

# SUDI Nationwide Study

increasing understanding of Sudden Unexpected Death in Infancy



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## Sudden Unexpected Death in Infancy and the SUDI Liaison

Sudden Unexpected Death in Infancy, (SUDI), happens most frequently when a number of risk factors come together at a vulnerable time for the baby. Each year in New Zealand about 70 babies die from SUDI and about half of these are Māori. Families/whānau can never be prepared for what happens as a result of losing a baby.

There are legal and medical concerns and processes to be negotiated, difficult decisions to be made, as well as financial pressures, all at a time of shock and grief.

The SUDI Liaison team assists families/whānau working through these processes by informing and ensuring understanding without judgment or influence or coercion.

All SUDI Liaison team members have health, social and/or research backgrounds and have been specially trained to undertake their roles.



## The SUDI Liaison role

The SUDI Liaison team has two components to their role:

**1. To gather information for the coroner** under the authorisation of Judge A N MacLean, Chief Coroner of New Zealand, by interviewing family/whānau or caregivers that have experienced a SUDI as soon as possible to collect initial data and objective measures. We work within the guidelines of the Ministry of Justice and balance the sensitive needs of the family with the requirements of various professionals across a range of disciplines. We are mindful of the need to work in a

complementary manner with other services and their processes.

The SUDI Liaison team also **provide quality information** for bereaved families/whānau about Coronial Service processes in a compassionate and culturally sensitive manner; **notify** agencies regarding a baby's death; and **identify health or other services** that may be required by family/whānau, and ensure appropriate referral.

**2. To gather information for the SUDI Nationwide Study** through in depth research interview with family/whānau or caregivers.



### Scope of the SUDI Liaison Role

The SUDI Liaison team is employed by consultancy company, Communio, and as such, we work independently of the NZ Police.

While not clinical specialists, members of the SUDI Liaison team are able to refer the family to the Community Paediatrician to discuss clinical matters concerning the baby's death.

We do not provide grief counseling, but can offer family members specific information about appropriate ongoing care and services that are available in their region. These services may help in dealing with the aftermath of SUDI, especially grief and loss, anger, blame and guilt issues within the wider family/whānau dynamic.



### SUDI Nationwide Study

Starting in 2012, more than 400 families/whānau will be interviewed over three years for the **SUDI Nationwide Study**.

The study is funded by the Health Research Council and led by Principal Investigator Prof. Ed Mitchell, University of Auckland.

This study follows on from the ground-breaking research of 25 years ago which informed the practice of putting babies to sleep on their back. This is the most in-depth study of infant care practices, especially around the sleep environment. The research will investigate sleeping practices in the

baby's life, together with baby's antenatal and postnatal health and current living situation.

The study aims to increase understanding about SUDI, including the impact of co-sleeping and whether it is possible for co-sleeping to occur safely, and the factors, if any, which might mitigate the effects of adverse social and environmental factors.

Families/whānau in the control group are selected from the birth register to match the age, sex, ethnicity and obstetric hospital of a baby who has died of SUDI sometime before 2009.

Families/whānau are invited to participate in the study, and in so doing will be contributing to a valuable body of information that will increase current knowledge enabling policy makers and health professionals to give informed advice that will lead to the prevention of infant deaths in the future.

Communio manages the implementation of data collection for the study and employ the SUDI Liaison team for this purpose. Communio:

- Specialises in project management and implementation; programme and service evaluation; and quality and healthcare improvement, including healthcare incident management
- Employs staff with relevant specialist clinical/health backgrounds
- Values the importance of quality research data and the secure storage and transmission of sensitive data
- Ensures the quality of communication and interactions with stakeholders.

### The SUDI Liaison Team:

- Melanie MacFarlane, SUDI Study Project Manager
- Shelley Jonas, Rebecca Passi, Genevieve Ali – SUDI Liaison Upper and Central North Island;
- Judy McIntyre, SUDI Liaison Lower North Island
- Elaine McLardy, SUDI Liaison South Island

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