Fifth Report to the Minister of Health
Reporting mortality 2002–2008

Chapter 1  Sudden Unexpected Death in Infancy (SUDI)
1 Sudden Unexpected Death in Infancy (SUDI)

1.1 Introduction

Sudden infant death syndrome (SIDS) has been defined as 'The sudden death of an infant, which is unexplained after the review of the clinical history, examination of the circumstances of death, and post-mortem examination' (Rognum and Willinger 1995). Controversies associated with the classification of SIDS (eg, deaths in the presence of known risk factors such as cigarette smoke, prematurity, bed sharing or minor infections, where the contribution of the risk factor remains uncertain) have led more recently to the adoption of the term sudden unexpected death in infancy (SUDI), 7 which encompasses both SIDS and these more grey scenarios (Fleming et al 2006).

In New Zealand during the 1980s SIDS rates were high by international standards, and they were not declining, as they were in some other developed countries (Mitchell 1990). As a consequence, a large case control study was commissioned, which found that SIDS was associated with three key risk factors: placing babies on their fronts to sleep, cigarette smoking and a lack of breastfeeding (Mitchell et al 1991). Later, a fourth risk factor, bed sharing, was added, although it was subsequently revealed that bed sharing was of greatest concern for babies exposed to cigarette smoke in utero (Mitchell et al 1992, Scragg et al 1995).

The National SIDS Prevention Campaign was launched in 1991 and resulted in a large decline in SIDS mortality during the early 1990s, which was largely attributed to the recommendation not to put infants to sleep in the prone position (Mitchell et al 2007). Although rates for European babies declined markedly, declines for Māori babies were much less marked, possibly as the result of a higher proportion of risk factors other than sleep position among Māori babies (Tipene-Leach et al 2000).

1.2 SUDI numbers and rates from the CYMRC database

1.2.1 SUDI numbers and rates, by ethnicity and gender, 2003–2007

In New Zealand during 2003–2007 8, 328 infants (aged 4 weeks to 52 weeks) died as the result of SUDI. During this period 61.6% of infants dying from SUDI were Māori, 24.4% were Other (including European), 12.8% were Pacific and 1.2% were Asian. Rates for Māori (2.34 per 1000) and Pacific (1.31 per 1000) infants were significantly higher than for Other (including European) infants (0.52 per 1000), while rates for Asian (0.14 per 1000) infants were significantly lower. Mortality rates were similar for males and females, except for in the Other (including European) group, where rates for male infants were 1.9 times higher than for female infants (see Tables 1.1 and 1.2).

7 In some cases of sudden unexpected death, explanations were found, including unrecognised illness or infection, heart rhythm disorders and metabolic disease. In this report these cases have been entered into the sections related to their specific causes. (See the glossary for more detail.)

8 Data including 2008 is included in the appendices, which are on-line at the CYMRC website. 2008 data is not used in this Chapter because some cases are still awaiting the coroner’s report.
Table 1.1 Sudden unexpected deaths in infancy, infants aged 4–52 weeks, by ethnicity and gender, New Zealand, 2003–2007

<table>
<thead>
<tr>
<th>Year</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>N</th>
<th>Rate</th>
<th>N</th>
<th>Rate</th>
<th>N</th>
<th>Rate</th>
<th>N</th>
<th>Rate</th>
<th>N</th>
<th>Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>Female</td>
<td>Māori</td>
<td>44</td>
<td>2.81</td>
<td>45</td>
<td>2.72</td>
<td>33</td>
<td>1.94</td>
<td>47</td>
<td>2.62</td>
<td>33</td>
<td>1.71</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>Pacific peoples</td>
<td>4</td>
<td>0.65</td>
<td>8</td>
<td>1.26</td>
<td>7</td>
<td>1.12</td>
<td>15</td>
<td>2.34</td>
<td>8</td>
<td>1.14</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Asian</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>3</td>
<td>0.56</td>
<td>1</td>
<td>0.16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>13</td>
<td>0.44</td>
<td>19</td>
<td>0.63</td>
<td>9</td>
<td>0.30</td>
<td>20</td>
<td>0.65</td>
<td>19</td>
<td>0.59</td>
</tr>
<tr>
<td>2004</td>
<td>Female</td>
<td>Māori</td>
<td>97</td>
<td>2.31</td>
<td>105</td>
<td>2.36</td>
<td>202</td>
<td>61.59</td>
<td>202</td>
<td>61.59</td>
<td>202</td>
<td>61.59</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>Pacific peoples</td>
<td>19</td>
<td>1.22</td>
<td>23</td>
<td>1.39</td>
<td>42</td>
<td>12.80</td>
<td>42</td>
<td>12.80</td>
<td>42</td>
<td>12.80</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Asian</td>
<td>2</td>
<td>0.15</td>
<td>2</td>
<td>0.14</td>
<td>4</td>
<td>1.22</td>
<td>4</td>
<td>1.22</td>
<td>4</td>
<td>1.22</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>27</td>
<td>0.36</td>
<td>53</td>
<td>0.68</td>
<td>80</td>
<td>24.39</td>
<td>80</td>
<td>24.39</td>
<td>80</td>
<td>24.39</td>
</tr>
<tr>
<td>2005</td>
<td>Female</td>
<td>Māori</td>
<td>97</td>
<td>2.31</td>
<td>105</td>
<td>2.36</td>
<td>202</td>
<td>61.59</td>
<td>202</td>
<td>61.59</td>
<td>202</td>
<td>61.59</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>Pacific peoples</td>
<td>19</td>
<td>1.22</td>
<td>23</td>
<td>1.39</td>
<td>42</td>
<td>12.80</td>
<td>42</td>
<td>12.80</td>
<td>42</td>
<td>12.80</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Asian</td>
<td>2</td>
<td>0.15</td>
<td>2</td>
<td>0.14</td>
<td>4</td>
<td>1.22</td>
<td>4</td>
<td>1.22</td>
<td>4</td>
<td>1.22</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>27</td>
<td>0.36</td>
<td>53</td>
<td>0.68</td>
<td>80</td>
<td>24.39</td>
<td>80</td>
<td>24.39</td>
<td>80</td>
<td>24.39</td>
</tr>
<tr>
<td>2006</td>
<td>Female</td>
<td>Māori</td>
<td>97</td>
<td>2.31</td>
<td>105</td>
<td>2.36</td>
<td>202</td>
<td>61.59</td>
<td>202</td>
<td>61.59</td>
<td>202</td>
<td>61.59</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>Pacific peoples</td>
<td>19</td>
<td>1.22</td>
<td>23</td>
<td>1.39</td>
<td>42</td>
<td>12.80</td>
<td>42</td>
<td>12.80</td>
<td>42</td>
<td>12.80</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Asian</td>
<td>2</td>
<td>0.15</td>
<td>2</td>
<td>0.14</td>
<td>4</td>
<td>1.22</td>
<td>4</td>
<td>1.22</td>
<td>4</td>
<td>1.22</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>27</td>
<td>0.36</td>
<td>53</td>
<td>0.68</td>
<td>80</td>
<td>24.39</td>
<td>80</td>
<td>24.39</td>
<td>80</td>
<td>24.39</td>
</tr>
<tr>
<td>2007</td>
<td>Female</td>
<td>Māori</td>
<td>97</td>
<td>2.31</td>
<td>105</td>
<td>2.36</td>
<td>202</td>
<td>61.59</td>
<td>202</td>
<td>61.59</td>
<td>202</td>
<td>61.59</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>Pacific peoples</td>
<td>19</td>
<td>1.22</td>
<td>23</td>
<td>1.39</td>
<td>42</td>
<td>12.80</td>
<td>42</td>
<td>12.80</td>
<td>42</td>
<td>12.80</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Asian</td>
<td>2</td>
<td>0.15</td>
<td>2</td>
<td>0.14</td>
<td>4</td>
<td>1.22</td>
<td>4</td>
<td>1.22</td>
<td>4</td>
<td>1.22</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>27</td>
<td>0.36</td>
<td>53</td>
<td>0.68</td>
<td>80</td>
<td>24.39</td>
<td>80</td>
<td>24.39</td>
<td>80</td>
<td>24.39</td>
</tr>
<tr>
<td>Total</td>
<td>Female</td>
<td>Māori</td>
<td>194</td>
<td>2.33</td>
<td>210</td>
<td>2.38</td>
<td>404</td>
<td>61.88</td>
<td>404</td>
<td>61.88</td>
<td>404</td>
<td>61.88</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>Pacific peoples</td>
<td>38</td>
<td>1.33</td>
<td>46</td>
<td>1.39</td>
<td>84</td>
<td>12.82</td>
<td>84</td>
<td>12.82</td>
<td>84</td>
<td>12.82</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Asian</td>
<td>2</td>
<td>0.15</td>
<td>2</td>
<td>0.14</td>
<td>4</td>
<td>1.22</td>
<td>4</td>
<td>1.22</td>
<td>4</td>
<td>1.22</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other</td>
<td>54</td>
<td>0.57</td>
<td>106</td>
<td>0.67</td>
<td>160</td>
<td>24.72</td>
<td>160</td>
<td>24.72</td>
<td>160</td>
<td>24.72</td>
</tr>
</tbody>
</table>

Note: Rates are per 1000 live births.

Table 1.2 Sudden unexpected deaths in infancy, infants aged 4–52 weeks, by ethnicity and gender, New Zealand, 2003–2007 combined

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Female</th>
<th>Male</th>
<th>Total</th>
<th>Rate</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Rate</td>
<td>N</td>
<td>Rate</td>
<td>Rate</td>
</tr>
<tr>
<td>Māori</td>
<td>97</td>
<td>2.31</td>
<td>105</td>
<td>2.36</td>
<td>202</td>
</tr>
<tr>
<td>Pacific peoples</td>
<td>19</td>
<td>1.22</td>
<td>23</td>
<td>1.39</td>
<td>42</td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
<td>0.15</td>
<td>2</td>
<td>0.14</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>27</td>
<td>0.36</td>
<td>53</td>
<td>0.68</td>
<td>80</td>
</tr>
<tr>
<td>Total</td>
<td>145</td>
<td>0.99</td>
<td>183</td>
<td>1.19</td>
<td>328</td>
</tr>
</tbody>
</table>

Notes: Rates are per 1000 live births. Rate ratios compare SUDI rates for Māori, Pacific and Asian infants with those of Other (including European) infants. 95% confidence interval (CI): LL = lower limit; UL = upper limit.

1.2.2 Post-neonatal mortality, by DHB

In New Zealand during 2003–2007 there were regional variations in post-neonatal mortality by DHB. Although much of this regional variation was probably due to demographic variations and the small number of cases involved, post-neonatal mortality rates in Counties Manukau were significantly higher than the New Zealand average, while rates in Waitemata, Auckland, Nelson Marlborough and Canterbury DHBs were significantly lower (see Figure 1.1).
**Figure 1.1** Post-neonatal mortality rates per 1000 live births, by DHB of residence, New Zealand, 2003–2007 combined

**Mortality rate per 1000 live births**

Note: The Exact Method of Agresti and Coull has been used to estimate 95% confidence intervals. The line shows the national post-neonatal mortality rate per 1000 live births.

### 1.2.3 Post-neonatal SUDI mortality by DHB

In New Zealand during 2003–2007 there were also regional variations in post-neonatal SUDI mortality by DHB. Although much of this regional variation was again probably due to demographic variations and the small number of cases involved, post-neonatal SUDI mortality rates in Northland, Counties Manukau, Waikato and Taranaki were significantly higher than the New Zealand average, while rates in Waitemata, Auckland, Nelson Marlborough, Capital & Coast and Canterbury DHBs were significantly lower (Figure 1.2).

**Figure 1.2** Post-neonatal SUDI mortality rates per 1000 live births, by DHB of residence, New Zealand, 2003–2007 combined

Note: The Exact Method of Agresti and Coull has been used to estimate 95% confidence intervals. The line shows the national post-neonatal SUDI mortality rate per 1000 live births.
1.3 Risk factors for SUDI in the CYMRC database

1.3.1 SUDI deaths, by age

In New Zealand during 2003–2007 there were 359 neonatal and post-neonatal SUDI deaths. SUDI deaths were most frequent in infants less than five months of age, with the peak number of deaths occurring at 1 to 2 months (Figure 1.3).

1.3.2 SUDI deaths, by sleep surface

In New Zealand during 2003–2007 there were 154 SUDI cases (43%) where the sleep surface was known to be shared at the time of death. At least 130 of these were infants aged 0-4 months. In 14 (9%) of the shared sleep surface cases the person sharing the sleep surface was not an adult. During this period the number of deaths in infants sleeping on a shared surface (ie, shared with adults or other children) was highest for those less than five months of age. The relatively large number of cases where bed sharing status was not known, however, makes precise interpretation of the proportion sharing a sleep surface at each age difficult (Figure 1.4 and Figure 1.5).

1.3.3 Completeness of SUDI risk factor information in the CYMRC database

In the CYMRC database during 2003–2007 the completeness of information on known risk factors among SUDI deaths varied markedly by condition, with information on preterm birth and low birth weight being relatively complete, in contrast to the high proportion (64%) of missing responses for exposure to cigarette smoke (Figure 1.6).

---

9 This includes 31 neonatal (aged 0–28 days) and 328 post-neonatal (aged 4–52 weeks) SUDI deaths.

10 The Perinatal and Maternal Mortality Review Committee (PMMRC) states in its Third Report to the Minister of Health that “of the 11 babies who died in the neonatal period where no obstetric antecedent was present (PDC 11), 10 deaths were associated with unsafe sleeping practices” (2009: 22). The CYMRC and PMMRC have agreed that future SUDI deaths under 28-days outside of a hospital will be reviewed by the CYMRC.
Figure 1.3  Number of sudden unexpected deaths in infancy (SUDI), by age at death (months), New Zealand, 2003–2007 combined

![Graph showing number of deaths by age at death (months)](image1)

Note: Deaths during the first month include all registered deaths during 2003–2007, plus unregistered deaths known to the CYMRC and Perinatal and Maternal Mortality Review Committee data collection systems.

Figure 1.4  Number of sudden unexpected deaths in infancy, by bed sharing status and age at death (months), New Zealand, 2003–2007 combined

![Graph showing number of deaths by bed sharing status and age at death (months)](image2)
Figure 1.5  Sudden unexpected deaths in infancy rates (per 1000 live births) and bed sharing status in infants aged 0–4 months, New Zealand, 2003–2007

Figure 1.6  Distribution of known SUDI risk factors (including those with missing data) among SUDI deaths, New Zealand, 2003–2007 combined

Notes: Not infant sleep surface: infant put to bed in a sleeping environment not designed for infants (eg, single/double bed or mattress, couch, chair, car seat, cushion, hammock); Shared sleep surface: infant shared a bed with another person (adult or child); Cigarette smoke exposure: 1 or more people living in the household smokes; Low birth weight: birth weight < 2500 g; Preterm: gestation < 37 weeks.
1.4 Local review group recommendations from the CYMRC database

During 2003–2008, a number of recommendations were entered into the CYMRC database as the result of reviews of SUDI deaths by local mortality review groups. Although some of these recommendations applied only to the local setting, a number appeared to be relevant to the national context as well. Many of these recommendations were similar or overlapping, so the list below reflects the general themes that emerged from these reviews.

- **Dissemination and implementation of safe-sleeping messages.** In many cases families were still not aware of or implementing standard SUDI prevention strategies. There was a particular need for greater awareness about providing safe sleeping environments. Specifically, the dangers associated with the following items need to be widely known: using car seats or couches as sleeping surfaces for babies, the use of pillows to prevent babies from moving in their sleep or to prop the head, co-sleeping with adults who have consumed alcohol, or the risk of infants overheating in the co-sleeping environment. The role of Lead Maternity Carers and Well Child providers in providing health promotion advice on safe sleeping (eg, through home visiting, with a review of sleep arrangements) was seen as being crucial, but not all families had a Well Child provider.

- **Reasons why infants have slept in unsafe situations.** As well as lack of awareness, a variety of other circumstances lead to infants sleeping in unsafe situations. Some families were aware of safe sleep practices but as the infant was unsettled a less favourable arrangement occurred apparently contributing to death. For others no safe arrangement was possible because of lack of a cot, household overcrowding or a house that was too cold. At times it was noted that infants normally slept in a safe place but because of a social gathering or parental intoxication an alternative unsafe arrangement occurred. Particular attention needs to be given to ensure safe sleeping arrangements when infants are away from home (eg, visiting grandparents).

  These observations lead groups to recognise the importance of stressing that every sleep must be a safe sleep, whether this is in the hospital, at home, with friends, on the marae or at another gathering of people. Groups recommended that families be better supported in having access to safe sleep spaces, knowledge on methods to settle distressed infants and understanding the need for a sober caregiver. The role of Lead Maternity Carers, Maternity Units and Well Child providers was seen as crucial to ensuring support for families in being ready for the infant birth, ensuring infants have access to a safe sleep space wherever they may be, modelling safe sleeping from birth and providing continuing support to families.

- **Dissemination and implementation of other SUDI prevention messages.** Many of the other known risk factors for SIDS were present among babies who died from SUDI (eg, maternal smoking, prematurity, or socio-economic disadvantage), potentially providing opportunities for (a) the identification of high-risk babies by Lead Maternity Carers and Well Child providers, (b) tailoring SUDI prevention messages (eg, in different languages), and (c) providing more practical support to the caregivers of vulnerable infants. In this context, education on the risk of smoking during pregnancy was seen as being of particular importance.

- **Communication with families and between agencies.** The timely hand-over of care from the Lead Maternity Carer to the Well Child provider, as well as the need to communicate information regarding the infant’s potential risk of SUDI, was seen as being crucial. Ensuring that all new mothers have a Well Child provider and General Practitioner, or that there is evidence that such services have been offered but declined, was seen as being particularly important.
• **Support to families dealing with socioeconomic stress.** The identification of, and provision of support to, families under significant social and economic stress was also seen as being of prime importance, with a number of families already being known to social agencies prior to their baby’s death, but with resources not being put in place soon enough to assist (eg, families coping with several children in difficult economic circumstances). Where several agencies are involved, it was recommended that one agency be appointed to take the lead in co-ordinating the services the family receive. For some families the high level of support needed was not available even though risks were identified.

• **Establishing a care pathway after the death of a child.** Concern was raised that communication issues after the death of the infant were exposing families to additional stress and/or feelings of guilt at a particularly vulnerable time. In this context, ensuring that the family’s general practitioner (GP) has access to the results of post-mortems in a timely manner, and that these results and the cause of their child’s death are explained to families in a way they can understand, was seen as being of prime importance. In addition, the use of SUDI death scene investigation protocols by police, and the need for a clear explanation by police of the various procedures required in such situations, was also seen as being important, particularly in cases where additional communication barriers are present (eg, hearing or vision impairment of caregivers). The attendance of a paediatrician or trained health investigator at the death scene was seen as being useful in this context.

To achieve these goals and improve care, establishing a care pathway for families after the death of an infant or child was seen as being crucial (see also Chapter 5). Elements might include a national protocol for investigation (including death scene investigation, and post-mortem performed by a pathologist with the appropriate level of skill), follow-up with a paediatrician, turning off the process of health care so recalls for events such as immunisation or hospital appointments stop, and ensuring families are connected with the appropriate support.

### 1.5 Approaches taken by the CYMRC to SUDI prevention

#### 1.5.1 Advice to health practitioners

In April 2008 the Ministry of Health and the CYMRC released a leaflet aimed at health professionals, which summarised the current Ministry of Health recommendations for preventing SUDI. In September 2009 a new leaflet was created by Change for Our Children, with endorsements from the CYMRC, the Ministry of Health’s Child, Youth and Maternity Policy team, and the Chief Coroner.¹¹

#### 1.5.2 SUDI Referral Advisor

The CYMRC obtained funding for a one-year pilot programme to allow a health trained investigator to work with the Coroner’s office to improve information collection for SUDI deaths and to provide support to families that have suffered a SUDI death. The role commenced at the end of 2008. A formal evaluation is forthcoming. Meanwhile, initial feedback suggests it has been a great success for increasing the information available on SUDI deaths. The benefits to families and communities are highlighted in the text written by Barbara Wright. The focus is now looking at evaluation and exploring ways to provide ongoing funding for what seems to be

---

¹¹ This leaflet can be obtained from the Change for Our Children website at [http://www.changeforourchildren.co.nz/files/docs/Safe%20Sleep%20DLE.pdf](http://www.changeforourchildren.co.nz/files/docs/Safe%20Sleep%20DLE.pdf).

Barbara Wright, SUDI Referral Advisor at the Coroner’s Office in Auckland, describes her role:

As I work in the Coroner’s office I hear of deaths very soon after they occur. My role is to collect information to better understand and prevent the toll of SUDI. I also have an important role supporting families acting as a navigator to guide them through tragic times.

The process of support in my role is as follows:

I support the family at the mortuary to understand the need for autopsy. This may involve taking the baby to the pathologist. I will enquire if they have had Victim Support and, if necessary, contact them. Some families, especially in close knit communities do not want them. The feelings are that they are not victims and no crime has been committed against them. The baby is certainly innocent.

At this time I can guide them through the process and need for a funeral director, so that they can have their baby back after the post-mortem as quick as possible. From this point I will leave them for about five days and then contact them again, by telephone, to arrange a visit to their home to have a chat. At this visit I will make sure that they have adequate support and invite them to contact their local representative for SANDS or SIDS New Zealand. At times I may become involved in finding help for other crises that occur as a direct result of the SUDI (eg, relationship and housing issues). Throughout the process, I am also collecting data on the death.

I contact all relevant parties immediately (eg, the GP, Whànau Ora workers, and Plunket) to stop the embarrassing, and at times distressing, contact that may happen if home visits or vaccinations are scheduled, and to help activate support.

I remain in contact with the family throughout the coronial process to give them the information when it comes through and to support their varying concerns during their grief process. As the case inquiry comes to an end, I support the family through an inquest or Chambers and ensure they understand the findings and recommendations. If necessary, I will pick the family up and drive them to the inquest. This is a very emotional and stressful time. They feel blame and anxiety whilst still grieving.

1.5.3 Màori Caucus

Guidance was sought from the Mortality Review Committee Màori Caucus on the development of relevant messages and enablers for Màori women and their whànau. The Caucus met on 30 July 2009 in Wellington specifically to discuss SUDI. The Caucus agreed that SUDI is an issue that requires a collective approach. It was agreed that SUDI messages have not been adequately crafted for Màori whànau and that the messages that target Màori must be culturally appropriate and come with enablers that help families to implement the desired changes.

The changing of some behaviours can make a huge difference in the rate of deaths attributed to SUDI. The changes required are not large, but they pose challenges for individuals and whànau. The Màori Caucus would like to see an opportunity for all providers of services to have

12 Stillborn and Infant Death Support can be found at http://www.sands.org.nz/. SIDS New Zealand can be found at http://www.sids.org.nz/site/.
13 See Appendix A8 for more information on the Mortality Review Committee Màori Caucus.
workforce development around those actions/activities and messages that are likely to make a difference, eg, around bed sharing, smoking and safe sleeping environments. This is likely to need a change in emphasis with national leadership to reduce the toll from this very preventable condition.

Post mortems are a difficult and controversial issue from a cultural perspective. The Māori Caucus indicated a potential shift in values which may make post mortems easier to accept because of a view to supporting the safety of the next generation. Whānau devastated by a death may find the system threatening, which is not helped by a poor understanding and limited explanations of the post mortem processes.

All those involved after a death need to remember to take a humane approach that supports understanding and gives families time. The Mortality Review Committees have a responsibility to facilitate this process as post mortem is an integral part of mortality review. The Perinatal and Maternal Mortality Review Committee (PMMRC) has developed a resource to better help families understand the need for and process of a post mortem.14 The local networks established by the Local Child & Youth Mortality Review Group (LCYMGRG) process offer a powerful system to allow those involved in after death care to be involved in a shared process of continuing quality improvement. Further work in this area is particularly important to the Māori Caucus. (See the discussion and recommendations on After the Death of a Child in Chapter 5.)

1.5.4 Cots for Tots

The CYMRC is of the belief that as much effort needs to be put into ensuring infants have a safe place to sleep as is currently put into having a safe place to ride in cars. For some families financial issues can make getting a cot for an infant difficult. Joint work between CYMRC, Child, Youth and Family (CYF), and Work and Income is focusing on increasing awareness of the vulnerability of unsafe sleeping and on increasing professional awareness of the financial support that is available from Work and Income to purchase a cot if necessary. Information will be passed on to Lead Maternity Carers, Well Child providers, and other professionals working with families.

There is also a development in some Māori communities of a programme which aims to increase the provision of safe sleeping places. A woven flax basket called a wahakura is targeted to mothers who smoked in pregnancy in an effort to mitigate some of the SIDS/SUDI risk of these infants and prevent bed sharing with a parent or caregiver.

1.6 Observations by the CYMRC on SUDI prevention

1.6.1 Observations

Following review of the data contained in the international literature and the CYMRC database, the recommendations made by local mortality review groups and the feedback provided by the SUDI Working Group and the Māori Caucus, the CYMRC makes the following observations.

1. A substantial reduction in numbers of SUDI in New Zealand is achievable and should be a high national priority. Attention to the needs of high risk Māori infants is paramount.

2. The importance placed on the safe sleeping of infants, by the community as a whole and families and professionals in particular, needs to increase.

3. Despite considerable evidence regarding the risk factors for SUDI and consensus on the most important actions needed to prevent SUDI, large numbers of infants continue to die. This suggests that SUDI prevention messages are not reaching families of high-risk infants in a way that meets their needs and/or there are significant barriers to implementing SUDI prevention messages by the caregivers of vulnerable infants.

4. New approaches to the dissemination of SUDI messages to families with infants at high risk of SUDI need to be developed, with a particular emphasis on meeting the information needs of Māori and Pacific families and those living with significant socioeconomic constraints. Lead Maternity Carers and Well Child providers are ideally placed to disseminate such messages but need to be supported with workforce development and resources. Greater national co-ordination plus the development of informational resources that are particularly targeted to high risk families is likely to be beneficial.

5. To further support families, a range of enablers and other more general forms of support may need to be provided in order to ensure that caregivers are better able to act on current SUDI prevention advice. Examples might include:

   a. Schemes that support all babies leaving hospital having access to a safe sleeping environment. Examples might include cot hire schemes or assistance through LMCs or social workers to access Work and Income funds for a cot purchase, similar to the processes that support babies having an approved car-seat.

   b. Programmes to offer extra support and guidance to vulnerable families who are most at-risk for SUDI, such as support and guidance offered from a respected elder or community health worker with time assigned to spend with the family to reduce risky behaviour and promote safe sleeping practices.

   c. Other enablers developed following consultation with Māori and Pacific people, review of available evidence and extra research as needed.

As a result of these observations the CYMRC makes the following recommendations.

1.7 Recommendations from the CYMRC on SUDI prevention

The CYMRC recommends:

1.7.1 Policy

1. That the Ministry of Health consolidate within the Child, Youth, and Maternity Policy work-stream all its efforts to prevent SUDI. This would provide greater central cohesion and more support for providers to maximise their impact, while also respecting the need for a plurality of approaches. Likewise, the funding of Ministry of Health contracts to providers must align with this work-streams’ SUDI-related policy goals. Key goals should include:

   15 If the recommendation for research is followed (item 3 below) it is hoped that a variety of safe sleeping solutions may become available, thereby giving families more choice.
a. that the Ministry of Health develop a SUDI Prevention Toolkit, which provides an evidence base for:

i. messages to prevent SUDI

ii. enablers of change that are appropriate to the community targeted

iii. methods of bridging the gap between what is known and what actually happens for infants

The target audience would be DHBs and health professionals working with families. A special focus should be on what works to support vulnerable families in communities with the highest needs, especially Māori.

b. that lead maternity carers and well child services be required to assess for vulnerability to SUDI, share information and personalise support for families at time-appropriate points during pregnancy and in a baby’s first year.

c. systems should be developed to support families better in preventing SUDI and enabling change.

2. That action on smoking cessation, before, during, and after pregnancy, be elevated to a level consistent with its status as a major health concern, especially for Māori and be more clearly linked to prevention of SUDI. DHBs should be required to report the smoking/smokefree pregnancy status of their populations as a requirement of funding agreements. 16

3. Research into SUDI needs to be targeting to fill knowledge gaps, particularly with regard to safe sleeping environments for Māori babies. There is evidence about unsafe sleeping practices but a paucity of evidence about what represents safe sleeping practices and innovations, as well as what practically works to bridge the gap between what is known about safe sleep and what is done to keep infants safe.

1.7.2 District Health Boards

4. That every DHB implement a safe infant sleeping policy:

a. for modelling safe sleeping practices in neonatal and postnatal facilities

b. to ensure safe sleeping arrangements are in place for all babies at every sleep before discharge home

c. to advise on safe strategies for night feeds and settling infants.

5. That DHBs monitor and report on:

a. the continuity of care in early infancy between Lead Maternity Carers, hospital services, Well Child providers and general practitioners

b. the proportion of infants who have a named general practitioner recorded in the National Immunisation Register by four weeks of age (which is one potential performance indicator).

---

16 The new ICD Code Z58.7 Exposure to tobacco smoke that came into force September 2009 could capture this on the Newborn Record.
Protecting infants from SUDI

Babies are safest when they sleep face-up (on the back), with the face clear (plenty of space in front of their face and no pillows), in their own safe sleep space and are smokefree from conception.

<table>
<thead>
<tr>
<th>DO</th>
<th>DO NOT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep baby “smoke free” in the womb and after birth</td>
<td>DO NOT sleep babies in a place where the face can get covered or where they can get trapped or strangled – avoid pillows, soft surfaces, gaps and cords</td>
</tr>
<tr>
<td>Sleep babies on their backs on a firm flat surface not propped – any other position increases risk</td>
<td>DO NOT sleep babies in the same bed or on the same surface as adults who are intoxicated or very tired</td>
</tr>
<tr>
<td>Breast feed</td>
<td>DO NOT sleep in spaces not designed for infant sleep (eg, couches or adult beds)</td>
</tr>
<tr>
<td>Sleep babies in a room with parents/caregivers when the parent/caregiver is also asleep</td>
<td>DO NOT over heat or wrap too tight</td>
</tr>
</tbody>
</table>

Risks of SUDI are reduced if babies sleep alone, not sharing a sleeping surface with anyone (adult or child) while they are under three months of age.

Where infants are more vulnerable, extra efforts are needed to reduce SUDI risks. Always use a safe sleep space that is designed for a sleeping baby (eg, a cot).

Planning ahead for night feeds, unsettled behaviour and social gatherings can prevent any change to unsafe sleeping arrangements – “keep every sleep a safe sleep.”

---


19 Vulnerability is increased if there is exposure to smoking before or after birth, infants are born before 36 weeks gestation, infant birth weight is less than 2500 grams, or there are medical conditions, illness or caregivers intoxicated with any substance.

20 A safe sleep space is a firm mattress, with baby protected from face covering and entrapment and safe from suffocation under a parent or other child. A fact sheet on cot safety is available from: http://www.consumeraffairs.govt.nz/productsafety/consumerinfo/cots.html#PDF.