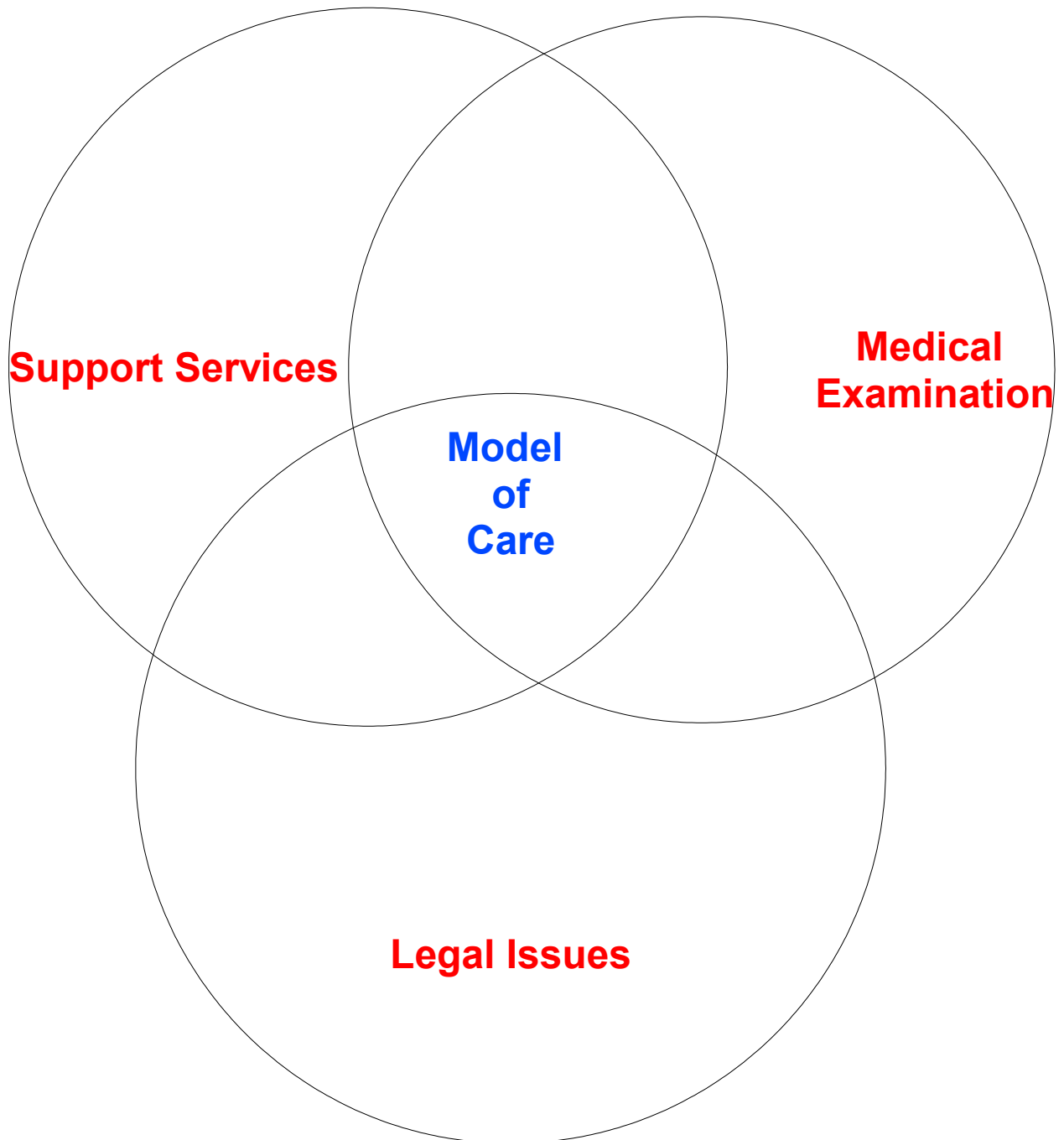


Sudden Death in Infancy
SIDS Model of Care for Professionals



Sudden Death in Infancy

Sudden Infant Death Syndrome (SIDS) is defined as “the sudden death of an infant or young child which is unexpected by history and in which a thorough post mortem examination fails to demonstrate an adequate cause of death”.

In Ireland the SIDS rate has declined from an average of 2.1/1000 live births throughout the 1980's to 0.8/1000 live births for the years 1994-2000 inclusive with 70-80 less infant deaths per year. However SIDS continues to be the leading cause of death in babies aged four weeks to one year. Based on the Central Statistics Office (CSO) infant mortality figures for 2000, over a third (37%) of all deaths in this age group are due to SIDS. The largest number of cases occurs within the 2-3 month age group. The number of SIDS cases born prematurely and of low birth weight has been higher than the national average every year since 1992.

This Model of Care is an endeavor to assist you in dealing with all sudden deaths in infancy. ISIDA's National Sudden Infant Death Register is available 24hours through its HOTLINE which can be contacted on **(087) 2423777** to assist and empower you to help families at this traumatic time. ISIDA's Register can also be contacted by the FREEPHONE number **1800-332-332**.

Medical / Paramedical Issues

Infant dies

Call for help

Ambulance

- Inform parents / family members of the hospital you are taking the child to
- Allow parents the opportunity to travel in the ambulance with their child
- Go to the accident and emergency department and **not to the mortuary**
- Inform the Gardai and senior nurse of all relevant information
- Leave your name and work contact number with a member of the family

General Practitioner / Public Health Nurse / Practice Nurse / Community Midwife

- Make contact with the parents/family member as soon as you are notified of the child's death
- If the child is pronounced dead at home organize transport of the child to Casualty for post-mortem
- If parents wish to take their child home after the post-mortem, give support and guidance with this request
- Inform the family about the SIDS support group and initiate contact where required
- Ensure that mementos of the baby are obtained e.g. photos, hand and foot prints etc.

Senior Designated Nurse

- Ensure that a medical person has advised the family of their infant's death
- Take parents/family members to a private room and remain with them offering support for as long as they wish
- Facilitate parents/family members in understanding the information then receive from various members of staff
- Ensure parents have as much time as possible with their child before and after the post-mortem examination
- Encourage parents to hold their child for as long as they wish
- Arrange for mementos of the baby eg photos, hand and foot prints and a lock of hair to be given to the parents. Suggest that they bring to the hospital the clothes that they wish their baby to be dressed in.

- Ensure that parents have your name and contact number and ensure that all staff are aware of the child's death
- Inform ISIDA's National Sudden Infant Death Register of the sudden unexpected death on the **24 Hour Hotline for Professionals: 087 242 3777**
- Inform the relevant professionals:
 - Paediatrician
 - Pastoral Care
 - Gardai (make sure parents understand reason for visit)
 - Pathologist
 - Social Worker
 - Coroner
 - ISIDA
 - General Practitioner
 - Public Health Nurse
 - Obstetrician

Paediatrician

- Collect the medical, social and family history
- Answer any medical questions the family may ask
- Explain the preliminary post-mortem process to the family
- Provide the pathologist with essential information for the post-mortem examination
- Explain the full post-mortem results to the family
- Give families medical support and information

Social Support / Pastoral Care / Chaplaincy

- Facilitate parents in coming to spend time with their child who has died
- Ensure that parents are allowed privacy
- Offer to accompany parents at any time during their stay at the hospital
- Offer prayers, blessings, naming ceremonies, and funeral rites as requested by parents
- Offer spiritual and emotional support
- Facilitate different religious beliefs and practices, and liaise with ministers of other religions, as requested by parents
- Help in making funeral arrangements and liaising with the parents local parish, as

requested

Pastoral care is offered in conjunction with the local parish of the parents, such as:

- Visit families of a child who has died, in their own home
- Celebrate funeral services, and help families to organize and arrange the funeral, burial or cremation services
- Usually offers help and support on an ongoing basis, through local clergy and parish bereavement groups

ISIDA

- ISIDA is notified by senior nurse at Casualty
- Offers support and guidance to parents
- Offer to visit the family to give support and evidence-based information on SIDS
- Together with family, offer to assess ongoing needs and ensure the availability of bereavement counseling
- Offer long-term services, information and support

Social Worker

- Encourage parents to involve other siblings
- Ensure that school teachers of siblings are aware of the child's death
- Offer to inform parent's workplace of the child's death
- Offer support with funeral arrangements
- Offer ongoing and long term support

Teachers

- Ensure that all teachers with whom the siblings have contact are aware of the bereavement
- Offer the opportunity for classmates and friends of the children to attend the funeral
- On sibling return to school, teachers can contact the **24 Hour Hotline for Professionals: 087 242 3777** for guidelines and support

Legal Issues

Coroner

- Coroner is notified of death
- Makes preliminary inquiries in relation to the death
- Directs autopsy to be performed
- Reviews autopsy and garda report
- Makes copy of the post-mortem report available to the GP and to ISIDA's Register

An Garda Siochana

- Visit family at home / hospital on notification of death and explain the role of the gardai
- Advise parents of the role and functions of the coroner in enquiring into the death and the likelihood of a post-mortem examination being carried out
- Meet with parents in plain clothes if possible
- Ensure that procedures are adhered to so that the post mortem results are made available promptly

Pathologist

- Discuss the post-mortem procedure with the family
- Advise parents about the estimated time and duration of post-mortem
- Be mindful of the cosmetic end results in conjuncture with the pathology technician and explain to parents that their child's body may look different following post mortem procedure
- Offer the family the opportunity to discuss the results of the post-mortem with you
- Ensure that the full post-mortem results are available within a 12-16 week period

Key Points

- **Allow parents privacy and time with their child**
- **Ensure that mementos of the baby e.g. hand and foot prints, a photo and a lock of hair are taken and given to a family member**
- **Ensure the paediatrician explains the post-mortem procedure to the parents**
- **Give parents the opportunity to hold their baby before and after the post-mortem**
- **Give your name and contact number to the family**
- **Ensure parents are given preliminary post-mortem results as soon as possible**
- **Arrange for parents to obtain final post-mortem results**
- **Allow for cultural difference**

Suggested Checklist Following the death of a child:

- **Paediatrician**
- **Pastoral Care**
- **Gardai**
- **Pathologist**
- **Social Worker**
- **Coroner**
- **ISIDA**
- **General Practitioner**
- **Public Health Nurse**
- **Obstetrician**

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