Citizen Participation and Public Petitions Committee Wednesday 7 May 2025 8th Meeting, 2025 (Session 6)

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

Introduction

Petitioner Kevin McIver

Petition summary Calling on the Scottish Parliament to urge the Scottish

Government to stop promoting The Lullaby Trust to Scottish families for cot death support, as this charity only provides support to families who live in England and Wales; and improve the practical support available to families by prioritising the promotion of The Scottish Cot Death Trust who have been

supporting families since 1985.

Webpage https://petitions.parliament.scot/petitions/PE2082

1. <u>The Committee last considered this petition at its meeting on 29 May 2024.</u> At that meeting, the Committee agreed to write to the Scottish Cot Death Trust.

- 2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.
- 3. The Committee has received a new written submission from the Scottish Cot Death Trust, which is set out in **Annexe C.**
- 4. Written submissions received prior to the Committee's last consideration can be found on the petition's webpage.
- 5. <u>Further background information about this petition can be found in the SPICe briefing</u> for this petition.
- 6. The Scottish Government gave its initial position on this petition on 12 March 2024.
- 7. Every petition collects signatures while it remains under consideration. At the time of writing, 16 signatures have been received on this petition.
- 8. Members may wish to note that <u>the Scottish Government published updated</u> <u>quidance for professionals on Safe Sleep for Babies on 30 September 2024</u>, which includes strengthened messaging on bed sharing.

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Action

9. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee May 2025

Annexe A: Summary of petition

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

Petitioner

Kevin McIver

Date Lodged

14 February 2024

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to stop promoting The Lullaby Trust to Scottish families for cot death support, as this charity only provides support to families who live in England and Wales; and improve the practical support available to families by prioritising the promotion of The Scottish Cot Death Trust who have been supporting families since 1985.

Previous action

Written to our MSP.

Background information

I am a parent who lost a child to cot death.

When we had another baby, support was provided by The Scottish Cot Death Trust. The Scottish Cot Death Trust hand out free baby monitors to help prevent cot death. They also offer free CPR and first aid training, and access to a Bereavement Support Worker to support families.

Now we have had another child and, on all literature, the Scottish Government promotes The Lullaby Trust, who do not offer support or help to Scottish families, only to those living in England and Wales. What is the point of promoting an England-based charity? As the saying goes "charity begins at home", but clearly the Scottish Government don't see this. As a parent of a child who passed with cot death/SIDS (Sudden Infant Death Syndrome), I am angered our government doesn't provide more support to a Scotland-based charity. Our NHS in Scotland should not be sending any money south of the border.

Annexe B: Extract from Official Report of last consideration of PE2082 on 29 May 2024

The Convener: PE2082, on improving the support provided to families affected by cot death, has been lodged by Kevin McIver and calls on the Scottish Parliament to urge the Scottish Government to stop promoting the Lullaby Trust to Scottish families for cot death support, as that charity provides support only to families who live in England and Wales, and instead to provide practical support to families by prioritising the promotion of the Scottish Cot Death Trust, which has been supporting families since 1985.

Mr McIver tells us that he lost a child to cot death, also known as sudden unexpected death in infancy, and that he has received support from the Scottish Cot Death Trust. He is concerned that the literature provided by the Scottish Government since he had another child promotes the Lullaby Trust, an England-based charity that does not support families living in Scotland.

In its response to the petition, the Scottish Government notes that, although it has worked in partnership with the Lullaby Trust and other organisations to develop and deliver resources on safer sleep for babies, it does not promote the Lullaby Trust as a baby-loss support organisation. It states that the Scottish Cot Death Trust was invited to become involved in the development of those resources, but it declined.

The response then goes on to detail work to support families who have experienced pregnancy and baby loss, including through the national bereavement care pathways. It also notes that the Scottish Government has provided funding to the Scottish Cot Death Trust to deliver its sudden unexpected death in infancy simulation and awareness training.

I am minded to try to establish with the Scottish Cot Death Trust, which is funded by the Scottish Government, why it declined to participate in the drafting of the resources that the Government sought to make available. That seems to be a curious lack of engagement. I understand the Scottish Government's principal point in relation to the petitioner's point about promoting the Lullaby Trust, in which it says that it does not promote that organisation but promotes the Scottish Cot Death Trust. I am curious, though, as to why the trust declined to participate.

Are we content to keep the petition open so that we can inquire on that point?

Members indicated agreement.

Annexe C: Written submission

Scottish Cot Death Trust written submission, 26 June 2024

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

Almost every week a baby or young child dies suddenly and unexpectedly in Scotland. The Scotlish 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 2000^2 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.

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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.

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

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We must provide families with all the information to enable them to make a fully informed choice about sleep practices for their children.

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.