

Scottish Government submission of 12 March 2024

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

Thank you for asking for the Scottish Government's view on the public petition [PE2082: Improve the support provided to families affected by cot death](#) 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.

The loss of a baby is a traumatic event that can have a profound impact on families. The Scottish Government recognises this impact and is clear that women and their families who have experienced baby loss must be provided with the right information, care and support taking into account their individual circumstances.

This response will outline the Scottish Government's commitment to delivering that support and its current involvement with The Lullaby Trust, the Scottish Cot Death Trust and other pregnancy and baby loss charities in Scotland.

It's important to clarify from the outset that whilst the Scottish Government worked in partnership with The Lullaby Trust to develop and deliver national Safer Sleep for Babies resources, we do not promote The Lullaby Trust as a baby loss support organisation because, as mentioned in public petition PE2082, they do not provide a baby loss support service in Scotland.

The Scottish Government and NHS Scotland Safer Sleep resources were developed in partnership with the Lullaby Trust, the UNICEF Baby Friendly Initiative and internationally recognised safer sleep experts including BASIS, the Baby Sleep Information Source based at Durham University. Healthcare Improvement Scotland and the Chair of the National Hub for Reviewing and Learning from the Deaths of Children and Young People were also involved in their development, along with

charities working in Scotland such as Bliss, Twins Trust and Held In Our Hearts.

The resources include a guide for parents and carers, a quick reference card which compliments the parent guide and a guide for health professionals that they can use to talk to parents about safer sleep. The parent and carers guide is available in the 18 most commonly used languages in Scotland. Accessible easy read, British Sign Language, audio and Braille versions are also available. The information provided in the resources which includes advice on bed sharing is clear, consistent with advice given across the whole of the UK and based on current research and evidence. The information is in line with Royal College of Midwives guidance and National Institute for Health and Care Excellence (NICE) clinical guidelines on postnatal care, which is clear that parents should be given information on bed sharing and health professionals must have open conversations with parents about this.

The Scottish Cot Death Trust were invited to become involved in the development of these resources but declined to do so.

The Scottish Government is also committed to supporting families who have experienced pregnancy and baby loss by delivering high-quality, sensitive bereavement care and provide funding to Sands UK to develop the National Bereavement Care Pathways for pregnancy and baby loss in Scotland (NBCP). Sands UK worked with health professionals, bereaved parents, baby loss charities and Royal Colleges to deliver the pathways, putting voices of bereaved parents at the heart of the development of the pathways.

The pathways provide health professionals with evidence based care and describe best practice for bereavement care following a miscarriage, ectopic and molar pregnancy, termination of pregnancy for fetal anomaly, stillbirth, neonatal death, or the sudden unexpected death of an infant (SUDI). The Scottish Cot Death Trust led and developed the National Bereavement Care Pathway for SUDI and its Executive Director Lynsey Kidd sits on the NBCP Core Group and is currently co-leading work ensure that the SUDI pathway remains up to date.

A link to the NBCP can be found here: [Home | SANDS \(nbcpscotland.org.uk\)](https://www.nbcpscotland.org.uk).

Additionally, the Scottish Government has provided the Scottish Cot Death Trust, with grant funding of £12,414.56 in financial year 2023/24 to deliver their SUDI simulation and SUDI awareness training.

I hope that this reassures the Committee that the Scottish Government does not promote The Lullaby Trust to Scottish families for SUDI support and that we are working with the Scottish Cot Death Trust to support families in Scotland, through the NBCP and by funding their SUDI simulation and SUDI awareness training.

**Maternal and Infant Health
Children and Families Directorate**