

CONI

Care of Next Infant

Room C1,
Stephenson Wing,
Academic Unit of Child Health
University of Sheffield
Sheffield Children's Hospital,
Western Bank,
Sheffield
S10 2TH

0114 276 6452
Coni@sheffield.ac.uk

National CONI Co-ordinator
Mrs Alison J Waite

Steering group
Professor M Campbell, Professor R G Carpenter, Dr M Cohen, Dr R Coombs, Dr C Daman-Willems,
Professor J Huber, Mrs A McKenzie

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Introduction

There is great public awareness of cot death or sudden unexpected infant death (SUDI) and it is therefore common for parents with young babies to worry about the possibility of SUDI. When a family has already suffered this tragedy it is inevitable that the next pregnancies and first few months of subsequent children's lives will be a time of both joy and anxiety. Experience has suggested that informed professional support during this time helps to alleviate anxiety and is of value in ensuring appropriate care for the new baby (1).

The aim of the Foundation for the Study of Infant Deaths (FSID) is that every family in the country should receive adequate support with a subsequent baby following a SUDI. The purpose of the CONI programme is to help NHS community health and hospital services to provide integrated care for families with any subsequent infants. The programme is a collaboration between FSID and the health services with the clinical care of the baby and the family remaining the responsibility of local services, while FSID resources central services making training, information packs and advice available as well as conducting national audit.

The CONI PLUS programme extends CONI to a wider group of families with essentially healthy babies but where either the baby is identified to have increased vulnerability and/or the parents have cause for increased anxiety.

The core elements of the programme are regular contacts with a health visitor, symptom diaries, weight charts and apnoea (movement) monitors.

Background

The Infant Home Surveillance Research project was funded by FSID from 1980-1988 to provide and evaluate support for families who had a subsequent child following a SUDI. A pilot study was conducted with 100 families randomised to use either an apnoea monitor or weighing scales, both combined with daily symptom diaries and weekly health visitor visits. It was found that parents were prepared to accept randomly issued equipment. The apnoea monitors were well received by parents and although experiences were very varied, an average of 1 alarm per week was well tolerated. Parents also appeared equally satisfied with a schedule of daily weighing and charting of weights. The most valuable aspect of this study was shown to be the weekly health visitor visits plus the symptom diaries (2).

From 1984 the project was run as a multi-centre study, expanding to include 27 Health Authorities and 686 babies were enrolled. A small number of unexpected infant deaths occurred in families using monitors, scales or both and neither method was shown to be effective in preventing deaths. Extensive experience was gained in caring for these families and FSID decided that this should be used and combined with experience from others practised in supporting the families, to produce a protocol for support (CONI). This was made available to community health and hospital services to assist them in providing care for subsequent siblings. It must however be noted that the procedures recommended are based on user reaction only and have not been subjected to controlled scientific evaluation.

Current relevance

There are 190 centres offering the CONI programme which is available to families in 90% of the Primary Care Trusts in England, 92% of NHS Trusts in Wales and 100% of Health and Social Service Trusts in Northern Ireland. In December 2006, the 10,000th baby was enrolled on to the programme. All participating parents are invited to consent for their CONI records to be held at the central office in Sheffield and are asked to complete an evaluation questionnaire. A substantial databank has been collected and analysed concerning the experiences of families participating in the programme. Information is available in a report on 5000 babies (1) and a report on 10,000 babies is in preparation. The programme is consistently highly valued by

parents and health professionals. The Department of Health has recommended that Strategic Health Authorities provide leadership in developing services to prevent SUDI, including the CONI programme (3).

Epidemiological studies have identified a number of factors which are associated with an increased risk of SIDS. However we are aware that babies may die even when parents make every effort to avoid these. In addition, a study from Avon in 1992-2003 identified that 74% of infants dying as SIDS came from socio-economic groups IV, V and the unemployed and 48% lived in the 10% most deprived postcode areas (4). We have shown a 2-5 times increased risk of recurrence of SIDS following the first SIDS (5). The history of SIDS in a family identifies a particularly vulnerable group of families and evidence suggests that the CONI programme is acceptable to parents and professionals and may therefore offer an opportunity to engage effectively with them.

The recent trend has been to move away from a universal health visiting service to a service targeted at the most vulnerable families (6). The majority of parents eligible for CONI because of a previous SUDI will show multiple indices for deprivation. Health visitors have the particular skills to work effectively with these families (7). The ability to professionally 'befriend' the family, to listen to the parents' concerns, empathise with them, develop strategies to help them, liaise with relevant agencies and identify causes for concern, are core skills. These are fundamental to helping build a trusting but effective therapeutic relationship between the health visitor and the parents. The CONI programme offers additional resources to help the health visitor hold effective dialogue and monitor the general health of the child. While there is no evidence that the use of a movement (apnoea) monitor will prevent SUDI, with close supervision the monitor can help to reduce parental anxiety. Monitors remain very attractive to parents and the costs to support a monitor are modest. The acceptability of monitors to parents is used to engage them with other beneficial strategies.

NATIONAL ORGANISATION OF CONI

The CONI programme is managed by the National CONI co-ordinator, Mrs. Alison Waite, who has been involved with both the preceding studies. She is supported and advised by a Steering Group¹ and the FSID Support and Information Committee. She is based at Room C1, Stephenson Wing, Sheffield Children's Hospital, Western Bank, Sheffield, S10 2TH, telephone 0114 276 6452.

She is available to help in the setting up of the programme locally and provides ongoing advice, support and training to centres.

LOCAL ORGANISATION OF CONI

CONI Paediatrician

It is essential that there is a clearly identified route to consultant advice in the event that the surveillance highlights any cause for concern about a baby. The role of the CONI paediatrician may be undertaken by one individual or shared among colleagues. When the consultant is a community-based paediatrician without direct access to hospital beds, care of the families will need to be shared with a hospital-based consultant.

The CONI paediatrician is asked to see families at the request of the local co-ordinator in the antenatal period. At this time it can be very important for a small number of parents to have an opportunity to discuss the findings concerning their

¹ Professor M Campbell, Professor R Carpenter, Dr M Cohen, Dr R Coombs, Dr C Damen-Willems, Professor J Huber, Ms A McKenzie.

previous child's death and the care of their future child. The newborn infant needs to be examined by a senior paediatrician (consultant or specialist registrar) to consider whether any special investigations are required and a routine follow-up appointment should be offered close to the age at which the SUDI occurred. Additionally, many centres offer open access or fast access to senior paediatric advice (consultant or specialist registrar) This is rarely abused and can provide considerable comfort to parents.

Local CONI Co-ordinator

This may be an experienced health visitor, often the paediatric liaison health visitor, but could also be another suitable member of staff e.g. midwife, community paediatric nurse. The co-ordinator needs to be able to support health visitors working with families with complex emotional needs who commonly have multiple problems associated with disadvantage. The co-ordinator's function is to administer the support programme. This includes interviewing the parents to explain the support in detail; briefing the health visitor, midwife and general practitioner; arranging training in resuscitation; organising the distribution of stationery and equipment as well as training staff. While the care of the family remains with the primary health care team, the co-ordinator is available for advice and support and can liaise with the paediatrician. The co-ordinator needs to ensure all relevant staff are aware of the programme and how to refer families. The role is described in detail in the CONI co-ordinator manual available from the CONI office.

METHODS OF SUPPORT FOR INDIVIDUAL FAMILIES

The care of the family remains with the health visitor, general practitioner midwife and paediatrician and the family can choose from the following:

1. **Regular contact in the home** - with an informed health visitor. Experience has shown the value of weekly home visits at least until the age of the previous infant death. Regular contact should be maintained until the baby is aged 6 months or two months older than the age the previous child died, whichever is the longer (over 80% SIDS occur under 6 months old) (8). It has been shown that intensive health visitor contacts with infants identified as having a high risk for SIDS, reduced the number of predicted deaths in the target population (9). CONI families have consistently rated the health visitor visits as an essential component of the support. They identify listening and commitment to regular contact for an agreed time, as the key essential elements of the help provided by the health visitor.
2. **Symptom Diaries** - completed by parents and discussed with health visitors, allow parents to express anxiety about illness, identify changes and facilitate health education. They also serve to emphasise to parents the importance being observant of their children and contacting help if their child appears unwell.
3. **Weight Charts** - all babies on the scheme should have their weights recorded on the Sheffield Weight Chart at weekly intervals. SIDS victims are more likely to be born with low birth weights compared to living controls and to gain weight more slowly (10).
4. **Room thermometers** - to be used to monitor the air temperature in the room in which the baby sleeps. The temperature should be kept within the recommended range of 16-20C or bedding and clothing adjusted appropriately.
5. **Movement (apnoea) monitor** - used to monitor movement in sleep, the monitor can reassure parents that a crisis has not occurred and, with professional help, gradually re-build confidence. The monitors alarm after a pre-set period of no movement and can audibly register each movement detected.

Clinicians may wish to introduce other methods of surveillance in their own areas.

FUNDING

FSID will make every attempt to source funds to purchase equipment for new centres. Our previous experience suggests that this does not usually present a difficulty. Donations can be received for named centres, these are paid into designated accounts held by FSID and are used to purchase equipment.

Each centre receives an initial stationery supply. Centres are expected to meet the recurrent expenses for running the programme, including the purchase of further stationery packs and the costs of maintaining the equipment. (See Appendix 1)

CONI GUIDELINES FOR CARE OF FAMILY

From April 2008 it is required that enquiries into all unexpected infant deaths are held; these findings should form a basis for recommending the most appropriate care of the next infant.²

1. Case finding during subsequent pregnancy

It is necessary to have more than one source of referral, as no single system is fool proof. Obstetricians, hospital & community midwives, GPs and health visitors should be asked to refer mothers with a history of SUDI to the CONI co-ordinator, early in subsequent pregnancies. Reliance on self-referral will result in many of the families who wish for or who are in most need of support, remaining unidentified.

2. Introduction of programme (see Figure 1)

There should be an opportunity for parents to meet with the paediatrician in early pregnancy, if appropriate, to discuss the results of the post mortem investigations (if not taken up previously) as well as discussing the care of the next baby. The local co-ordinator will visit families at home to explain the programme in detail. The optimal time for this is about 2 months before the expected date of delivery. Appropriate methods of support should be discussed and selected and consent obtained for the information to be shared with the CONI team.

3. Resuscitation training

All parents should receive training in resuscitation and be given the opportunity to practise on a resuscitation doll.

4. Neonatal investigations

All babies should be examined by a consultant or specialist registrar before discharge from the maternity unit. Further investigations should be guided by the outcome of the review of the sibling's death.

5. Open or fast access to paediatrician

It is appropriate that babies on the CONI programme are given fast or open access to the paediatric team in line with local arrangements for other vulnerable babies.

6. General Practitioner

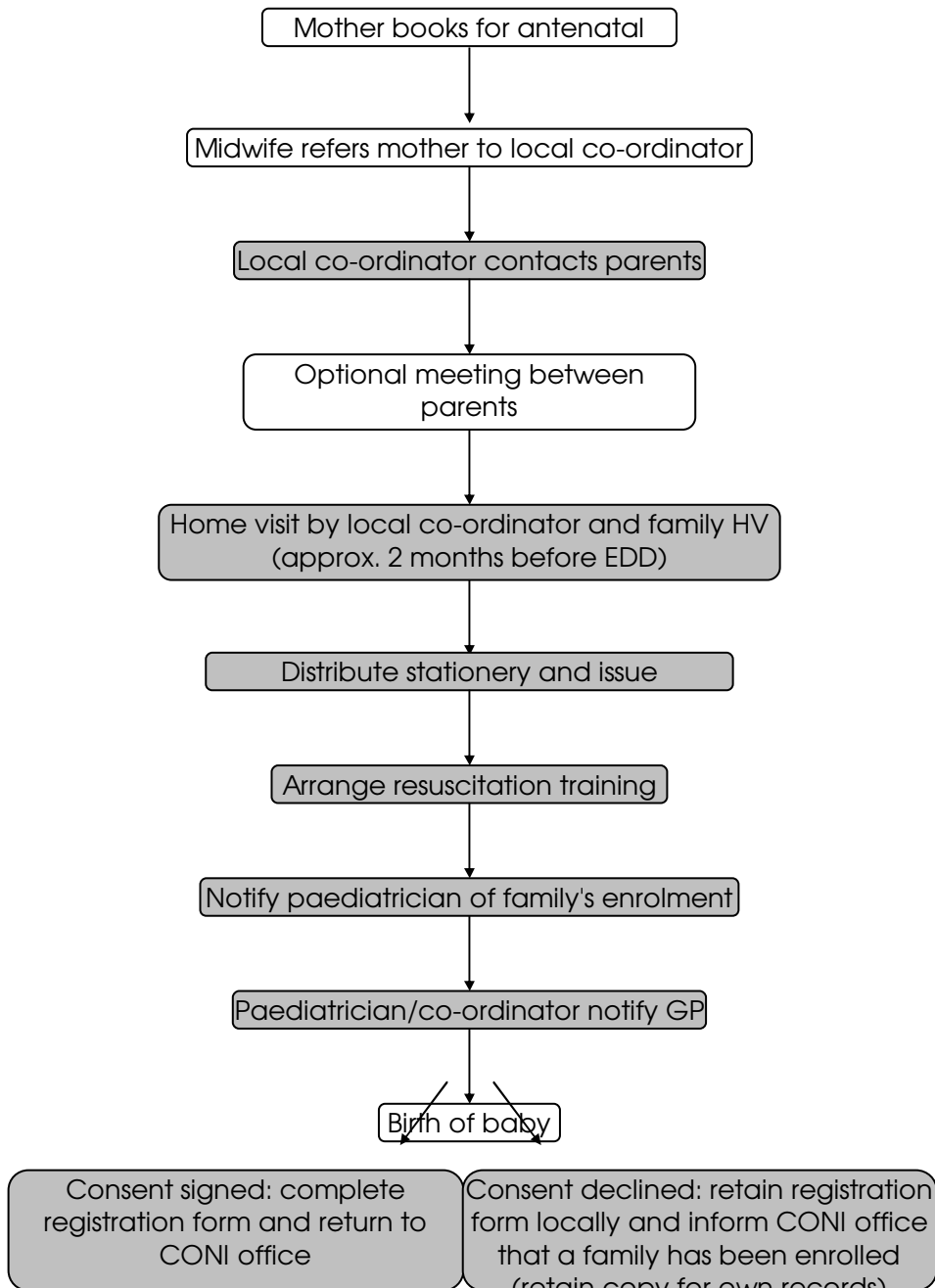
The family doctor needs to be involved throughout all procedures. Information regarding the implementation of CONI should be circulated to all surgeries. The

² Guidelines for professionals involved in the care of families following a SUDI have been prepared by FSID and can be downloaded from www.fsid.org.uk/guidelines-for-professionals.html

family's GP should be informed when a new baby is enrolled on to the programme and provided with the handbook - Guidelines for Users. An alert slip is available for paper records and electronic records should be flagged.

Figure 1

ENROLMENT PROCEDURE FOLLOWING ANTENATAL REFERRAL



(Grey shading identifies tasks for CONI local co-ordinator)

7. Health Visitor

A schedule of planned home visits has been shown to be most effective and weekly visiting at least until the CONI baby passes the age at which the sibling died has been found to be suitable for parents and health visitors. A HV caring for a baby on the programme should be supplied with the handbook - Guidelines for Users.

8. Midwife

Midwives have a principle role in identifying mothers early in their pregnancy and in the newborn period. Parents gain confidence in the surveillance more quickly the earlier it commences. Therefore it is useful to instigate the programme immediately after birth while they are still in the care of the midwife.

9. Visit at 6-7 months and feedback from parents

Where possible the local co-ordinator should visit the family at or towards the end of the planned programme to discuss the withdrawal of the extra support and to offer the feedback questionnaire.

10. FSID support to parents

Parents can be put in contact with an FSID befriender at any time following their baby's death and contact can continue for as long as the bereaved parents wish. This support may be by telephone, letter, e-mail or face-to-face.

11. Enquiry following a repeat death

Rarely families have experienced a further child death. When these occur the CONI Steering Group can offer a confidential enquiry into the circumstances of both deaths, involving a full family history and review of post mortem findings and sections. The findings of the enquiry are shared and discussed confidentially with the local personnel involved with the family with the prime objective of facilitating provisional plans for the management of any subsequent children. Should a death occur, members of the CONI steering group may be contacted for further advice via the CONI office.

PROCEDURES FOR SETTING UP CONI

1. Preliminary meeting with FSID National CONI Co-ordinator

This is held between the National CONI co-ordinator and local personnel: paediatricians, nurse managers for health visiting and midwifery, and others as appropriate.

It includes consideration of

- i) System of identifying pregnant women with previous history of SUDI
- ii) Discussion of support measures:
 - use of symptom diaries
 - weighing
 - breathing movement monitors
 - room thermometers
 - other locally used support measures
- iii) Provision of support:
 - counselling parents during pregnancy
 - supply of equipment and forms (see Appendix 1 for current costs)
 - initial supervision by midwives
 - health visitor visits
 - paediatric follow up
 - GP support
 - arrangement for any special investigations indicated and other investigations

as

they become available or appropriate

- training of all parents in resuscitation before birth of the baby
- liaison with other agencies eg Social Services

iv) Role and selection of local co-ordinator

v) Collection of data for local and central analysis and "end of survey" confidential questionnaires

vi) Consultation with all staff

vii) CONI launch to provide publicity for local health services and the Foundation for the Study of Infant Deaths

2. Local follow up meetings to finalise local support measures

These are held locally between paediatricians, health visitor managers and others as appropriate for more detailed discussion of topics considered at the preliminary meeting. The National CONI co-ordinator does not usually attend these meetings unless specifically required by the local team.

3. Presentation of support measures to local personnel

The National CONI co-ordinator and the local co-ordinator present the support measures to a meeting of local personnel eg health visitors, midwives and paediatricians. Where numbers warrant 2 or more meetings are held.

A training session is held with the local co-ordinator.

4. Continued support of centre from National CONI co-ordinator

The National CONI co-ordinator will remain available by telephone and by correspondence and will organise regional meetings for local co-ordinators.

Each centre will gradually become autonomous but will continue to receive circular information and attend meetings as appropriate.

5. Regional meetings

Once in approximately 12-18 months local co-ordinators will be invited to small regional meetings with the National CONI co-ordinator and a member of the CONI Steering group to discuss recent research papers, local problems and innovations.

6. Implementation of new procedures

The protocol will be revised as necessary in the light of current research and practice.

EVALUATION OF DATA COLLECTED

Evaluation of the CONI programme is made by analysis of questionnaires completed by parents and analysis of information extracted from the CONI records completed by the parents and health visitor. Reports on the combined data from all centres are regularly made available. The report on the first 5000 babies is available to download from: www.fsid.org.uk/professional-advice.html The CONI programme was set up to provide support for parents, not for research, but it is anticipated that separate research projects may be set up in association with the CONI programme.

CONI PLUS

The CONI programme has been extended as CONI PLUS to be available to other families whose babies may be at increased risk of SUDI or who have reason to be anxious about their child. Following a survey of paediatricians and CONI local co-ordinators, 3 groups have been identified.

1. Close relatives

The first group is parents who are close relatives of cot deaths i.e. one of the parents has had a sibling die as a cot death or has had a niece or nephew die as a cot death. Their babies are not at increased risk due to the family history. However, the parents may be very anxious, depending on the closeness of their relationship to the baby that died or because the new baby is premature etc. It may be appropriate to offer CONI PLUS when counselling cannot allay these fears.

2. Other baby deaths

The second group is parents of babies born following a post-perinatal death from causes other than SIDS occurring after discharge from the neonatal or postnatal unit. Parents of cot deaths have been considered as special cases for support because no cause of death can be given. However, any parent whose child dies has feelings of guilt, inadequacy and failure that may not be put to rest by counselling. Where anxiety persists, CONI PLUS may provide appropriate help.

3. ALTE

The third group is parents whose babies suffer an apparently life-threatening event (ALTE). They can have fears about the survival of their baby that persist for many weeks following the event. Any ALTE episode needs to be investigated but for as many as half of such events no cause will be found (11). The fears that these parents have for their child's subsequent safety are similar to those expressed by parents with a sibling born following a cot death, namely that the child will suddenly die, that they are frightened of the responsibility of parenthood and that professionals will not understand their anxieties. These babies are known to be at increased risk of dying (12, 13).

4. Additional groups

Centres may agree a local protocol that allows the inclusion of parents made anxious for reasons other than 1-3 above.

Each family meeting the criteria for the local CONI PLUS protocol should be assessed prior to the programme being offered. Not all families who may be eligible will be anxious or at increased risk of SUDI.

CONI PLUS PROTOCOLS

FOLLOWING AN APPARENTLY LIFE THREATENING EVENT (ALTE)

Definition of ALTE (14)

An ALTE is a sudden and unexpected event which is frightening to the observer who perceives the baby to be at risk of death and feels there is a need to take some immediate action. The event has a defined onset and ending and does not lead to death or persistent collapse. The baby displays a change in at least two of the following:-

colour, tone, consciousness, movement, breathing.

Incidence and Mortality

The incidence of ALTE in the UK is not recorded. ALTE is not identified in the Hospital Episodes Statistics recorded by the Department of Health and a search of literature has not produced an incidence rate within a clearly identified population of babies. In Warrington, (population 300,000) ALTE is reported in 2/1000 live births (N. Mir, personal communication). Discussions with CONI co-ordinators who also have involvement with supporting families following ALTE suggests a referral rate of families on average equal or slightly less than for cot death families, ie in the range of 1.0 - 1.5/1000. In the period 2002-2006, the ALTE referrals to the CONI PLUS programme for the city of Sheffield ranged between 1.0 - 2.2/1000 live births with a mean of 1.8. However, rates quoted outside the UK show a wide variation in incidence. In South Australia, with 20,000 births per annum, ALTE is reported as 0.9/1000 live births (S. Beale, personal communication). In W. Virginia a risk intervention programme identified babies with ALTE at 11/1000 live births (6/1000 in full term infants and 86/1000 in premature infants) (12).

Discussions with clinicians in the UK prior to setting up CONI PLUS led us to estimate a mortality following ALTE of 10/1000. This estimate is supported by our experience to date of 12 deaths among 1354 babies enrolled following ALTE, however some of these babies had progressive degenerative disease or severe congenital abnormalities. This is comparable to the risk attributed to siblings of cot deaths in 1989 when CONI was set up. However, the mortality in W. Virginia of babies was 16/1000 who had experienced an ALTE. ALTE encompasses a heterogeneous group of babies and individual risk will vary widely.

Identification of cases

All babies presenting immediately after ALTE should be admitted for observation and investigation and the local CONI co-ordinator notified. Babies referred to the paediatrician by letter from their General Practitioner should be assessed in a paediatric clinic. Babies with recurrent ALTE may need to be assessed at a specialist paediatric respiratory unit.

Guidelines of management following ALTE (see Figure 2)

1. Clinical history

A full history should be taken to include:

- i) Events and baby's health preceding the ALTE.
- ii) A full description of the ALTE episode.
- iii) Details of all clinical investigations.
- iv) Diagnosis of cause, where this can be determined.

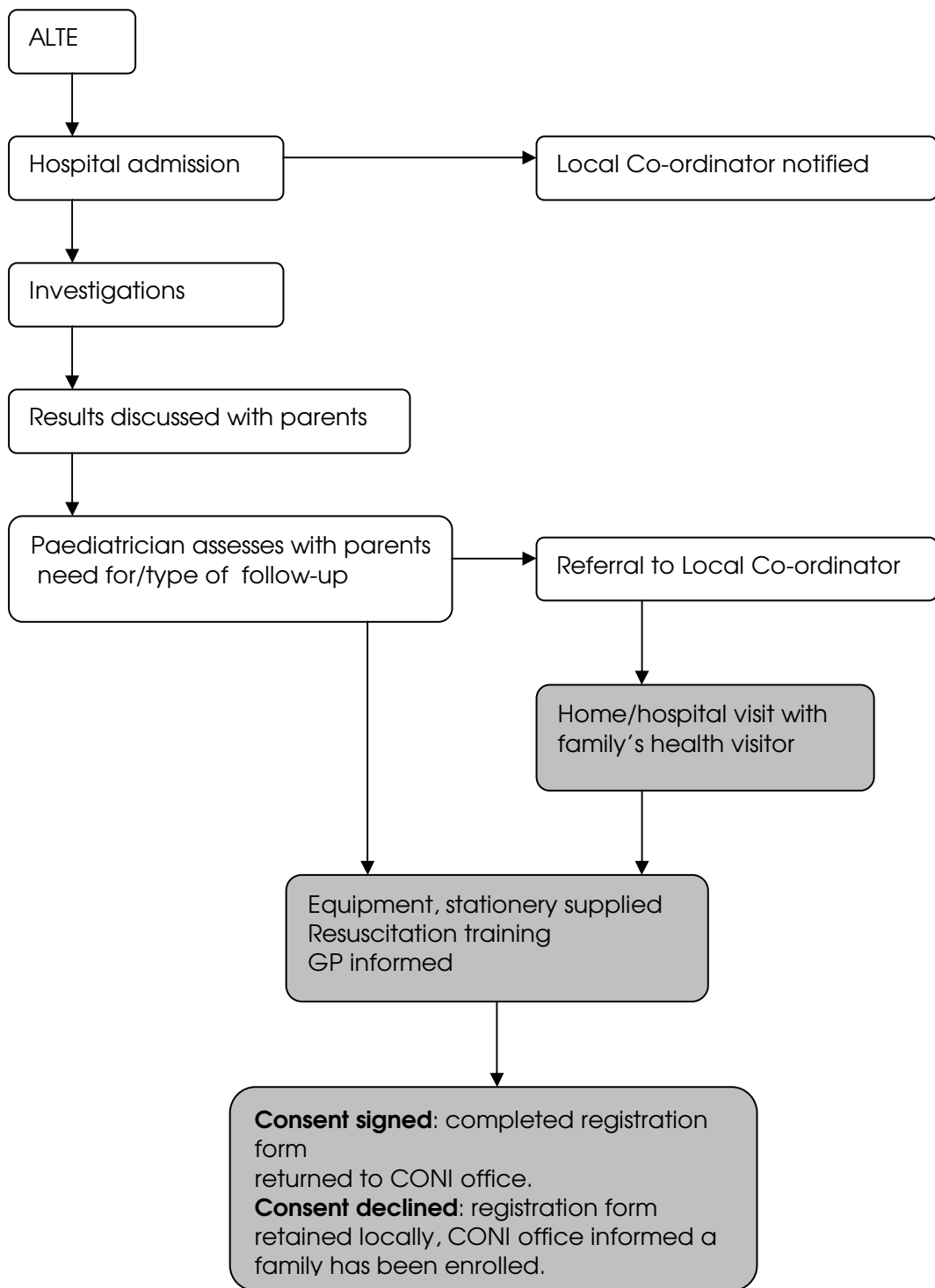
2. Discussion with parents

When investigations are complete a discussion is held with parents, consultant paediatrician and where possible, local CONI co-ordinator:

- i) The clinical findings are explained.
- ii) It is determined whether there is a need for follow up support at home. Parents may not want or require organised support.
- iii) If organised support is appropriate, the support methods are explained and selected.
- iv) The equipment and forms are issued or firm arrangements made for these to be issued by the local co-ordinator.

Figure 2

ENROLMENT FOLLOWING ALTE



(Grey shading identifies tasks for CONI local co-ordinator)

3. Discontinuation of hospital monitoring

If the baby is to be discharged home without monitoring equipment, it is important that all monitoring in hospital is stopped at least 24 hours before discharge.

4. Setting up home support

This is conducted by the local co-ordinator, ideally with the family's health visitor. It should be undertaken before discharge from hospital, or as soon as practicable following discharge. The chosen methods of support are explained in detail including the demonstration of any equipment.

5. Resuscitation training

All parents should receive training in resuscitation and be given the opportunity to practise on a resuscitation doll.

6. General Practitioner

It is essential that the family doctor is fully informed about the baby's hospital admission and subsequent arrangements for the support of the family. The GP should be provided with the information booklet and made aware of the CONI PLUS information contained in the parent held record. An alert slip is available for paper records and electronic records should be flagged.

7. Health Visitor

The health visitor should discuss with the parents a schedule of home visits while the child is being monitored. The health visitor should receive training from the CONI co-ordinator and be given the Guidelines for Users booklet.

8. Completion

The duration of the surveillance needs to be flexible. However there should be a formal completion of the programme involving the parents, paediatrician, local CONI co-ordinator, health visitor and GP. Local practices may vary, but for example the local co-ordinator may visit the family, discuss their experiences and remove equipment and completed stationery or the completion may be marked by an attendance at the paediatric out-patient clinic.

BABIES BORN TO CLOSE RELATIVES OF A COT DEATH

Definition

- i) Babies born to parents who have had a sibling die as a cot death.
- ii) Babies born to parents who have had a niece or nephew die as a cot death.

Incidence

Whilst there are many babies born each year that would meet the definition it is anticipated that only certain families require the full programme. These may include, for example, a sibling who was older than the cot death baby at the time of death and who has a clear recall of the trauma caused by the death of their sib; relatives involved on a day to day basis with the baby before cot death; relatives whose new baby is at increased risk e.g. due to prematurity. The number of families requiring support is approximately 1-2 per CONI centre per year.

Identification of cases

These cases are identified during the pregnancy by those providing ante-natal care either in the hospital or the community. The families are referred to the local co-ordinator.

Guidelines for management

The families are managed according to the protocol for the CONI programme.

BABIES BORN FOLLOWING A POST PERINATAL DEATH AFTER DISCHARGE FROM THE POST NATAL UNIT AND FROM CAUSES OTHER THAN SIDS

Definition

A baby dying from causes other than SIDS after discharge home from the neonatal or postnatal unit aged from 7 days to under 1 year.

Incidence

There were 1600 post perinatal deaths in 2005 in England & Wales, 2.48/1000 live births (15).

Of the 1600, there were about 200 associated with cot death, about 250 died in hospital due to congenital anomalies and about a further 500 died in hospital from conditions principally related to prematurity. Thus there are potentially about 650 who would meet the terms of our definition.

Identification of cases

These cases are identified by the midwife taking the booking history from the mother at her first visit for ante-natal care. Other members of the primary health care team may also identify them and parents may self-refer.

Guidelines for management

The families are managed according to the protocol for the CONI programme.

PROCEDURES FOR SETTING UP CONI PLUS

CONI PLUS is designed to be an extension to existing CONI programmes. Each centre will need to draw up a local protocol, which identifies the categories of babies to be included, and the local procedures for the delivery of the support programme. This should consider:

- i) System for ensuring
 - a) ALTE babies are identified to local co-ordinator before discharge and home support discussed
 - b) other eligible babies are identified and referred to the local co-ordinator as early as possible in the pregnancy
- ii) Procedure for investigation of ALTE
- iii) Provision of support:
 - health visitor visits
 - symptom diaries
 - room thermometers
 - weight charts
 - weighing scales
 - clinical monitors
- iv) Funding of equipment and stationery (see Appendix 1 for current costs)
- v) Involvement of the health visitor
- vi) Involvement of general practitioner
- vii) Follow-up by paediatrician
- viii) Extended role of local CONI co-ordinator(s)
- ix) Collection of data and "end of survey" questionnaire
- x) Consultation with all staff

The National CONI co-ordinator is available to advise on the introduction and implementation of CONI PLUS.

References

- 1) Waite A, McKenzie A, Carpenter R, Coombs R, Daman-Willems C, Emery J. Report on 5000 babies using the CONI (Care of Next Infant) programme. The Foundation for the Study of Infant Deaths, London 1998. ISBN 0 9510753 7 3.
- 2) Emery JL, Waite AJ, Carpenter RG, Limerick SR, Blake D. Apnoea monitors compared with weighing scales for siblings after cot death. *Archives of Disease in Childhood* 1985;60:1055-1060.
- 3) Implementation Plan for Reducing Health Inequalities in Infant Mortality: A Good Practice Guide. DOH 2007.
- 4) Blair PS, Sidebotham P, Berry PJ, Evans M and Fleming PJ. Major epidemiology changes in sudden infant death syndrome: a 20 year population-based study in UK. *Lancet* 2006;367:314-319.
- 5) Carpenter RG, Waite A, Coombs RC, Daman-Willems C, McKenzie A, Huber J, Emery JL.
Repeat Sudden Unexpected & Unexplained Infant Deaths: Natural or Unnatural?
Lancet 2005;365:29-35.
- 6) Supporting Local Delivery. National service framework for children, young people and maternity services. DOH 2004.
- 7) Facing the future. A review of the role of health visitors. Crown copyright 2007
- 8) Health Statistics Quarterly 03 Autumn 1999. The Stationery Office.
- 9) Taylor EM, Spencer NJ, Carpenter RG. Evaluation of attempted prevention of unexpected infant death in very high risk infants by planned health care. *Acta Paed* 1993;82:83-86.
- 10) Blair PS, Nadin P, Cole TJ et al. Weight gain and sudden infant death syndrome: changes in z scores may identify infants at increased risk. *Arch Dis Child* 2000;81:112-116
- 11) Samuels MP, Poets CF, Noyes JP et al. Diagnosis and management after life threatening events in infants and young children who received cardio pulmonary resuscitation. *BMJ* 1993;306:489-492.
- 12) Myerburg DZ, Carpenter RG, Myerburg CF et al. Reducing post neonatal mortality in W Virginia: A statewide intervention program targeting risk identified at and after birth. *Am J Public Health* 1995;85:631-637.
- 13) Shannon DC. Prospective identification of the risk of SIDS. *Clinics in Perinatology* 1992;19:861-869.
- 14) Gibb SM, Waite AJ. The management of apparent life threatening events. *Current Paediatrics* 1998;8:152-6.
- 15) ONS London. Personal communication.

Appendix 1

Estimated costs based on prices at January 2008

Capital Costs

Breathing movement monitors

- For CONI estimates are based on the average incidence of SUDI i.e. 4 SUDI per year suggests 4 monitors will be required.
- For CONI PLUS estimation is more difficult as use of the programme varies widely depending on local criteria. As a rough rule, if all 3 CONI PLUS criteria are included, monitor requirements will at least double the provision for CONI.

Weighing scales

It is recommended that one or two pairs of scales are available to loan to families on the programmes.

Resuscitation Doll

A resuscitation doll should be available for teaching parents mouth-to-nose-and-mouth resuscitation though the use for CONI and CONI PLUS will be quite light. Thus ideally the doll should be shared with other users to maximise utilisation of the doll.

Current prices for equipment purchased through the Foundation for the Study of Infant Deaths are:

Graseby MR10 (sensor monitor)	£386.25
Eastwood RE200 (mattress monitor, battery power)	£315.00
Eastwood RE200C-U (mattress monitor, mains power)	£375.00
Seca 834 (weighing scale with carrying case)	£115.79
Laerdal Resusci Baby Basic (resuscitation doll)	£220.00
Ambu Baby (resuscitation doll)	£295.00

Donations can be made to FSID to support the CONI programme and this enables FSID to donate equipment to centres. Contact the National CONI Co-ordinator to apply for funding for equipment.

Recurrent costs

Average cost per family using CONI or CONI PLUS

Stationery pack	£11.50
Sensors (for Graseby MR10) 13 @ £1.34	£17.42
Batteries £2.50	£ 2.50
Tape (usually prescribed) £4	£ 4.00
<u>Total</u>	<u>£35.42</u>

Annual servicing of monitors: costs vary but typically £30-80

Training for new co-ordinators £35 plus travel costs