

Bereaved parents should be given full details about how to reduce sudden infant death syndrome risk

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A new study indicates that health professionals should tell bereaved parents about what they could have done to reduce the risk of the sudden death of their baby.

The University of Warwick research, funded by The National Institute of Health Research (NIHR), is thought to be the first of its kind in the UK and contradicts the current practice of many paediatricians who don't discuss risk factors for fear of causing grieving mothers and fathers additional upset.

The research, Parental understanding and self-blame following sudden infant [death](#): a mixed-methods study of bereaved parents' and professionals' experiences, by Dr Joanna Garstang of Warwick Medical School has been published in *BMJ Open*; Dr Garstang was funded by an NIHR Doctoral Research Fellowship.

Dr Garstang, who is also a Consultant Community Paediatrician in the Child and Family Services at Coventry and Warwickshire Partnership NHS Trust, found that bereaved parents want to be given detailed information about their child's death. Her research suggests parents value [health professionals](#) explaining the role of risk factors in Sudden Infant Death Syndrome (SIDS). Her study found no evidence that sharing this information is a direct cause of parental self-blame.

SIDS occurs more commonly with social deprivation and a number of factors which increase the likelihood of it occurring have been identified in previous studies. These include infants not sleeping on their backs, parental smoking, head-covering, use of soft-bedding and co-sleeping on a sofa or with parents who have consumed alcohol or smoke. With this knowledge SIDS could be considered to be partly related to parental actions and choices therefore the previous explanations and reassurances, that SIDS is unpreventable, given to parents may no longer be appropriate.

Dr Garstang said: "The research highlights the need to talk to parents about how to avoid SIDS. "Bereaved parents often blame themselves and feel guilty for these deaths due to the lack of explanation for them but self-blame is also a common feature of grief. Prior to our current understanding of SIDS, recommended practice for healthcare professionals was to reassure parents that their actions played no role in the death as SIDS was neither predictable nor preventable; it was perceived this would help alleviate the parents' feelings of self-blame

"As professionals, we need to sensitively share this information about risk factors with bereaved parents. If these aren't explained to parents they may be more likely to repeat their behaviour with their next baby and go through the heartache of losing a child again."

The study was conducted across the Herefordshire, Shropshire, Staffordshire, Warwickshire West Midlands & Worcestershire area between 2011-2014. Dr Garstang interviewed 21 sets of parents who lost a baby due to sudden death between 1 December 2010 and 1 August 2013.

In-depth interviews and questionnaires were used to explore how bereaved parents understand the cause of death and [risk factors](#) identified during the legally required investigation following a sudden

unexpected infant death. The association between bereaved parents' mental health and this understanding, and healthcare professionals' experiences of sharing such information with families was also explored.

She found that of the parents who were interviewed more than half didn't refer to blame; of these six families didn't mention 'blame' and six didn't blame anyone for their child's death. Three of 21 mothers said they blamed themselves completely for the death and had feelings of over-whelming guilt; two of the infants died of medical causes and one of SIDS. Notably, all three mothers scored highly for both anxiety and depression but none of the other mothers had clinically significant scores. The families interviewed were a mixture of those who believed they received excellent, good and poor support from hospitals and healthcare professionals following their child's death.

Dr Garstang conducted the research because she felt more could be done to help families immediately after the death of their child. She said: "As a junior doctor I used to see SIDS families in the Emergency Department and knew that we not offering parents adequate support or information. In some cases bereaved mothers were allowed to walk out of hospital and left to get on with their lives. With the introduction of the new joint working practices with police and social care professionals I wanted to make sure that we were improving care for families and wanted bereaved parents to have a voice. These factors prompted me to conduct research in to this area."

The Lullaby Trust which provides specialist support for bereaved families, promotes expert advice on safer baby sleep and raises awareness on sudden [infant death](#). Their Head of Care Of Next Infant (CONI) scheme, Alison Waite, said: "We welcome this research. The study shows how important it is for parents to be told about the findings of an investigation into the death of their child. They need a clear

explanation of the cause of death or what is meant by a natural but unexplained death and the factors that may have contributed.

"This study suggests that professionals should not be afraid of having these discussions. It is not unusual for bereaved parents to experience feelings of blame but the study shows that talking about the risks will not make this worse. It is vital that parents understand the risks, to help prepare them, should they have more children in the future."

More information: Garstang J, Griffiths F, Sidebotham P. Parental understanding and self-blame following sudden infant death: a mixed-methods study of bereaved parents' and professionals' experiences. *BMJ Open* 2016;6:e011323. [DOI: 10.1136/bmjopen-2016-011323](https://doi.org/10.1136/bmjopen-2016-011323)

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