NCMD
National Child Mortality Database

Frequently asked questions about our SUDIC report

What can we do to strengthen the impact and quality of the Health Visiting offer and the safe sleep advice?

Give health visitors both training and time with families. The safer sleep advice should be personalised to the family's circumstances, and this means that health visitors need time to get to know each family and baby. Having constructive conversations is a really important part of this. **The Lullaby Trust** offers **training for professionals** which covers the safer sleep advice but also how to have opportunistic conversations with families. It is important for health visitors to ask to see the baby's usual sleep environment when they visit the home and that they ask the family how things might be different if they have visitors to their home or if they are visiting others so they can plan alternative safe arrangements before such events occur.

Do we need to look at basic standards for habitable homes?

Yes. We know the specific situations that babies need to sleep in to greatly reduce the possibility that they might die suddenly and unexpectedly, and housing should be able to meet these standards. This is in the recommendations of the NCMD report.

Any further research on the febrile convulsions issues and what we should be doing locally to protect children impacted by them?

There is research taking place in the US to further understand the characteristics of febrile seizures and their association with SUDC (contact **nikki@sudc.org.uk** for more info), but nothing currently underway in the UK. We hope this will change now the association has been highlighted in the NCMD report and discussions are underway to talk about the possibility of collaborative research between the UK and US in this area.

Safe sleep advice puts parents off planned bed sharing, where a safer sleep environment can be planned. Does this lead to a higher risk of accidentally falling asleep?

Safer sleep advice in the UK has, since early 2019, been open in talking about how to reduce the risks of bedsharing if you are planning to do so, or even if you are not, given we know that unplanned bedsharing is also a common occurrence. **The Lullaby Trust** has **resources** available on their website including safer sleep leaflets for both carers and a separate one for professionals which give advice on getting these messages out to families. One of the reasons that the advice was changed was the exact situation described in your question – that families sometimes tried to avoid one risk and end up in a far riskier situation.

Does infant's sleep position still needed to be emphasized when advising parents?

Yes, absolutely – sleeping a baby on its back remains one of the most important safer sleep messages.

Families will co-sleep, could there be more push on ensuring this is done in a safer and more planned way?

Yes – the links to the Lullaby Trust resources on the previous page. These follow the NICE postnatal guidelines and the Royal College of Midwives safer sleep guidelines, which both say that bedsharing must be discussed with all families. The Lullaby Trust has plenty of resources that help to discuss how to minimise the risks of sharing a bed with a baby.

Do you see the worth in baby box schemes?

There is certainly a place for schemes that offer cardboard boxes for babies to sleep in who do not have an alternative separate sleeping place for their baby. There is now a BSI standard for these boxes, and they should always meet this as a minimum. A cardboard box does not substitute for a baby's cot however, which can be used on a longer-term basis and would not be subject to concerns around issues such as the box getting wet.

In the unexplained unexpected deaths cohort, how extensive is the genetic screening?

Genetic screening is not standardised in these cases, it is usually completed after the investigation is closed (if at all) and varies case-by-case and across the country. There are opportunities for further investigation via the National Genomics Service Alliance test directory and international **SUDC research projects**. We hope and anticipate that genetic investigation will become more consistently and proactively offered in unexplained cases.

Did the seizure association involve only febrile seizure, or both febrile and afebrile seizures?

The seizures in this study included both febrile and non-febrile seizures. The recording of whether seizures are febrile or not is often unclear from the records and therefore not available to CDOPs when they are reviewing deaths, In previous studies a similar association is evident in only febrile seizures (contact **nikki@sudc.org.uk** for more info).

Is there still a place in safer sleeping advice for generic campaigns or is this 'personalised dialogue' approach where we should be focussing our attention in the context of reduced capacity and resources?

In an ideal world we would have both. The majority of safer sleep advice has not changed for many years, and we will always need to spread these messages to those looking after young babies. However, we know how successful the personalised approach can be and this is something professionals can take into account right now, to support families to give their babies the safest sleep place possible.

Although we don't have the evidence could we surmise that febrile convulsions could be connected with problems in regulating temperature?

Peter Fleming The association between excess wrapping and/or high environmental temperature and the risk of death is seen only for infant deaths. There is no evidence that this applies to unexpected deaths of older children. This is not to say there is no connection, however. The work I am currently hoping to collaborate on with researchers in the US aims to try to understand some of the links between various brainstem functions - thermoregulation, hearing, blood pressure control and respiration.

Nikki Speed (SUDC UK) This is an interesting point. We desperately need research to understand the association between seizures and child death and identify risk factors and prevention strategies.

With the known link to febrile convulsions, what advice should be given to parents whose child does have a history of convulsions?

If their child has died and had a history of febrile seizures, a rich, detailed history should be documented, and the family should be connected with **SUDC UK** for information and support. Epilepsy panel genetic testing should be considered. Information on caring for a sibling with febrile seizures can be found **here**. In general, the **NICE guidelines** should be followed following any febrile seizure, with the child's seizure history and the possible need for paediatric/neurological review considered at each acute episode.

Would the seizure element change practice for hospitals when children attend with febrile convulsion or first-time convulsions?

All such children should be treated in line with NICE guidance. The risk to any individual child who has had a febrile seizure is extremely low, (less than 1 in a thousand) and at present we do not know how to modify advice to reduce the risk of later unexpected deaths.

In health protection (public health) we have to speak to recently bereaved families about risk factors if the death was from as a result of an infectious disease. We are looking for training to help us when having these challenging conversations - any suggestions gratefully received.

Peter Fleming The most important potentially preventative aspect of deaths from infections is full immunisation of all infants. This is a point that is very hard to raise with families whose child has died from a potentially preventable infection who chose not to immunise the child, but for future children it is important to ensure families are aware of the huge benefits and very small risk from immunisation.

Jenny Ward (The Lullaby Trust) This can be really challenging for staff, and you are right to look for training firstly. **Child Bereavement UK** have some **ongoing training programmes**, but you may wish to contact them directly about doing some **in-house training** that is targeted to your needs.