Management of Sudden Unexpected Death in Infancy (SUDI)

Summary This Policy Directive outlines mandatory requirements for management of Sudden Unexpected Death in Infancy (SUDI) in NSW Health facilities. The Policy also outlines the response of NSW Health in the context of the NSW Government response to SUDI, which includes the NSW Coroner and Police.

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Distributed to Ministry of Health, Public Health System, Divisions of General Practice, Government Medical Officers, NSW Ambulance Service, Private Hospitals and Day Procedure Centres, Tertiary Education Institutes

Audience All Staff and Executives of Public Health Organisations;medical records;All Pathology Laboratory Staff;Ambulance

Secretary, NSW Health

POLICY STATEMENT

MANAGEMENT OF SUDDEN UNEXPECTED DEATH IN INFANCY (SUDI)

PURPOSE

This Policy Directive outlines the mandatory requirements for management of Sudden Unexpected Death in Infancy (SUDI) in NSW Health facilities. It also outlines the role of NSW Health in the context of the NSW Government response to SUDI which includes the NSW Coroner and Police.

MANDATORY REQUIREMENTS

SUDI is a reportable death under the Coroners Act 2009.[1] Most SUDI deaths occur in the community and are brought to their local emergency department, however SUDI can also occur in hospital. NSW Health's role in management of SUDI includes that local health districts and specialty health networks must:

- Ensure that local policies that guide management of SUDI are easily accessible for staff. This includes emergency departments as well as other areas that SUDI may occur such as maternity, paediatrics and intensive care. Information for staff on how to access locally networked paediatric services should be included.
- Ensure that adequate resources and education are provided so that staff can meet the needs of the infant and the parents/carers, and that parents/carers have access to expert medical advice, nursing care and social work. If necessary, these can be accessed via locally networked paediatric services. In some instances the situation may warrant transfer of the infant to a higher level facility.
- Nominate a hospital contact who will coordinate the SUDI response for example a social worker or nurse. This health professional will provide support to the parents/carers and coordinate completion of documentation required by NSW Health. A list of roles and responsibilities of agencies and staff involved in the SUDI response is at Section 6.1 Response to Sudden Unexpected Death in Infancy (SUDI) - Roles and Responsibilities.
- Ensure that the infant's medical history is completed by a senior medical staff member and documented in the health care record. A checklist to support this is at Section 6.2 Medical History Guide – Sudden Unexpected Death in Infancy. A copy of the infant's health care record must be forwarded to Forensic Medicine (NSW Health Pathology) within 24 hours of the infant's death.
- Ensure that support is available for staff who provide care to infants and parents/carers who have experienced SUDI. If necessary, this can be accessed via locally networked paediatric services.
- Ensure there are processes to maintain the quality of care and patient experience of SUDI cases. This includes incident notification, documentation, case discussion that includes the perspective of parents/carers and staff and implementation of any identified improvement opportunities.

1. NSW Health Policy Directive Coroners Cases and the Coroners Act (PD 2010_054 section 5)

IMPLEMENTATION

Local health district chief executives are responsible for:

- Assigning responsibility, personnel and resources to implement this policy.
- Establishing mechanisms to ensure the mandatory requirements are applied, achieved and sustained as usual processes in the instance of a SUDI. This should include nomination of an executive sponsor.
- Ensuring that any local policy reflects the requirements of this policy and is written in consultation with the hospital executive, clinical governance unit and clinical staff.

REVISION HISTORY

Version	Approved by	Amendment notes
July-2019 (PD2019_035)	Deputy Secretary, Health System Strategy and Planning	Updated policy directive replaces PD2008_070 Death Management of Sudden Unexpected Death in Infancy.

ATTACHMENTS

1. Management of Sudden Unexpected Death in Infancy (SUDI): Procedure.

Management of Sudden Unexpected Death in Infancy (SUDI)

NSW GOVERNMENT Health

PROCEDURES

Issue date: July-2019

PD2019_035

CONTENTS

1 INTRODUCTION

1.1 About This Document

Every year in NSW between 40 and 50 infants under the age of 12 months die suddenly and unexpectedly, with a cause unable to be determined immediately.[1] This procedure document explains and outlines NSW Health's role in the management of Sudden Unexpected Death in Infancy (SUDI) and should be used:

- When an infant is brought to a NSW Health facility, following a sudden, unexpected death
- When an infant is brought to a NSW Health facility after a 'near SUDI' and dies in hospital
- When there is a sudden, unexpected infant death during a hospital admission.

NSW Health's role in the management of SUDI includes:

- Care of the infant and the parents/carers
- Completion of the infant's medical history, with a copy of the infant's health care record forwarded to Forensic Medicine (NSW Health Pathology) within 24 hours of the infant's death
- Completion of the post mortem examination and liaison with other agencies involved in the Coronial process
- Participation in the NSW Government response to SUDI. A flowchart that outlines NSW Health's role in the SUDI response can be found at Section 6.1 Response to Sudden Unexpected Death in Infancy (SUDI) - Roles and Responsibilities.

The SUDI response outlined in this document aims to:

- Establish where possible, the cause of death and assist parents/carers and their families to understand how and why the death may have occurred
- Provide parents/carers with information about any potential health risks for surviving family members
- Ensure timely completion of the infant's medical history. A checklist to support completion of the infant's medical history is attached at Section 6.2 Medical History Guide – Sudden Unexpected Death in Infancy
- Support Forensic Medicine (NSW Health Pathology) to complete the post mortem examination, establish the cause of death and provide information for future SUDI prevention activities of NSW Health and other agencies
- Ensure that statutory obligations are met.[2] This includes assisting the NSW Coroner and Police in their role of investigating the infant's death.

1 NSW Child Death Review Team. NSW Child Death Review Team Annual Report 2017-18. Sydney: NSW Ombudsman; 2018.

2 NSW Health PD 2010_054 Coroner's Cases and the Coroners Act 2009

1.2 Changes From the Previous Policy

1. This Policy Directive emphasises the need to provide parents/carers with any support they may need, including medical and nursing care, social work and referral to other services such as Red Nose Grief and Loss
2. All episodes of SUDI are to be accepted and managed in hospital, regardless of whether the infant's death occurred in hospital or prior to presentation. Facilities without an onsite paediatrician, paediatric nurse or social worker and can access support via their locally networked paediatric services. For more information about locally networked paediatric services see GL2017_010 NSW Paediatric Service Capability Framework
3. Local Health Districts/Specialty Health Networks (LHDs/SHNs) are not required to have facilities designated to respond to SUDI. It is expected that all facilities are able to initiate a SUDI response
4. The SUDI Medical History Protocol has been revised. For more information see Section 6.2 Medical History Guide – Sudden Unexpected Death in Infancy (SUDI)
5. Information about requirements of a post mortem examination relates to Forensic Medicine and is therefore out of the scope for this policy.

1.3 Definitions

Sudden Unexpected Death in Infancy (SUDI):

The sudden, unexpected death of an infant:

- Less than 12 months of age
- And where the cause was not immediately apparent at the time of death.

This definition excludes infants who die unexpectedly in misadventures due to external injury (such as transport incidents) and accidental drowning.[3]

Sudden Infant Death Syndrome (SIDS):

The sudden, unexpected death of an infant:

- Less than 12 months of age
- With onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation including performance of a complete autopsy, review of the circumstances of the death and the clinical history.[4]

3 NSW Child Death Review Team. NSW Child Death Review Report 2015. Sydney: NSW Ombudsman; 2015.

4 Krous HF, Beckwith JB, Byard RW et al. Sudden infant death syndrome and unclassified sudden infant deaths: A definitional and diagnostic approach. Pediatrics 2004;114:234-8. https://doi.org/10.1542/peds.114.1.234

2 CLINICAL GOVERNANCE

2.1 Incident Notification

Where a sudden, unexpected death of an infant death occurs in the community and the infant is brought to a NSW Health facility, notification in the Incident Information Management System (IIMS) is not required and the presentation is to be managed as a SUDI, as outlined in this Policy.

As per NSW Health PD2014_004 Incident Management Policy all deaths in hospital that are unrelated to the natural course of illness must be reported promptly in the IIMS. The Ministry of Health must be notified of the incident via a Reportable Incident Brief (RIB) within 24 hours.

2.2 Health Care Record

Where a post mortem is to be conducted under the direction of the Coroner, the forensic pathologist (NSW Health Pathology) must have access to a copy of the infant's health care record. The health care record should be forwarded within 24 hours. For more information see 4.8 Management of the Infant's Health Care Record.

2.3 Case Review

Following an episode of SUDI, by the next business day, the senior medical officer overseeing the case should review the infant's health care record and address any outstanding issues, including any referrals or follow-up for the parents/carers have been arranged.

LHDs/SHNs should also review all SUDI cases, this may be as part of a mortality and morbidity meeting. Where possible, other agencies involved in management of the case should be invited such as Forensic Medicine (NSW Health Pathology), Ambulance and Police.

Forensic Medicine (NSW Health Pathology) may also invite clinical staff to participate in a multi-disciplinary review.

2.4 Staff Debrief

All staff involved in an episode of SUDI should be offered the opportunity to debrief, both with other staff and individually, if preferred, and be assisted in accessing other support services where required.

3 GENERAL PRINCIPLES

SUDI is a tragic event likely to create an intense response from the parents/carers and their families as well as health professionals. As there is no 'appropriate' response to an overwhelming experience such as SUDI, behaviour of the parents/carers and their families may seem unusual. The immediate care and support provided by health professionals can make a significant difference to parents/carers and their family's grief.

Regardless of the NSW Health facility that the SUDI case presents to, appropriate physical space that allows for privacy should be accessible so that discussions between the infant's parents/carers and staff can occur and that the SUDI response can be managed.

As with all episodes of patient care, where a SUDI case is managed in a NSW Health facility, accurate documentation in the health care record is required. For more information see NSW Health PD2012_069 Health Care Records – Documentation and Management.

4 PROCEDURE FOR MANAGEMENT OF SUDI

SUDI cases will present in various ways, all of which require initiation of the SUDI response outlined in this document. This includes unresponsive or deceased infants brought by their parents/carers or by Ambulance, with or without Police involvement. Infants may be pronounced deceased prior to arrival, on arrival to the Emergency Department (ED), or after admission. Each of these presentations is considered a SUDI case and should be managed as outlined below.

The roles and responsibilities of each agency (Health, Police, Ambulance, Forensic Medicine and the Coroner) has been summarised at Section 6.1 Response to Sudden Unexpected Death in Infancy (SUDI) - Roles and Responsibilities.

4.1 Sudden Unexpected Infant Death in the Community

- Any infant that dies suddenly and unexpectedly in the community is to be taken to their nearest ED
- On arrival, any immediate care should be provided as per usual ED practice and the ED senior medical officer and nurse in charge notified
- The ED senior medical officer is to verify the infant's death (extinction of life) and let the parents/carers know. The infant should be registered as a patient and admitted
- A decision is to be made as to who will coordinate immediate care of the infant and the parents/carers, this may be a senior nurse or social worker
- The infant's medical history must be completed by a senior medical officer, using the Medical History Guide – Sudden Unexpected Death in Infancy (SUDI) (Section 6.2). This should be the on-call paediatrician. If a paediatrician is not available, the locally networked paediatric service should be contacted to determine who will complete the infant's medical history

- Where the infant's death occurs outside of business hours, and social work is not available, clinical staff should provide a handover to social work by the next business day.

4.2 Sudden Unexpected Infant Death in Hospital

- Where a SUDI death occurs in a NSW Health facility, the Admitting Medical Officer (AMO) and nurse in charge of the shift are to nominate a staff member to coordinate care of the infant and the parents/carers, this may be a senior nurse or social worker
- The infant's death (extinction of life) is to be verified and the parents/carers informed
- The infant's medical history must be completed by a senior medical officer, using the Medical History Guide – Sudden Unexpected Death in Infancy (SUDI) (Section 6.2). This should be the AMO or on-call paediatrician. If a paediatrician is not available, the locally networked paediatric service should be contacted to determine who will complete the infant's medical history
- Where the infant's death occurs outside of business hours, and social work is not available, a handover from clinical staff to social work should be provided by the next business day.

4.3 Reporting a Death to the Coroner

As per NSW Health PD2010_054 Coroner's Cases and the Coroner's Act 2009 and IB2010_058 Coronial Checklist sudden and unexpected deaths are reportable to the Coroner.

Where any doubt exists as to whether a death should be reported, call the duty forensic pathologist or the clinical nurse consultant at the relevant Forensic Medicine (NSW Health Pathology) facility:

Business hours (8am - 4:30pm):

- Sydney (Lidcombe): 02 9563 9000
- Wollongong: 02 4222 5466
- Newcastle: 02 4935 9700

After hours calls should be directed to the Lidcombe Forensic Medicine facility. The relevant duty pathologist will be notified by the Lidcombe Forensic Medicine staff.

The State Coroner's Court may also be contacted for advice on 02 8584 7777.

Where a death is reportable to the Coroner, a death certificate must not be issued. Verification of death (extinction of life) is to be documented in the Report of a Death of a Patient to the Coroner (Form A) (State Form SMR010.510). For more information see NSW Health PD2015_040 Death – Verification of Death and Medical Certificate Cause of Death.

4.3.1 Police

Where an infant is brought to a NSW Health facility without any contact with Police, Police should be notified of the death via the Police Area Command so that Police can notify the Coroner. Police will liaise with Family and Community Services where required.

If the infant is brought to a NSW Health facility by Police, the senior medical officer in charge of the shift or their delegate should take a handover, including whether the death has been reported to the Coroner and whether the parents/carers have any objections to a post mortem examination.

Once the infant's death has been confirmed, Police, in their role representing the Coroner, are responsible for the care of the infant's body, timely transfer of the infant to the appropriate Forensic Medicine (NSW Health Pathology) facility and investigation of the infant's death. Police will organise formal identification of the infant, this is to occur before the infant's body leaves the hospital.

Where there is uncertainty or concerns about the roles and expectations of Police in a NSW Health facility, the senior medical officer and nurse in charge should discuss their concerns with the most senior attending Police officer. Any ongoing concerns should be escalated via the Hospital Executive and the Police Area Command.

4.3.2 Notifying Forensic Medicine (NSW Health Pathology)

Once Police have been notified, the senior medical officer must inform the duty forensic pathologist or clinical nurse consultant at the relevant Forensic Medicine of the SUDI death as soon as possible. Ideally this should be the senior medical officer who completes the infant's medical history.

Forensic Medicine should also be informed of any existing pathology samples taken prior to death, such as blood and urine, as these samples may be required for further testing as part of the Coronial investigation process. Contact details for Forensic Medicine are in Section 4.3.

4.4 Care of the Infant's Body

As per NSW Health PD2010_054 Coroner's Cases and the Coroner's Act 2009 the hospital in whose care the infant's body is in, is responsible for the safe custody of the body until it is removed by Police. This implies that the infant's body will be in the same condition as when the death occurred and includes no interference with cannulas, incisions or dressings.

All contact with the infant's body must be supervised by Police or a health professional. From arrival to hospital and/or the time of death, no evidence relating to the possible cause of the infant's death is to be altered. However parents/carers may stay with their infant, under supervision, and with support of the hospital contact person. The parents/carers may hold their swaddled infant, however handling of the infant's body should be limited. The parents/carers will be able to see their infant again after the post-mortem examination has taken place.

Hand/foot prints and locks of hair must not be taken until after the post mortem. Parents/carers can request that hand/foot prints and locks of hair are taken after the post mortem by the Forensic Medicine social worker.

4.5 Initial Care of the Parents/Carers

The hospital contact person is to coordinate care of the parents/carers, including organising a private space for discussions, access to toilets and refreshments, introductions to staff members, contacting of family/friends and access to any services they may need such as interpreter services, Aboriginal Liaison Services and religious/cultural organisations. Where parents/carers require medical review such as lactation advice or referral to mental health services, this should be discussed with the senior medical officer overseeing the SUDI response. See also Section 6.3 Factsheet - Breast care after the death of an infant.

On arrival to hospital parents/carers are to be informed of each step in the process, using terminology they can understand, and be given the opportunity to ask questions, including that:

- The circumstances of the infant's death means that the death is reportable under the Coroners Act.[5] Therefore any contact with the infant must be supervised by a health professional (or Police) at all times
- A comprehensive medical history of the infant and family members will be taken by a senior medical officer, while the infant's body is in hospital, to assist with establishing the cause of death
- The Police, in their role representing the Coroner, will likely ask questions about the circumstances of the infant's death and request that a next of kin formally identifies the infant's body
- The Police will explain the coronial process and provide them with a copy of the Initial steps after a death is reported to the Coroner brochure. Information provided should include:
    - That the purpose of the post mortem examination is to establish the cause of death
    - That the results of the post mortem may benefit surviving family members including siblings, for example by identifying any genetic diseases
    - Details of where the post mortem will occur
- The Coroner must be notified of objections to the post mortem. If the parents/carers decide to object to the post mortem:
    - The Coroner must be made aware of objections to the post mortem. If health staff become aware of objections to the post mortem, Police should be informed. Objections to the post mortem should be recorded in the infant's health care record
    - Assistance in exploring the objection should be offered, further information can be sourced from the social worker at the appropriate Forensic Medicine facility

5. NSW Health PD 2010_054 Coroner's Cases and the Coroners Act 2009

- If the parents/carers object to a post mortem, they will be contacted by a representative from the Coronial Information and Support Program to discuss the objection and post mortem

- The Forensic Medicine social worker will contact the parents/carers by the next business day after the infant's body is admitted to the Forensic Medicine facility. Information and support about the coronial process and viewing of the infant's body can then be discussed
- A representative from the Coronial Information and Support Program may contact the parents/carers following the post mortem to discuss any organ retention
- A Forensic Medicine social worker will contact the parents/carers to provide interim results of the post mortem.

4.5.1 Initial Care of Siblings

SUDI presentations are particularly difficult when siblings of the infant have witnessed the death, discovery or resuscitation attempts of the infant. The assessment and care of surviving siblings, who may also present to hospital, is an important part of care. LHD/SHN social work should be able to provide resources and referrals to services that can provide support for siblings experiencing grief and loss, such as Red Nose Grief and Loss.

4.6 Completion of the Infant's Medical History

The Medical History Guide - Sudden Unexpected Death in Infancy (SUDI) (Section 6.2) is to be completed by a senior medical officer, as soon as possible after the infant's death. This should be the on-call paediatrician. If the paediatrician is not available, the senior medical officer should contact the locally networked paediatric service to determine who will complete the infant's medical history.

The Medical History Guide - Sudden Unexpected Death in Infancy (Section 6.2) includes details about the infant's health, parents/carers and events in the hours leading up to the infant's death, including the exact position the infant was found and the response of the parents/carers. Some questions may seem intrusive however they relate to known risks for infant mortality and may assist with establishing the cause of death. Where possible, information provided by the parents/carers should be recorded verbatim. Parents/carers should be given the opportunity to ask questions and discuss any concerns that they have.

It is recommended that a second staff member, ideally the hospital contact person, is present throughout the discussion with the parents/carers, about their infant's medical history. If you choose to include Police as observers during the medical history discussion, it is recommended that roles are agreed on before the discussion starts. Parents/carers should be reassured that Police presence does not indicate an assumption of implication of the death of the infant.

Details of those present during the discussion should be documented in the health care record.

4.6.1 Child Protection and Wellbeing

There are cases of SUDI that are the result of a non-accidental injury or neglect, therefore the safety and care of any children the parents/carers are responsible for must be considered. Care should be provided as per NSW Health's PD2012_007 Child Wellbeing and Child Protection Policy.

Where there are concerns for the safety of any children the parents/carers are responsible for see:

- NSW Mandatory Reporter Guide
- Child Protection Helpline 132 111 (Family and Community Services).

NSW Health Child Wellbeing Units 1300 480 420 (Mon - Fri 8:30am - 5pm) can also be contacted for advice.

4.6.2 Screening for Metabolic and Genetic Diseases

In all SUDI cases, the senior medical officer should refer the infant's parents and siblings to their local GP for an ECG. More information can be found in NSW Health's Management of the Death of a Child in Hospital Resource.

The senior medical officer is to consider any conditions that may have implications for surviving family members for example metabolic disease or cardiac dysrhythmia. Features of possible genetic problems include a history of sudden, unexpected death in family members, recurrent syncope, epilepsy and drowning. If there are concerns, the medical officer should contact the relevant medical specialist about possible investigations of the infant and/or family members.

As the infant's death is reportable to the Coroner, no samples of any kind can be taken after death without the permission of the Coroner. If there is a request for peri-mortem specimen collection, call the forensic pathologist at the relevant Forensic Medicine facility. For contact details see Section 4.3.

4.7 Role of the GP

The paediatrician or senior medical officer is to contact the local GP to:

- Inform them of the infant's death
- Discuss any relevant information about the infant and the parents/carers
- Discuss investigations required, for example an ECG on the infant's parents and siblings
- Discuss advice provided about lactation
- Offer assistance with support and referral for the infant's parents/carers

4.8 Management of the Infant's Health Care Record

As per PD2010 054 Coroner's Cases and the Coroner's Act where a post mortem is to be conducted under the direction of the Coroner, the forensic pathologist must have access to a copy of the health care record as soon as possible.

The hospital is responsible for providing a copy of the health care record to the Coroner. Release of copies of health care records should be handled by the medical records department or their delegate. The health care record may be sent with the infant's body but should be collated, packaged and forwarded in a sealed envelope. Records should be sent to Forensic Medicine within 24 hours of the infant's death.

Admission documentation, the infant's medical history, the Ambulance clinical record, records of any medications given and the infant's growth charts should be sent to Forensic Medicine as part of the infant's health care record.

4.8.1 Following Transfer to Forensic Medicine (NSW Health Pathology)

Agencies that request a copy of the infant's health care record, including Forensic Medicine and Police, after the infant's body has been transferred to Forensic Medicine, should be referred to the hospital's medical records department.

If the infant's health care record is not received by Forensic Medicine within 24 hours of the infant's death, Forensic Medicine are to contact the hospital's medical record department.

Where a copy of the infant's medical history has not been received or further information is required, Forensic Medicine is to contact the senior medical officer who completed the infant's medical history. If the senior medical officer is not able to be contacted, the Director of Medical Services/Administration of the hospital or facility should be contacted.

4.9 Departure From the Hospital or Health Care Facility

Before parents/carers leave the hospital or health care facility, the hospital contact person should confirm any appointments made and discuss with the parents/carers notification of other health professionals previously involved in the infant's care.

Parents/carers may want to nominate a family member to act as a contact to assist with decision making on their behalf. Information, both written and verbal, about how to access further support and advice should also be provided such as:

- Child and Family Health Services
- Their local GP
- A medical specialist
- Mental Health Services
- Other health services such as the Aboriginal Maternal and Infant Health Service or NSW Refugee Health Service
- Red Nose Grief and Loss.

Practical assistance and advice should be offered to parents/carers including arranging transport home, care of siblings and funeral arrangements. Note parents/carers should not set a date for their infant's funeral until they have made contact with the Forensic Medicine social worker.

A representative from the hospital or health care facility overseeing care of the infant and the parents/carers should contact the parents/carers within a week of the infant's death, to offer support and confirm any referrals have been organised. This may be the social worker, the hospital contact person or the senior medical officer.

4.10 Forensic Medicine (NSW Health Pathology)

Once parents/carers have had the opportunity to spend time with their infant and the infant's medical history is complete, Police will arrange for the infant's body to be transferred to the appropriate Forensic Medicine facility. This should occur as soon as possible as extended delays can impact the post mortem examination and therefore timing of the report. Police arrange transfer of the infant's body via a government contractor, there is no cost for the transfer.

The hospital contact person should provide a handover to the Forensic Medicine social worker where the post mortem will occur. Contact details of the Forensic Medicine (NSW Health Pathology) social worker should be given to the parents/carers prior to transfer of the infant's body.

The Forensic Medicine social worker will:

- Accept a handover from the hospital contact person (usually by email)
- Contact the parents/carers to confirm that the infant's body has been admitted to the facility (by the next business day).

Forensic Medicine social work is available during office hours (8:00am to 4:30pm) at all sites. After hours social work service is available as follows:

- Sydney: 6pm - 10pm on weekdays, 8am - 8pm on Saturdays and Sundays
- Newcastle: 1pm - 5pm on Saturdays and Sundays
- Wollongong: no after-hours social work support is available however the Wollongong Hospital social work team may accommodate requests for viewings after hours.

While the Coronial process is ongoing, up until after the final post mortem report has been discussed, parents/carers who have experienced the sudden unexpected death of an infant can access support, advice and referral to other services from Forensic Medicine social work.

4.11 The Post Mortem Examination

A post mortem (or autopsy) is a detailed examination of a body by a doctor who has training in this field. A post mortem is requested by the Coroner to inform a balanced, accurate finding regarding the cause of death. In NSW, all post mortem examinations after a SUDI death are undertaken at one of the three Forensic Medicine facilities, in Sydney, Wollongong or Newcastle.

As per Section 4.5 Initial Care of the Parents/Carers the Forensic Medicine social worker will contact the parents/carers to provide interim results of the post mortem. The Forensic Medicine social worker will also:

- If requested, arrange for hand/foot prints and locks of hair to be taken
- Facilitate viewings of the infant's body after the post mortem
- Ask if the parents/carers would like to be contacted by a Forensic Medicine social worker when the final post mortem report is available
- Confirm that the infant's body can be released to the funeral director.

If organ retention occurred as part of the post mortem, the parents/carers will be contacted by a representative from the Coronial Information and Support Program (CISP) to discuss approval by the Coroner, release, retention timeframes and options for disposal or return of organs.

4.12 Final Post Mortem Examination Report

Once the final post mortem report is complete, the Coroner will notify the parents/carers via a letter. Parents/carers can request a copy of the final post mortem report, requests by the parents/carers must be made to the Coroner in writing, this may be via email. There is no charge to parents/carers for a copy of the report. Some of the tests undertaken are complex so it may take months for the post mortem report to be available. It is not uncommon for the post mortem report to be inconclusive.

Note that requests for a copy of the post mortem report from NSW Health to the Coroner, must be made in writing from the hospital's Director of Medical Services (DMS) or Director of Clinical Governance (DCG) directly to the relevant Coroner. If the senior medical officer or paediatrician overseeing care of the infant and the parents/carers would like a copy of the post mortem report they should contact their DMS or DCG.

Once the final post mortem report is available, if parents/carers agreed to be contacted, the Forensic Medicine social worker will contact the parents/carers and offer to discuss the report. The Forensic Medicine social worker can also assist parents/carers with requesting a copy of the post mortem report from the Coroner.

Parents/carers can discuss the post mortem report with the Forensic Medicine social worker and the forensic pathologist. Parents/carers can also discuss the report with the hospital contact person, social worker, senior medical officer, paediatrician or general practitioner involved in their care.

Where there are unanswered questions about the post mortem report, parents/carers or clinical staff can contact Forensic Medicine social work at the relevant Forensic Medicine (NSW Health Pathology) facility for further discussion. Forensic Medicine social work will facilitate any discussion with the forensic pathologist that is required.

During discussions about the final post mortem report, any referrals or further support required by parents/carers are to be provided.

5 RELATED DOCUMENTS

NSW Child Death Review Team. NSW Child Death Review Team Annual Report 2017-18. Sydney: NSW Ombudsman; 2018.

NSW Child Death Review Team. Child Death Review Report 2015. NSW Government Publication: NSW Ombudsman; 2016.

NSW Health PD2013_007Child Wellbeing and Child Protection Policies and Procedures for NSW Health

NSW Health PD 2010_054 Coroner's Cases and the Coroners Act 2009

NSW Health IB2010_058 Coronial Checklist Summary

NSW Health PD2015_040 Death - Verification of Death and Medical Certificate of Cause of Death

NSW Health PD2014_004 Health Incident Management Policy

NSW Health Management of the Death of a Child in Hospital Resource (Office of Kids and Families, 2015)

NSW Health GL GL2005_063 Sudden Infant Death Syndrome (SIDS) and Safe Sleeping For Infants

NSW Health GL2017_010 NSW Paediatric Service Capability Framework

The Royal College of Pathologists Sudden unexpected death in infancy and childhood. Multiagency guidelines for care and investigation 2016. The Royal College of Pathologists, London.

6 ATTACHMENTS

6.1 Response to Sudden Unexpected Death in Infancy (SUDI) - Roles and Responsibilities

Response to Sudden Unexpected Death in Infancy (SUDI) - Roles and Responsibilities	
Role	**Responsibilities**
Ambulance	Ambulance to attend, assess, attempt resuscitation (if indicated) and transport infant to hospital Complete an Ambulance Clinical Record and handover
Police	Attend scene Explain Coronial process, provide Initial steps after a death is reported to the Coroner brochure Interview parents/carers and complete Police P79A form Ensure any objection to the post mortem is documented Liaise with Family and Community Services (FACS) Complete formal identification of the infant's body Coordinate transfer of the infant's body to Forensic Medicine (NSW Health Pathology) Preserve and examine scene (Forensic Services, Police)
Senior ED MO or AMO	Manage medical care, including verification of life extinction Coordinate completion of the infant's medical history (by the on-call paediatrician) Coordinate ongoing medical care of parents/carers, including documentation and referrals Coordinate staff debrief
Paediatrician	Complete infant's medical history and documentation Consider medical cause or non-accidental injury Contact GP and relevant medical specialists Participate in Forensic Medicine (NSW Health Pathology) multi-disciplinary meeting if required
Nurse in charge	Coordinate nursing care Liaise with hospital contact person about care of parents/carers Coordinate staff debrief
Hospital contact person (social work/nurse)	Inform parents/carers of SUDI process Support parents/carers in spending time with infant (under clinician supervision with minimal handling) Organise practical support including private space, refreshments, support such as extended family, religious, cultural and Aboriginal Offer contact with Red Nose Grief and Loss Coordinate lactation support and/or referral, where required Provide handover to Forensic Medicine social work Provide handover to hospital social work (if not already aware)
Forensic Medicine (NSW Health Pathology)	Pathologist completes post mortem examination Social work offers parents/carers support, advice and referral Social work and pathologist offer to discuss post mortem results with parents/carers Coordinates multi-disciplinary case review
General practitioner	Provide information about the infant and parents/carers where required Organise ECG for parents and siblings Provide ongoing support and referral for parents/carers
Medical records/clerical	Forward copy of infant's health care record to Forensic Medicine (NSW Health Pathology) within 24 hours of infant's death
Coroner	Determine manner and cause of death and need for inquest based on post mortem report and police investigation Consider requests for release of post mortem report
Clinical governance/ director medical services	Manage requests for post mortem report Distribute post mortem report to relevant clinician
NSW Health PD2019_035 Management of Sudden Unexpected Death in Infancy (SUDI)	

6.2 Medical History Guide – Sudden Unexpected Death in Infancy (SUDI)

Medical History Guide - Sudden Unexpected Death in Infancy (SUDI)

The unexpected death of an infant is a tragedy for the parents/carers. Investigating infant deaths can be difficult as the situation is highly charged and emotional, and so it requires a unique and sensitive approach.

This guide includes high level of detail about the infant's health, the infant's family and events in the hours before the infant's death, including the infant's exact position and the parent/carer behaviour and use of alcohol or drugs. While these questions may feel intrusive, they relate to known risks for infant mortality, help determine why the infant died and can be asked in a sensitive way.

A detailed medical history will help the forensic pathologist determine a cause of death, including whether the infant may have suffocated, or died from an undiagnosed medical problem. The history is also important in determining the presence of risk factors for Sudden Infant Death Syndrome (SIDS) and any potential child protection concerns.

The following points may assist you with the discussion:

- Where possible, have another clinician, such as a social worker or nurse, with you during the discussion with the family to provide support. If you choose to include the Police as observers while you take the history, agree on roles before starting.
- To build trust with the parents/carers start with less sensitive questions including contact information, general family history, the mother's pregnancy and health, psychosocial aspects and the infant's health, before moving onto the events leading up to the infant's death.
- Use the infant's name whenever possible. The Medical History Guide – Sudden Unexpected Death in Infancy (Section 6.1) uses [infant's name] as a prompt.
- A suggested introduction is:

  'I am so sorry about your loss. Some people describe feeling that it is not quite real, like a nightmare. I would like to help make sense of what has happened. I would like to find out why [infant's name] died and help you understand why. To do that I would like to find out as much as possible about your pregnancy, [infant's name] general health and sleeping and feeding patterns. I also need to ask some questions about you and your health as it will help us understand why some young babies die suddenly. Please let me know if you are uncomfortable with any of these questions.'

Medical History Guide - Sudden Unexpected Death in Infancy (SUDI)

1. Identification

Infant's name
Date of birth
Date of death
Sex M/F
Ethnicity/Aboriginal/Torres Strait Islander
Address
Postcode

Personal information

Name of mother (and address if different from infant)
Date of birth
Name of father (and address if different from infant)
Date of birth
Consanguinity (degree of relatives)

Healthcare providers

Name of doctor completing the medical history
Social worker
Hospital contact person
Other professionals
Interpreter present
GP name and address

Information retrieved from medical record

As relevant, hospital, GP, midwife, infant's personal health record ('Blue Book')
Ambulance staff
Include growth chart in copy of medical record

Medical History Guide - Sudden Unexpected Death in Infancy (SUDI)

2. Details of transport of infant to hospital

Place of death, home address as above/another location (specify)
Time found
Time arrived in emergency department (triage time)
Resuscitation carried out
At scene of death – police/ambulance/emergency department/hospital
By who? Parents/carers/GP/ambulance paramedic/hospital staff/other (specify)
Confirmation of death
By who
Time and date
Location

3. Medical history

Taken to emergency department/hospital by
History given by
Relationship to infant

Family history

Details of family and household members, including names, dates of birth, health, any previous or current illnesses including mental health, medications, occupation
Maternal parity and obstetric history
Parental relationships
Children, including children by previous partner
Household composition
Any previous childhood deaths in the family

Social history

Type and nature of housing
Major life events
Wider family support networks
History of family involvement with Family and Community Services
Domestic and family violence
Smoking, alcohol use

Infant's medical history

Pregnancy and delivery, perinatal history, feeding, growth, behaviour and development
Health and any previous or current illnesses, hospital admissions, medications
Routine checks and immunisations
Body systems review

Detailed narrative account of last 24 – 48 hours

(To include details of all activities and carers during the last 24-48 hours)
Any alcohol, medication consumed by parents/carers
Any medication given to infant
Details of infant's last sleep, including where and how placed to sleep
Details of feeding and care given
Further details of previous 2-4 weeks, including infant's health, any changes to routine, when infant last seen by a health professional

Medical History Guide - Sudden Unexpected Death in Infancy (SUDI)

Events surrounding death

When infant was last seen alive and by who
Who found the infant, where and when, appearance when the infant found
Details of sleep environment, type of surface, mattress, bedding, objects, overwrapping or over-heating. Face or head covered. Co-sleeping. Alcohol or drugs consumed by carers.
Who called emergency services
Details of any resuscitation at home, by ambulance and in hospital
For accidental/traumatic deaths, details of circumstances around the death, witnesses

Any other relevant history

May vary according to the age of the infant, nature of the infant's death

Genetic or metabolic disease

For concerns about genetic or metabolic disease, contact the paediatric metabolic specialist for advice about investigations required
For concerns about a condition that may have implications for other family members, for example cardiac dysrhythmia, contact the relevant specialist for advice about investigations required

Child protection and wellbeing

If you have any concerns about non-accidental injury or neglect, follow usual child protection procedures

4. Conclusion

Cause of death

From this history do you have an impression of the possible cause of death?

6.3 SCHN Factsheet - Breast Care After the Death of an Infant

Copies of this brochure can be accessed via the Sydney Children's Hospitals Network website:

Factsheet: Breast care for breastfeeding mothers after the death of a child

FACTSHEET

This fact sheet is for education purposes only. Please consult with your doctor or other health professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form

Breast care for breastfeeding mothers after the death of a child

Time after the death of your infant can be physically and emotionally exhausting. It is important that you have support during this time. When milk is not regularly removed from the breast, milk production eventually stops of its own accord. Some women experience breast engorgement, leakage of milk, discomfort and some pain during this time.

Often the only treatment needed to stop making milk, is limiting milk removal. To give your body the message to stop making milk, it is best to express only enough to keep your breasts comfortable, unless you need to clear a blockage to prevent mastitis. Caring for your breasts at this difficult time is important, as it will help make them more comfortable and reduce the risk of a blocked duct or mastitis. The following suggestions may provide some relief during this time.

Suggestions as breasts become uncomfortable:

- Wear a well-fitting bra to provide firm breast support, rather than a tight breast binder.
- Breast pads will help absorb leaking milk. These can be the disposable or the reusable type. Change them as they become wet.
- Avoid excessive stimulation of the breast.
- Regularly applying cold compresses may provide pain relief e.g. chilled washers, cool gel packs or washed cabbage leaves can also help.
- Avoid excessive heat on your breasts.
- Consider taking analgesia as required to relieve pain and discomfort (for example paracetamol).
- Breasts should be handled gently during this time as they can bruise easily when engorged.
- Express a little milk to relieve fullness and make the breasts more comfortable. This won't interfere with the progress of suppression, as you are not emptying the breast. Hand expressing in a warm shower or bath can be effective as warmth and relaxation will encourage milk ejection without added nipple and breast stimulation.
- Maintain a normal fluid intake.

Things to watch out for:

- Engorgement- breasts become swollen, hard and painful. If this occurs it is recommended that you express your breasts completely once to relieve the pain. Then over the next few days express enough milk to keep your breasts comfortable. Applying cool packs, avoiding excessive heat and taking analgesia as needed to increase comfort may also help.
- Mastitis –lumps, red areas on the breast. Temperatures or flu like symptoms may indicate you have mastitis and medical assessment should be sought promptly.

How long will I have milk for?

It may take weeks or months for your milk to disappear completely. Leakage may occur for some time after discomfort has settled.

the children's hospital at Westmead
The Sydney Children's Hospitals Network

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The day of the funeral:

This will be a difficult and emotional day. The following hints may be helpful to consider:

- Express milk for comfort before the funeral and during the day as required.
- Wear a bra which is comfortable and well supported. Your bra should not be too tight.
- There may be some leakage of milk, so be prepared with some extra breast pads.
- Patterned and dark coloured tops are often less likely to show wet patches.
- Jackets or cardigans may help cover up wet spots.
- Use analgesia as required, to help relieve breast pain.

It is important you are well supported during this difficult time.

Helpful organisations you may wish to contact for support include:

- SIDS and KIDS – phone 1300308307
  (24 hour bereavement support, counselling, support groups and workshops)
  www.sidsandkids.org
- Your local General Practitioner
- SANDS - phone 1300 0 sands (1300 072 637)
  (Still born and Neonatal Death support
  24/7 volunteer supporters are on call)
  www.sands.org.au
- Australian breastfeeding Association helpline - phone 18006862686
  www.breastfeeding.asn.au
- Grief line – phone 1300 845 745
  (Confidential and anonymous telephone support, including counselling in diverse languages)

6.4 Implementation Checklist

LHD/Facility:			
Assessed by:		**Date of Assessment:**	
IMPLEMENTATION REQUIREMENTS	**Not commenced**	**Partial compliance**	**Full compliance**
1. Local policies that guide management of SUDI are easily accesible for staff. This includes that all facilities are able to initiate a SUDI response.	❑	❑	❑
	Notes:		
2. Information about how to access locally networked paediatrics services is easily accessible for staff.	❑	❑	❑
	Notes:		
3. Adequate resources and education are provided so that staff can meet the needs of the infant and parents/carers, including providing parents/carers with support and relevant referrals.	❑	❑	❑
	Notes:		
4. Local guidance on allocation of the hospital contact person role is provided.	❑	❑	❑
	Notes:		
5. Local processes support transfer of the infant's health care record to Forensic Medicine (NSW Health Pathology) within 24 hours of the infant's death, and include a copy of the infant's medical history.	❑	❑	❑
	Notes:		
6. That support is available for staff who provide care to infant's and their parents/carers who have experienced SUDI.	❑	❑	❑
	Notes:		
7. Local processes maintain the quality of care and patient experience of SUDI cases.	❑	❑	❑
	Notes:		