

PE2082/B: Improve the support provided to families affected by cot death

Scottish Cot Death Trust written submission, 26 June 2024

Almost every week a baby or young child dies suddenly and unexpectedly in Scotland. The Scottish Cot Death Trust (the Trust) is Scotland's **only** charity dedicated to all aspects of Sudden Unexpected Death in Infancy (SUDI). In the last year we directly supported over 80 families through our bereavement support and provided training for over 3300 practitioners.

Although petition PE2082 was submitted independently of the Trust without our knowledge, we empathise with the concerns raised; they reflect concerns shared by other families and those raised by us with the Scottish Government.

It was a difficult decision not to support the Scottish Government's current safer sleep messaging despite significant engagement. Numerous communications, meetings, and discussions between us counter the suggestion that we declined to take part. We did however have a fundamental difference with the final message relating to bedsharing and how to do so 'more safely', and without reference to the risks of bedsharing in the absence of additional hazards. There is an important difference between declining to participate further in the discussion and ethically being unable to support the Scottish Government's final position.

Whilst we align with, and support most of the Scottish Government's safer sleep messaging, we diverge on a key point relating to bedsharing. Based on evidence, and in line with the majority of the international community, we believe that the safest sleep space for a baby under 3 months is always flat, firm, clear and **separate**. We agree that evidence tells us that risks to infants sharing an adult sleep space increase when hazards such as alcohol, substances and smoking are involved, but we cannot ignore that in the absence of any additional hazards bedsharing still carries a risk.

Case control studies are used to study rare events like SUDI.

An early study compared 110 babies who died in Cambridgeshire from 1958 to 1961 with 196 controls who did not die¹. Of statistical significance, more babies who died 14/110 (13%) were bedsharing compared to 2/196 (1%) control (live) babies who were bedsharing.

A study in Scotland from 1996 to 2000² showed that, for babies less than 11 weeks, 33/49 (67%) who died were bedsharing compared to 13/72(18%) controls, a statistically significant 10-fold increased risk.

In 2004, SIDS International asked if all case control data could be brought together to try to definitively answer the question regarding the risk of bedsharing. Published

¹ Carpenter RG, Shaddick CW. Role of infection, suffocation, and bottle feeding in cot death. *Brit J prev soc Med* 1965;19:1-7

² Tappin D, et al. Bedsharing, roomsharing, and sudden infant death syndrome in Scotland: a case-control study. *J Pediatr* 2005;147:32-7.

in 2013³, data collected from 20 European regions and all other available case control data from around the world (1472 SIDS cases and 4679 controls) were examined. If parents did not smoke or recently drink alcohol and the baby was less than 3 months of age, there was a statistically significant 5-fold increased risk of dying of SIDS if the baby shared a bed with parents. The International SIDS Community has set policy based on this work and a priority for safety:

- USA – Infants sleep in the parents' room, close to the parents' bed, on a separate surface designed for infants, ideally for the first year of life, but at least for the first 6 months
- New Zealand – Place baby in their own baby bed in the same room as parent or caregiver
- Australia – Sleep baby in their own safe sleeping place in the same room as care-giver for the first six to twelve months
- Europe – Co-sleeping should be avoided
- Canada – Place your baby to sleep in a crib, cradle or bassinet next to your bed
- Ireland – Do not fall asleep in bed with your baby if baby is less than 3 months of age.⁴

Finally, a New Zealand study collected data from 2012 to 2015⁵, 73/126(58%) babies who died of SIDS were bedsharing compared with 46/258(18%) of controls. There was a statistically significant 10-fold increased risk when bedsharing for babies less than 3 months with no other hazards such as parental smoking or alcohol use.

The Trust has a history of working with the Scottish Government in relation to infant safer sleep advice and have been a key vehicle for disseminating information to professionals and the public across Scotland. We partnered with the Scottish Government on the previous safer sleep guidance, which was endorsed by UNICEF UK. We understand that part of the rationale for modifying the message that the 'safest sleep space is a separate space' relates to concerns about breastfeeding rates, however UNICEF UK's own data would indicate that the previous safer sleep literature had no negative impact on breastfeeding rates during the many years it was shared with Scottish families. The Trust recognise the evidence of the many benefits of breastfeeding, particularly in relation to SUDI. However, we do not believe that a positive breastfeeding agenda cannot coexist with the safest infant sleep information. We believe that universal messaging produced by the Scottish Government should ensure that families are aware that a **separate sleep space** is always safest. We consider our position on safer sleep messaging continually and acknowledge that some families may choose to bedshare and should have access to information about reducing the risks of that practice, but that should be in the context that **a risk is always present and that a separate sleep space reduces this risk**. We must provide families with all the information to enable them to make a fully informed choice about sleep practices for their children.

³ Carpenter R, et al. Bed sharing when parents do not smoke: is there a risk of SIDS? An individual level analysis of five major case-control studies. *BMJ Open* 2013;3:e002299.

⁴ Tappin D, et al. Bed-sharing is a risk for sudden unexpected death in infancy. *Archives of Disease in Childhood* 2023;108:79-80.

⁵ MacFarlane ME, et al. Infant Sleep Hazards and the Risk of Sudden Unexpected Death in Infancy. *J Pediatr* 2022; 245:56-64

In January 2024, the Solicitor General released a public statement relating to infant safer sleep practices as in 2023:

- 19 children under 18 months died whilst co-sleeping
- around 63% of those situations involved alcohol / drugs consumed by parents / carers.

We know from our contact with the Scottish Government that there are plans to update their safer sleep guidance and ask that this be used as an opportunity to consider seriously re-engaging with the Scottish Cot Death Trust on this matter. We have been encouraged by our contact with the Scottish Government in the past 12 months and hope that any ongoing relationship will be one based on openness, respect, and our shared commitment to ensuring Scottish families have access to the most robust infant safer sleep messages. We ask members of the Committee to advocate for a review of the Scottish Government's safer sleep messaging that is driven by providing the safest advice and reducing the risk and number of sleep accidents and preventable infant deaths.