



Guidelines for health visitors and midwives when a baby dies suddenly and unexpectedly

These guidelines have been written to help health visitors and midwives through a stressful and difficult time when they are involved with the family of a baby who has died suddenly and unexpectedly. They should be read alongside FSID's guidelines for the other professionals responding to sudden infant deaths. You need to ensure these guidelines form a part of your PCT strategy.

If you are one of the first on the scene

1. Check that an ambulance has been called
2. If in doubt, resuscitation should always be attempted en route to hospital
3. If the mother goes to hospital with the baby, check on the care of the siblings. If the mother is left alone, arrange for her to be supported by her partner or a friend
4. Give the parents a number where they can contact you
5. Inform the GP and your line manager
6. Spend time listening to the parents. Mention the baby by name and don't be afraid to express your sorrow.

If you learn later a baby has died

1. Visit the day the death occurs, or as soon as possible afterwards, to acknowledge the death and offer condolences. Make sure you use the baby's name. Ask the parents to tell you what happened. Spend time listening. If the parents are out, leave a note and try again soon.
2. Try to help the parents face their grief together and to ensure that neither is left alone for long. If necessary contact relatives and friends to support them.

3. Ask the parents about the reactions of siblings; tell them how they can get advice if they need it.
4. Support the parents emotionally and explain the procedures carefully, especially the role of the coroner, police and post mortem examination.
5. Ask whether they wish to see the baby again before the post mortem and find out how this can be arranged. Check that an undertaker has been arranged and explain about the Funeral Payment available through their local Benefits Agency. Some funeral directors will not charge for a baby's funeral. Ask if they would like you to attend the funeral.
6. If the mother was breastfeeding, discuss methods of suppression of lactation.
7. Ensure the parents have a copy of FSID's booklet 'When a baby dies suddenly and unexpectedly' (keep a supply at the clinic and don't assume somebody else will have given them one) and FSID's Helpline number (0870 787 0554). Tell them they can have a phonecard to call the Helpline free of charge. Ask if they would like to be put in touch with an FSID befriender.
8. Tell the parents they can contact you at any time and give them a number where you can be reached.
9. Don't forget grandparents who may be supporting their children at this time; they too are grieving for their grandchild and might welcome the opportunity to express their feelings.
10. Check the following agencies have been informed of the baby's death:
 - Medical records departments of maternity/children's hospitals to avoid follow up appointments being sent
 - Child Health records to avoid letters being sent about immunisations and development checks
 - The school if there are school age children in the family.
12. Advise parents to return the Child Benefits Book to their Post Office.
13. Liaise with the general practitioner throughout to ensure that everything necessary is done without excessive duplication.
14. Please ensure that all parents are given a copy of the DOH's leaflet 'A guide to the post mortem examination procedure involving a baby or child' (reference 29768/A) and that the content is discussed. Every parent should be given the opportunity to donate tissue for research, education and audit. Please ensure that the consent form for parents 'Post mortem examination on a baby or child ordered by the coroner' (reference 29773) is explained. Don't assume that someone else has already discussed the post mortem and tissue retention with the family. Always check with the parents. The leaflets are available to download from www.dh.gov.uk

Further measures

1. Visit again after the funeral and regularly during the following weeks. Listen and share memories. Remember anniversaries of the baby's birth and death.
2. Assess whether the parents need more help with their grief (remembering that people grieve in different ways). If necessary get advice from a psychologist.
3. Ensure that a meeting has been arranged with the paediatrician designated for cot deaths so that the parents can discuss the post mortem examination findings and to ask questions.
4. Attend the case discussion that should be held about a month after the death. The other main participants are the general practitioner, paediatrician and pathologist who carried out the post mortem examination. The purpose is to discuss all aspects of the death including possible causes and contributory factors, any lessons to be learnt and support for the family.
5. Say that support with subsequent babies is available through FSID's Care of the Next Infant (CONI) scheme and when the time comes encourage them to use it.
6. Call FSID's Helpline on 0870 787 0554 if you have any concerns or queries and make use of the resources available from FSID.

Support during the next pregnancy

1. Acknowledge the previous death using the baby's name
2. Aim for continuity of care and involvement in the choices available e.g. community care if appropriate.
3. Note anniversaries when the parents may need additional support.
4. Establish a Care of the Next Infant (CONI) contact, if available, at first booking. Remember that support from FSID and CONI is available for clinicians as well as bereaved parents.
5. The midwife at delivery should be someone who is known and trusted by the mother.
6. Whenever appropriate discuss risk factors such as sleep position smoking and be up to date with the latest research (resources are available from FSID).
7. Make sure that information about cot death and risk reduction is included in parentcraft classes, pre-conceptual and health promotion clinics.
8. Have available FSID's Helpline number (0870 787 0554) and the nearest CONI contact.

NB Some of these points may have been covered by other health professionals but don't assume that they have.

Some fundamental rules:

- Don't use technical terms or jargon. When you give families information check to see it has been understood
- Don't say things like:
 - “You can always have another”
 - “He was so young you hardly got to know him”
 - “At least you have other children”
 - “You'll soon get over it”
 - “You will never get over it”
- Always refer to the baby who died by name.

For further advice and support on responding to sudden infant deaths call FSID's Helpline on 0870 787 0554 or email support@sids.org.uk

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