

MANAGEMENT OF + THE DEATH OF A CHILD IN HOSPITAL

RESOURCE



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1. INTRODUCTION

Anyone who has experienced the death of someone close knows how painful and overwhelming the experience of grief can be, and how confusing the thoughts and feelings accompanying it are. The death of a child, whether anticipated for some time or unexpected and sudden, usually creates the most intense response in the family and professionals involved.

At some time during their careers, clinicians are likely to manage the care and support for a dying child and their family. Following the child's death, you may be part of the communication and decision making process, and be involved in the completion of management. Effective teamwork and communication are critical in supporting the family.

Although the impact of the experience might be personally overwhelming at the time, it is our responsibility as health care professionals to ensure that the parents and family are fully informed as well as optimally supported and comforted. Depending on your individual level of experience and your relationship with the child and their family, you may feel comfortable being the main resource person or you may prefer to call upon the help of a senior colleague, social worker or chaplain.

When communicating with family members after the death of a child, always listen patiently and be prepared to go through what has happened many times. Family members may be devastated and numb or elated and thankful that the child's suffering is finally over. Acknowledge that all feelings are normal. Explain the necessary procedures, such as the issuing of a death certificate, the need to register the death and make funeral arrangements. The family will vividly remember the emotional experience of these moments for years to come, and they will remember your patience, empathy and support.

Ask the parents whether there are any specific religious or spiritual needs or requirements. You may consult with the hospital chaplaincy/ pastoral services or encourage the family to invite their spiritual leader to support them at the hospital.

Encourage the family to make and maintain contact with their primary care team, who may have known the child for several years and will be able to offer ongoing support.

In the event of a death, the initial steps are to screen the child and notify the senior medical officer, if not already present. The senior medical officer should notify the parents/ carers that the child has died, explain the process following the death of a child in hospital and assist them accessing the support they require.

In order to provide the highest standard of management of care and support to grieving families and ensure documentation of essential information for subsequent or future analyses, this hospital resource provides information about pathways and procedures that are to be followed under defined circumstances.

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2. MANAGEMENT OF THE DEATH OF A CHILD IN HOSPITAL

It is the responsibility of all health care providers to ensure that the parents and family are fully informed as well as optimally supported and comforted during and following the death of a child. Cultural, religious and spiritual issues should always be considered in meeting the needs of the family. Effective teamwork and communication are critical in supporting the family.

2.1. Key Points about the Resource

This document provides information on what to do in the event of the death of a child (less than 16 years of age) in hospital and makes reference to relevant NSW Health Policy documents. This document should be used when:

- Death occurs during an admission to hospital AND
- Following a sudden and unexpected death outside hospital, where the child is brought into an Emergency Department.

This document does not provide information on what to do in the event of stillbirths or perinatal deaths or Sudden Unexpected Death of an Infant. Refer to:

- Stillbirth Management and Investigation (PD2007 025)
- Deaths Review and Reporting of Perinatal Deaths (PD2011 076)

Sudden and Unexpected Death of an Infant (SUDI), is defined as an infant is less than 12 months of age AND the death is sudden and unexpected. This definition excludes infants who die unexpectedly in misadventures due to external injury (such as transport incidents) and accidental drowning. This Hospital Resource does not include SUDI. For the management of SUDI, refer to Death - Management of Sudden Unexpected Death in Infancy (PD2008 070)

The policy directive 'Death – Extinction of Life and the Certification of Death – Assessment' (PD2012_036) outlines the process for the assessment and documentation to verify death (previously referred to as extinction of life), and the medical verification of death. It describes the roles of medical practitioners, registered nurses and qualified paramedics employed by NSW Health in relation to assessment and documentation required when patients die. At the time of publication of this resource, the Ministry of Health is revising the Policy Directive Verification of death and medical certification of death and forms. The state-wide forms have been submitted to the State Forms Management Committee for approval. The revised Policy Directive will not be released until the forms process is complete. In addition, a training resource targeting registered nurses in the process of verification of death is being commissioned from HETI.

For easy reference and an overview of the roles and decisions see:

<u>Confirmation of Death & Reportable Deaths - Flow Sheet (1)</u> - is a guide to determining whether the death is a coroner's case or not and whether an autopsy is to be performed

<u>Completing the Death Certificate - Flow Sheet (Part 2)</u> - provides specific details about death certificate completion, urgency and correct nomenclature.

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In the event of the death of a child in hospital one of 3 pathways is to be followed:

- 1. Non-coroner's case without a hospital autopsy
- 2. Non-coroner's case with a hospital autopsy
- 3. Reportable deaths Coroner's case

See Confirmation of Death & Reportable Deaths - Flow Sheet (1)

2.2. Key Information in the Resource

A facility may choose to have one or more designated areas or containers to hold a copy of this resource together with the forms and any other relevant information. Key information found within this document includes:

- Assisting parents / families with their wishes / preferences including:
 - taking the child home,
 - o viewing the child
 - o cleaning/ dressing the child
 - o holding the child
 - o parents/ families wishing to transport the body to the funeral directors
 - cultural/ spiritual/ traditional needs
- Management of care and support for the child, the family and staff
- If the deceased child was infectious or recently treated with radioactive material:
 - Infection Control Policy (PD2007 036)
 - o Medication Handling in NSW Public Health Facilities (PD2013_043)
- Social work and/ or Aboriginal services involvement
- A new Medical Certificate Cause of Death (MCCD) was released in December 2014.
- Other relevant NSW Health Policy Documents:
- Consenting to treatment and end of life care
 - Consent to Medical Treatment Patient Information (PD2005_406)
- Determining if the death is a coroner's case
 - o Coroner's Cases and the Coroners Act 2009 (PD 2010 054)
- Determining if a hospital autopsy is required
 - Non-Coronial Post Mortems (PD2013_051)
- Organ and Tissue Donation
 - Deceased Organ and Tissue Donation- consent and other procedural requirements (PD2013_001)
 - Human Tissue Act
- Documentation, Death certificates, and Designated officers
 - Organ Donation After Circulatory Death (GL2014_008)
 - <u>Deceased Organ and Tissue Donation-Consent and Other Procedural</u> Requirements (PD2013 001)
 - Non-Coronial Post Mortems (PD2013 051)

NOTE: If the death is a coroner's case:

- Any contact must be supervised and the body must not be disturbed
- o Medical equipment should not be removed
- o Families will be given the opportunity to spend time with their child, when appropriate.

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2.3. Expected Death of a Child In Hospital

1

Priority to be given to the welfare and support of the bereaved families

2

•The family should be given the option of staying with their child and caring for the child as planned.

2.4. Unexpected Death of a Child brought in by Ambulance and Resuscitation was Unsuccessful

1

Priority to be given to the welfare and support of the bereaved families

2

• If resuscitation efforts are in process they should be continued while the history is obtained and the response to resuscitation is assessed

3

 If in the Emergency Department, the child should be triaged and have a clerical entry made including the general practitioner (GP) and paediatrician details, if possible

4

 Unless the case is considered suspicious by the police, the family should be given the option of staying with their child or offered a quiet area nearby.

5

 Once the child is verified dead, the decision whether to make it a coroner's case proceeds as described in Coroners Cases and the Coroners Act 2009 (PD 2010_054)

2.5. Unexpected Death of a Child in Emergency Brought in by Ambulance Deceased OR Resuscitation in Hospital was Unsuccessful

1

· Priority to be given to the welfare and support of the bereaved families

2

• Unless the case is considered suspicious by the police, the family should be given the option of staying with their child or offered a quiet area nearby.

3

•If the death is a coroner's case, including SUDI, any contact must be supervised and the body must not be disturbed

4

•Once the child is verified dead, the decision whether to make it a coroner's case proceeds as described in Coroners Cases and the Coroners Act 2009 (PD 2010_054)

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to the coroner's autopsy.

MANAGEMENT OF THE DEATH OF A CHILD IN HOSPITAL RESOURCE

3. CONFIRMATION OF DEATH & REPORTABLE DEATHS: FLOW SHEET (1)

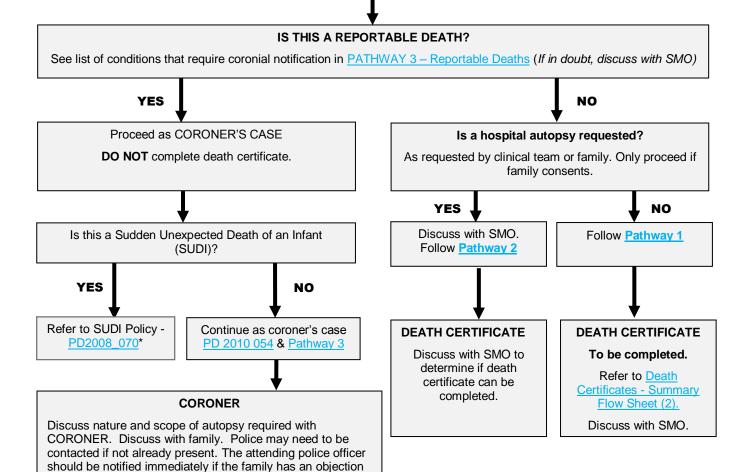
Medical Officer (MO) asked to complete death certification after child death. MO is to inform the Senior Medical Officer (SMO) responsible for the care of the child that the child has died. SMO leads the completion of the medical certificate of cause of death.

The SMO responsible is expected to actively participate in this process and will ensure that all documentation is accurate and complete. The SMO is to ensure other MOs and SMOs involved in the child's care are kept informed.

Prior to entering room, MO to discuss with Nurse in Charge or other relevant staff circumstances of death and family issues as relevant. Assess if psychosocial needs of family have been met and request assistance (social worker, cultural, spiritual, religious support) as required.

CONFIRM DEATH

MO to introduce themself to family member(s) in room briefly explains their role. PD2012 036 Death – Extinction of Life and the Certification of Death – Assessment outlines the process for the assessment and documentation to verify death (previously referred as extinction of life), and the medical certification of death. It describes the roles of health professionals employed by NSW Health in relation to assessment and documentation when patients die.



NOTES: In coronial cases only, if a hospital autopsy is requested or diagnostic tissue or organ removal required SMO **MUST** discuss with coroner first and only proceed if family consents. Metabolic samples are best obtained within 2 hours of death. Follow <u>GL2014_008</u> and <u>PD 2013_001</u>.

An autopsy may be performed by a paediatric pathologist only with the approval of the coroner.

*This Hospital Resource does not include SUDI. For the management of SUDI, refer to PD2008_070

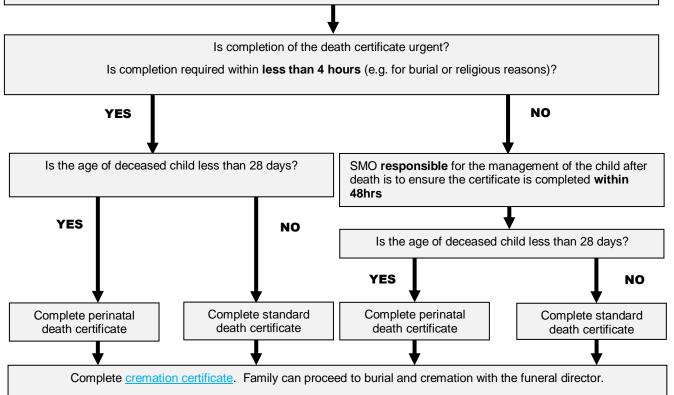
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4. COMPLETING THE MEDICAL CERTIFICATE OF CAUSE OF DEATH: FLOW SHEET (2)

Medical Certificate of Cause of Death (MCCD) to be completed:

Medical Officer (MO) asked to complete the Medical Certificate of Cause of Death (MCCD) after child death. MO is to inform the Senior Medical Officer (SMO) **responsible** for the care of the child that the child has died. SMO leads the completion of the medical certificate of cause of death and all other documentation as appropriate.



KEY POINTS TO CONSIDER WHEN COMPLETING DEATH CERTIFICATE

- The Senior Medical Officer (SMO) is responsible for the accurate completion of the death certificate.
- Cause of death is not 'cardiopulmonary arrest'. This is a process not a cause of death.
- Line (a) is the direct cause of death. There must always be an entry in line (a). The senior doctor responsible must be consulted with regard to documenting the underlying cause of death.
- Lines (b)-(e) are underlying causes that have contributed to death.
- If (a) is not a consequence of other conditions then (b) (e) can be left blank.
- Do not forget to complete the 'Duration' column on the right hand side of the form.
- · Complete 'Part 2 Other Significant Conditions'.

For further information and guidance on how to complete a Cause of Death Certificate please refer to <u>'Information Paper. Cause of Death Certification'</u> 2004 produced by the Australian Bureau of Statistics (ABS).

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5. PATHWAY 1: NON-CORONER'S CASE WITHOUT A HOSPITAL AUTOPSY

Refer to:

PD2012_036_Death - Extinction of Life and the Certification of Death - Assessment

Pathway 1 Checklist

5.1. Families

Recognise the importance of the welfare and support of the bereaved families. Consider involving extended family, social worker, counselling, Aboriginal Health Liaison Officers and spiritual support.

5.2. Documentation

Senior Medical Officer

- Complete clinical documentation in the patient's medical record.
- Complete Medical Certificate of Cause of Death form or Medical Certificate of Cause of Perinatal Death form1.
- Complete any other locally required documentation.
- If needed, complete <u>Attending Practitioner's Cremation Certificate</u>. The medical officer completing the certificate must identify the patient's body.

If death occurred as a result of or within 24 hours of anaesthetic administration

 (Category 1 Scheduled Medical Condition), complete Report of Death Associated with Anaesthesia / Sedation Form and send to:

Secretary, NSW Health c/o Special Committee Investigating Deaths Under Anaesthesia Clinical Excellence Commission Locked Bag 8 Haymarket NSW 1240

Further information about the Special Committee Investigating Deaths under Anaesthesia (SCIDUA) is available on the Clinical Excellence Committee's website (see SCIDUA).

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¹ BIRTHS DEATHS AND MARRIAGES REGISTRATION ACT 1995 Section 39 Notification of deaths by doctors

⁽¹⁾ A doctor who was responsible for a person's medical care immediately before death, or who examines the body of a deceased person after death, must, within 48 hours after the death:

⁽a) give the Registrar notice of the death and of the cause of death in a form and manner required by the Registrar, or (b) if the doctor is of the opinion that it is impracticable or undesirable to give notice of the cause of death of the person within that time, give the Registrar notice of the death, and of the doctor's intention to give notice of the cause of death, in a form and manner required by the Registrar.

Maximum penalty: 5 penalty units.

⁽²⁾ However, a doctor need not give a notice under this section if:

⁽a) another doctor has given the required notice, or

⁽b) the death has been reported to a coroner under the Coroners Act 2009.

⁽³⁾ A doctor must not give a notice under this section if the doctor is prevented from giving a certificate as to the cause of death of the person by section 38 of the *Coroners Act 2009*.



If the patient was under the care of a surgeon at some time during their hospital stay regardless of whether an operation was performed

 Complete the <u>Surgical Case Form.</u> Advise your Local Health District / Specialty Health Network Clinical Governance Unit. Forward completed form to:

Clinical Excellence Commission CHASM Locked Bag 8 HAYMARKET NSW 1240

Further information about the Collaborating Hospitals' Audit of Surgical Mortality (CHASM) is available on the Clinical Excellence Committee's website (see CHASM).

Nursing Unit Manager (NUM) or After Hours Nurse Manager (AHNM) if death occurs after hours

- Ensure a patient pronounced 'dead on arrival' receives a medical record number.
- Complete a 'Death Notification' form.
- Ensure the medical record is complete, including documentation of all communications and procedures that have occurred, for example, removal of medical devices, time of death and time of transport to the mortuary.
- Ensure the medical record is clearly marked and placed in the designated tray for the ward clerk.

Nursing Staff

- Notify the mortuary (business hours) or, if the death occurs after hours, contact After Hours Nurse Manager (AHNM).
- Complete documentation in the patient's medical record.

Ward Clerk

Take medical record to the Clinical Governance Unit.

Clinical Governance Unit

 Check completeness of medical record, documentation and send to the medical records department.

5.3. Transfer of the patient's body

Nursing Staff

- Initiate the transfer and accompany the patient's body, take the original of any locally required documentation to the mortuary and place the body in the fridge.
- The mode of transport to the mortuary for infants and children can be subject to local policy and family preferences, and may include carrying, bassinettes or mortuary trolley.
- In the mortuary, document the deceased patient's details in the Mortuary Register and leave any locally required documentation in the Mortuary Register.
- Complete the patient information card and place it in the holder on the mortuary fridge door.

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5.4. Completion of management

Senior Medical Officer

As soon as practical after the death:

- Notify GP, referring paediatrician, other health care providers and relevant services, for example, early childhood centre / pre-school / school.
- Arrange follow-up for the family.
- Offer the mother of the patient use of a breast pump or medication for suppressing lactation, if required.
- Complete discharge paperwork.

Senior Medical Officer/ Nurse Managers

Assess and act upon the possible need for staff debriefing.

Nursing Staff

 After discussion with the family, contact social work, religious or spiritual services and other family members, as required.

Social Work

As soon as appropriate:

• Offer the family counselling and support (see 19: Management of care and support of the family).

Communicate relevant information to the family, for example, issues relating to social security payments.

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6. PATHWAY 2: NON-CORONER'S CASE WITH A HOSPITAL AUTOPSY

Refer to

PD2012_036_Death - Extinction of Life and the Certification of Death - Assessment

PD2013_051 Non-Coronial Post Mortems

PD 2013 001 Deceased Organ and Tissue Donation-Consent and Other Procedural

Requirements

GL2014_008 Organ Donation After Circulatory Death: NSW Guidelines

Pathway 2 Checklist

11. The role of a hospital autopsy

12. Designated officers

13. Inborn error of metabolism

6.1. Families

Recognise the importance of the welfare and support of the bereaved families. Consider involving extended family, social worker, counselling, Aboriginal Health Liaison Officers and spiritual support.

6.2. Documentation

Senior Medical Officer

- Discuss the request for a hospital autopsy with the histopathologist prior to obtaining informed consent. This is necessary in order to clarify the extent and details of the examination required to answer clinical questions.
- Discuss the autopsy with the family and provide the brochure Information for Parents about Hospital Autopsy.
- Complete a Hospital Autopsy Consent form.
- Contact a designated officer to authorise the autopsy (see 12: Designated officers).
- Formally consult the histopathologist once consent has been obtained.
- Ensure the parents receive a copy of the completed consent form (this is a legal requirement).

Designated Officer

Authorise the hospital autopsy, as appropriate (see 12: Designated officers).

Nursing Unit Manager (NUM) or After Hours Nurse Manager (AHNM) if death occurs after hours

- Ensure a patient pronounced 'dead on arrival' receives a medical record number.
- Complete a 'Death Notification' form.
- Ensure the medical record is complete, including documentation of all communications and procedures that have occurred, for example, removal of medical devices, time of death and time of transport to the mortuary.

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 Ensure the medical record is clearly marked and placed in the designated tray for the ward clerk.

Nursing Staff

- Notify the mortuary (business hours) or, if the death occurs after hours, contact the AHNM.
- Complete documentation in the patient's medical record.

Ward Clerk

Take medical record to the Clinical Governance Unit.

Clinical Governance Unit

- Check completeness of medical record, documentation and forms.
- Forward medical record to medical records department.

6.3. Completion of management

Senior Medical Officer

- Communicate results of the autopsy to the family.
- Once the final report is available meet with the family. Consider providing support for the family at this meeting, such as social work or the chaplain.
- Arrange follow-up for the family.
- Notify GP, referring paediatrician, other health care providers and relevant services, for example, early childhood centre / pre-school / school.
- Offer the mother of the patient use of a breast pump or medication for suppressing lactation, if required.
- Complete discharge paperwork.

Senior Medical Officer/ Nurse Managers

Assess and act upon the possible need for staff debriefing.

Nursing Staff

 After discussion with the family, contact social work, religious or spiritual services and other family members, as required.

Social Work

As soon as appropriate:

- Offer the family counselling and support (<u>see 19: Management of care and support of the family</u>).
- Communicate relevant information to the family, for example, issues relating to social security payments.

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6.4. Tissue removal / peri-mortem specimen collection

6.4.1. Communication and responsibilities

Senior Medical Officer

- In the case of a possible metabolic disorder, contact:
 - Sydney Children's Hospitals Network (Randwick) Metabolic & Biochemical Genetic Services (02 9382 1704 / 9382 1111)
 - Sydney Children's Hospitals Network (Westmead) Genetic Metabolic Diseases
 Service (02 9845 3452 / 02 9845 0000)
 - John Hunter Children's Hospital Hunter Genetics, (02 4985 3100 /02 4921 3000)
- Specimen collection should occur as soon as possible after death, preferably within two hours.

Designated Officer

- Authorise tissue removal / peri-mortem collection, as appropriate (see 12).
- Specimen collection should occur as soon as possible after death, preferably within two hours.

6.4.2. Collection of peri-mortem samples from patients with a suspected inborn error of metabolism

- Discuss with one of the metabolic services (contact details above).
- A member of the histopathology team will usually be responsible for collection.
- Specimen collection should occur as soon as possible after death, preferably within two hours.
- For some disorders it is essential that other tissue samples (in particular, liver and muscle in addition to skin) are collected. There are two scenarios where these samples need to be collected:
 - The first category of patient is the patient in the Paediatric Intensive Care Unit (PICU) or the Neonatal Intensive Care Unit (NICU) who presents and dies suddenly. Samples required to exclude inborn errors of metabolism.
 - The second category of patient, who could be in either a PICU, NICU or ward, is likely to have had a partial workup and, therefore, additional samples will be required.

6.4.3. Coordination of peri-mortem sample collection

- The metabolic services team or, preferably, the general medical team primarily responsible for the management of the patient, is responsible for discussing the collection of peri-mortem samples with the family during the consultation process.
- It is important during this discussion that parents are made aware of the timing of the sample collection.
- The general medical, PICU or the NICU team will notify nursing staff that peri-mortem samples will be collected.
- The senior doctor is responsible for completing the Removal of Tissue after Death MR-3b form which must be signed by a designated officer (see 12: Designated officers).
- With sensitivity, the medical team will need to decide on a time that the child will be transferred to the mortuary and communicate this to nursing staff.

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7. PATHWAY 3: REPORTABLE DEATHS - CORONER'S CASES

Refer to:

PD2012_036_Death - Extinction of Life and the Certification of Death - Assessment

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

IB2010_058 NSW Health Information Bulletin _Coronial Checklist Coroners Act 2009 No 41,

PD 2013_001 Deceased Organ and Tissue Donation-Consent and Other Procedural

Requirements

Coroners Amendment Act 2012 No 24

Pathway 3 Checklist

7.1. Families

Recognise the importance of the welfare and support of the bereaved families. Consider involving extended family, social worker, counselling, Aboriginal Health Liaison Officers and spiritual support.

7.2. Supervision

If the death is a coroner's case any contact must be supervised and the body must not be disturbed.

This means:

DO NOT remove any IV lines, drains, dressings or tubes,
DO NOT clean any part of the body,
DO NOT perform hand or foot prints,

A death certificate is not issued if the death is reportable to the coroner.

7.3. Documentation

It should be noted that the category of reportable deaths has been changed to require deaths to be reported to the coroner if the death is not the 'reasonably expected outcome of a health related procedure.' The term 'health related procedure' has been defined to mean a medical, surgical or other health related procedure including the administration of anaesthesia, sedative or drug. NSW Health policy PD2010_054_Coroner's Cases and Coroners Act 2009 and the Coroners Act 2009 No 41 include guidelines regarding whether a death is a reasonably expected outcome of a health related procedure.

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Senior Medical Officer

- The Senior Medical Officer in charge of the patient's care is responsible for coronial notification, in consultation with the patient's GP.
- Medical, nursing and midwifery staff requiring further advice If there is doubt as to whether
 the death is reportable, contact must be made with a senior medical team member or
 senior nurse manager or in their absence the NSW Police or the Office of the NSW State
 Coroner on 02 8584 7777 (business hours)
- Once determined to be a coroner's case, the Senior Medical Officer in charge of the
 patient's care will need to consider the scope of the coroner's autopsy and the possible
 need for tissue removal / peri-mortem specimen removal
- The Senior Medical Officer in charge should discuss the case directly with the coroner, keeping in mind that ultimate decision making responsibility lies with the coroner.

Families with objections should be reassured that coronial staff will be in regular contact with them during the process. Therefore, ensure that the current contact numbers for the family are included on the paperwork submitted to the coroner. The family's objections to an autopsy should be recorded on the Report of Death of a Patient to the Coroner (Form A).

The family may choose to submit an objection to the coroner about the autopsy being conducted. Details of how to contact the Coroner's Court can be found at http://www.coroners.justice.nsw.gov.au/Pages/contact_us.aspx. If the coroner decides that an autopsy is required, the family may apply to the Supreme Court within 48 hours of the death to seek to stop the autopsy occurring.

7.4. Notification

Senior Medical Officer

- Contact local police station and advise that you would like to report a death to the coroner.
- Do not report stillbirths to the coroner.
- Give parents a copy of the brochure <u>NSW Coroner's Court: A guide to services</u> and discuss any questions or concerns they may have. Inform parents:
 - to expect the arrival of uniformed police who may ask them questions
 - that the police are likely to ask for someone to formally identify the child's body
 - that viewing of the body by family or friends should be organised through the funeral director **after** the post mortem. In special circumstances, viewing may be arranged before the post mortem process.

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7.5. Identification of the body to police

- Next of kin or the attending medical officer is required to identify the patient's body to the police on the ward.
- Police may need to ask staff members and / or parents questions to establish background information for a police report. Staff members and parents are entitled to obtain legal assistance if they are required to provide a formal statement.
- Providing accurate and timely information to the police facilitates completion of the coronial process, which in turn can reduce distress for families.
- Police should be notified if the family objects to the coroner's autopsy.
- Police do not have the authority to access the patient's medical record.

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7.6. **Documentation**

Senior Medical Officer

- In most cases the patient's medical record will be formally requested by the coroner and / or the forensic pathologist.
- Timely completion of documentation by staff will facilitate the coronial process and in turn reduce distress for families:
 - Report of Death of a Patient to the Coroner (Form A) must be completed immediately. If uncertain, discuss with the Senior Medical Officer in charge of the patient's care, NUM / AHNM or Emergency or Intensive Care Unit consultant on-call. The police are given the original and one copy, the third copy remains in the medical record.

OR

If death occurred as a result of or within 24 hours of anaesthesia administration

 (Category 1 Scheduled Medical Condition), complete Report of Death Associated with Anaesthesia / Sedation Form and send to:

Secretary, NSW Health c/o Special Committee Investigating Deaths Under Anaesthesia Clinical Excellence Commission Locked Bag 8 Haymarket NSW 1240

Further information about The Special Committee Investigating Deaths under Anaesthesia (SCIDUA) is available on the Clinical Excellence Committee's website (see SCIDUA).

If the patient was under the care of a surgeon at some time during their hospital stay regardless of whether an operation was performed

 Complete the <u>Surgical Case Form.</u> Advise your Local Health District / Specialty Health Network Clinical Governance Unit. Forward completed form to:

Clinical Excellence Commission CHASM Locked Bag 8 HAYMARKET NSW 1240

Further information about the Collaborating Hospitals' Audit of Surgical Mortality (CHASM) is available on the Clinical Excellence Committee's website (see CHASM).

- Complete any other locally required documentation.
- Ensure the details of the family's GP are documented in the medical record.

Nursing Unit Manager (NUM) or After Hours Nurse Manager (AHNM) if death occurs after hours

- Ensure a patient pronounced 'dead on arrival' receives a medical record number.
- Complete a 'Death Notification' form.
- Ensure the medical record is complete, including documentation of all communications and procedures that have occurred, for example, noting medical devices have not been removed, time of death and time of transport to the mortuary.
- Ensure the medical record is clearly marked and placed in the designated tray for the ward clerk.

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Nursing Staff

- Notify the mortuary (business hours) or, if the death occurs after hours, contact the After Hours Nurse Manager.
- Complete documentation in the patient's medical record.

Ward Clerk

Take medical record to the Clinical Governance Unit.

Clinical Governance Unit

- Check completeness of medical record, documentation and forms.
- Send any other locally required documentation to mortuary.
- Ensure nominated hospital contact person for communication with coroner is aware of the case.
- Forward medical record to medical records department.

Medical Records

• Prepare and forward medical record to the Department of Forensic Medicine.

7.7. Transfer of the patient's body

Nursing Staff

- One of two situations can occur:
 - The patient's body may be transferred to the hospital mortuary before being transferred to the Department of Forensic Medicine at Sydney, Newcastle or Wollongong OR
 - 2. The patient's body may be transferred directly from the ward to the Department of Forensic Medicine at Sydney, Newcastle or Wollongong
- If transferring the patient's body to the hospital mortuary, as directed by the police:
 - Accompany the patient's body to the mortuary, take the original of any other locally required documentation and place the body in the fridge.
 - In the mortuary, document the deceased patient's details in the Mortuary Register and leave any other locally required documentation in the Mortuary Register. This must occur even if the body is directly transferred from the ward to the Department of Forensic Medicine at Sydney, Newcastle or Wollongong.
 - Complete the patient information card and place it in the holder on the mortuary fridge door.

OR

- If transferring the patient's body to Department of Forensic Medicine at Sydney, Newcastle or Wollongong, as directed by the police:
 - On the ward, hand the patient's body over to the government contractors who transport the body to the Department of Forensic Medicine.
 - The original and a copy of any other locally required documentation remain with medical record.

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Police

- The police identify the body to the government contractors who transport the body to the Department of Forensic Medicine. Identification of the body occurs in the mortuary, not on the ward.
- The police give the contractors the Report of Death of a Patient to the Coroner (Form A).

Government Contractors

 Sign the patient's body out (in the Mortuary Register) and transfer the body to the Department of Forensic Medicine.

7.8. Completion of management

Communication between the coroner and the hospital

Each hospital will have a nominated contact person for communication with the coroner who will:

- Ensure that relevant clinicians are informed if the coroner decides that a coronial autopsy
 is not required. This will allow timely decision making regarding a hospital autopsy.
- Receive a copy of all coronial autopsy reports and facilitate timely distribution of the reports to the involved clinicians.

Senior Medical Officer

As soon as practical after the death:

- Notify GP, referring paediatrician, other relevant Senior Medical Officer and health care providers, for example, early childhood centre / pre-school / school.
- Arrange follow-up for the family.
- Offer the mother of the patient use of a breast pump or medication for suppressing lactation, if required.
- Complete discharge paperwork.

Senior Medical Officer/ Nurse Managers

Assess and act upon the possible need for staff debriefing.

Nursing Staff

 After discussion with the family, contact social work, religious or spiritual services and other family members, as required.

Social Work

As soon as appropriate:

- Offer the family counselling and support (see 19: Management of care and support of the family).
- Communicate relevant information to the family, for example, issues relating to social security payments.

Provide the family with information about the Coroner's Court Counselling Service, ph. 02 8584 7777 or visit the Coroner's Court website

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8. TISSUE REMOVAL / PERI-MORTEM SPECIMEN COLLECTION

Ensure compliance with NSW Health policy directives:

PD 2013_001 Deceased Organ and Tissue Donation-Consent and Other Procedural

Requirements

If the death is reportable to the coroner, no sample of any kind can be taken after death without the permission of the coroner.

Senior Medical Officer

- In the case of a possible metabolic disorder, contact:
 - Sydney Children's Hospitals Network (Randwick) Metabolic & Biochemical Genetic Services, (02 9382 1704 or 9382 1111)
 - Sydney Children's Hospitals Network (Westmead) Genetic Metabolic Diseases Service, (02 9845 3452 or 9845 0000)
 - John Hunter Children's Hospital Hunter Genetics, (02 4985 3100 or 4921 3000)
- Specimen collection should occur as soon as possible after death, preferably within two hours.
- If doubt exists about the possibility of peri-mortem specimen collection, telephone the Duty Pathologist:
 - Dept of Forensic Medicine, Sydney, (02 8584 7800 available 24 hours, however, you may need to leave a message and your call will be returned). The State Coroner's Court may also be contacted for advice on 02 8584 7777.
 - Northern Forensic Hub, Newcastle, 02 4922 3700 (business hours) and 02 4929 0822 (after hours).
- Send the results of any metabolic studies to the Department of Forensic Medicine. In the
 case of a neonatal death reported to the coroner, indicate the location of the placenta, if
 known (for example, whether the placenta is in anatomical pathology, will accompany
 infant or has been discarded).

Genetic Services / Histopathologist

If permission is granted to perform peri-mortem collections, the histopathologist / genetic services initiate the procedures for collection of peri-mortem samples from patients with a suspected inborn error of metabolism see <u>6.4.2.</u> <u>Collection of peri-mortem samples from patients with a suspected inborn error of metabolism</u>.

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9. ORGAN AND TISSUE DONATION

Ensure compliance with NSW Health policy directives:

PD 2013_001 Deceased Organ and Tissue Donation-Consent and Other Procedural

Requirements

GL2014 008 Organ Donation After Circulatory Death: NSW Guidelines.

Human Tissue Act 1983 No 164

Every family of every potential donor should be routinely offered the opportunity for donation, regardless of the circumstances surrounding the child's death. Conversations regarding the possibility of organ or tissue donation require skill and understanding of processes involved.

Neonates, infants and children are potentially suitable to be a multi-organ donor when they have either been certified dead using brain function criteria (brain dead) or there is a planned removal of cardiorespiratory support (mechanical ventilation and inotropes). Potential organ donors are identified using the GIVE clinical trigger, available in critical care areas. Each potential donor should be referred to the NSW Organ and Tissue Donation Service and will be assessed individually for medical suitability.

Neonates, infants and children are potentially suitable for tissue donation after death and are not limited to those cared for in critical care areas. There are more potential and actual tissue donors than organ donors. The main tissues donated are cardiovascular tissue, such as heart valves and vessels, and eyes (for corneal donation). Sometimes musculoskeletal tissue such as bones and tendons can also be donated in patients older than fifteen years of age.

9.1. Communication and responsibilities

The NSW Organ and Tissue Donation Service (OTDS) coordinates organ and tissue donation in NSW and develops and maintains clinical and operational protocols for organ and tissue donation in NSW. Coordination of multi-organ and tissue donation at LHD/specialty network level is managed by Donation Specialist Nurses (DSN) and Donation Specialist Medical (DSM) staff employed at the hospital.

Senior Medical Officer

Optimising end-of-life care for the patient and the family should take precedent at all times.

All referrals for potential organ and tissue donation should be made to the DSN and/or DSM. They can be contacted 24hrs a day, typically via the hospital switch board. Staff should refer to their local hospital policies regarding the specific requirements for contacting donation specialist staff

Medical suitability is assessed by the DSN and/ or DSM in collaboration with the NSW Organ and Tissue Donation Services. There is no expectation that hospital Medical staff assess medical suitability due to variability between individual cases and ongoing changes in criteria.

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Designated Officer

In accordance with the Human Tissue Act a Designated Officer must be contacted to authorise the removal of organs and/or tissues in accordance with the consent provided by the family. Before issuing their written authority, the Designated Officer must be satisfied that the deceased child had not, when living, expressed an objection to organ or tissue donation. The Designated Officer has discretion as to whether they participate in the consent interview with the senior available next of kin, conduct their own separate interview, or discuss the consent with the DSN, Donation Specialist Coordinator or Tissue Donation Coordinator.

9.2. Coroners Cases

A case being a coroner's case does not preclude organ and tissue donation; decisions are made on a case by case basis and every effort is made to facilitate organ and tissue donation whenever possible. Consent from the Coroner for donation will need to be obtained by the Donation Specialist Coordinator of the NSW OTDS or Tissue Bank Coordinator.

9.3. Child in the Care of the State

Where a child was in the care of the State immediately prior to their death (i.e. in FACS care/under the care of the Minister for Community Services), consent must be obtained from:

- The Coroner
- The Principal Care Officer of the designated agency which has full case management responsibility of the child, must "...use reasonable efforts to contact persons who have been significant in the child's or young person's life and who the PCO considers to be appropriate to assist in the decision making process. These may include: Birth parents; Foster parents; Extended family; if the child/young person is Aboriginal or Torres Strait Islander, appropriate persons from the child's or young person's Aboriginal and/or Torres Strait Islander community; and persons considered relevant by the PCO".
- The Designated Officer; must ensure that the above has occurred prior to authorising the removal of organs and/or tissues.

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10. FURTHER INFORMATION

Refer to:

A Cause of Death Certificate must not be completed if the death is a coronial case - see

Pathway 3

The role of a hospital autopsy

PD2012 036 Death - Extinction of Life and the Certification of Death - Assessment

10.1. Documentation in the medical record following the declaration of the death of a patient

This policy outlines the process for the assessment and documentation to verify death (previously referred as extinction of life), and the medical verification of death. It describes the roles of medical practitioners, registered nurses and qualified paramedics employed by NSW Health in relation to assessment and documentation when patients die.

10.2. How to complete a medical certificate of cause of death

The senior doctor leads the completion of the Paediatric Medical Certificate of Cause of Death.

There are two types of death certificates:

- Medical Certificate of Cause of Death
- Medical Certificate of Cause of Perinatal Death

A new Medical Certificate Cause of Death (MCCD) was released in December 2014. At the time of publication of this resource, the MCCD is completed as a paper document, however the NSW Registry of Births, Deaths and Marriages is developing an on-line tool for the reporting of deaths and a move to on-line reporting is expected in due course.

PD2012_036_Death - Extinction of Life and the Certification of Death - Assessment outlines the process for the assessment and documentation to verify death (previously referred to as extinction of life), and the medical verification of death. It describes the roles of medical practitioners, registered nurses and qualified paramedics employed by NSW Health in relation to assessment and documentation when patients die. At the time of publication of this resource, the Ministry of Health is revising the Policy Directive Verification of death and medical certification of death and forms. The state-wide forms have been submitted to the State Forms Management Committee for approval. The revised Policy Directive will not be released until the forms process is complete. In addition, a training resource targeting registered nurses in the process of verification of death is being commissioned from HETI.

The booklet entitled 'Information Paper. Cause of Death Certification' (2004) produced by the ABS provides guidance for clinicians on how to complete Cause of Death Certificates. An extract for quick reference (p. 28 'Quick Reference Certification Guide') is provided below (information used with permission from the ABS).

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10.3. Death Certification - Quick Reference Guide

QUICK REFERENCE- COMPLETING THE MEDICAL CERTIFICATE OF CAUSE OF DEATHCOD)

Part One of the Certificate: Example of Completed Medical Certificate of COD

Direct Cause of death Line Ia The direct cause of death KLEBSIELLA PNUEMONIA Line Ib The cause of Line Ia 2 months Antecedent causes INACTIVITY CEREBRAL INFARCTION Line Ic The cause of Line Ib lc 2 months

Line Id The cause of Line Ic

Part Two of the Certificate:

Other significant conditions contributing to death but Part II ISCHAEMIC HEART DISEASE 10 years not related to the disease or condition causing it.

Where two independent diseases have contributed equally to the fatal sequence they may be entered on the same line.

Duration between onset and death: Enter the duration of time, between onset of each condition and the date of death.

QUICK REFERENCE CERTIFICATION GUIDE GENERAL CONDITIONS AND DISEASES

This principle applies to ALL conditions and diseases that are documented on the Medical Certificate of Cause of Death, not only those listed below and overleaf. For information on the required detail for other conditions,

Pneumonia Primary, hypostatic or aspiration. Infarction Ateriosclerotic or thrombolytic

Cause of any underlying condition

Causative organism.

If due to inactivity/debility -

condition leading to inactivity/debility

Infection Primary or secondary

Causative organism If primary - bacterial or viral

If secondary - details of primary infection

HITI Site within urinary tract

Causative organism

Underlying cause

If due to inactivity/debility -

condition leading to inactivity.

Renal Failure Acute, chronic or end stage,

Underlying cause, eg hypertension,

arteriosclerosis, pregnancy or

heart disease

If due to immobility - condition

leading to inactivity/debility.

Acute or chronic HepatitİS

Pregnancy

Due to alcohol

Of new born

Of pregnancy, childbirth, puerperium

If viral - type (A,B,C,D OR E)

Document pregnancy on certificate even

if unrelated to COD

- If pregnant at time of death or within 42 weeks

If pregnant between 6 weeks and 12 months of

ATERIOSCLEROSIS

vears

ALCHOHOLISM AND SMOKING 20 years

Note: The shortest duration should be on Line la and increase sequentially to the last entry in part one. See example above.

If you have any questions regarding Cause of Death Certification Freecall the ABS on 1800 620 963

Please provide the required detail for the conditions and diseases listed below. Where your best medical opinion does not permit you to document the required detail, please document this detail as UNKNOWN.

not listed below, refer to the booklet "Cause of Death Certification Australia" pages 22 - 27.

If thrombolytic - see Thrombosis below.

Thrombosis If arterial -specify artery

If intra cranial sinus - pyogenic non-pyogenic, late effect, post-abortive, puerperal, venous (specify vein).

If post-op or due to immobility - condition

necessitating surgery or immobility.

If venous - specify vein

Pulmonary If under 75 years of age - underlying cause

Embolism If postoperative-condition requiring surgery

Cardiac Arrest Underlying cause

Septicaemia Site of original infection

Underlying cause and organism

Leukaemia Acute, sub acute or chronic

Type - lymphatic, myeloid or

monocytic

Alcohol/Drugs Harmful use or addiction

Complication Condition requiring surgery

Of Surgery

Dementia Cause (senile, Alzheimer's, multi infarct etc)

Accidental Circumstances surrounding the death.

Accidental, suicidal, homicidal or Death undermined intent

Place of occurrence & Activity at time of death

death

If ANY of the detail requested above is UNKNOWN, please document this on the certificate.

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11. THE ROLE OF A HOSPITAL AUTOPSY

Ensure compliance with NSW Health policy directives:

PD2013 051 Non-Coronial Post Mortems

PD 2013_001 Deceased Organ and Tissue Donation-Consent and Other Procedural

Requirements

In principle, most hospitals are in favour of autopsies being performed. The advice of the Attending Medical Officer must always be obtained. In seeking permission for an autopsy from the parents or next-of-kin, details of the procedure should be discussed, preferably with a senior medical officer known to the family.

An autopsy is a surgical procedure, conducted with dignity and care by skilled pathologists. It involves macroscopic inspection of the internal organs and microscopic examination of samples of tissues. An autopsy does not disfigure the body any more than an operation, the only changes in the outward appearance of the patient is carefully stitched incisions, one from the sternum to the pubic symphysis and one across the scalp. Every effort is made to restore the body following the autopsy.

An autopsy is likely to identify the cause of the patient's death, confirm or refute the diagnoses made during life and the effects on vital organs. It may also clarify the effects, if any, of treatment given. In some instances, an autopsy may provide valuable information for parents and family members, particularly if an underlying genetic disorder is suspected. Under these circumstances, appropriate tissue samples are collected and analysed, cell lines are established for chromosome analysis and DNA extracted and stored for further genetic studies. This information may be important for prenatal diagnosis of subsequent pregnancies.

Some families feel strongly for religious, cultural or personal reasons that organs should be returned to the body, that a limited autopsy be performed or that certain organs, such as the brain or heart, not be examined, if it is felt not to be relevant to the cause of the child's death. This is possible and must be clearly documented on the Consent for Hospital Autopsy form and / or the Removal of Tissue after Death Form MR 3b. This must be communicated to the pathologist who will perform the autopsy. Limited procedures may reveal incomplete but nevertheless valuable information. After resolution of their grief, families rarely regret allowing an autopsy but may come to regret not doing so.

If a hospital autopsy is performed after the coroner has issued a death certificate without an autopsy, and a disparate or more precise cause of death arises as a result of the autopsy, the coroner is usually willing to re-issue a death certificate that reflects those results.

The family will usually be given preliminary results of the autopsy. Once the final report is available the Attending Medical Officer should arrange a meeting with the family. Consider providing support for the family at this meeting, such as social work or the chaplain.

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12. DESIGNATED OFFICERS

For more detailed information see:

Human Tissue Act 1983 No 164

Human Tissue Legislation Amendment Act 2012 No 72

PD 2013_001 Deceased Organ and Tissue Donation-Consent and Other Procedural

Requirements

The designated officer has discretionary authority not simply administrative authority. The role may require decision-making, conflict resolution and high level communication and negotiation skills.

Designated officers are appointed under Section 5 of the Human Tissue Act 1983. A designated officer must not act in a case in which he / she has a personal interest or clinical involvement.

Appointment of designated officers

The governing body of a hospital may, by instrument in writing, appoint such persons as the governing body considers necessary to be designated officers for the hospital.

The appointment of several designated officers may be necessary to ensure that one is available when required, particularly after hours.

Staff should be aware of how to contact the designated officers (in and out of business hours), for example, via switch or administrative staff.

The functions of a designated officer are to authorise the:

- removal of tissue from the body for transplant or other therapeutic, medical or scientific purpose (coronial or non-coronial);
- performance of a non-coronial autopsy; and
- release of a body for anatomical examination.

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13. INBORN ERROR OF METABOLISM

Inborn errors of metabolism often present as an acute life-threatening condition which can affect one or more organs. With prompt diagnosis, acute resuscitative procedures can be implemented, but all too frequently the diagnosis is not established in life. As these disorders have genetic implications, it is imperative that an accurate diagnosis be made. This involves the collection of urine, blood, and sometimes cerebrospinal fluid (CSF) and skin.

In order to maximise the chance of diagnosing inborn errors of metabolism, muscle, liver and skin specimens should be collected as soon as possible after death, preferably within two hours. However, specimens should only be collected after consulting with metabolic services.

As much as possible, sterile technique should be used such that the removal of tissues for metabolic studies does not preclude full autopsy examination, including microbiological and viral studies. Incisions should be closed with adhesive material or sutures and an occlusive dressing applied. An attempt should be made not to violate the thoracic cavity. Also, the procedure should be minimally invasive so as not to preclude optimal restoration of the body. The incision should be made vertically at the abdominal midline. Skin biopsies should be obtained from an area that is not readily visible or along the edge of the abdominal incision, if one is made.

If there is to be a subsequent coronial autopsy, send the results of any metabolic studies to the Department of Forensic Medicine (02) 8584 7800. In the case of a neonatal death reported to the coroner, indicate the location of the placenta if known (for example, whether the placenta is in anatomical pathology, will accompany infant or has been discarded).

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14. PARENTS WISHING TO TAKE THEIR CHILD'S BODY HOME OR TRANSFER THEIR CHILD'S BODY TO THE FUNERAL HOME

(only possible under Pathway 1: Non-coroner's case without a hospital autopsy)

Parents may take their child's body home or transfer it to the funeral home, only if:

- the death is not a coroner's case
- a hospital post mortem is not required AND
- there are no infection control issues

Senior Medical Officer or Delegate

- Document in the medical record the parents' request to take their child's body home / transfer it to the funeral home.
- Provide parents with a copy of the death certificate and a letter that briefly outlines the circumstances of the death and transport arrangements.

Nursing Unit Manager (NUM) / After Hours Nurse Manager (AHNM) / Social Work

Discuss transport and funeral arrangements:

- Advise parents that it is recommended that their child's body is transferred by a funeral
 director to an appropriately refrigerated body storage facility within no more than eight
 hours. The time that the patient's body remains outside of a refrigerated body storage
 facility is dependent upon the condition of the body and health regulations.
- Contact the funeral directors chosen by the parents to discuss the arrangements.
- If the child's body is to be discharged via the mortuary, advise histopathology / mortuary staff and liaise with hospital security regarding the collection of the child's body by the parents from the loading dock.

Document in the medical record the discussion with parents regarding:

- taking the body into their care
- arrangements for transport
- referral to a funeral director (name and address of funeral home)
- if the child's body is discharged into the parents' care directly from the ward they are required to sign this entry.

Nursing Staff

 Transfer the body as usual to the mortuary or discharge the child's body into the care of the parents directly from the ward.

The child's details must be completed in the Mortuary Register. This must be completed by nursing staff after the child has been taken by the parents.

Alternatively, if the parents wish to transport the body and the child has been in the mortuary, the Mortuary Register may be signed by the parents together with the nurse or social worker in the mortuary viewing room. At no time should parents be taken into the refrigeration area of the mortuary.

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Mortuary Staff

 Prepare the child's body for transport. It should be sealed in a leak-proof / water-proof coffin (or similar) for transport. If ice is used then ice (not dry ice) should be sealed in leak-proof bags.

Parents

- If the child's body is discharged into the parents' care directly from the ward, they must sign an entry in the medical record to that effect.
- If the body is discharged via the mortuary, parents sign the Mortuary Register in the viewing room (witnessed and co-signed by nursing staff or social work) when taking the body into their care.

If the parents refuse to comply with NSW Health policy, they are required to sign a statement such as 'I am taking my child home in a way that does not comply with Public Health Policy'. This is put in the medical record.

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15. PARENTS WISHING TO VIEW THE BODY OF THEIR CHILD IN THE MORTUARY

Families may wish to view their child after the body has been transferred to the mortuary. This can be arranged only if the death is not a coroner's case.

For coroner's cases, the body will be transferred to the coroner's mortuary, either in Glebe or Newcastle:

- Dept of Forensic Medicine, Sydney, (02 8584 7800 available 24 hours, however, you
 may need to leave a message and your call will be returned). The State Coroner's Court
 may also be contacted for advice on 02 8584 7777.
- Northern Forensic Hub, Newcastle, 02 4922 3700 (business hours) and 02 4929 0822 (after hours).

Senior Doctor or Delegate (Medical or Nursing staff)

- Document the family's request in the child's medical record.
- Liaise with nursing staff and social work.

Viewing the body

- Nursing staff or social work can discuss with the family the options available for viewing their child's body. Support should be offered to the family.
- To arrange viewing during business hours, contact the hospital mortuary. Ideally, two
 hours' notice should be given to allow the body to come to room temperature. After hours,
 security or the After Hours Nurse Manager can assist.
- Nursing staff or social work must accompany the family to the mortuary for viewing. The
 on-call social worker may be contacted for viewings after hours. Nursing staff or social
 work usually stay with the family once the child's body has been prepared for viewing;
 however the family is also free to choose to be alone with their child.
- The child is best removed from the refrigerator prior to viewing to allow the body to feel less cold. This can take up to two hours. The body can be left in the viewing room unaccompanied as long as the room is locked.
- The child should be prepared for viewing prior to the family's arrival.
- A roller slide is available to transfer the child's body to and from the viewing table / bed. It
 is preferable that equipment for preparation of the child is in the viewing room (such as a
 quilt and a bassinet). Staff should check the body for visible signs of body fluids or
 condensation and wipe them away.
- In the viewing room, the family may want to hold or dress their child, or spend time alone
 with their child. The family should be given a contact number to call when they are ready
 to leave.

Following the viewing, transfer the body back to the mortuary refrigerator.

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16. INDIGENOUS FAMILIES

16.1. Aboriginal Hospital Liaison Officer

The Aboriginal Hospital Liaison Officer (AHLO) can provide support to Aboriginal families or staff in the event of the death or sudden serious deterioration of an Aboriginal child in hospital. The Aboriginal Hospital Liaison Officer can be contacted during business hours via the social work department.

The Aboriginal Hospital Liaison Officer (AHLO) may be asked to:

- Initiate the first conversation with the family in need
- Broker between the Aboriginal community and the hospital
- Help to determine whom the most appropriate Next-of-Kin are
- Seek or refer to other appropriate professional services such as the hospital social work department
- Provide appropriate advice with regard to culturally appropriate patient care
- Help Aboriginal patients and their families to better understand the information presented to them by medical or clinical staff, particularly considering that many Aboriginal & Torres Strait Islander people experience low literacy and numeracy issues or they may speak a traditional language
- Facilitate 'smoking ceremonies' to be performed to cleanse the room where the child passed away
- Facilitate viewing the body
- Assist the family when making funeral arrangements
- If an autopsy is required, the AHLO should, with the support of a qualified grief counsellor or social worker, discuss this matter with the family to explain why it is required legally.

16.2. Contacting AHLO

Depending on the organisational structure and size of the hospital, AHLOs are in most cases based with and can be contacted through the social work department during business hours, otherwise through the main hospital switchboard number.

If the hospital does not employ an AHLO, then support for the family should be sought from appropriate departments of the hospital such as the social work department. The social work department may be able to engage other appropriate services locally such as the Aboriginal Health Unit and/or Director for Aboriginal Health within their Local Health District or their local Aboriginal Community Controlled Health Service/s for further advice and support.

16.3. Information relating to Aboriginal families

When a child is dying or has died, Aboriginal community members may gather at the hospital, sometimes resulting in the presence of large numbers of female family members. They may request that the child die outside or near a window. Where possible, these requests should be respected and supported.

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Staff should be aware that decisions may not be made solely by the mother and father of the child, but may be made by the extended family and / or Aboriginal Elders, who play an important role. Reasonable time should be given to the family and Elders for decision making.

If the parents or next of kin are not present at the hospital and are not contactable by phone at the time of a sudden death or serious deterioration, the AHLO should contact the closest Aboriginal Medical Service (AMS) to the family's place of residence. If the AMS cannot contact the family, the police have access to the Aboriginal Community Liaison Officer (ACLO) who will visit the family home to inform them.

16.4. Aboriginal cultural considerations when viewing the child

Nursing staff, social work staff and / or the AHLO will discuss with the family the options available for viewing the child's body at the hospital. This may require two separate visits by Aboriginal males and Aboriginal females. The AHLO should accompany relatives viewing the child, when possible.

16.5. Transport of the child's body

The AHLO can assist with organising transport of the child's body, if required. They may also be able to assist with community resources, including services that can assist families who may find it difficult to afford funeral costs.

Offer the family the service provided by the Aboriginal Medical Service Western Sydney, 02 9832 1356. The service provides culturally secure transport for Aboriginal people who require transportation back to their home country for burial, with the main focus on NSW.

16.6. Bereavement follow-up

The AHLO can organise follow-up management of care and support with the family through the Aboriginal medical service or other relevant services closest to the family's place of residence.

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17. DEATH REVIEW AND SUPPORT FOR STAFF

It's ok not to feel ok. It is not a sign of failure or weakness to seek help and support but a sign of taking care of yourself. There are a number of ways to seek support following the death of a patient. Depending on your personal or cultural preferences or your emotional, cognitive or spiritual needs, you may wish to speak to other members of staff (such as a senior colleague or mentor), a social worker, a chaplain or a staff counsellor.

You may also choose to participate in the review process organised for a group of staff involved in the management of the care and support of the child and family. This is usually held within a few days of the event. Depending on circumstances and needs, this review process may take the form of a critical incident review. This may be facilitated by a professional from the Employee Assistance Program or peers specifically trained in this process. A critical incident review is not intended to be therapy. Attendance is voluntary and there is no pressure to disclose personal information.

The goals of a critical incident review are to:

- Acknowledge the impact of the event in order to reduce the likelihood of cumulative stress (which can contribute to burnout).
- Normalise commonly experienced reactions.
- Discuss the variety of ways emotions can be expressed (such as anger, sobbing or withdrawal).
- **Educate** how to manage particularly uncomfortable or distressing feelings, e.g., discuss helpful strategies for dealing with emotions and reactions.
- Inform about where to go for further confidential assistance.
- Create and strengthen effective networks within the team.

A critical incident review is not the place to review procedures and protocols. Concerns or suggestions for improvement to work practices can be communicated to your supervisor.

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18. MANAGEMENT OF CARE AND SUPPORT OF THE FAMILY

Anyone who has experienced the death of someone close knows how painful and overwhelming the experience of grief can be, and how confusing the thoughts and feelings accompanying it are. The death of a child, whether anticipated for some time or unexpected and sudden, usually creates the most intense response in the family and professionals involved.

Although the impact of the experience might be personally overwhelming at the time, it is our responsibility as health care professionals to ensure that the parents and family are fully informed as well as optimally supported and comforted. Depending on your individual level of experience and your relationship with the child and their family, you may feel comfortable being the main resource person or you may prefer to call upon the help of a senior colleague, social worker or chaplain.

When communicating with family members after the death of a child, always listen patiently and be prepared to go through what has happened many times. Family members may be devastated and numb or elated and thankful that the child's suffering is finally over. Acknowledge that all feelings are normal. Explain the necessary procedures, such as the issuing of a death certificate, the need to register the death and make funeral arrangements. The family will vividly remember the emotional experience of these moments for years to come, and they will remember your patience, empathy and support.

The following is a list of specific issues to be considered when supporting a family:

- If needed, provide **information** about coronial investigations, autopsies and procedures.
- Consider cultural (including Indigenous Families), religious and spiritual issues prior
 to handling the child's body. Open dialogue between health care professionals and
 parents is essential as many families want to adhere to their specific religious practices or
 spiritual needs. You may choose to consult a chaplain or encourage the family to invite
 their spiritual leader to support them at the hospital.
- Prepare the family by informing them of how the child looks, how the body will feel to touch, and of any odours in the room prior to them seeing their child.
- Ensure privacy for the family when they are with their child.
- Determine the **parents' wishes** and their level of involvement in washing and dressing their child. Inform parents that hand and footprints can be taken using a stamp pad or paint and offer the options of cutting a lock of hair and taking photographs. **Support** family members who wish to hold their child.
- Consider the needs of siblings, and work with the family to ensure their needs are met.
- Assist the family in **contacting support people** (for example, other family members, and religious or pastoral care workers).
- Encourage the family to make and maintain contact with their primary care team, who may
 have known the child for several years and will be able to offer ongoing support.
- It is preferable for the family to say goodbye to their child prior to the body being taken to
 the hospital mortuary. However, inform families that they may view their child at the
 mortuary. See 15: Parents wishing to view the body of their child in the mortuary. Also
 see 17: Indigenous Families.

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- For children with an infectious disease, explain necessary precautions to the family and ensure they are adhered to. Parents are to be given the opportunity to farewell their child in the same manner as any other child.
- **Refrigeration:** The maximum length of time a child's body can remain unrefrigerated is eight hours after this time the body must be refrigerated in the mortuary.

18.1. Further bereavement information

Social work will provide the family with general information about arranging a funeral, including the names of funeral directors in their area.

Social work also provides bereavement follow up for all families whose child has died in hospital. This may be by telephone and / or letter (as appropriate) and with the use of the interpreter service, if required.

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19. MANAGEMENT OF THE DECEASED CHILD

(only possible under Pathway 1: Non-coroner's case without a hospital autopsy)

Prior to handling the child's body, review 'Management of the care and support of the family' (above).

Always communicate with the family to determine their wishes and level of involvement in tasks like washing and dressing their child. Let the family know that hand and footprints can be taken using a stamp pad or paint, and offer options such as cutting a lock of hair or taking photographs.

The following is a list of specific issues to be considered when caring for the child's body:

- Use standard precautions when attending to body secretions see <u>PD2007_036 Infection</u>
 Control Policy.
- If the child was recently treated with radioactive material, safe handling is required. Refer
 to the Australian Government's Radiation Health Committee's <u>Statement on Safe</u>
 Handling of <u>Deceased Persons Recently Treated with Radioactive Material.</u>
- Be aware that after death the body can continue to leak bodily fluids and may make noises (such as expulsion of air).
- Close the child's eyelids.
- Discuss the removal of any medical devices with the family (such as feeding tubes, oxygen, drains and central lines*). Do not remove sutures, clips or staples and tape any gaping wounds closed. If drainage from a wound is excessive, cover it with an absorbent or occlusive dressing.
- (*NOTE: central lines can be used for embalming).
- If the child's skin or clothes are contaminated, wash the child with soap and water and dress them in clean clothes. The family may want to wash and dress their child or they may prefer staff to do so. Support their decision.
- Remove any jewellery or valuables and give them to the family. If the family does not want them removed, document this in the child's medical record. Also document if the family wishes to have other special items remain with the child (such as toys or cards).
- Ensure the child's body has two identification bracelets attached (wrist and ankle).
- Place the child's body in a natural supine position. If the mouth is open, support the chin
 with a rolled towel or nappy.
- The family may choose to pack up belongings themselves. Offer support and provide bags, if required. If the family prefers staff to pack their belongings, ensure the bed unit and all drawers are checked. Give all belongings to the family or arrange for them to be picked up later from the Nursing Unit Manager or Social Worker.

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19.1. Transport of the child's body to the mortuary

- During business hours, notify the mortuary when to expect the child's body. After hours, the After Hours Nurse Manager will open the mortuary.
- The child's body is moved onto the mortuary trolley. A roller slide is available in the
 mortuary to assist with this task. It is easier for two people to transfer the body onto the
 trolley.
- Move the mortuary trolley into the refrigerator. Small infants may be placed on a shelf within the fridge.

19.2. Mortuary staff

As per <u>NSW Public Health Regulation 2012</u> the body of a deceased person is not to be removed from a place unless:

- The body has been placed and secured in a bag or wrapping in a manner that prevents the leakage of any bodily exudate or other substance.
- The name, or identification, of the deceased person is clearly and indelibly written on the top outer surface of the bag or wrapping.

If there is reason to believe that the body is infected with a prescribed infectious disease, the bag or wrapping must be clearly and indelibly marked with the words 'PRESCRIBED INFECTIOUS DISEASE – HANDLE WITH CARE'.

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21. PATHWAY 1 CHECKLIST: NON-CORONER'S CASE WITHOUT A HOSPITAL AUTOPSY

PD2012 036 Death - Extinction of Life and the Certification of Death - Assessment Decisions regarding non-coroner's case and no hospital autopsy Discussed with senior doctor in charge of the patient's care Print senior doctor's name: Locally required mortuary documentation Completed, signed and placed in medical record (original accompanies patient's body to the morgue, copy remains in medical record) Identification (ID) labels are correctly on child's body **Medical Certificate of Cause of Death (MCCD)** (Perinatal OR normal death certificate) Completed, signed and placed in medical record **Cremation Certificate** Completed, signed and placed in medical record **Medical record documentation** Completed, signed and sent to Clinical Governance Unit All forms put into envelope and placed in medical record

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22. PATHWAY 2 CHECKLIST: NON-CORONER'S CASE WITH HOSPITAL AUTOPSY

PD2012 036 Death - Extinction of Life and the Certification of Death - Assessment PD2013_051 Non-Coronial Post Mortems PD 2013_001 Deceased Organ and Tissue Donation-Consent and Other Procedural Requirements GL2014_008 Organ Donation After Circulatory Death: NSW Guidelines Decisions regarding non-coroner's case with hospital autopsy Discussed with senior doctor in charge of the patient's care Print senior doctor's name: Discussed with histopathologist (prior to obtaining consent) (to allow informed discussion with the parents about the extent and details of the post-mortem examination, e.g., retention of tissue or organs) Consent for hospital autopsy Information for Parents about Hospital Autopsy brochure - given to parents/next-of-kin Consent form completed and enclosed (parents / next-of-kin signed, witness signed, designated Copy of consent form given to parents / next-of-kin (legal requirement) Locally required mortuary documentation Completed, signed and placed in medical record (original accompanies the patient's body to the morgue, copy remains in medical record) Identifiication (ID) labels are correctly on child's body **Medical Certificate of Cause of Death (MCCD)** (Perinatal OR normal death certificate) Completed, signed and placed in medical record **Cremation Certificate** Completed, signed and placed in medical record **Medical record documentation** Completed, signed and sent to Clinical Governance Unit All forms put into envelope and placed in medical record

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23. PATHWAY 3 CHECKLIST: REPORTABLE DEATHS - CORONER'S CASE

PD2012 036 Death - Extinction of Life and the Certification of Death - Assessment

PD2010 054 Coroner's Cases and the Coroners Act 2009

PD2013_051 Non-Coronial Post Mortems

PD 2013 001 Deceased Organ and Tissue Donation-Consent and Other Procedural Requirements

GL2014 008 Organ Donation After Circulatory Death: NSW Guidelines

IB2010_058 Coronial Checklist

Coroners Amendment Act 2012 No 24

DO NOT DISTURB THE BODY	A death certificate is not issued if the death is reportable to the coroner. DO NOT remove any IV lines, drains, dressings or tubes, DO NOT clean any part of the body, DO NOT perform hand or foot prints.	Decisions regarding coroner's case Discussed with senior doctor in charge of the patient's care Print senior doctor's name:
		Local police notified
		Relevant information provided to parents / next-of-kin (including NSW Coroner's Court: A guide to services brochure)
		Locally required mortuary documentation Completed, signed and placed in medical record (original accompanies the patient's body to the morgue, copy remains in medical record)
		Identifiication (ID) labels are correctly on child's body
		Report of Death of a Patient to the Coroner (Form A) Completed, signed and given to police. Copy placed in medical record
		Report of death associated with anaesthesia/sedation Completed, signed and given to police. Copy placed in medical record.
	A death o	Medical record documentation Completed, signed and sent to Clinical Governance Unit
		All forms put into envelope and placed in medical record

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24. EXPERT DEATH CERTIFICATE REVIEW (EDCR) COMMITTEE

Executive Sponsor:

Professor Les White, NSW Chief Paediatrician

Chair:

Dr Jonny Taitz, Director of Patient Safety, Clinical Excellence Commission

Members:

Cheryl McCullagh, Director of Clinical Integration, Sydney Children's Hospitals Network

Dr Ray Chaseling, Clinical Risk Manager, Sydney Children's Hospitals Network

Deborah Giles, Patient Safety Officer, Sydney Children's Hospitals Network

Dr Jonathan Egan, PICU, Sydney Children's Hospitals Network

Dr Sharon Ryan, Paediatric Palliative Care, John Hunter Children's Hospital

Dr Damien McKay, Chief RMO (now Staff Specialist), Sydney Children's Hospitals Network

Ellen McKinnon, Chief RMO, Sydney Children's Hospitals Network (now Paediatric Advanced Trainee, Princess Margaret Hospital, Perth)

Dr Alison Rowland, Paediatrician, Hunter New England Local Health District

Dr Marion Mateos, Haematology Oncology, Sydney Children's Hospitals Network Fellow Haematology Oncology, SCHN

25. ACKNOWLEDGEMENTS

The NSW Health - Death of a Child Resource Guideline was developed in response to the Child Death Review Team's *Report on Trends in Death in NSW 1996-2005*.

It was developed by the NSW Chief Paediatrician and NSW Kids and Families in collaboration with the Expert Death Certificate Review (EDCR) Committee.

The Resource Kit is based on available documents from Sydney Children's Hospitals Network (Westmead), supplemented with merged components from Sydney Children's Hospitals Network (Randwick) and John Hunter Children's Hospital.

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26. POLICY LIST

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NSW Health Policy Directive Coroners Cases and the Coroners Act 2009 (PD2010_054) (accessed June 2015).

Coroners Amendment Act 2012 No 24, Amendment of Coroners Act 2009 No 41 Schedule 1 (accessed June 2015).

NSW Health Policy Directive Deaths - Review and Reporting of Perinatal Deaths (PD2011_076) (accessed June 2015).

NSW Health Policy Directive PD2012_036_Death – Extinction of Life and the Certification of Death – Assessment (accessed June 2015).

NSW Health Policy Directive Interpreters – Standard Procedures for Working with Health Care Interpreters (PD2006_053) (accessed June 2015).

NSW Health Policy Directive PD2012_049 Forensic Pathology - Code of Practice and Performance Standards in NSW (accessed June 2015).

NSW Health Guideline GL2005_057 End-of-Life Care and Decision-Making – Guidelines (accessed June 2015)

NSW Health Guideline GL2013_015 Retention of Bodies - Approval to Retain Bodies for Longer than Permitted (accessed June 2015).

27. REFERENCE LIST

Australian Bureau of Statistics Information Paper Cause of Death Certification Australia 2004 [1205.0.55.001]

<u>Australian Government Family and Community Services Legislation Amendment Bill 2002</u> <u>C2004B01157</u> (accessed June 2015).

NSW Child Death Review Team (2008) Trends in Child Deaths in New South Wales 1996–2005 NSW Commission for Children and Young People: Sydney. ISBN 978-0-7347-7190-2.

Sydney Children's Hospitals Network (Westmead) Procedure: Death of a Child Procedure No: 1/C/06:8059-01:04 (accessed June 2015).

New South Wales Government Child Welfare Act, 1939 (accessed June 2015).

New South Wales Government Children (Detention Centres) Act 1987 No 57 (accessed June 2015).

New South Wales Government Children and Young Persons (Care and Protection) Act 1998 (accessed June 2015).

New South Wales Government Community Welfare Act 1987 No 52 (accessed June 2015).

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