

Communication with parents

1.1 Why is it important that you are able to communicate well with the parents of a newborn infant?

Most parents are excited and thrilled to meet their healthy newborn infant. For many months they have been imagining what their infant will look like and how the infant will behave. The first few days after delivery are a very special time for parents, therefore, and it is a pleasure for the nurses and doctors to share this experience with them.

However, if the infant is not normal and healthy, then the parents are anxious, afraid and confused. They need a lot of help from the nurses and doctors caring for their infant. To give this care to the parents you must be able to communicate well with them. Poor communication makes this unhappy experience all the more difficult and unpleasant.

Parents of unplanned (often unwanted) infants also need extra help with bonding.

1.2. What can you do to improve your communication skills?

1. Make time to speak to parents.
2. Be honest when you tell parents about their infant.
3. Listen to what they say and ask.
4. Use simple language.
5. Allow parents to ask questions.
6. Look at the parents when you speak to them.
7. Address the parents by name.
8. Watch, listen and learn when more experienced colleagues speak to parents.
9. Try to understand what the parents are feeling.
10. Be kind and helpful.
11. Find a place where the parents can speak to you in private.

Parental bonding

2.1 What is parental bonding?

Bonding is the special emotional relationship that parents develop with their infant. Bonding starts during early pregnancy, especially after the mother first feels her fetus move. Bonding can be compared to 'falling in love'. Every effort must be made to ensure that bonding takes place, especially in teenage mothers and mothers who do not want the pregnancy. Bonding is often poor with preterm infants when the parents are separated from their newborn infant. Anxiety about a sick infant or an infant with a congenital disorder can also interfere with the normal bonding process.

2.2 How can you encourage the bonding process?

1. During pregnancy you should encourage the parents to speak about their unborn fetus. They should think of possible names. Most prospective parents will imagine what their infant will look like. When available, an antenatal ultrasound photograph of the fetus strengthens bonding.
2. Allow the mother to hold her infant and put the infant to the breast as soon as possible after birth. The father should also see and hold the infant. If possible, the father should be present during the labour and delivery.
3. Let the mother room-in with her infant and encourage her to demand feed.
4. Practicing skin-to-skin care (kangaroo mother care) is a very powerful way of promoting and strengthening bonding with both parents.
5. The infant should be given a name soon after delivery.
6. Take a photograph of the infant for the parents if the mother and the infant cannot be together.
7. If the infant is small or ill and has to be cared for in the nursery, the parents must be allowed to visit their infant whenever they want. After washing their hands, they can touch their infant. They can also help with simple nursing procedures such as changing

nappies and giving nasogastric feeding. Intermittent kangaroo mother care (KMC) can be used with small infants in an intensive care unit once they are stable.

8. Parents should be encouraged to bring greeting cards and toys for their infant. Mothers can also bring clothes for the infant. This helps them realise that it is their infant and that the infant 'does not belong to the hospital'.

It is very important to promote parental bonding.

2.3 Should grandparents and siblings be allowed to visit a newborn infant?

Grandparents should be encouraged to visit the newborn infant, especially if the grandmother is going to help care for the infant. This is particularly important with single mothers. Brothers and sisters should also be allowed to visit the infant. They can even touch the infant if they first wash their hands. However, visiting children must not be allowed to become a nuisance in the nursery.

2.4 How can parents be encouraged to bond with an infant who has a congenital disorder?

1. The sooner the parents are told of the abnormalities the better. If possible, tell the parents together.
2. Encourage them to handle the infant. Point out the normal as well as the abnormal features.
3. Handle the infant yourself as if you care and are not afraid to touch the infant.
4. If possible, try to be optimistic. Explain the implications of the abnormalities and stress what can be done to correct them. Tell the parents what the management will be.
5. Where applicable, show photographs of a corrected abnormality, e.g. a repaired cleft lip and palate.

Managing the family of a sick or dying infant

3.1 How should bad news be told to parents?

1. If a fetus or newborn infant has died or is very sick, it is important that the parents be told as soon as possible. Sedation for the parents is usually not needed.
2. A member of staff who knows the parents, or the most experienced member of staff, should give the bad news. Never delegate this responsibility to a junior staff member.
3. If possible, tell the parents together. Allow them to cry if they so wish.
4. Make sure that the parents have some privacy. Even a screen around the bed is helpful.
5. Give the parents the best explanation possible for the cause of the death. Use simple language and always be honest. These details may have to be repeated over a few days.
6. Give the parents a memento such as a name band, piece of hair or a Polaroid photograph.
7. Prepare the parents for having to break the news to any other children and other family and friends.

3.2 Should parents visit and touch a sick or dying infant?

Yes, parents of a sick infant should be encouraged to visit as often as possible. They must be allowed to touch their infant and, if possible, to help with the nursing care. Many parents want to be present when their infant dies. If an infant is dying on a ventilator, the endotracheal tube can be removed and the infant given to the mother to hold. Intravenous lines can be disconnected and the infant can be wrapped in a blanket. Kangaroo mother care can be used with terminally ill infants.

Parents must be allowed time with terminally ill infants.

3.3 Should the other children in the family be told that the infant has died?

Yes, it is very important that the parents tell the siblings the truth. They should be given a simple explanation and be told that the infant's death has made the whole family sad. Siblings often feel jealous about the new infant and, therefore, feel guilty when the infant dies. Children need to be reassured that it is not their fault and that they will not also die.

Bereavement

4.1 What is bereavement?

Bereavement (or mourning) is the normal emotional process that a person experiences when a close family member or friend dies. Bereavement is the same after a miscarriage, stillbirth or neonatal death as when an older child or adult dies. Bereavement lasts from a few weeks in some people to many months in others. As death and bereavement are often taboo subjects, their correct management is commonly not discussed or taught. Many doctors and nurses feel distressed, threatened and inadequate when discussing death and, therefore, avoid the subject.

There are 5 major stages in bereavement:

1. **Denial.** At first the parents cannot believe that their fetus or newborn infant has died. They often ask if there has not been a mistake; 'it cannot be true'. The parents may appear shocked and dazed, and do not seem to understand what the doctors and nurses tell them. This phase usually lasts a few hours.
2. **Anger.** After the initial denial, parents often express their distress as anger. They may believe that the nurses or doctors are the cause of their infant dying. One parent may blame the other parent. They may even blame themselves for something that they did or did not do during the pregnancy. Parents often feel very guilty and believe that they are responsible for the infant's death.
3. **Bargaining.** Parents often bargain with themselves, e.g. 'if the infant is not really dead I promise that I will never ...'
4. **Depression.** The following are common features of depression after a stillbirth or neonatal death:
 - The parents feel very sad and distressed.
 - They cry a lot.
 - They often feel restless and cannot sleep at night.
 - They lose their appetite.
 - They have difficulty concentrating at work.
 - Life seems empty and hopeless.
 - They keep thinking about the infant all the time.
 - They often dream about the infant.
 - They may even think that they hear the infant crying, and fear that they are going mad.
5. **Acceptance.** After a varying amount of time, most parents eventually accept that their infant has died and that nothing can be done to bring the infant back. They realise that life must continue and that they have responsibilities to other members of the family. With time they think about the infant less often as other needs and problems of day to day living take up their time. Some parents do not pass through all the above stages of bereavement, while others often move backwards and forwards from one stage to another. However, most bereaved parents gradually progress from denial, anger and bargaining, through depression, to eventual acceptance. The time it takes for different people to work through the bereavement process varies. Often one parent takes longer than the other. Each person's personality, outlook on life and religious convictions influence the process of bereavement. Some parents do not complete the mourning process but develop a severe, chronic depression and need professional help.

Bereavement is the normal emotional process that a person experiences when a close family member or friend dies.

4.2 What are the goals of bereavement counselling?

Every effort should be made to help the parents and family to progress through and complete the normal mourning process. With the correct management, parents can experience bereavement without suffering permanent emotional damage. For the successful achievement of this goal, however, the parents must be encouraged to accept that they have had an infant who has died. In the past the opposite was practised by doctors, nurses, family and friends who tried to prevent bereavement by advising the parents to forget about the painful experience and to even pretend that it never took place. It was also thought that the suffering would be less if the parents did not bond with their infant. The mother, therefore, was not shown her dead infant, the subject was not discussed or even mentioned, and the parents were told to 'put the loss behind them' and to 'get on with their lives'. Every attempt was made to protect the parents from sadness and stress. Unfortunately, these well-intentioned actions often interfered with the normal bereavement process because the infant's death was emotionally denied.

Today, parents who have had a stillbirth or neonatal death should still be supported with kindness and understanding but, at the same time, must be helped to accept the reality of the dead infant.

4.3 What can be done to help parents during bereavement?

1. Tell them that you are sorry that their infant has died. A hand on the shoulder, a hug or even a handshake makes physical contact with the parent and helps to indicate to them that you care. If possible, speak to the parents together.
2. Make yourself available to listen to them, to explain the process of bereavement and to be sympathetic. Do not avoid grieving parents.
3. Remember that people from different cultural and religious groups sometimes have different beliefs about death. These attitudes must always be respected.
4. Allow the patient to decide whether she wants a private room or to be with other mothers. If she is still in hospital, try to discharge the patient as soon as possible.
5. Allow parents to cry.
6. If necessary, the mother's breasts can be strapped with a crepe bandage to help suppress milk production.
7. Sedatives are usually not helpful, but a hypnotic to help parents sleep for the first few nights is sometimes needed.
8. Allow the parents to keep a memento of their dead infant, such as a name band, piece of hair or a Polaroid photograph.
9. Contact a local person or group that is experienced in helping bereaved parents, e.g. a minister of religion or social worker.
10. Ensure that the paper work (notification of birth and death certificates) and funeral arrangements are completed rapidly and efficiently.
11. Encourage parents to contact you if they would like to discuss the infant's death or their own feelings after the patient is discharged.
12. Advise them not to plan another pregnancy for at least 6 months, or until the mourning process is completed, so that they can fully recover from the death. Never suggest that they should have another infant as soon as possible to replace the dead infant.
13. Start a local support group that can discuss the management of bereavement and offer help to bereaved parents. A support group may already be available.
14. If possible, the parents should be seen again in 6 weeks time to assess whether the mourning process is progressing normally. Signs such as persistent insomnia, loss of appetite and depression suggest that further counselling is needed. This meeting allows parents to ask further questions and the doctor or nurse to provide guidance and the results of any outstanding investigations.

4.4 What should you not say to bereaved parents?

1. 'It does not matter.'
2. 'I understand how you feel'. Unless you have had a perinatal death yourself, you cannot know what they are feeling.
3. 'It is better that the infant died than survived with brain damage.' While this might be true, the parents are still sad that their infant has died.
4. 'You can always fall pregnant again'. They can never replace the infant that has died.
5. 'Try to forget about the infant.'
6. 'You are lucky to have other healthy children.'
7. 'You must pull yourself together and stop crying.'
8. 'You are lucky that your infant died now rather than later.' Parents mourn the death of an infant even if they did not have the opportunity of getting to know the infant.
9. 'It is your fault that your infant died.' Even if this might be true, it is very cruel to blame the parents. Rather suggest that the pregnancy might be successful the next time if they take your advice.

4.5 Should parents see and hold their dead infant?

Yes. The parents should be allowed to spend some time with their dead infant, alone if they wish. It is important that they see and hold the body. Although distressing to both parents and staff at the time, most parents are very grateful for the opportunity to say farewell to their infant. Even infants with severe congenital disorders can be dressed and shown to parents. Always stress the normal parts of the body, e.g. hands, feet and genitalia in an anencephalic infant. The imagined malformation is often worse than the real thing. However, if parents do not want to see and hold their dead infant, they must never be forced to do so.

Parents should be allowed to see and hold their dead infant.

Case study 1

An infant of 1500 g has poor breathing at birth after a vaginal delivery. After resuscitation the infant is taken to the nursery and not shown to the mother. Only the mother, who is unmarried, is later allowed into the nursery but she is not allowed to touch her infant. The rest of the family can only view the infant through the nursery windows. As the infant will need to spend a few weeks in an incubator, the mother is discharged home on the second day after delivery. She is told to bind her breasts to suppress her milk.

1. What should have been done to improve bonding in the delivery room?

The mother should have been shown her infant before it was moved to the nursery. Even if the infant is too small or too sick to be held and put to the breast, the parents should briefly see their infant.

2. What do you think about the visiting policy in the nursery?

The father of the infant and the grandparents should also be allowed to visit the infant in the nursery. This is particularly important if the mother is unmarried, as she needs her parents' support. The grandparents must also bond with the infant as they often have to care for the infant when the mother returns to work.

3. Why should the mother be allowed to touch the infant?

This is a very important part of bonding. If a mother washes her hands first, there is very little risk of spreading infection to her infant. She can also help with simple nursing tasks such as changing the nappy and giving nasogastric feeds.

4. How could kangaroo mother care have helped?

The mother should have been encouraged to give KMC as soon as the infant was stable. Probably within the first few hours with this infant. KMC in the labour ward may have been possible.

5. Do you think that it was a good idea to discharge the mother and to suppress her lactation?

The mother should be kept in hospital with her infant for as long as possible. Mothers and infants should not be separated. In many hospitals, mothers stay until their infant is discharged. She should have been encouraged to express her breast milk for nasogastric feeds until the infant was old enough to start breastfeeding. Suppressing her milk will prevent her breastfeeding.

6. What may be the result of this bad bonding experience?

The mother, father and their families may not bond as well with this infant as they would have if the hospital policies had been different. The unmarried mother may abandon the infant.

Case study 2

An infant with severe intrapartum hypoxia dies when attempts at resuscitation fail. The body is immediately wrapped up and not shown to the parents. Only hours later is the mother told that her infant has died. The father is very angry when she tells him the news as he feels that the nursing staff are to blame for the infant's death. No arrangements are made for the burial.

1. Is it better for the mother if she does not see her dead infant?

No. Most parents want to see their infant. The parents should have been allowed to spend some time with the dead infant before it was taken away.

2. When should the parents have been told of the infant's death?

As soon as possible. If the father was at the delivery, both parents could have been told together when it was realised that the infant was dying.

3. Why was the father angry with the nursing staff?

Anger is a common reaction to news of an infant's death and is part of the normal mourning process. Staff must realise that the anger is usually not directed personally at them.

4. Should the hospital staff help with the funeral arrangements?

Yes. They should issue a notification of death certificate as quickly as possible and advise the family about arranging the burial.