Paediatric Pathology

The following sections will help pathologists respond appropriately to a SUDI. Other professionals involved may have addressed some of the issues, but you should not assume that they have. The information may also be useful to other professionals interacting with the pathologist through their involvement following a SUDI.

Interactive timeline and flow chart

The interactive timeline demonstrates the role and responsibility of a pathologist in relation to other professionals involved, and in the subsequent SUDI Review meeting. The scenario illustrated in the flow chart highlights some of the key points but does not aim to show everything that may arise in what is a unique circumstance for each case of SUDI.

View example scenario (flow chart) »

The role of the paediatric pathologist

1. Establishing the cause of death:

a. is death attributable to a natural disease?
b. is death likely to be non-natural and if so is the cause of death accidental or inflicted?

2. Documenting the extent and nature of any disease present, whether or not considered a cause of death.

3. Documenting and evaluating any injury present, irrespective of its contribution to death.

4. Identifying or refuting the presence of inherited metabolic disease (IMD) or other inheritable condition.

5. Providing information relevant to the future reproductive health of parents and the future health of siblings of the deceased.

6. Collecting and securing evidence as required by the Procurator Fiscal.

7. To prevent unnecessary delays in the post-mortem examination and follow up of supplementary pathology investigations, for example if leave is planned, arrange cover (from a neighbouring health board if a necessary).

When a SUDI occurs

1. Emergency Department staff inform the pathologist of the death, particularly where there is a request to take any samples post-mortem.

2. No samples should be taken post-mortem except by prior discussion with, and agreement by, the paediatric pathologist.

3. Any samples taken during resuscitation should, where possible, be acquired using existing access points such as venous access ports already sited.

4. Any samples taken should be sent to the laboratory marked “not for destruction”.

5. The laboratory should be contacted and requested that those samples already sent during the resuscitation process should be marked as above.

6. The Area Procurator Fiscal requests a post-mortem examination.

7. The paediatric pathologist and paediatrician have relevant discussions prior to the post-mortem examination (this dialogue ensures that the paediatric pathologist has the required background information surrounding the circumstances of the death).

8. The pathologist may also discuss matters with other healthcare professionals and the police prior to the post-mortem examination.

9. The pathologist will receive a copy of the police report from the Procurator Fiscal.

10. Any copies of digital photographs taken by police at the location where the infant was first discovered should also be made available prior to the post-mortem examination.

11. The pathologist will have access to medical records such as the primary care notes, maternity records, and hospital notes if applicable.

12. A post-mortem examination is conducted as per the Guidelines on autopsy of SUDI (Scenario 8: Sudden unexpected deaths in infancy (SUDI)) issued in 2005 by The Royal College of Pathologists.

13. The post-mortem examination summary sheet should be completed.

14. Access the pathology notification card, complete and return to Healthcare Improvement Scotland. This notification process ensures Healthcare Improvement Scotland can make contact with the relevant paediatrician and alert them to the incident if not already aware.

15. A meeting with bereaved parents/family is organised one to two weeks following the death to explain any initial post-mortem examination findings and/or ongoing tests. Prior to this meeting make any necessary arrangements with the paediatrician involved regarding who will lead the meeting and if there are any likely delays (eg scheduled leave, etc) that may impact on the availability of the final post-mortem examination report.

16. The parents/family should be informed of a possible SUDI Review meeting.

17. A paediatrician will make contact with the bereaved parents/family at approximately 6-8 weeks after the death mainly to reassure that results will be available as soon as all further pathology investigations are completed.

18. Copies of the post-mortem examination report may be issued to healthcare professionals who had previously requested them in writing from the Procurator Fiscal, such as the GP or paediatrician.

19. Relevant feedback should be provided to the Emergency Department consultant, ensuring members of the resuscitation team receive appropriate feedback.

20. In remote and rural areas, in particular, the island communities, the time until post-mortem examination may be increased. Local arrangements should, where possible, try to ensure the quickest transfer onto the mainland for specialist paediatric pathology services. The area Procurator Fiscal should liaise with the local police forces to ensure that any possibility of air transfer is discussed before deciding on using scheduled ferry crossings.

Initial parent support

Staff initially involved with the SUDI will speak with the bereaved parents/family about the need for pathology input.

1. Appropriate staff (eg members of the Emergency Department or a paediatrician) will explain to the bereaved parents/family the legal need for a post-mortem examination and the likelihood that only provisional findings will be available immediately after the post-mortem examination.

2. The parents/family will also be made aware that information taken regarding the circumstances of the death/previous medical history, etc **will be shared** with the paediatric pathologist to assist all involved in helping to establish a cause of death.

3. There may be further explanation to parents/family about what will happen next, eg possible

transfer of the infants body to the mortuary (perhaps in another town/ city where specialist pathology services are available) and that they can arrange (via the paediatrician supporting them) contact with the paediatric pathologist, to arrange seeing the body at the mortuary.

4. Each pathology department/mortuary service accommodates a number of memory boxes for use by parents/families that have experienced a SUDI to retain a number of keepsakes in (eg hand/foot prints or locks of hair). These are obtained once the post-mortem examination is complete. Pathology and mortuary staff should ensure, where possible, that the infant is dressed in their own clothing for "keepsake" photographs and placed in a Moses basket or small bed if the bereaved parents/family wish to see the infant.

Terminology

1. All SUDIs are both unexpected and also unexplained at the outset.

2. After post-mortem examination, many cases will remain SUDIs (as meaning unexplained) if no medical cause of death is identified.

3. Once all ancillary post-mortem investigations are complete cases may still remain unexplained. However pathology or circumstantial factors, for example social or parenting issues, may be highlighted as being present, although not causing the death. In these instances SUDI may be entered on a death certificate.

4. Only when there is no fatal pathology or other factors noted, would the term Sudden Infant Death Syndrome (SIDS) be considered by pathologists.

Forensic pathology input

1. If concerns are raised about possible neglect or abuse contributing to the infant's death, two paediatric pathologists, one of which may be a forensic pathologist will follow a joint post-mortem protocol.

2. If at any stage during a post-mortem examination the paediatric pathologist becomes concerned that the death may be a consequence of abuse, and another pathologist is not present, the procedure must be stopped.

3. The examination should resume as a joint procedure by two pathologists, one of whom may be a forensic pathologist.

4. The Procurator Fiscal may also request the presence of the senior investigating police officer or other designated police representative in any post-mortem examination.

The role of Child Protection

Child protection underpins **all** investigations following SUDI. It is **standard practice for a child protection team to be contacted in all cases to make them aware of the infant's death.** The degree of involvement of a child protection team will vary for each SUDI, from maintaining a very peripheral role and concluding their part in the investigation as soon as the initial post mortem findings are known, to providing ongoing support to the family and staff involved, if child protection issues are raised. Child protection teams include professionals from health care, social work and police.

Child protection staff collaborate with health care professionals, social workers and police to:

1. Initiate and maintain good communication between all agencies involved to ensure clarity of roles.

2. Gather relevant background information.

3. Provide support to primary care colleagues regarding access to medical notes, interviews with members of the police etc.

4. Support the management of a SUDI until post mortem findings are known.

5. Advise as well as develop policies and practice in child protection.

6. Ensure that the bereaved family understands that child protection involvement is **standard practice in all SUDIs**.

7. Provide the necessary support packages available for the family should they be required.

Child Protection team involvement

1. The child protection team in the hospital is notified by Emergency Department staff when a SUDI occurs.

2. There is interaction with relevant hospital and primary care colleagues, police and social work, as appropriate and an agreement on who makes contact with the following:

- lead paediatrician for the area
- clinical director for children's services
- executive director with responsibility for child protection
- nurse consultant for vulnerable children
- designated doctor for vulnerable children
- the Child Health Commissioner
- chief nurse for the area
- family health visitor for pre-school children.

3. The advisor involved with the case will assess and decide on the level of engagement with maternity and child health services, background history including any previous child protection concerns.

4. The team will remain involved with the case until the outcome of the post-mortem examination is known.

5. The parents/family are informed by Emergency Department staff or a paediatrician it is **standard practice** that initial **information** gathered regarding the circumstances of the death will be **shared** with the local child protection team.

6. The parents/family should be reassured that this **does not** imply suspicion or criticism of their care of the deceased infant.

Staff support

The professionals involved may require support. Some professionals may have prolonged involvement in the investigative process and will have no experience of SUDI. This toolkit provides information on staff support.

Steps and timelines around the investigation of a SUDI

Each case has unique circumstances which require investigation so there is never an absolute timescale to follow. However there are some milestones which should prompt professionals involved, especially when there may be information to share with the parents.

1. The police will provide the Procurator Fiscal with a Sudden Death report the next lawful day (Monday if the death occurred over the weekend).

2. The pathologist will receive a copy of the police report.

3. Original medical records will be requested by the police on behalf of the Procurator Fiscal, and made available to the pathologist.

4. A post-mortem examination will take place as early as possible but normally within 48 hours.

5. The paediatrician following up the case will offer to meet with the parents after 1-2 weeks to discuss the process to date and offer ensure appropriate support is available for the family

6. The final post-mortem examination report may take several months as several further examinations on samples need to be concluded.

7. The Procurator Fiscal will confirm with Healthcare Improvement Scotland that it is appropriate for the SUDI Review meeting to take place once the final post-mortem examination report is available. Healthcare Improvement Scotland will liaise with SUDI paediatrician for the NHS Board.

8. Pathologists may also complete a post-mortem examination summary sheet prior to the SUDI Review meeting.

9. The clinician taking the lead for follow up with the family will meet with them to discuss the summary of the SUDI Review meeting.

The SUDI Review

The SUDI Review is a multidisciplinary meeting at which the case is discussed. The meeting is held shortly after the final post mortem examination report is available, which may be several months after the infant has died. The purpose is to discuss all aspects of the death, including possible causes or contributing factors, to see what lessons can be learned and to plan support for the family, in particular during and after any future pregnancies.

Participants may include:

- paediatrician
- pathologist
- general practitioner
- community health visitor
- community midwife
- social worker.

The meeting will be held at a suitably convenient time and place for all involved. The SUDI Review meeting will **not** take place if there is any suspicion of criminality or if a Significant Case Review has to take place through Child Protection.