

Death - Management of sudden Unexpected Death in Infancy

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Functional Sub group Clinical/ Patient Services - Baby and child
Clinical/ Patient Services - Critical care

Summary This document relates to the management of sudden unexpected infant death. Two aspects of management are described, including the diagnosis of the cause of death and the support of the surviving family members.

Replaces Doc. No. Death - Unexpected Infant - Hospital Protocol [PD2005_493]

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Applies to Area Health Services/Chief Executive Governed Statutory Health Corporation, Board Governed Statutory Health Corporations, Affiliated Health Organisations, Affiliated Health Organisations - Declared, Community Health Centres, NSW Ambulance Service, Public Hospitals

Audience Emergency Depts, Maternity, Paediatric Units, Medical Records Depts, Information Systems

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Director-General

This Policy Directive may be varied, withdrawn or replaced at any time. Compliance with this directive is **mandatory** for NSW Health and is a condition of subsidy for public health organisations.

**PROCEDURES FOR MANAGEMENT OF SUDDEN UNEXPECTED DEATH IN
INFANCY**

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Introduction

This document represents policy for the management of sudden unexpected infant death. It has been developed in response to recommendations in the Child Death Review Team (CDRT) Sudden Unexpected Death in Infancy Report (2005). There are two aspects of management: the diagnosis of the cause of death, and the support of the surviving family members. The aim of the process is to take a comprehensive medical history to assist the forensic pathologist in the post-mortem assessment to establish as far as is possible the cause of death.

Each Area Health Service is responsible for ensuring that local protocols based on this policy are developed. Each Area Health Service must develop mechanisms to coordinate and provide this response, and designate the facilities where this service will be available. Area Health Services are also responsible for ensuring that all staff treating paediatric patients are educated in the use of the locally developed paediatric guidelines and protocols.

Throughout this document the senior paediatrician is referred to as being the person who supplies the paediatric medical expertise required for the health response. While this is the ideal, local protocols may be developed in which a General Practitioner Visiting Medical Officer with paediatric expertise undertakes this role.

It is critical that contemporaneous, accurate and complete documentation is maintained during the course of patient management.

Overview

Definition of sudden unexpected death in infancy (SUDI)

The death of an infant:

- Less than 12 months of age;
- That was sudden in nature;
- That was unexpected.

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

When this protocol should be used

- When there is an unexpected infant death during an admission to hospital
- Following an unexpected death of an infant outside hospital, where the infant is brought into an Emergency Department.

The multi-agency response to SUDI

The health response is one aspect of the multi-agency response to SUDI. The involvement of health professionals should complement the work of police, ambulance, forensic pathologists and the Coroner. All sudden, unexpected deaths in infancy must be reported to the Coroner. Failure to work within the context of the multi-agency response may increase confusion and distress for the family, and undermine the work of other agencies. A summary of the multi-agency response, including the health response, is included in Appendix A for the information of Health workers.

The role of health in the SUDI response

The role of health workers in SUDI is to provide health care and assessment for the family, remembering that the infant's death will be investigated by other services. In some cases the cause(s) of death may have relevance to the health of other family members, including subsequent children. A thorough health assessment is in the best interests of the family, as well as acting to complement the other components of the multi agency response to SUDI.

Care of the family

The unexpected death of an infant is a tragedy for the parents. The immediate care provided for parents by police and ambulance officers in the home or by staff in hospitals may make a great difference to the resolution of the family's grief. Staff involved should have appropriate knowledge, skills and sensitivity.

The parents may be in shock. Their behaviour may be atypical. There is no "correct" or "appropriate" response to such an overwhelming shock. If they so desire the family should be given the opportunity to say goodbye to their infant, and to hold the infant for a time in the presence of a health professional. It is important that they are given support during this time. **This process cannot be hurried but it should be acknowledged that an urgent post mortem is required.**

Sudden Infant Death Syndrome (SIDS)

Successful diagnosis of the cause of unexpected infant death is dependent on the post mortem being carried out as soon as possible after the death of the infant. A comprehensive medical history of the infant and other family members is an important contribution to the post mortem process, and provides the basis for a well informed post mortem examination by the Forensic Pathologist.

As SIDS is a post mortem diagnosis by exclusion, the term SUDI, 'sudden unexpected death in infancy' should be used until the cause of death is classified as SIDS following post mortem examination.

Title: Procedures for Management of Sudden Unexpected Death in Infancy

Even though SIDS has not been confirmed as a cause of death all parents are still able to access support from SIDS and KIDS NSW and contact details should be provided to the parents.

Facilities Providing the Health Response

Each Area Health Service will have clear policies designating which facilities can provide the SUDI response. Area Health Service policies will be in place to ensure that appropriate physical space is available for the SUDI response, and that arrangements are in place to ensure key staff involved in providing the SUDI response are able to provide uninterrupted care to the family. For most facilities, a SUDI presentation will be a rare event.

An appropriate multidisciplinary response to SUDI includes paediatric expertise, social work and nursing care as a minimum. Treating health professionals need to be excused from other duties while providing care to the family. Hospitals with the capacity to ensure paediatric, nursing and social work care should be nominated by the Area Health Service to undertake the SUDI response.

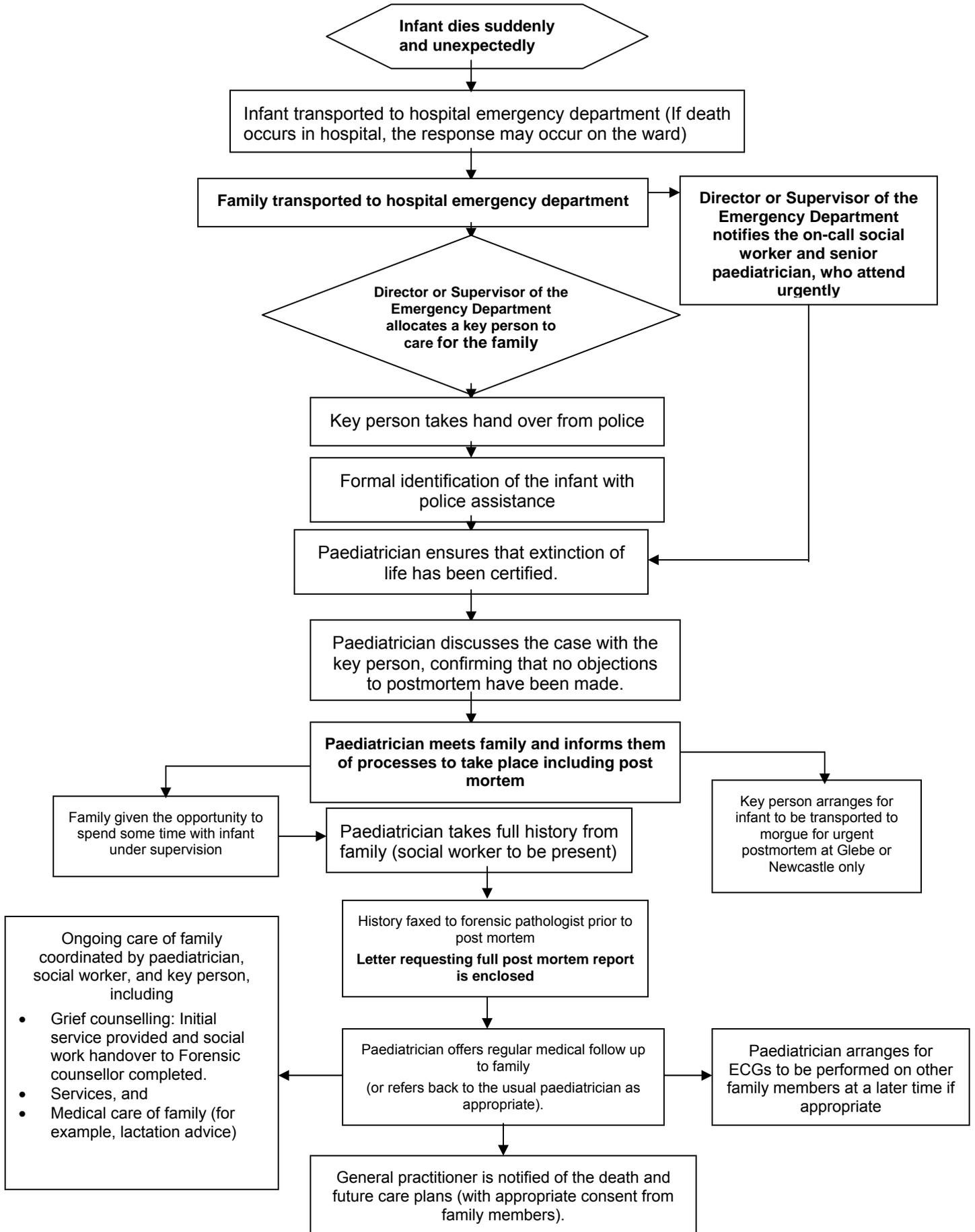
Area Health Services will develop clear protocols describing how the response to SUDI will be undertaken in their designated facilities. Area Health Service protocols should provide pathways for the transfer of SUDI cases from non-designated response hospitals to those sites able to provide a SUDI response.

Area Health Services must also ensure that other services involved in the multi-agency response to SUDI such as NSW Police Force, Ambulance and Government Contractors are aware of those hospitals designated to provide the SUDI response, and can transport the infant and family members directly to those sites in the event of a SUDI.

Because the cause of death can be difficult to establish, it is very important that the post mortem examination be done by a pathologist with extensive experience in infant post mortems at a centre with appropriate facilities for special tests. **The NSW State Coroner has therefore directed that all post mortems following unexpected deaths of infants be done in Sydney, either at the Department of Forensic Medicine at Glebe or in Newcastle at the Department of Forensic Medicine, Royal Newcastle Hospital.** The agreed protocol for post-mortem *Standard guidelines: Sudden Unexpected Death in Infancy (SUDI)* has been included at Appendix D for information only.

Based on the post mortem results, the NSW Health Department monitors the occurrence of SUDI, looking for trends which might provide information that will help in the prevention of these types of deaths.

Flowchart of the Emergency Department Response to SUDI



Title: Procedures for Management of Sudden Unexpected Death in Infancy

Initial Management

Following an unexpected death of an infant:

All babies dying unexpectedly and brought to the hospital should be taken into the **Emergency Department**. The Emergency Department is a “safe place” where parents and other relatives are able to talk with health professionals.

The **senior on call paediatrician** must be notified and attend as soon as possible, in order to confirm that life is extinct, and to take a history from the family.

The Director or Supervisor of the Emergency Department in the SUDI response hospital nominates a **key person** to coordinate the immediate care of the parents. This will usually be the social worker, but could be the senior nurse on duty, the duty social worker or the senior paediatrician on call. A senior nurse should act as the key person until the social worker or paediatrician arrives.

The infant should be registered as a patient and hospital labels printed.

The paediatrician ensures that extinction of life has been certified. The Duty Forensic Pathologist should be contacted as soon as death is established.

Initial care of the family

If the infant is deemed dead on arrival, the parents should be informed as soon as possible by the Emergency Department doctor or nominated key person.

It is important to keep the parents/family informed at every step of the process that is taking place with their child. The parents may be in shock and need information to be repeated.

Handling of the infant’s body should be minimised. However, the parents may want to hold the infant after death has been established and should be given the opportunity to do so in the presence of a health professional. As any SUDI death is a matter for the Coroner, the health professional is required to witness that no evidence relating to potential cause of death has been altered after arrival at the hospital. The health professional should be as supportive as possible while providing the necessary supervision.

Ink prints of the infant’s feet or hands must not be made until after the post mortem examination. At the parents’ request, ink prints can be taken at the forensic facility where the post mortem takes place by a forensic counsellor at Glebe or the SIDS and Kids representative at Newcastle.

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Handover from Police

The key person takes a hand over from the police officers in attendance, including:

- Any objections that have been raised by the family to a post mortem
- Confirmation that the death has been reported to the Coroner, or the arrangements made for this to occur.

If the infant and family have arrived at the hospital without contact with the Police, the key person must arrange for the Police to be notified immediately.

Once the infant is declared deceased the police officer, as the representative of the Coroner, is responsible for the care of the body, the investigation of the death, and timely removal of the infant for examination by a forensic pathologist.

Formal identification of the infant

Formal identification by the police is necessary in all coronial cases. In view of the circumstances surrounding an unexpected infant death, positive identification may be obtained in a number of ways. The parents may be asked to do this. The police or anyone who knew the infant's identification in life, or to whom the infant's body has already been identified, can assist in this formality. **Formal identification is best done before leaving the Hospital Ward or Emergency Department.**

When a sudden infant death occurs during a hospital admission:

The Admitting or Senior Medical Officer who had cared for the infant should nominate a **key person** to coordinate the care of the parents. This could be the nurse unit manager, the ward social worker or other appropriate person depending on the circumstances and/or who has been involved with the family during the admission. The parents should be informed of the death of the infant as soon as possible. The senior on call or treating paediatrician must be notified and attend urgently.

The nominated **key person** should ensure that the police have been promptly informed of the death of the infant so that an early post mortem can be conducted, and ensure that the appropriate report is made to the Coroner.

If the infant has been a hospital in-patient, some pathology samples such as blood and urine may have been taken prior to death. In this case, it may not be necessary to obtain repeat samples post-mortem. The availability of such samples for metabolic analyses should be confirmed with the pathology service.

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The Guidelines for Nursing Staff and Medical Officers on Coroners' Cases Dying in Hospital as detailed in section (3) of PD2005_352 *Coroner's Cases and Amendments to the Coroner's Act 1980* should be followed by nursing staff and medical officers following a sudden infant death that occurs during a hospital admission.

Medical Intervention with a Family after a SUDI

1. Take a history from the family

On arrival at the Emergency Department, the senior paediatrician should introduce him or herself to the family.

The family may not fully understand that a post-mortem examination is necessary in the case of unexpected infant death. The senior paediatrician should explain to the family that the postmortem will be undertaken at a designated facility, that this is important to help establish the cause of death, and that the diagnosis of the cause of death may benefit other family members, especially future siblings. The Forensic Pathology Service to which the infant is sent will undertake this testing. The senior paediatrician should explain that a comprehensive medical history of the infant and close family members is important to ensure that the post mortem examination is as comprehensive as possible. A full history should be taken according to the protocol attached at Appendix B.

2. Objections to post mortem examination

The police who transport the family to hospital will normally have discussed the post mortem with the family and provided them with *The Coroner's Court* brochure. This brochure provides information on the coronial system, why the Coroner has become involved and the processes that may be necessary to determine the cause of death.

The outcome of the discussion regarding post mortem between police and the family should be communicated by police to the nurse manager or key person on arrival at the hospital.

Parents should be informed that unexpected infant deaths have to be reported to the Coroner, who will order a post mortem examination. Some parents may have reservations about a post mortem examination because of cultural, religious or other reasons. It should be explained that a post mortem is required to ensure that the cause of death was thoroughly investigated and no illness was missed.

If the family has raised an objection to post mortem in writing, the senior on call paediatrician should ensure that the Coroner has been informed.

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If parents have continuing concern regarding the post mortem process they can discuss this with the Coronial Information and Support Program during business hours and the Department of Forensic Medicine Counsellors after hours. Contact details for these services are:

- The Coronial Information and Support Program (CISP) at Glebe on (02) 8584 7777
- Department of Forensic Medicine at Glebe, telephone (02) 8584 7800 (After hours ph. 02 8584 7821)

Electrocardiograph (ECG)

The senior paediatrician is responsible for recommending screening at a later time of first-degree relatives for long QT interval and inherited cardiac disorders. This may be valuable both for the family's sake and to inform the post mortem process. Results should be made available to the forensic pathologist undertaking the infant's post mortem.

Transporting the Infant for Post-mortem

The infant should be transported to Glebe or Newcastle for the post-mortem as soon as possible. This will normally be done by the government contractor who delivered the infant to hospital. The key person will need to contact the Police to ensure the arrangements are in place for this. If the infant was brought to hospital by ambulance, the key person should contact police to arrange transport to the morgue by the government contractor.

There is no charge to the parents for transporting the infant to Glebe or Newcastle or returning the infant to the home locality. Every effort will be made to ensure that post mortems are done as quickly as possible.

Prior to leaving the hospital the parents should be given the contact details of the Forensic Counsellor at the institution to which the infant is being transferred for post mortem examination. The parent should be advised they can contact a counsellor at Glebe 24 hours a day 7 days a week to seek information and support regarding the post mortem process. Newcastle provides this service Monday to Friday during business hours.

The Forensic Counsellor will contact the parents/senior next of kin when the post mortem examination is to take place. The counsellor will telephone the parents/senior next of kin and convey the Interim Cause of Death and confirm when the infant is ready to be released into the care of the funeral director. The Forensic Counsellor can facilitate viewings of the infant after post mortem examination.

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Ink prints of the infant's feet or hands will not be made until after the post mortem examination. At the parents' request ink prints can be taken, by the forensic counsellors or by the SIDS and Kids representative, at each of the forensic facilities.

The post mortem report

Post mortem reports are available to parents from the Coroner's offices in Sydney, or the clerk of the local court in country areas. The initial report can be obtained by telephone, usually within 48 hours. Requests for the final report must be made in writing. There is no charge to parents for the report. Because the tests are complex it may take several months to produce the final report.

Taking the Medical History

Key Points

- The senior paediatrician takes the history in the presence of a social worker
- Use the protocol as a guide and encourage parents to use their own words
- Be sensitive to the needs of the parents
- Take a full comprehensive history from the family to inform pathology testing
- Consider child protection issues for surviving siblings
- Fax the medical record to the forensic pathologist prior to post mortem

Using the protocol

The importance of the history being taken by an experienced paediatrician, with knowledge and understanding of the care of infants and sensitivity to the needs of the family, cannot be over-emphasised. The social worker is to be present during this consultation.

This list is meant as a guide. It cannot be comprehensive, as additional specific questions may arise as a consequence of information given by the parents. Encouraging the parents to talk spontaneously, with prompts about specific information, is likely to be better than trying to collect a structured history in the more usual way. In recording parents' accounts of events, it is important to use their own words as far as possible. Ideally, information should be recorded *verbatim*.

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Sensitive interviewing

Much of the information is sensitive. Parents may feel vulnerable when asked about their sleeping arrangements, alcohol intake or drug use, so great skill is needed in asking the questions in a non-threatening way, with no implication of value judgment or criticism.

At the end of the interview, it is essential that the paediatrician spends some time with the family ensuring they know what will happen next, when they will next be contacted by the paediatrician, when and where the post mortem will take place, and how they will be informed of the preliminary results.

Time will also be needed for the paediatrician and the social worker to help the parents deal with the very powerful emotions that are commonly brought out by this discussion.

Child protection issues

A small percentage of SUDIs are the result of non-accidental injury. Thus child protection issues should be borne in mind by health professionals assessing SUDIs. If there are any concerns that child protection issues may be present, a report to DoCS should be considered to ensure the safety of surviving siblings. Health workers do not need to be certain that abuse or neglect has occurred. A report relates to a reasonable suspicion of risk of harm. Risk of harm refers to the likelihood that a child or young person may suffer physical, psychological or emotional harm as a result of what is done (physical, sexual or emotional abuse, exposure to domestic violence) or not done (neglect) by another person.

When this information has been collected, the full medical record should be faxed (see sample fax coversheet at Attachment C) to the morgue where the post mortem will take place:

Department of Forensic Medicine	Phone	Fax
Glebe	02 8584 7800	02 9552 1613
Newcastle	02 4922 3703	02 4922 3730

Care of the Family

Practical help for the family

Practical help should be offered to the parents, including:

- Arranging transport home
- Making sure they are calm enough to drive if they brought their infant in the family car

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- Care of the other children
- Discussing funeral arrangements
- Contacting any relatives (with permission)
- Helping the mother if she has been breastfeeding.

If there is a surviving twin, initial management and advice should be given by the senior on-call paediatrician. Further appointments with a paediatrician should be made as appropriate.

Ongoing care of the family

The social worker and the senior paediatrician should co-ordinate plans for future care of the family prior to them leaving hospital. The Forensic Counsellor should be contacted and a handover given.

The names of all health professionals (for example, the general practitioner, child and family health nurse, paediatrician, obstetrician or postnatal clinic nurse) involved in the infant's care should be sought so that they can be informed (with permission) and become involved in the parents' care. The infant's Personal Health Record (blue book), if available, may give details of health professionals involved in the infant's care. The parents should be offered the support services of SIDS and Kids (contact details below).

The senior paediatrician should include a letter applying for a copy of the forensic pathology report with the faxed full medical record. The paediatrician should arrange a follow up appointment with the family to discuss the findings of the post mortem. If possible, the family's general practitioner should also attend this meeting. This should ideally occur within six months of the death.

Professional and organisational support available to the family

1. Family general practitioner
2. Paediatrician
3. Community Health and/or the Community Mental Health Team
4. Department of Forensic Medicine Forensic Counselling Unit
5. SIDS and Kids NSW and SIDS and Kids Hunter

The Role of the Forensic Counsellor

Forensic Counsellors are employed at the Department of Forensic Medicine Glebe and Newcastle to assist relatives and friends when they experience a sudden unexpected death that is reported to the Coroner.

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The Counsellors role is to provide information, support and counselling to family and friends of the infant. The Counsellors are available to facilitate viewings of the infant after the post mortem examination and to make hand and foot prints at the parent's request.

The counsellors at the Department of Forensic Medicine at Glebe (02) 8584 7800 or the Department of Forensic Medicine, Newcastle (02) 4922 3703 are also available to help parents, relatives and professional staff to obtain information where possible. A pamphlet on post mortems is available.

SIDS and Kids NSW and SIDS and Kids Hunter are self-help organisations that support all who experience the sudden and unexpected death of a young child, as well as undertaking community education, research and fundraising activities.

Professional counsellors and trained volunteers are available to provide phone support and information to parents and families following the death of a child. Home visits can be arranged when the family is ready. SIDS and Kids NSW and SIDS and Kids Hunter provide information booklets to both parents and health professionals.

SIDS and Kids NSW can be contacted on 1800 651 186 (for country and after hours support). SIDS and Kids Hunter is available for families in the Hunter region and can be contacted on (02) 4969 3171 (24 hours).

Paediatric Hospitals

Contacts for further information on SIDS at NSW Paediatric Hospitals are listed below.

HOSPITAL	TELEPHONE	CONTACT PERSON
The Children's Hospital at Westmead	(02) 9845 0000 (24 Hours)	<ul style="list-style-type: none"> • Sleep Unit Social Worker on call
Sydney Children's Hospital Randwick	(02) 9382 1111 (24 Hours)	<ul style="list-style-type: none"> • Emergency Department Director on Duty • Paediatric Social Worker • Sleep Medicine Department
John Hunter Children's Hospital Newcastle	(02) 4921 3676 or (02) 4921 3000 (24 hours)	<ul style="list-style-type: none"> • Department of Respiratory Medicine • Paediatric Social Worker

Title: Procedures for Management of Sudden Unexpected Death in Infancy

Appendix A: Summary of Agency roles in responding to Sudden Unexpected Death in Infancy (SUDI)

<p>Parent or caregiver - Infant found unresponsive</p> <ul style="list-style-type: none">• Ambulance usually called.
<p>Ambulance</p> <ul style="list-style-type: none">• Attend immediately• Resuscitation if appropriate• Takes care of the family while present• Record details on Ambulance Patient Health Care Record• Reports to Department of Community Services (DoCS) if appropriate• Informs police of receiving Emergency Department of the nominated SUDI response facility• Notifies local Emergency Department of impending transfer• Hand over to Police before leaving scene when no longer required
<p>NSW Police Force</p> <ul style="list-style-type: none">• Immediate response• Interview of family• Completion of P79a and P534 (NCIS) form• Examination of death scene• Explain to family that death is a coronial matter• Give brochure on post mortems to family• Explain the right to object to post mortem• Notify NSW Police Force Forensic Services• Report to DoCS if appropriate• Take care of family after ambulance officers have departed• Advise of other immediate support for family as required (relatives, SIDS and Kids NSW or SIDS and Kids Hunter, etc)• Transport family to hospital at the same time as infant is transported by government contractor• Hand over to hospital staff prior to leaving hospital• Assist with formal identification of the infant in the Emergency Department• Arrange transport of infant by government contractor from home to hospital and from hospital to morgue
<p>Forensic services, NSW Police Force</p> <ul style="list-style-type: none">• Notified and attend as a matter of urgency• Undertake thorough death scene investigation including taking of photographs and exhibits• Scene remains preserved until released by the Crime Scene Investigator or the Officer in Charge• On completion, call government contractor for transport of infant to hospital

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Government contractor

- Transports infant to hospital
- Transports infant from hospital to morgue for post mortem

Nurse manager of emergency department

- Retrieves policy directive/procedure and makes available to staff involved in case
- Calls senior on call paediatrician
- Notifies social worker on call, if available
- Receives hand over from police regarding post-mortem objection and government contractor arrangements
- Initiates care of family
- Co-ordinates transport of infant to morgue by government contractor
- Faxes medical records to morgue

Social worker

- Provides care of family according to Policy Directive.
- Assists at interview of family by paediatrician
- Co-ordinates ongoing care of family with other health practitioners
- Pages Forensic Counsellor and gives handover.

Senior on call paediatrician

- Follows policy directive
- Ensures extinction of life has been certified
- Informed regarding objections to post mortem
- If objections have been raised, discusses further with family
- Takes comprehensive history from family
- Ensures that this history is received by the forensic pathologist prior to post mortem
- Co-ordinates care of family according to clinical practice guideline
- Ensures ongoing care of family according to clinical practice guideline, including (as appropriate):
 - Investigation for long QT interval in surviving family members
 - Grief counselling
 - Services
 - Medical care of family (for example, lactation advice)
- Ensures GP is notified of death and future care plans
- Offers regular medical follow up to family, including discussion of post mortem and coronial findings when available and appropriate (or refers back to usual paediatrician) as appropriate

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Forensic Counsellor

- Calls parents to confirm infant is at mortuary. Inform when post mortem examination will take place.
- Calls parents after post mortem to convey Interim Cause of Death and confirm date of release into the care of funeral director.
- Discuss opportunity to view and take hand and foot prints.

Forensic pathologist

- Ensures that the comprehensive history taken by the paediatrician has been received and read prior to post mortem
- Completes the post mortem according to the NSW revised version of the International Standardised Autopsy Protocol
- Provides a post-mortem report to the Coroner.

Coroner

- Forwards post mortem and coronial findings to managing paediatrician if requested.

Department of Community Services

- The Department will visit a family where there are siblings or other children are residing in, or are expected to return to, a household where a child death has occurred that is or may be due to abuse, neglect or suspicious circumstances.

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Appendix B: History protocol

NSW DEPARTMENT OF HEALTH

SUDDEN UNEXPECTED DEATH IN INFANCY

MEDICAL HISTORY PROTOCOL

Site _____

D.O.B. ____ / ____ / ____

M.O.

ADDRESS

**SUDI
MEDICAL HISTORY**

LOCATION

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

PROTOCOL – CONFIDENTIAL**DEFINITION OF SUDDEN UNEXPECTED DEATH IN INFANCY (SUDI)**

The death of an infant:

- Less than 12 months of age;
- That was sudden in nature;
- That was unexpected.

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

NOTES ON USING THIS PROTOCOL

The history should be taken by an experienced paediatrician. While this is the ideal, local protocols may be developed in which a General Practitioner Visiting Medical Officer with paediatric expertise undertakes this role. A social worker should also be present.

This form is meant as a guide. Encourage the parents to talk spontaneously, with prompts about specific information. In recording parents' accounts of events, it is important to use their own words as far as possible.

Ask the questions in a non-threatening way, with no implication of value judgment or criticism.

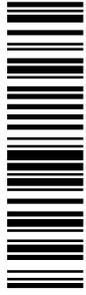
It is critical that contemporaneous, accurate and complete documentation is maintained during the course of patient management.

When this information has been collected, the full medical record should be faxed to the morgue where the post-mortem will take place:

Department of Forensic Medicine	Phone	Fax
Glebe	02 8584 7800	02 9552 1613
Newcastle	02 4922 3703	02 4922 3730

CHILD PROTECTION ISSUES

A small percentage of SUDI deaths are the result of non-accidental injury. If there are any concerns that child protection issues may be present, a report to DoCS should be considered to ensure the safety of surviving siblings. See PD2006_104 *Child Protection Roles and Responsibilities – Interagency*.



SMR040250

BINDING MARGIN - NO WRITING

SUDI MEDICAL HISTORY

SMR040.250

Site _____

D.O.B. ____/____/____

M.O. _____

ADDRESS

**SUDI
MEDICAL HISTORY**

LOCATION

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

**ATTACH A COPY OF THE COMPLETED SECTIONS OF THE PERSONAL
HEALTH RECORD (BLUE BOOK) IF POSSIBLE**

Date: _____

Name of examining paediatrician: _____

Name of social worker present: _____

Nominated key person: _____

Name and designation of other health workers present: _____

PERSONAL AND CONTACT INFORMATION**INFANT**Date of birth: _____ Male Female

Given name: _____

Family name: _____

Other names by which known: _____

Aboriginal Torres Strait Islander Both Aboriginal and Torres Strait Islander

Place of birth: _____

Residential address: _____

Copy of infant's Personal Health Record ('Blue Book') taken (Y/N): _____

General Practitioner (name, address, phone number): _____

Paediatrician (name, address, phone number): _____

Early Childhood Health Centre attended (address, phone number and contact person):



SMR040250

BINDING MARGIN - NO WRITING

SUDI MEDICAL HISTORY

SMR040.250

Site _____

D.O.B. ____ / ____ / ____

M.O. _____

ADDRESS

**SUDI
MEDICAL HISTORY**

LOCATION

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

MOTHER / GUARDIAN 1

Given names: _____ Family name: _____

Other names by which known: _____ Date of birth: _____

Cultural identity: Caucasian Asian Pacific Islands Maori

Other (please specify): _____

Residential address: _____

Home phone number: _____ Work phone number: _____

Mobile phone number: _____

Name and telephone number of a close relative or friend (to facilitate making contact again):

Address and phone number of location on leaving hospital: _____

FATHER / GUARDIAN 2

Given names: _____ Family name: _____

Other names by which known: _____ Date of birth: _____

Cultural identity: Caucasian Asian Pacific Islands Maori

Other (please specify): _____

Residential address: _____

Home phone number: _____ Work phone number: _____

Mobile phone number: _____

Name and telephone number of a close relative or friend: _____

Address and phone number of location on leaving hospital: _____



SMR040250

BINDING MARGIN - NO WRITING

SUDI MEDICAL HISTORY

SMR040.250

Site _____

D.O.B. ____/____/____

M.O. _____

ADDRESS _____

SUDI MEDICAL HISTORY

LOCATION _____

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

OTHER MEMBERS OF HOUSEHOLD PRESENT AT TIME OF INCIDENT OR IN RECENT PAST

PERSON 1

Relationship to deceased infant: _____

Given names: _____

Family name: _____

Date of birth: _____

Residential address: _____

Telephone Number: _____

PERSON 2

Relationship to deceased infant: _____

Given names: _____

Family name: _____

Date of birth: _____

Residential address: _____

Telephone Number: _____

PERSON 3

Relationship to deceased infant: _____

Given names: _____

Family name: _____

Date of birth: _____

Residential address: _____

Telephone Number: _____

PERSON 4

Relationship to deceased infant: _____

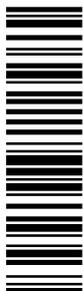
Given names: _____

Family name: _____

Date of birth: _____

Residential address: _____

Telephone Number: _____



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MEDICAL HISTORY OF INFANT

Gestation at birth: _____ Singleton birth Multiple birth

Birth weight: _____ Birth length: _____
(Plot weights on a percentile chart)

Type of feeding: _____

If type of feeding has changed, date and reason for change: _____

Medication, including prescription, over-the-counter, and complementary (record regular medications and recent medications): _____

Immunisation status: _____

At any time in the infant's life did he or she have a history of (record yes or no – if yes, describe)

Perinatal or neonatal problems (including any birth defects): _____

Evidence of failure to thrive: _____

Abnormal growth or weight gain/loss: _____

Developmental delay or mental retardation: _____

Metabolic disorders: _____

Recent contact with infection: _____



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COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

Allergies: _____

Apnoea (stopped breathing): _____

Cyanosis (turned blue/grey): _____

Seizures or convulsions: _____

Cardiac abnormalities: _____

Document any growth, development and other past assessments (eg health home visit, GP, well child health checks): _____

Has the child been investigated for neurological disorders, eg seizures or any other disorder?
If yes, give full details: _____

Details of any deaths in infancy or childhood of any offspring, siblings or other close relatives of any member of the current household: _____

Other medical history – record full details: _____

SLEEPING ARRANGEMENTS OF INFANT

Location of infant when found (cot, cradle, adult bed, sofa, etc): _____



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Bedding found with the infant (sheet, pillows, blankets, quilts, cot bumpers, etc): _____

Other objects found with the infant (soft toys, etc): _____

Were any items covering the infant's head or face? _____

Position of infant when put down (record exact position – on side, on back, on stomach, head to left or right side, or unknown): _____

Position of infant when found (record exact position – on side, on back, on stomach, head to left or right side, or unknown): _____

Recent changes in sleeping arrangements or sleeping patterns: _____

MEDICAL HISTORY FOR THE 48 HOURS PRIOR TO THE INFANT'S DEATH (Record yes or no – if yes, describe)

Changed level of alertness: _____

Fussiness/excessive crying: _____

Diarrhoea: _____

Fever: _____

Decrease in appetite: _____



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COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

Changes in stool: _____

Changes in passages of stool or urine: _____

Difficulty sleeping: _____

Lethargy or more sleep than usual: _____

Difficulty waking infant: _____

Excessive sweating: _____

Vomiting: _____

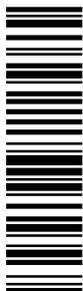
Choking: _____

Respiratory problems (including difficulty breathing, wheezing, stridor, in-drawing of ribs, snoring):

Any fall or injury: _____

Visit to a health professional (record presenting problem and advice given):

Other:



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OTHER ACTIVITY IN PAST 48 HOURS

Changes in routine care: _____

Changes in routine activity levels: _____

Disruptions to normal patterns: _____

DETAILED NARRATIVE ACCOUNT OF INFANT'S FEEDING, SLEEPING, ACTIVITY AND HEALTH OVER THE TWO WEEK PERIOD PRIOR TO DEATH

Include:

- Changes in feeding or sleeping patterns
- Changes in place of sleep or sleeping arrangements
- Changes in individuals responsible for caring for infant
- Any social, family, or health-related changes in routine
- Any illness, accident or other major event affecting other family members
- Any visits to a health professional, including reason for visit and outcome



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HISTORY OF THE FAMILY AND OF THE HOUSEHOLD

Include:

- Detailed information on tobacco use, including exposure of the infant to passive smoking (including smoking in the house and car, and any close contact of the infant with smokers)
- Detailed information on alcohol and other drug use
- Information on any prescription or non-prescription medications that may have been present or in use in the household
- Information on recent changes in composition of the household (eg who has come and who has gone, and for what reason)

Activity and location of all significant members of the household in past 48 hours:

Alcohol intake and recreational drug use by members of the household in past 48 hours:



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Title: Procedures for Management of Sudden Unexpected Death in Infancy

Appendix C: Fax coversheet

fax



TO	The examining forensic pathologist	FROM
FACILITY		FACILITY
FAX		FAX
TEL		TEL
DATE		PAGES INCLUDING THIS PAGE
SUBJECT		

Please find following the medical history of (insert child's name) taken on (date) from (insert names of parent(s)/caregivers interviewed) by (insert name of examining doctor) in the presence of (insert name of social worker).

Continuing health care for this issue will be provided to the family by (insert name of examining doctor). An autopsy report is requested in order to facilitate the continuing care of surviving family members of (insert child's name). Please send a copy of the autopsy report to:

For further information regarding this history, please contact: (insert name of the key person for further contact)

Appendix D: Standard Guidelines: Sudden Unexpected Death In Infancy (SUDI)

This protocol is based on “The autopsy protocol for sudden unexpected deaths in infancy”, outlined in Appendix III of “The report of a working group” convened jointly by the Royal College of Pathologists and The Royal College of Paediatrics and Child Health. It was published in September 2004 and can be viewed in full at <http://www.rcpath.org> and <http://www.rcpch.ac.uk>.

In all cases of sudden unexpected death in infancy total body radiographs (a skeletal survey) must be considered and appropriate photography carried out prior to post-mortem examination.

1. Introduction

In all cases of potential SIDS it is important before determining that the death is from natural causes to exclude accidental death such as trauma, drowning or poisoning, to consider the possibility of airway obstruction (as in overlaying due to co-sleeping) and to exclude non-accidental injury. There are certain other protocols of varying complexity available; the pathologist should conform to the local requirements.

Prior to autopsy, a full police report of death to the coroner and the police child death scene investigation protocol should be available. If not, there should be a documented verbal discussion with the police officer in charge of the scene, circumstances of death and available history.

All cases of sudden unexpected death in infancy must be reported to one of the three specialist forensic pathology departments for specialist examination.

2. External examination

- Measure weight, crown-heel length, crown-rump length, chest and head circumference.
- Assess nutritional status and extent of hydration.
- Note evidence of injuries and assess age.

3. Internal examination

- All organs are to be systematically examined and weighed, including the thymus.
- Note the distribution of, or absence of, petechial haemorrhages.
- Brain to be examined. Discuss with the neuropathologist the value of examining the spinal cord.

4. Organ retention

- This can only be done with the specific consent of the Coroner and after discussion with the family.

Title: Procedures for Management of Sudden Unexpected Death in Infancy

5. Histology

All major organs including:

- Five lobes of lung stained with H&E.
- Epiglottis and larynx.
- Trachea including thyroid.
- Heart including right and left ventricles. Depending on the size, a complete transverse section of the heart can be embedded as a single block, or possibly two blocks.
- All internal organs including duodenum with head of pancreas.
- Bone marrow including costochondral junction.
- Skeletal muscle.
- Brain - If the brain is cut unfixed a minimum of the following sections should be taken: hippocampus, cerebellum, frontal cortex, basal ganglia, medulla, pons, and midbrain.
- Frozen sections of liver and kidney for fat stains depending on case.

6. Other samples

- Toxicology. (Toxicology should always be performed in cases of SUDI. If there has been a significant period of survival in hospital, ante mortem specimens should be obtained for analysis.)
- Biochemistry: Vitreous humour/CSF (sodium, potassium, chloride, urea, creatinine, ketones, glucose).
- Virology and microbiology as required.
- DNA for genetic testing, e.g. for prolonged QT interval 5 ml blood in EDTA.

In all cases, blood (or other specimen suitable for extraction of DNA) should be retained for prolonged QT genetic testing in case it is required later. If there is a history of similar death in other family members and siblings, which is suggestive of long QT syndrome, then the pathologist should discuss the case with a cardiologist and strongly consider genetic testing for inherited causes of cardiac arrhythmias particularly prolonged QT.

Where indicated by autopsy and/or clinical findings, testing for genetic and/or inherited metabolic disorders should be undertaken.

Title: Procedures for Management of Sudden Unexpected Death in Infancy

Samples required for metabolic testing

1. Blood

This procedure is the same as normal clinical practice for a live infant. Blood collection may be difficult, especially as the time since death increases. The first attempt to take blood should be from the femoral vessels. Peripheral blood is better than heart blood, particularly for toxicological analysis.

If insufficient blood is obtained peripherally, blood should be taken from the heart. Use a large (e.g. 14-gauge) needle and aspirate blood from the right ventricle of the heart first for blood culture to minimise the chances of contamination. Then incise the right ventricle anteriorly and aspirate any remaining blood using a syringe. This technique provides the largest amount of blood, which can then be used for other purposes.

The order of priority for blood collection and analysis is:

- Sample of blood from syringe for Guthrie card. Send the newborn screening card for metabolic analysis to the Biochemical Genetics, The Children's hospital at Westmead.
- Blood for toxicological analysis.
- Blood for blood culture.

2. Bile

Bile should be collected from the gall bladder and frozen at -70°C and sent on dry ice to Biochemical Genetics, The Children's Hospital at Westmead for storage and possible later analysis for diagnosis of metabolic analyses.

3. Urine

It may not be possible to collect urine from the infant, however even a very small amount can be analysed (2mls of urine is sufficient).

Priorities for urine are:

1. toxicological analysis
2. metabolic analysis

Open the trunk and directly visualise the bladder, followed by either opening the bladder or using a syringe and needle to obtain urine.

Freeze sample at -20°C . Urine should be sent on dry ice to the Children's Hospital at Westmead for analysis. This sample can also be used for toxicology.

4. Cerebrospinal Fluid (CSF)

Place the CSF into two sterile CSF tubes, one for microscopy and culture, and the other to be stored frozen for later PCR for viruses and/or metabolic testing as appropriate. CSF for metabolic analysis should be sent to the Biochemical Genetics, The Children's Hospital at Westmead.

Title: Procedures for Management of Sudden Unexpected Death in Infancy

Note the colour and type of CSF and site of collection of CSF.

Depending on the sample size, CSF can also be used for biochemistry – urea, creatinine and electrolytes.

Samples for metabolic screening should be forwarded to Biochemical Genetics Department in the Children's Hospital at Westmead and should arrive between the hours 8.30am – 5pm Monday to Friday. Telephone number: (02)9845 3654. For enquiries out of office hours, page the Senior Scientist through the Children's Hospital switchboard: (02)9845 0000.

Sampling muscle, liver and skin

These samples can all be taken via the same abdominal incision. **In exceptional circumstances** where metabolic disease is likely, consideration should be given to a paediatrician taking the liver samples immediately after the infant's death. This should be done in consultation with the forensic pathologist, the coroner and the pathology laboratory.

5. Skin

Take a thin ellipse of skin from the edge of the incision under sterile conditions. Place in cytogenetics fluid (Hanks). If this is not available, then sterile normal saline or Stuart's viral transport medium can be used. Place in normal fridge. **Do NOT freeze.**

6. Muscle

Note the state of the muscle and take a rectangular biopsy approximately 10x20mm if possible. Stay anterior to the peritoneum.

Wrap half the muscle sample in foil. Place in a suitable sealed container and snap freeze in liquid nitrogen then maintain at -70°C or place on dry ice. **Do NOT allow to thaw.** If available, place half of remainder in formalin and freeze other half on a chuck with fibers orientated transversely. The most important step is freezing the muscle at -70°C.

7. Liver

Cut through the peritoneum and expose the liver. Note any free fluid in the abdomen - amount, colour, blood etc. Note the appearance of the liver - colour, presence of contusions, haemorrhage and texture.

Take a wedge of liver 10x10mm. Wrap majority in foil, place in a suitable container and snap freeze in liquid nitrogen then maintain at -70°C or on dry ice. **Do NOT allow to thaw.** Place the remainder of the liver sample in formalin.