Confident Conversations; empowering parents to make choices to prevent their baby dying from Sudden Unexpected Death in Infancy

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No conflicts

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Sponsors: Perpetual Guardian & Procare Foundation
Provision of a wahakura or Pepi-pod as part of a safe sleep education programme significantly improves breastfeeding rates.

- Pepi-pod RCT infant age 4-months (any breastfeeding): 54% intervention group vs 32% control group $P = 0.03$ ¹

- Wahakura vs Bassinet RCT at age 6-months (full breastfeeding) 22.5% vs 10.7%, $P = 0.04$ ²


Overview

- What is SUDI
- SUDI messaging
- Calculating the risk
- Confident conversations
- Objective and targeted
How do we support Kate and her partner to prevent SUDI?

Kate is 22 years old. She smokes, no alcohol or drugs. Her partner does not smoke. Her baby is a boy, BW 2850g.

She’s sleeping baby Sam on his side she’s bed-sharing. She’s not sure she wants to continue breastfeeding.
Sudden Unexpected Death in Infancy

Clinical history, death scene investigation, autopsy

No cause identified

W75 Accidental suffocation and strangulation in bed
W78 Inhalation of gastric contents
W79 Inhalation and ingestion of food, causing obstruction of upper respiratory tract

Medical cause
infection, congenital abnormality, arrhythmia, metabolic

Excluded from SUID deaths

Unsafe Sleep

Sleep

Hypoxaemia/hypercarbia mechanisms:
- Airway obstruction: positional asphyxia, wedging, overlaying, gastric contents, foreign bodies
- Reflex apnoea: laryngeal chemoreflex
- Thermal stress: excessive bedding and/or clothing, infection, fever
- Rebreathing: face down, face covered

Failure of Arousal

Abnormal brainstem response

Risk factors: Maternal smoking, prone sleeping, formula feeding, prematurity, low birth weight

Failure of Auto-resuscitation

Inadequate cardio-respiratory response

Bradycardia +/− gasping

Auto-resuscitation

Recovery

Recovery

Vulnerable baby

Death

The SUDI sequence

SUDI - a lack of response to a breathing problem in sleep

Colonisation, Marginalisation, Poverty

Young baby, LBW/SGA, Prone sleep, Smoking, Alcohol, Drugs, Prematurity, Young mother, Formula feeding

Vulnerable baby and Unsafe sleep

SUDI

Prone & side sleeping, Alcohol, Drugs, Bed-sharing, Overheating, Pillows, Face covering
Young baby, LBW/SGA
Prone sleep, Smoking, Alcohol, Drugs, Prematurity, Young mother, Formula feeding

Vulnerable baby and Safe sleep

Alive

Own Baby bed
On back
Face clear
...the advice she received from health professionals was confusing and contradictory, she says.

...Coroner Wallace Bain’s condemnation was not directed toward the mothers of dead babies, it was a "criticism of our system and the information we impart".

NZ Herald 9 July 2016
Effective SUDI Messaging and Interventions

1. Multi-pronged, consistent messaging across multiple levels.

2. Safe sleep interventions should be crafted specifically for higher risk groups.

The challenges
• Too many messages!
• Who is the target audience?
• What is the priority message?
• SUDI risk is not the only consideration.
In an ideal world…

THE SAFE SLEEP SEVEN BEDSHARING SONG
(to the tune of “Row, Row, Row Your Boat”)
No smoke, sober mom
Baby at your breast
Healthy baby on his back
Keep him lightly dressed.
Not too soft a bed
Watch the cords and gaps
Keep the covers off his head
For your nights and naps.


https://www.babycentre.co.uk/x7766/how-can-i-make-co-sleeping-safe
The reality in NZ...


- 65% births, 73% of SUDI (65% births, 73% of Sudden Unexpected Death in Infancy)
- Greatest number of SUDI in the largest birth cohort

- 3% births, 5% of SUDI

Table 4.2: Post-neonatal SUDI mortality (three-year rolling rates per 1,000 live births) by prioritised ethnic category and year of death (rolling three-year periods), Aotearoa/New Zealand 2002–17 (n=764 deaths*)

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Rate per 1000 live births (95% CI)</th>
<th>Deaths 5 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Māori</td>
<td>1.36 (1.11-1.60)</td>
<td>116</td>
</tr>
<tr>
<td>Pacific</td>
<td>1.35 (0.97-1.83)</td>
<td>41</td>
</tr>
<tr>
<td>Non-M Non-PI</td>
<td>0.21 (0.15-0.29)</td>
<td>38</td>
</tr>
</tbody>
</table>

* Excludes one case with unknown ethnicity.

nMnP = non-Māori, non-Pacific.

Maternal smoking & bed-sharing significantly increases risk

The combination of bed sharing and maternal smoking leads to a greatly increased risk of sudden unexpected death in infancy: the New Zealand SUDI Nationwide Case Control Study. NZ Med. J. 2nd June 2017, Volume 130 Number 1456.

Table 2: Interaction between maternal smoking in pregnancy and bed sharing on risk of SUDI.

<table>
<thead>
<tr>
<th>Smoking</th>
<th>Bed sharing</th>
<th>Cases</th>
<th>Controls</th>
<th>Univariable OR (95%CI)</th>
<th>Multivariable OR (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
<td>21 (17.1)</td>
<td>138 (53.5)</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>No</td>
<td>Yes</td>
<td>11 (8.9 )</td>
<td>29 (11.2)</td>
<td><strong>2.75 (1.17, 6.48)</strong></td>
<td>1.59 (0.52, 4.87)</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>32 (35.2)</td>
<td>74 (28.7)</td>
<td><strong>2.64 (1.33, 5.26)</strong></td>
<td>1.91 (0.77, 4.72)</td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>59 (48.0)</td>
<td>17 (6.6)</td>
<td><strong>31.1 (14.0, 69.3)</strong></td>
<td><strong>32.8 (11.2, 95.8)</strong></td>
</tr>
</tbody>
</table>

Edwin A Mitchell, John MD Thompson, Jane Zuccollo, et al. The combination of bed sharing and maternal smoking leads to a greatly increased risk of sudden unexpected death in infancy: the New Zealand SUDI Nationwide Case Control Study. NZ Med. J. 2nd June 2017, Volume 130 Number 1456.
There is a trade-off when messaging about bed-sharing.
Effective enough?

Figure 4.1: Post-neonatal SUDI mortality (number of deaths and rates per 1,000 live births) by year of death, Aotearoa/New Zealand 2002–17 (n=765 deaths)

NO one set of SUDI prevention messages works for everyone.
## Risk factors

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>Multivariate Odds Ratio</th>
<th>95% Confidence Intervals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal and paternal smoking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>1.5</td>
<td>1.2-2.1</td>
</tr>
<tr>
<td>Father</td>
<td>1.1</td>
<td>0.8-1.4</td>
</tr>
<tr>
<td>Both</td>
<td>2.9</td>
<td>2.3-3.6</td>
</tr>
<tr>
<td>Bed-sharing* &lt; 3 months' age</td>
<td>2.7</td>
<td>1.4-5.3</td>
</tr>
<tr>
<td>Not breastfeeding</td>
<td>1.5</td>
<td>1.2-1.8</td>
</tr>
<tr>
<td>Sleep position</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Side</td>
<td>1.5</td>
<td>1.2-2.1</td>
</tr>
<tr>
<td>Prone</td>
<td>10.5</td>
<td>7.5-14.6</td>
</tr>
<tr>
<td>Maternal drug and or alcohol use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol (&gt; 2 units in last 24 hours)</td>
<td>4.8</td>
<td>2.6-8.9</td>
</tr>
<tr>
<td>Illegal drugs since baby born</td>
<td>11.5</td>
<td>2.2-59.5</td>
</tr>
<tr>
<td>Male gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Matched studies</td>
<td>0.8</td>
<td>0.6-1.1</td>
</tr>
<tr>
<td>Unmatched studies</td>
<td>1.6</td>
<td>1.3-1.9</td>
</tr>
<tr>
<td>Ethnicity ‘non-white’</td>
<td>1.5</td>
<td>1.1-1.9</td>
</tr>
<tr>
<td>Low birth weight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2500-3499g</td>
<td>1.7</td>
<td>1.4-2.0</td>
</tr>
<tr>
<td>2000-2499</td>
<td>4.2</td>
<td>2.9-6.0</td>
</tr>
<tr>
<td>&lt; 2000g</td>
<td>9.6</td>
<td>6.2-14.7</td>
</tr>
<tr>
<td>Younger maternal age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26-30 years</td>
<td>1.9</td>
<td>1.5-2.3</td>
</tr>
<tr>
<td>21-25</td>
<td>3.0</td>
<td>2.4-3.8</td>
</tr>
<tr>
<td>19-20</td>
<td>7.7</td>
<td>5.2-11.4</td>
</tr>
<tr>
<td>18 and under</td>
<td>9.1</td>
<td>5.9-14.1</td>
</tr>
<tr>
<td>Higher birth order</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>2.3</td>
<td>1.9-2.9</td>
</tr>
<tr>
<td>5 or more</td>
<td>7.7</td>
<td>5.3-11.3</td>
</tr>
<tr>
<td>Pacifier use</td>
<td>0.4</td>
<td>0.3-0.5</td>
</tr>
<tr>
<td>Mothers marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>1.9</td>
<td>1.5-2.4</td>
</tr>
<tr>
<td>Not sleeping in same room as parent</td>
<td>2.4</td>
<td>2.0-2.9</td>
</tr>
</tbody>
</table>


Combined data from 5 case control studies: ECAS, Scottish, New Zealand, Irish, GeSID

Risk factors multiply and some interact
An opportunity for individualised SUDI Risk Assessment

- Carpenter et al. SUDI case control study meta-analysis 2013
- SUDI Risk App. Mitchell 2014
- Safe Sleep Calculator – A strategic approach to SUDI prevention Care 2018-19
- Safe Sleep Calculator Webform Primary Care pilot McIntosh 2016-17
The Safe Sleep Calculator

1. Maternal age
2. Parity
3. **Ethnicity of infant**
4. Gender
5. **Infant age**
6. Birthweight
7. Twin/multiple
8. Breastfeeding
9. Maternal smoking
10. Father/partner smoking
11. Alcohol use
12. Illicit drug use
13. Sleep room
14. Sleep position
15. Sharing sleep surface (bed-sharing)
Healthcare provider focus groups

“I didn’t have a particular way of talking about it. People asked me about it [SUDI] if they were worried about it ... But it wasn’t actually part of what I did at that check”

“Just showing them if you did this, this would make this difference and as you are going through it step by step and just encouraging them to think about making those changes ... but even making three of the five changes is going to make a difference.”

“... and the higher risk is the more you want to talk about what the possibilities are of trying do something about it.”

“Sometimes we think that we are overwhelmed with the .. problems that they bring, the Pandora box opens up...”
Seven Māori and Pacific focus groups facilitated by Māori and Pacific health researchers

- Wanted to know if their baby was at high risk
- Feared being judged in the process
- Wrap around support for positive change that includes the family
Training for behaviour change conversations

- Trusted, non-judgemental care
- Same room, on back, own baby bed
- Breastfeeding
- Smokefree
- Alcohol free
- Drug free

SUDI Protective Care

SUDI Risk Assessment

Motivational Interviewing
## Safe Sleep Calculator Algorithm validation

<table>
<thead>
<tr>
<th></th>
<th>NZ SUDI Nationwide Case Control study 2012-15</th>
<th>Safe Sleep Calculator Data 2016-18</th>
<th>NZ population data 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SUDI Cases</td>
<td>Controls</td>
<td></td>
</tr>
<tr>
<td>Mean SSC score per 1000</td>
<td>8.4</td>
<td>0.6</td>
<td>0.1</td>
</tr>
<tr>
<td>Mean maternal age (years)</td>
<td>25.3</td>
<td>28.7</td>
<td>29.4</td>
</tr>
<tr>
<td>Mean Birth weight (g)</td>
<td>3158</td>
<td>3466</td>
<td>3463</td>
</tr>
<tr>
<td>Side/front sleeping (%)</td>
<td>34.1</td>
<td>16.7</td>
<td>6.6</td>
</tr>
<tr>
<td>Breastfeeding (%)</td>
<td>89.8</td>
<td>96.1</td>
<td>79.4</td>
</tr>
<tr>
<td>Bed sharing (%)</td>
<td>57.5</td>
<td>17.8</td>
<td>9.8</td>
</tr>
<tr>
<td>Maternal smoking (%)</td>
<td>74.2</td>
<td>35.3</td>
<td>17.3</td>
</tr>
</tbody>
</table>

Mitchell E, Thompson J, Zuccollo J *et al.* The Combination of bedsharing and maternal smoking leads to a greatly increased risk of sudden unexpected death in infancy: the New Zealand SUDI Nationwide Case Control Study.
80% of SUDI in 21% of higher risk population (higher risk = absolute risk ≥0.3/1000)

AOC 0.86
Aims:

• Ensure all families who have a baby at higher risk know that their baby is at increased risk and are therefore empowered to act to reduce risk.

• Targeted SUDI prevention support enables families to reduce modifiable SUDI risk.
Co-design of SUDI Protection Care

**Maternity care**
- Data
- Review maternity care

**Parents said:**
- ‘Who’ and ‘how’ important
- Non-judgemental
- Wanted to know risk
- Support for positive changes
- Cultural considerations
  - Training

**Midwifery, Neonates DHB said:**
- Equity through focussed care
- Scale – big enough to be effective
- Cons
- Avoid

**Community providers said:**
- Sufficient
  - Navigator role
- Good
  - Communication
- Work
  - Collaborative
- Addressing need
- Culturally competent

**Generate Information**
Use & Critique
Inform
Utilise

**Develop Framework for Exploration**

- Analyse & look for patterns
- Develop Framework for Exploration
- Listen
- Watch & Try

**Define needs**
Interact

**Inform**

**Utilise**

**Co-design of SUDI Protection Care**
Creating the SUDI protection care ecosystem

Develop a SUDI Protection model of care

- Understanding the services
- Virtual integration of providers
- Thinking about workflow
- Minding the ‘gaps’
- Distributing baby beds
- Building the software
- Implementation planning
- Monitoring and evaluation

Safe use of digital technology

- Cloud Risk Assessment
- Privacy Impact assessment
1. Midwife login to webform
2. Registers mother (& baby if born)
3. Safety-net for late presenters, prems
4. Midwife prompted to complete full SUDI risk after baby is born.
SUDI risk assessment

1. Speech bubbles – provide suggested conversation and information
2. Questions adapted from qualitative feedback
Individualised SUDI Protection Plan

1. Specific for mother/baby dyad
2. Enables mother and family to make choices about behaviour change
3. Communicated to family doctor, Well Child visiting nurse, and to hospital health record
Confident conversations: How about the bed-sharing?

Mother age 29 years, BW 3600, baby girl, breastfed, 2 siblings, sleeping on back, bed-sharing.
Quick referrals to wrap-around services

Key-worker model & Wrap-around services:

1. WellChild nurse
2. Baby bed
3. Smoking cessation
4. Breastfeeding support
5. Immunisation
6. Healthy Housing
7. Parenting support
8. Cultural support
9. Mental health
10. Contraception

SUDI Risk Assessments
No risk assessments recorded

SUDI Protection Care Required:
- Breastfed baby, if able.
- Sleep baby in their own baby bed (Wahakura, Peplomat, bassinet, cot)

<table>
<thead>
<tr>
<th>Care Plan</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safe-sleep baby bed</td>
<td>Requested</td>
</tr>
<tr>
<td>Smoerkfree</td>
<td>Not Actioned</td>
</tr>
<tr>
<td>Healthy Housing</td>
<td>Requested</td>
</tr>
<tr>
<td>Breastfeeding Support</td>
<td>Not Actioned</td>
</tr>
<tr>
<td>Parenting Support</td>
<td>Not Actioned</td>
</tr>
<tr>
<td>Fauau Ota Pacific Health Support</td>
<td>Not Actioned</td>
</tr>
<tr>
<td>Maternal mental health services</td>
<td>Not Actioned</td>
</tr>
<tr>
<td>Contraception</td>
<td>Not Actioned</td>
</tr>
<tr>
<td>Whanau Ora</td>
<td>Not Actioned</td>
</tr>
<tr>
<td>Homecare Nurses</td>
<td>Not Actioned</td>
</tr>
</tbody>
</table>
Pre/post implementation evaluation

Implementation Outcomes:

1. Proportion of birth cohort with safe sleep calculator assessment
2. Proportion of higher risk infants referred for SUDI wrap-around-care pathway
3. Proportion of infants at higher risk (≥0.3/1000) completing SUDI wrap-around-care

SUDI Prevention Care Programme Outcomes

1. Measurement of pre and post implementation individual level modifiable SUDI factors (sleep position, bed-sharing, non-room sharing, non-breastfeeding, non-immunization, maternal smoking, paternal smoking, maternal alcohol and drug use).
Key Points

- SUDI messages are complex because SUDI risk is complex
- The Safe Sleep Calculator
  - Objective
  - Targeted SUDI protection appropriate for population ‘at risk’
- Behaviour change conversation is critical
How about Kate and her baby Sam?

Risk at birth for infant for mother aged 22 years, first baby, single, male infant, birthweight 2850g, not breastfeeding, bed sharing, baby side sleeping, mother smokes, no alcohol or drugs.

- All risks modified: 0.24
- Not smoking only: 2.8
- Not bedsharing only: 1.21
- Back sleeping only: 7.49
- Breastfeeding only: 7.51
- Total risk: 14.78

Risk per 1000 live births
Em. Prof. Ed Mitchell

Assoc. Prof. John Thompson

Prof. Robert Carpenter (deceased)

The families and health practitioners who have provided their time and insights for this work.

Whatarangi family for their images.

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