some controversy about this**
- **The medical anthropologists often suggest that co-sleeping is natural for the human and has evolved over the past 5 million years**

Co-sleeping

- **However – it has to be admitted that for most of that 5 million years (up to – say- 15 years ago) the infant mortality was rather higher than might be considered acceptable in our society.**



Co-sleeping

- **I think the general point made by the anthropologists is that it would be helpful to try to define the factors in co-sleeping that make it dangerous rather than simply regard it as inappropriate – they often point out that it has beneficial effects also – such as the promotion of breast feeding**

Whatever the role played by co-sleeping

- **I think it is clear that environmental factors play a major role in SUDI**
- **The number of two SUDIs in a family is quite low – and I think that it is unlikely that more than a few cases actually have metabolic causes even in those cases with more than one death**

However ...

- **SUDI is essentially a diagnosis of exclusion so we can only really make it if we have excluded as many causes of sudden death as we are able to**
- **So we have to go on doing all the tests**



Case 3

A case of “out of hospital cardiac arrest”



6 week old boy

- **FTND, 9lb at birth, 2 older siblings**
- **Mother had been a methadone user in the past**
- **Terminal events commenced on evening of 5th April 2003, when mother went out leaving baby in care of father**

6 week old boy

- **Bottle fed at midnight**
- **0300hrs – put to sleep on sofa with father**
- **0630hrs – mother returned from her evening out and noted baby and father both asleep**
- **0640hrs – baby seemed to be breathing oddly – mother called ambulance – arrived promptly – baby in state of cardiac arrest on arrival**

6 week old boy

- **Taken to local A&E – intubated, ventilated**
- **Had CT scan showing diffuse cerebral oedema**
- **Transferred to RMCH PICU during the late morning**
- **Developed seizures**
- **Died 09 04 03 when MRI scan showed severe cerebral oedema with uncal herniation and coning. Developed intractable bradycardia**
- **No retinal haemorrhages seen during life**

Investigations during terminal illness

- **Admission blood culture – coagulase negative Staphylococcus**
- **Toxicology – urine positive for therapeutic drugs only**
- **DNA - negative for major LCHAD, MCAD mutations**
- **Normal acyl carnitines, ammonia, biotinidase**
- **ECG – some abnormalities in keeping with ischaemia but none that permit diagnosis of long QT syndrome**

It is important...

- **That relevant investigations be done prior to death in the situation of out of hospital cardiac arrest since it is likely to be too late to do toxicology, microbiology etc at post mortem**
- **Is there some way to ensure that blood, urine etc is taken as soon as possible after admission in this situation for toxicology?**



Post mortem examination

- **Normally grown, normally formed boy**
- **No external injuries**
- **Marks of medical intervention present**
- **No congenital abnormalities**



Skeletal survey

- **Multiple Lesions on posterior aspect of ribs that seemed like fractures**
- **No other abnormalities identified**



Neuropathology

- **Severe hypoxic ischaemic encephalopathy. NO subdural haemorrhages**
- **Spinal cord – no trauma**
- **Eye histology – multiple retinal haemorrhages – but the significance of this is in doubt since these were not identified on clinical examination shortly after admission**

Bone pathology...

- **Lesions involving ribs not confirmed to be fractures on histology**
- **Bone pathologist is not sure what they are – but could, in any case, date from birth**

Other investigations ...

- **Post mortem histology – no haemosiderin laden macrophages in lung – focal bronchopneumonia – but this may be terminal**
- **No other histological features of note**
- **No viruses or bacteria isolated from CSF – PCR negative**
- **No lipid in frozen sections of tissues**

So we have...

- **A case of out of hospital collapse in an infant sleeping on a sofa with his father**
- **At post mortem signs of brain hypoxia**
- **No definite evidence of trauma – at least none that can be identified as definitely post birth**
- **No natural disease that might have led to the collapse identified**

“Near miss” SIDS

- **We definitely do not use this term now for the cases of out of hospital cardiac arrest**
- **In some we find a definite natural cause but often we don't when the collapse occurs suddenly without a prodromal illness**
- **We then use the term “unascertained”**



Case 4



Case 4

- **Mother aged 16 years, drug abuser, unemployed, unsupported**
- **Slept with child on the settee and, in the morning found that the baby was lifeless**
- **Post mortem carried out by forensic and paediatric pathologist**



Case 4

- **Baby was clean, well nourished**
- **X-ray was normal – no injuries**
- **No injuries at post mortem**
- **No congenital abnormalities**
- **No evidence of infection**
- **No evidence of metabolic abnormality**
- **Essentially negative post mortem**



Case 4

- **So “unascertained” given as cause of death at Inquest**



Case 5

Case 5

- **Female infant aged 18 weeks. Body weight only 2Kg.**
- **Mother aged 17 years – drug abuser – also has 30 month old.**
- **Called an ambulance to say that she found her baby dead in her cot at 1630hrs. Last checked child at midnight previous night.**



Case 5

- **We found that baby had multiple rib fractures and long bone fractures**
- **There were multiple other injuries – bruises, burns**
- **Actually died of bronchopneumonia**
- **Toxicology – no abnormal substances**



We were in no doubt...

- **That the cause of death here was not wholly natural**
- **The baby had been abused and neglected**



Case 5

- **There was a criminal case**
- **Father pleaded guilty to manslaughter, mother to neglect.**