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Chapter 31

Disruptions around birth: prematurity and illness, still-birth and perinatal loss

31.1 PREMATURITY AND ILLNESS

'As I see it, the trauma of birth is the break in the continuity of the infant's going on being, and when this break is significant the details of the way in which the impingements are sensed, and also of the infant's reaction to them, become in turn significant factors adverse to ego development . . . In some cases this adverse factor is so great that the individual has no chance (apart from rebirth in the course of analysis) of making natural progress in emotional development, even if subsequent external factors are extremely good.' D.W. Winnicott (Birth memories, birth trauma, and anxiety, 1949, in *Through Paediatrics to Psycho-Analysis*)

31.1.1 Preterm labour and birth

Having a baby early is frightening. Nothing happens according to expectation and nothing is ready. The couple is caught unawares and usually without much warning the woman finds that pregnancy has ended and labour begun before she has completed the emotional processes of gradual separation. Invariably, she wonders why her baby wants to leave her: is there something essential lacking, something more she might have provided? Is she unable to retain good things, or useless at providing them? Has she been careless? Is she incapable of cherishing another being and if so how can she look after the baby now it is coming out? Is there something horrible in there that the baby is escaping from? Has she herself done something to trigger the expulsion of her baby? Was it sex that started the contractions? Is the baby impatient to come out and meet her or is the fetus responding to her own impatient inability to wait until the baby is ripe?

Psychologically, she is totally unprepared for birth, unless, with the aid of artificial hormonal intervention biofeedback and/or psychotherapy, she has managed to delay the onset of labour for a few days, allowing her a little time to adjust to the idea of imminent delivery and giving the fetal lungs a chance to mature before birth. Tension permeates a preterm birth as question marks hang above the delivery table – will it survive birth? will it breathe? will it be alright? can it be normal? and only then, what sex is it?

31.1.2 Bonding

Only rarely can the baby at risk be cuddled for long before it is whisked away. The premature baby looks even less like the baby-book pictures than those born at term and parents may feel desperately guilt-ridden about their initial shock and revulsion at seeing the scrawny little 'skinned rabbit' or hairy, bony E.T.-like creature. In addition to its small size, the baby might be ill and almost transparent in appearance, is likely to be weak, 'collapsed' and unresponsive. Superimposed upon the image of their healthy fantasy baby, this one seems alien and 'wrong'. When survival is in doubt, it is not unusual for parents to protect themselves from falling in love while unconsciously preparing themselves for possible loss. The mother, in particular, might feel devastatingly inadequate to the task ahead, having to defend herself against deep feelings of anxiety, deprivation and self doubt:

a. She feels she has failed to sustain her baby within her
b. The emotional process of pregnancy has been sharply curtailed, leaving her with unfinished 'business'
c. She has abruptly lost the fantasy baby of her dreams and the robust inner baby, with whom she had a relationship, has abandoned her and has been replaced with a fragile stranger
d. As a woman, she has failed to give birth normally at full term
e. The birth may have involved emergency procedures quite unlike the ideal birth she had fondly envisaged
f. The baby she has produced is puny, jaundiced, or ill and possibly at risk
g. She may not feel maternal, cannot count on the baby living, fears she may have irreversibly damaged it physically or psychologically and does not know whether she even wishes it to survive if it is impaired.

31.1.3 The parents of an incubated baby

Bonding is further complicated when the baby and mother are separated. In some cases the ill newborn may be transferred to a high-risk perinatal centre at another hospital leaving the separated mother surrounded by new mothers and their infants, marooned empty-armed and bewildered in the maternity unit geared to breastfeeding and baby-routines. If

antenatal ward and Neonatal Intensive Care Unit (NICU) are geographically separated and she has had a caeserian section or is incapacitated, it may be some time before she sees her baby again. It is recommended that where the baby is transported to another centre, even an ill baby should briefly be brought to his/her parturient mother before departure and the father encouraged to act as a link between mother and baby, by staying with and caring for the baby, and then carrying information (and polaroid photographs) to the separated mother until she is able to visit. When she does get to the special care unit, the physical and psychological barrier of the incubator as well as the off-putting paraphernalia of intravenous tubings, humming ventilators and high-tech machinery attached to her baby increase her sense of alienation. The preterm baby who is meant to be inside her safe and warm, is outside, in there, seemingly being tortured, and she has allowed it to happen. Alarms go off, monitors bleep, nurses rush around in an atmosphere of tension, instigating life-saving procedures for babies at-risk while their parents stand helplessly by, with no space of their own, no expertise, no clear role to play and, at first, little understanding of the routines involved. Parents seem not to belong in the unit. The baby seems not to belong to the parents. In the early days, mothers and fathers, too, may feel afraid even to look at their painfully scrawny baby lying forlornly in the little plastic box so encumbered with electrodes, tubes and special equipment, let alone touch him or her. Their deep-seated guilt, horror and fear may drive them away or keep them rooted to the spot, paralysed by impotence and exhaustion.

Following the birth of a premature baby, many new mothers and fathers are in a shocked state of crisis and need help in adapting to life in limbo. Unless helped to establish a caring relationship with the baby some bewildered parents will detach themselves from the neonatal care unit upon maternal discharge from hospital, telephoning for information but feeling that all they can do is wait for news in their home with her empty belly and the empty crib, avoiding embarrassed friends and relatives. However, with encouragement from the staff, these parents too can allow themselves to become involved by emotionally 'rooting' for their baby's survival and actively engaging in care which it seems, can actually contribute to his/her growth. Studies have revealed that premature infants who are touched, rocked, fondled or cuddled daily during their stay in neonatal nursery display fewer breathing problems, increase their weight gain, have fewer stools and an advance in some higher central nervous system functioning which persists for months after discharge from hospital [1]. In addition to helping with practical care, parents are especially geared to provide personal warmth, intimacy, continuity, and loving stimulation for their NICU baby who is largely deprived of meaningful human experience. Giving parents opportunities

for early contact with the newborn and adequate support during this crucial period while the baby is in hospital can have a positive effect not only on attachment in the unit but on the baby's behaviour and mother-baby interaction after discharge [2,3]. However, to be competently involved in care, stunned people will have to undergo the emotional unfreezing that will enable their transformation into the intuitively responsive mother and father of a critically ill or at-risk premature baby.

31.1.4 Increasing parental involvement

The double shock of preterm parenthood and an ill baby leave new parents emotionally reeling. They may need preparation before entering the NICU for the first time and, once there, explanation about the various procedures and equipment. Opportunities must be given for parents to express their initial anxieties and to voice some of the irrational feelings of self-recrimination and trepidation about their newborn's frail condition. Studies have shown that parental caresses and gentle stroking relax the baby, assist motor organization and accelerate weight gain in low birthweight babies [4,5]. Many parents not only fear touching the infant, but fear being emotionally touched by him/her. If grief and uncertainty can be experienced and expressed rather than defensively denied and held at bay, tentative parents can begin to form loving bonds even with a baby who may not survive. Some neonatologists advocate increasing parental attachment by getting the mother (or father) to try and send tactile 'messages' to the baby and watch for feedback [6].

Defensive means of coping with the stress of relating to a severely ill preterm neonate may include blaming others, including staff and each other, to avoid excessive personal guilt or self-hatred. Rather than becoming defensive themselves or irritated, members of staff should recognize these signs of maladjustment to the crisis and offer sympathy and understanding. If the marital relationship appears deadlocked, parents may require tactful referral for professional assistance, now, while it is needed. Parent groups held in some neonatal intensive care units have been found to reduce tensions and increase parental competence [7,8]. Some parents may not seem too concerned by it all. However, over-optimistic evaluation of the baby's condition could imply denial of the facts rather than ignorance. Indeed, a fairly high level of anxiety and active requests for information have been found to predict a favourable outcome after discharge from hospital [9]. Obsessional attention to the machinery may conceal a desperate attempt to bind anxiety by equipment-control or to deflect it with busyness. Rage may displace sadness or martyrdom can conceal rage. Pre-existing marital discord exacerbated by tension may erupt in mutual accusations ('her placenta was not good enough'; 'he insisted on making love and that triggered

labour') or be displaced onto the staff or acted out in mishaps or somatic symptoms. The painful strain of coping with ongoing uncertainty and long stressful hours of inactive sitting by the incubator waiting for the baby to wake, both tax individual resources and expose hidden rifts and weaknesses in the relationship. However, meaningful joint efforts could bring them closer together. One study has found that more couples divorced among parents who were allowed little contact with their premature baby than among those allowed to handle and care for their infants during the first five days of life [10]. During the critical period of a premature baby's life, some parents may be deeply affected by losses of other babies in the unit while others split-off their feelings in seemingly callous detachment or evolve magical 'statistics' wishing to believe that the death of another baby lessens the chances of the demise of their own. Similarly, envious feelings directed towards other parents whose well babies leave the unit, may engender angry suspicions that the previously idealized staff are now practising favouritism or have silently 'given-up' on their baby.

In sum, mothers and fathers of a baby in an NICU are undergoing a frightening traumatic experience and need help to adjust to this prolonged state of crisis. A study of mother's emotional responses to preterm birth finds their major concerns centre on feelings of alienation and worries over the infant's survival and long-term care [11]. Evasive answers or uncoordinated communication cause further confusion and resentment at a time when the parents are already overloaded emotionally. Daily exchanges with members of staff encouraging parental observations and reporting medical information can help the parents to come to terms with the baby's condition and prognosis. Stress-support, guidance and encouragement from health professionals can help parents develop competent skills and greater satisfaction in caring for the high-risk infant after discharge [12]. Group discussions with other parents facilitate exchange of feelings and self-help resources enabling parents to feel less isolated and singled out with their painful problem. Brief individual therapy or couple counselling may release coping resources, enabling grieving parents to talk together and become more effective in supporting each other.

31.1.5 NICU staff

Professionals working with severely ill neonates are under a great deal of pressure which has been found to lead to a 'burnout' syndrome of low morale, stress-related illnesses and absenteeism. A psychotherapist working with NICU professionals in a London teaching hospital has enumerated various stressful factors which contribute to their difficulties and the mode of coping with these. Their jobs entail crucial responsibility

for the lives of very fragile babies; constant exposure to technological noise and tension; need to make quick, unsupported decisions during crises; disruptive shifts and rotations; staff shortages, low status and pay; frequent death and loss of babies; exposure to ambivalent parental feelings of anger, envy and rivalry over babycare coupled with hope and idealization, while simultaneously experiencing their own professional helplessness at being unable to save babies [13]. Furthermore, staff have to face daily moral and ethical dilemmas in deciding how best to proceed in prolonging life and when to let it ebb. They have to accept that many of their caring procedures are painful and intrusive to the tiny babies in their care; that even those who survive will ultimately be removed from their nurturing and that the endearing baby's primary attachment should be to the parents. In this highly demanding profession it has been noted that with these babies whose utero-gestation has been shortened and extero-gestation lengthened, nurses provide round the clock substitute mothering requiring constant 'over-cathexis' of their tiny charges whom they are doomed to lose [14]. Some health professionals defend themselves against recurrent experiences of attachment and loss by instituting shifts and routines that militate against forming special relationships and, like the parents, employ a range of defence mechanisms from detachment, denial and avoidance to displacement, projection, splitting and manic reparation. For some NICU workers, an omnipotent drive to save previously doomed lives and an over-idealized process of caring for damaged babies and restoring them to health may signify unconscious guilt and compensation for destructive impulses. It has been suggested that staff working under such cumulative emotionally stressful conditions need:

a. A time and place for quiet reflection within a setting 'where action sometimes takes the place of thoughts'
b. A regular non-hierarchical neutral forum for expressing their anxieties and frustrations
c. A place in which to explore their observations and encourage intuitive feelings [15].

31.1.6 The experience of a preterm baby in the NICU

The incubated neonate often bonds not with a person but with a machine. We can only imagine what it must be like to be prematurely plucked from a dark, warm watery medium governed by maternal biorhythms and familiar human sounds to a space-age bombardment of unceasing activity, intense illumination, and low frequency and impulse noise. All psychoanalytical theories of primitive emotional development stress the infant's need for a loving caregiver's external organization to filter

intolerable impingements, bind unintegrated experiences and help the newborn form a sense of physical and personal continuity [16]. However, for the incubated baby, human contact often involves sleep-disruptive, painful manipulations and up to 234 handling procedures and interventions in a 24-hour period by many different busy professionals [17]. Meaningful stimulation within the incubator is minimal and limited to rhythmic vibrations of monitor and ventilator and tactile contact with tubes interrupted by sudden overstimulation of too bright lights or the deafeningly loud noises of alarms sounding and objects carelessly plonked on the incubator top. It has been argued that premature infants suffer from a poor fit between their needs and the intensive care unit environment and, indeed, that some of the current special care baby unit routines may actually contribute to the imbalance of the small ill baby [18]. A review of studies into iatrogenic effects of NICU experience cites an increased occurrence of hypoxaemia, bradycardia, apnoea and behavioural distress following handling. The higher incidence of hearing loss in very low birth weight infants has been attributed to synergistic effects of noise exposure and retinopathy of prematurity has been associated with unfiltered light and sunlight [19]. The notion that newborns feel no pain is currently being questioned and revised as evidence accumulates about fetal learning capacity and neonatal heightened perceptual sensitivity and silent crying. The long-term emotional effects of prematurity and incubation are methodically very complex to tease out. Subjectively 'prems' may feel different. ('Because I was premature, I feel terribly responsible for what happened before I was even born – as if I have to compensate my parents for arriving early and make it better . . . Mum's stainless steel logic leaves me no purchase on my life – I've got nothing good to offer myself.')

31.1.7 Improved NICU care

Changes are invariably the result of questioning set practices. The query: 'Why do we do this in that way?' often leads to startling conclusions about the obsolete, and at times, damaging nature of standard procedures. Thus, we are reminded that until Barnett showed that bacterial hospital flora constituted a greater threat to the baby's health than that of the visiting mother, parents of premature infants were held at bay behind the glass walls of the corridors [20]. Until recently, inflexible regulations about visiting also isolated some mothers and fathers from their infants in intensive care, drastically increasing parental anxieties and curtailing bonding. Some changes in visiting procedure have been instigated as a result of studies demonstrating that the sooner parents see the baby the less time they have to imagine the worst and the more rapidly they can reconcile their fantasies with the baby's true physical

condition [21]. In addition to researchers proposing novel ideas based on their findings, nurses and other members of staff are in an ideal position to be innovative and have the wealth of experience to recognize potential advantages of change. Thus a nurse recently invented a mobile incubator housed in an ordinary baby-pram, giving the parents a greater sense of homely normality and saving both expense and effort. A trial of light and noise reduction between 7pm and 7am in one unit, established day and night rhythms in the babies and resulted in longer sleep, shorter feeds and greater weight gain after being discharged home [22a]. Coordination of procedures by different professionals has been found to reduce adverse handling and increase the duration of rest periods for the ill infant [22b]. In some units, premature babies have been provided with means to simulate intrauterine conditions and increase stimulation, such as sheep-skin rugs or hammocks slung inside the incubator. Waterbeds have been shown to provide beneficial vestibular stimulation. In West Germany, phototherapy, feeds and ministrations take place with the baby on the mother's abdomen [23]. In some NICUs parents are being encouraged to try 'kangaroo'-type skin-to-skin incubation of the baby between the mother's breasts or under the father's shirt, providing unlimited sucking, closeness, continuity and movement.

To promote mutual bonding, it has been suggested that ideally mother and premature baby need not be separated at all, but could have the baby's incubator hinged to the maternal bed, carrying resuscitation equipment as a precaution. Furthermore, radiant heat panels above the mothers bed, which allow early skin-to-skin contact and provision of privacy, have been found to promote maternal vocalization (which is minimal in intensive care nurseries) while nurse availability ensures infant safety. Extended family visits of grandparents and siblings are welcomed and 24 hour telephone communication maintained both before and after infant discharge [24]. In some units, there is a predischarge 'nesting period' in which mothers and sometimes fathers return to spend 2–3 days rooming-in with their babies in hospital, taking complete care of the infant before taking him/her home [25].

Tube-feeding the baby with breast milk and later actual breastfeeding has been found to enable mothers to overcome some feelings of failure related to prematurity; it also reinforces their sense of being special to the baby rather than feeling ineffective compared with the efficient life-saving nurses. When staff respect the parents' intuitive capacity to soothe the baby, guidance focuses on training them to observe the ill neonate for signs of stress, to do routine tasks and work as a team with the staff, nurses are thereby freed for more specialized activities. As the baby's condition improves, staff ingenuity can focus on ways to enable parents gradually to take over further aspects of care for their baby in preparation for home-coming and full-time professionally unassisted care of their

child. In conclusion, it has been proposed that because there is no universal recipe for optimal physical and psychological care of the sick and preterm baby, the principle of individualized developmental care should be implemented by observing each baby, designing an individual careplan and changing it as the baby grows [26].

KEY POINTS

*Preterm labour abruptly curtails pregnancy before completion of the emotional processes of gradual separation.
*The parturient experiences guilt about her failure to sustain her baby and to give birth normally at full term. Having abruptly lost her fantasy baby before she is ready to replace it with the real one, she may not feel maternal, and have difficulty bonding with a baby who may not survive.
*Parents of an incubated baby need help to adapt to their crisis and establish a caring relationship with the baby, through early contact and meaningful interaction.
*While professional handling of the neonate may cause distress, parents are especially geared to provide personal warmth, comfort and continuity for their NICU baby who is often deprived of stimulating human contact.
*The parental burden may be eased by: daily exchanges, stress support and guidance, group discussions with other parents and brief personal therapy or couple counselling where special help is required.
*Health professionals defend themselves against recurrent experiences of attachment and loss by instituting routines that militate against forming special relationships and, like the parents, may employ defence mechanisms ranging from detachment, denial and avoidance to displacement, projection, splitting and manic reparation.
*Staff working under such cumulative emotionally stressful conditions often benefit from a staff support group and a regular non-hierarchical neutral forum for expressing anxieties and frustrations.

31.2 PERINATAL DEATH

Although advances in obstetrical and neonatal care have increased the survival rate of ever smaller and younger babies, nevertheless, according to the Health Education Council, some 6000 babies die in the UK shortly after birth. A death in the birth chamber is an obscene contradiction, an oxymoron that we have difficulty grasping. An awaited birth becomes a death or a brief life is snuffed out with all its attendant hopes and promise.

31.2.1 The process of mourning

Health professionals are no strangers to death. However, only rarely do they follow the grief-stricken person through the whole ongoing process of mourning. When death of a loved one occurs, bereavement constitutes a painful process of gradual 'detachment' of the emotions invested in the lost person to free the mourner for new attachments [27]. This transition entails emotionally reliving memories and hopes related to the dead person and, by acknowledging that he/she is no longer alive in the external world, incorporating them in the internal world.

Research into the emotional processes of mourning have established that normal grief follows a well-defined pattern. An initial sense of unreality, disbelief and numbness gives way to intense grief, unwarranted guilt and self-blame followed by irritability and anger towards others or towards the deceased for dying. Withdrawal of interest from other relationships and development of symptoms of physical distress may follow, including symptoms imitating the terminal illness of the deceased such as breathing difficulties, palpitations or motility disturbances; and depression-related symptoms of insomnia, loss of appetite and sexual desires. The bereaved person is mentally preoccupied with idealizing the dead person, experiencing his/her presence and 'forgetting' or erasing the fact of his/her demise in dreams, fantasy and reality. Gradually these experiences give way to acceptance of the death, increased social interaction and ability to integrate the dead person into the experiential history of one's being [28].

32.2.2 Reactions to a still-birth

Clearly, the more affectionate memories of a separate person that have been created, the greater the sense of loss yet, equally, the deeper the residue of loving experiences to draw upon. However, when a baby dies before the mother has had an opportunity to establish the baby as separate from herself, the death may be experienced as loss of part of her own being, like an amputation or wasted potential in herself. This vague undefined sense of dispossession and emptiness makes grieving following still-birth difficult, and parents may need help to recapture a sense of what is being mourned. A well-meaning 'conspiracy of silence' which often accompanies still-birth increases the parents' sense of a 'non-event' [29]. Whereas the impulsive reaction of staff to a still-born baby is protectively to whisk the evidence away, seclude the parents and dampen mourning reactions, bereaved mothers and fathers have found it helpful to be given time and space in which to take in the reality of the death. Due to such feedback, the old custodial approach of defending parents from the pain of losing their newborns has given way

to current understanding that since attachment begins prenatally, grief following a still-birth is inevitable.

Lewis has coined the phrase 'bringing the baby back to death' to describe the assistance required to focus mourning and avoid the experience of 'a black hole in the mind' [30]. In the case of a still-birth, physicians and midwives can help parents to create memories where few exist by enabling them to see the body, or encouraging them to touch and hold the dead baby should they so wish. Given the chance to see their child, parents may need time to decide whether to do so, and whether they would want to hold and dress the dead baby, which makes the baby real as well as providing tangible proof confirming the death. Routine photography makes this decision less irreversible for parents who have chosen not to see the baby. The chance to view the body is particularly meaningful following a still-birth when the mother has been sedated, and has no evidence of the birth of her baby or its existence. Naming the baby also facilitates mourning as it provides the baby with a continuing reality, as do keepsakes of the dead baby, such as a lock of hair, record of fetal heart monitor or name bracelet. Although hospitals dispose of dead babies (sometimes in mass graves of up to 200 bodies), many parents find the process of grieving is helped by arranging their own funeral or cremation for the baby despite the lack of a death grant for still-births. The burial signifies the reality of the birth/death experience which may remain nebulous and rootless without a ceremony and a marked grave. The funeral ritual is a form of saying goodbye to the baby they brought into the world, acknowledging parenthood and responsibility that the baby is theirs rather than the hospital's, and that it is a baby rather than a 'failure'. Symbolically, interment is a means of returning him/her to a 'womb=tomb' (in 'mother earth'), a comforting idea for mothers who feel the baby was born too soon.

31.2.2 Parental grief following perinatal death

When the baby has lived even for a short while, mourning is facilitated by having had a fleeting experience of a breathing, live baby. However ill the newborn, parents need to see their baby before s/he dies. Disconnecting the dying incubated baby from tubes and electrodes to enable parents to cradle the infant and have him/her die in their arms is often a painful yet cherished experience for parents who have never held their own baby. Such contact can help them make links between the baby experienced prenatally and the dying baby and for a brief instant reconcile an image of what is with what might have been. The glimmer of hope for a future is lopped off with the death, as evident from a poignant case of a bereaved mother opening the dead baby's mouth to see where the teeth would have been and 'walking' him in her attempt to create

'memories' of the childhood that was not to be [31]. Recognition of their grief by members of staff, in the form of a hand clasp, kind word or even single flower given to commemorate the baby whose care they have shared, adds richly to the few treasured memories of this sad time. ('It's over two years since my baby died but I can't see a white flower without getting tearful. It reminds me of that long night when I held her poor little body for the first time without the tubes and rocked her as she was dying throughout those long hours. Then the nurse came in at dawn with a single white rose. I just burst into tears and released all the pent up feelings I'd been holding in all those terrible weeks of suspense.') For a first-time parent, such memories also preserve their identity as 'mother' and 'father' when this role has been stripped from them by the death as they go home empty handed.

It is helpful for parents, particularly when the baby has died of birth complications, to have ample opportunities to talk over the details of the traumatic birth and its effect on the baby. This can be painful for the birth attendants who may be plagued by their own feelings of guilt and doubts whether another procedure might have been life-saving. Klaus and Kennell have defined as the 'Lombardi syndrome' the defensiveness that arises in units where the intensive struggle for life makes contemplating loss unacceptable [32]. To complete the process of mourning, bereaved parents need to know the cause of death and to work through their irrational feelings of self-blame and be relieved of them. They need to recount regrets, hopes and fantasies. When birth coincides with death they need to disentangle these momentous events in order to sustain a belief in future live births. The mother needs validation of her own experience by seeing her grief reflected in others, in simple gestures of sympathy and acknowledgement that there has been a tragedy and that other people, staff included, care. A father, feeling he is expected to appear calm and strong, may suppress his grief response and fail to mourn. Staff mindfulness of his loss helps him grieve.

Research has distinguished between prominent maternal and paternal grief patterns 8 weeks after the infant's death: mothers tend to suffer from sleep disturbance, depression, anorexia, weight loss, nervousness and morbid preoccupation with the baby. Father's symptoms include inability to work, denial of the death and alcoholism. Reactions of guilt/anger/hostility and social withdrawal are common to both [32] although mothers have been found to express more guilt. The couple also need to recognize each other's differing experience of the death of their baby and to keep open the channels of communication between them. If there is a disparity in the phases of their grief, one may become impatient with the other's prolonged mourning, feeling over-burdened by demands or devoid of fun in the marriage. Mutual bereavement may split the couple apart or draw them closer together, depending on a variety of

current and historical factors, including communication difficulties. Siblings need help in coming to terms with the death and may be hampered in their own grief process by parental emotional unavailability, overanxiety or difficulties in dealing with the loss (see Chapter 26 on sibling loss).

31.2.4 The death of one twin

This is a particularly poignant loss in its juxtaposition of a happy event with a sad one, and survival of one baby who serves as a constant and growing reminder of the loss. Parents may unconsciously feel that the wrong twin has died or that this one has lived on at the expense of the other [33]. The process of mourning might delay bonding with the live baby and interfere with normal parenting activities, particularly when the mother is severely depressed. The surviving baby may limit her opportunities to meet with other bereaved parents, and relatives/friends tend to focus on her new baby rather than allowing her to talk about the one who is absent. The dead baby cannot be wiped out of the mother's mind by well-meaning people, and every time she answers the question: 'How many children do you have?' she is lying. She may feel disloyal towards the dead baby if she enjoys her live child yet is also full of remorse at neglecting him/her in her bereaved state. Clearly the sentient baby is in need of support in this very distressing and confusing juxtaposition of life and death in the mother which few people can handle on their own without therapy. In view of possible travelling restrictions with the baby and hospital associations with the traumatic event, therapy for the mother–baby pair might have to be conducted in the home.

31.2.5 Reactions of professionals

Hospital staff are often shocked themselves by still-birth or neonatal death and fear that talking to the bereaved parents will stir up their own emotional feelings of failure, frustration and helplessness. However, for the parents a natural part of the process of grieving is an attempt to seek explanations and make sense of the unthinkable. Accusations and blame are their defensive means of deflecting pain in the form of anger, a common phase in the mourning process. It is important for the woman's future obstetric history, as well as her current bereavement, that trust in medical personnel may be restored. Equally important is the staff's own need to understand what went wrong and to be exonerated when falsely accused. This exchange is often postponed on the grounds of delicacy and naturally must take parental feelings into consideration. However, all too often, reluctance of professionals to talk to them is misinterpreted by the parents as coldness or cowardice. A comprehensive review of the literature on perinatal loss concludes that 'bereaved parents are exceptionally vulnerable to insensitive care and callous or paternalistic staff attitudes may adversely affect the mourning process' [34].

Unresolved emotional reactions of doctors and midwives to a perinatal death or still-birth may lead them to avoid the mother during or after delivery, discharge her prematurely ('see you next year!') or to concentrate on providing physical care. Communication may be stilted by attempts to steer away from the topic which they feel would upset the bereaved mother. Thus, far from providing opportunities for the parents to express their tearful emotions, these are often curtailed by distracting avoidance or 'cheering' phrases such as: 'never mind, you'll have another baby soon' disclosing the speaker's own inability to cope with loss and lack of understanding of the process of grief. The woman does not want 'another' baby. She wants this one now. She does not see her loss as 'a blessing in disguise' which implies her baby would have been a damaged monster. She needs to express what she is feeling not to be told what she ought to feel [35].

Precisely because such tragic events are uncommon in obstetric practice (one still-birth occurs in every 80 deliveries), birth attendants require training in dealing with death. Learning how to break the news of an imminent still-birth and helping the parents through a birth that does not produce life; understanding their own resistance to the painful task of informing parents of a negative prognosis and supporting them through a perinatal death, must also be coupled with personal exploration of what death in the face of birth means to people who have chosen as their life-work a profession which helps life come into being.

31.2.6 Helping bereaved parents

In general, the pattern of grief in parents who have lost a newborn is similar to bereavement following loss of other family members, acute symptoms gradually abating within the first year after the baby's death. However, unresolved grief and disordered mourning following perinatal loss has been noted in many studies, although only four investigators have examined predictors of such disturbance. These predictors include intensity of initial grief, lack of or problematic social support, previous loss, significant life stresses and crisis during pregnancy and unsatisfactory marital relationship [36]. Unfortunately, psychological factors such as antecedent mental health, childhood relationship history and maternal personality characteristics were not examined in these research projects. Bowlby has proposed a threefold division of disordered mourning: chronic unresolved mourning; prolonged absence of grief and, euphoria (yielding within a few weeks to one of two former patterns) [37]. Such disturbances may not be consciously apprehended

by members of the family but are revealed in recurrent interviews with the professional. A minimum of three contacts are recommended, the first shortly following the event to convey information about the death, which, however, may not be taken in at this stage. Research has disclosed that class, gender and ethnic discriminations affect the amount of information given to parents with working-class women and Asian mothers given minimal explanations of the cause of death [38]. A further interview will be necessary within the first week or preferably during the next 2–3 days to repeat information, register birth or death, check up on milk-suppression, talk about mourning processes and enable parents to express their puzzled, sad and angry feelings. A third meeting later on, once they have surfaced, offers a further opportunity to answer questions about the birth and illness, to convey post-mortem results and provide contraceptive advice and genetic counselling about future pregnancies. This visit provides an opportunity for the doctor to find out how the whole family is coping after the baby's birth and death. Following still-births and very early deaths, this visit may coincide with the 6-week postnatal checkup point during which a 3-month follow-up can be arranged.

Discerning interviewers may uncover persistent symptoms of pathological mourning: overactivity, psychosomatic reactions, agitated depression or prolonged hostility, insomnia, anorexia or apathy. Maternal envy of pregnant women or fear of harming or stealing a baby she might encounter, may prevent a bereaved mother from leaving her home. While these fantasies are normal in the early period, their persistence, enactment or agoraphobic isolation must be regarded as pathological. In addition to possible bereavement therapy following still-birth or perinatal death parents may also need sexual counselling. Sometimes, a bereaved mother may try and fill the gap with a 'replacement baby' before the process of mourning is completed. Experts have advised against this [39] as the new baby bears the brunt of having to live up to an impossible romanticized ideal or be forever devalued and resented for not being the baby who died. Pleasure in sex following a still-birth may be inhibited by guilt and association with the tragic birth. Both sexual withdrawal for fear of another pregnancy and further loss and a compulsion to conceive in order to replace the dead baby prevent the couple drawing closer and sharing their grief during lovemaking. If a vicious circle of defensive activity to prevent mourning has been established, professional help may be needed to remove the causes of anxiety.

In all these meetings with professionals, not only are the psychological needs of the bereaved couple acknowledged but their social identity as parents is maintained in their contact with general practitioner, health visitor, obstetrician and NICU/maternity ward staff who remember their baby. The social conspiracy of silence and avoidance around still-birth

or death of a neonate, is thereby broken and a space provided for open remembrance. A medical sociologist has commented that the mother-to-be's antenatal 'social process of identity construction' is reversed following death of her baby, if hospital and society conspire to deny her loss, thereby instigating a process of 'de-construction' of her motherhood [40]. Anniversaries remain particularly painful for years, and some NICUs show solidarity with the parents by sending a card from the staff to commemorate the first anniversary of the baby's death [41].

Where emotional difficulties are observed, a psychiatrist, psychotherapist or family-therapist attached to the hospital can work therapeutically with individuals or the whole bereaved family to enable them to resume their course. In some units supportive bereavement-counselling groups or hospice programmes are provided. Where these are unavailable Relate, previously known as the Marriage Guidance Council, offers private confidential counselling and organizations such as the Twins and Multiple Births Association (TAMBA, Grimsby) have support groups for those who have lost one or both twins. Other parents may benefit from joining a self-help group of bereaved parents who have experienced a perinatal death, such as the Stillbirth and Neonatal Death Society (SAND, London, who produce a booklet entitled: 'Saying Goodbye to your Baby') or Parents Experiencing Neonatal Death (PEND in America). Parents may either attend group meetings, be 'befriended' by individual couples or offered telephone counselling to help them cope with the problem themselves.

KEY POINTS

*The process of mourning a still-birth or perinatal death is complicated by dearth of memories and an embarrassed 'conspiracy of silence'.
*Professionals can help the bereaved parents to create memories of their dead baby where none exist, enabling them to see and hold the baby, name and bury him/her and to keep their status of parenthood alive, when no-one else acknowledges it.
*The death of one twin is particularly poignant, and the surviving twin may be neglected or overprotected as a result.
*Professionals may need special training to deal with bereavement, as their help during the critical period can make the difference between healthy and disordered mourning.