CHAPTER THREE

The sick baby in hospital

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Many babies come to hospital sick, some are very sick and stay a long time. A very small number may be so sick that they may die. In such circumstances, infant mental health workers have the responsibility to work with babies, their parents, and their carers. Extremely vulnerable babies may be cared for in a number of settings in the paediatric hospital, including a general paediatric ward, the neonatal intensive care unit (NICU) or the paediatric intensive care unit (PICU).

For mental health workers, the basic hypothesis is that we should begin by acknowledging the mind, the self of the baby and working with that concept in our own mind. This helps the baby with severe illness, prematurity, or malformation to develop a stronger sense of self, of confidence in his own "damaged" body without needing to have recourse to excessive defensive withdrawal.

This raises two questions.

1. How do ordinary parents cope with this—is there such a thing as the extraordinary devoted parent? (Winnicott (1965) wrote about the

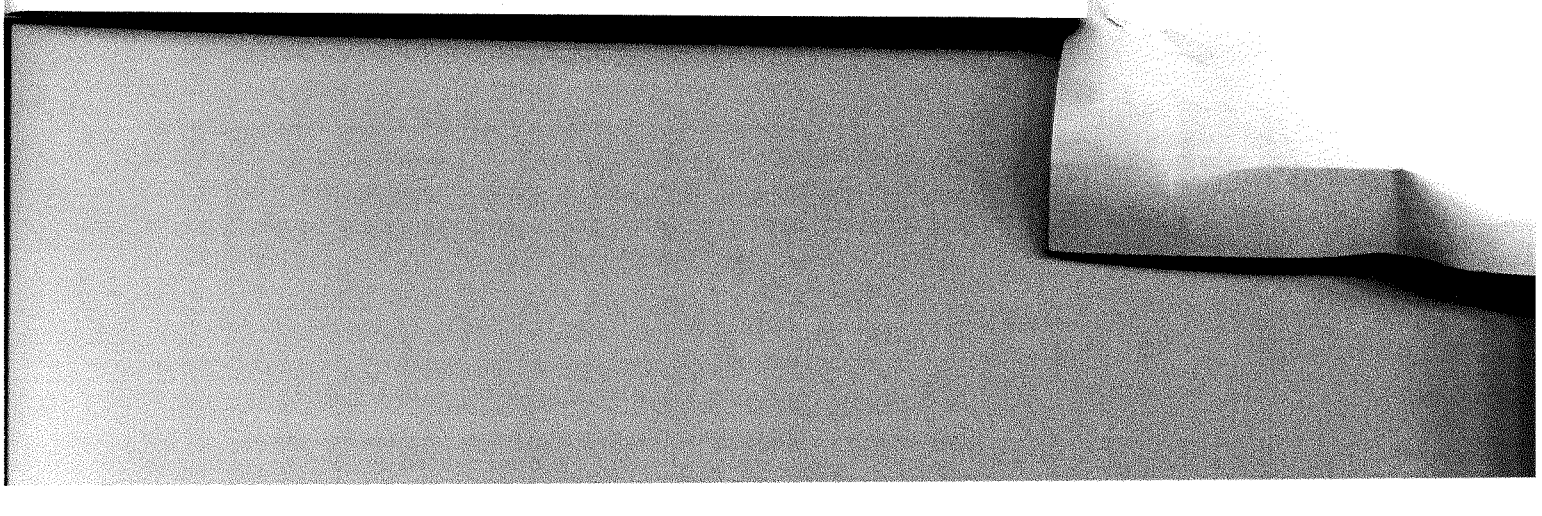
ordinary devoted mother who was "good enough"). What factors allow for the extraordinary devotion that is needed in extreme situations?
2. What are the roles of the infant mental health (IMH) worker?

I would like to discuss these issues with some clinical cases, in which I was able to engage the baby directly in front of parents in a way that allowed for understandable ambivalence and hate.

Frank

Three-month-old Frank's parents were from interstate. They came to Melbourne for his birth when antenatal ultrasound showed a severe hypoplastic left heart condition. The pregnancy had been closely monitored, for he was a very special baby born by IVF to parents desperate for a child after years of painful infertility. He was transferred to hospital for staged open heart surgery. At three weeks of age, he had been on an artificial heart and lung support system almost continuously, his lungs were poorly developed and were never likely to improve. His father, David, was referred to our mental health service because he was sure he was "cracking up—going psycho". He had periods of frozen immobility, could not get out of the parent accommodation bed, was crying and "sobbing like a child". He had pains in his body, and overwhelming feelings of dread. He said, "I'm not coping, I can't bear it. I have a terrifying feeling of dread and a crushing feeling in my chest. I can't use my right arm."

Frank seemed to love it when his father spent time with him, but David was feeling that he could no longer bear to be with him. Eventually he was able to say that he wished, "it would just be 'over'." It was like torture, not knowing—yet knowing—that his only child was likely to die. Would the machines need to be switched off and who would decide? How could he speak of such horrific things? I think that it was our role to enable him, and later his wife, to "talk" of such things. I met Frank over another five weeks and spent time with both parents and grandparents and the distressed staff. Eventually Frank succumbed to a cardio-respiratory event. David and Helen were distraught but returned home, knowing that they had really become parents—to a very brave infant.



The crisis of a premature or sick baby

It is a crisis for the baby—one of survival. While we think of premature babies as being born before thirty-seven weeks, extremely premature babies are born before twenty-eight weeks and some babies survive from twenty-two weeks gestation. Low birth weight is defined as under 2,500 grams, extremely low birth weight as less than 1,000 grams. In The Royal Children's Hospital NICU in 2003, premature infants with a birth weight of 500 to 750 grams had a forty to sixty per cent survival rate. Babies may be born prematurely with or without major complications.

Having a premature or sick baby is a crisis for the parents, with the potential loss of the hoped-for infant. There is a period of instability where there is a potential for change. The stress upon the parents is great, and the stress may see an increased rate of separation but it also allows for the possibility of emotional growth.

With which infants should we be working in NICU/PICU?

In the intensive care units there is a cast of thousands, and as an infant mental health worker we are but one of the many. We can ask, "Who is the patient?" and, "What is our role with the parents—and infants?" Our roles include direct work with the infant, work with the parents, work with the staff and with the systems in hospital. They also include engaging with the complex ethical issues, and in research and evaluation.

An infant with whom the IMH clinician works includes the symptomatic baby who is withdrawn, avoidant, severely regressed, crying,

Table 1. Infant referrals to Mental Health, The Royal Children's Hospital in a six month period in 2005

Reason for referral	*Number of infants*
Liver transplant	3
Congenital heart disease	2
Ventilator dependent	4
Multiple problems (e.g., tracheo-oesophageal fistula with complications)	5

Of these, four had been on the artificial heart lung machine, "Extracorporeal Membranous Oxygenation" (ECMO).
Others infants were discussed with the unit staff without formal referral.

dysregulated, and refusing to feed. How do we prioritise our work when there is a paucity of research about this? While it is very important to respond to each referral it depends on the urgency of the referral, the severity of the child's illness, and on the ongoing need to build relationships. We are not alone in the unit. The work of many other professionals overlaps with that of ours. We must work closely with other professionals involved such as the nurses, social workers, play specialists, speech pathologists, chaplains, and music therapists. It is important to develop close linkages in order to be clear about our respective roles and responsibilities.

Our ongoing role with sick children

Even when infants have managed the transition out of the neonatal intensive care unit to the general ward and then to home, there remains a significant role for us. This need not be continuous and intensive work but may be brief and serial interventions (see Stern (1995) on the importance of brief serial psychotherapeutic intervention).

Veronica

Five-month-old Veronica had a congenital laryngeal web in which the upper airway closes and there is vocal chord palsy. A tracheostomy was inserted. She had avoidant behaviour, feeding refusal, and management problems. Her mother said, "She will not eat! Does she sense my moods?" We needed to consider the impact of repeated trauma around the mouth/pharynx which led to an aversive response. The IMH worker's role was to do an assessment and then to work with Veronica to improve her sense of self through infant–parent therapy, and to desensitise her, her parents, and staff to feeding with the nasogastric tube. It was also to work with the parents and their anger, sadness and fear, and to work with the ward staff who had much ambivalence to the parents, resulting in conflict and confusion. They wondered why the parents kept bringing their daughter back to hospital with what seemed to be trivial events, such as colds and minor urinary tract infections. At eleven months old Veronica played at feeding a doll, which her father modelled. It was a complex scenario, given that her mother and grandmother had experienced eating disorders themselves. But her father helped in that he could identify with her and put himself in her shoes.

There are increasing numbers of babies in NICU/PICU with severe life threatening or disabling conditions. What are the influences upon the parents' extraordinary devotion to their baby? In this context, as IMH workers we see very few parents who abandon their infant or who cannot manage the task of care. Why? It may be some families do not have the capacity, and carefully considered decisions are made very early on to not undertake extensive or heroic treatments. The medical and nursing staff and parents reach a consensus that a life potentially so limited and disabled is not one with which medicine should intrusively and strenuously intervene. The IMH worker can sometimes play a role in ethical decision-making.

Parents' experience in NICU/PICU

Parents often feel traumatised at the outset and isolated; they may be fearful and often keep to themselves. They may fear finding out too much about the difficulties that the baby faces and fear being a burden to the parents or being burdened by their distress. They are often distanced from their baby and from most of their usual supports and networks. This may build on pre-birth family issues (Tracey, 2000). Mothers of high risk, very low birth weight premature babies report extreme stress two years later. Depression is a significant factor but parents may be too busy to consciously acknowledge it. (With babies born at less than thirty weeks gestation the prevalence of clinical depression in mothers is about thirty per cent and in fathers about ten per cent. Over time it gradually reduces). Anxiety symptoms (which may include anger, helplessness, hopelessness, terror, and guilt) are also significant, as are traumatic and post-traumatic stress disorders, with hypervigilance, re-experiencing symptoms and avoidance of affect and, in particular, avoidance of NICU and the hospital.

What parents provide their baby may be compromised. We need to consider whether we can enable them "to be with" their baby, practically and psychologically. The nursing staff must provide some of this emotional care (holding) for the baby in the interim if the parents cannot, but it is hard for the nurses too.

The basis for self in the body

The care given by parents provides a basis for the development of a working relationship between "psyche" and "soma" for the baby. The

parents can help their baby develop a sense of self in the face of serious illness. So if the baby has a disability or deformity, the ordinary (or perhaps here necessarily extraordinary) devoted parents handle the baby and her body in such a way that, as Winnicott said, there is a "satisfactory working relationship" between the psyche and soma.

What does the baby experience? Ordinary physical care leads the baby to an understanding of her damaged body such that the baby tends to assume that what is there is normal—"normal is what is there". It is only much later that the baby becomes aware she is different to other children. Distortions of the ego may come from distortions of the attitude of those who care for the child.

A mother with a baby is constantly introducing and re-introducing the baby's body and psyche to each other. This task can become difficult when the baby has an abnormality that makes the mother feel ashamed, guilty, frightened, excited, or hopeless. Under such circumstances, as Winnicott said, she can only do her best. It is our job to help "hold" the mother and father when they do feel ashamed, guilty, angry, resentful, faithless, and rejecting—for them to know such feelings can be experienced and shared without the annihilation of their child. This can be a very big problem in places such as NICU/PICU.

"Personalisation"

What do parents do to help their baby? Winnicott wrote about the ordinary devoted parent and their role in personalisation of their baby. The way the parent holds and handles her baby—the actual physical care driven by a belief-investment in the baby—allows the baby in Winnicott's apt term to "inhabit" her body. The way the parent holds, touches, bathes, picks up, talks to, and looks at his baby allows for the person to emerge connected with limbs, skin, chest, hair, lips, bottom etc.!

Winnicott gives a great account of how a mother picks up her baby—not like a sack of potatoes, but gently as part of a subtle dance, giving warning, a preparation that a gentle enfolding would occur. This leads to the acquisition of a personal body schema, the "psyche indwelling in the soma". In their handling, the parents manage the infant as if the baby's mind and body form one unit. Their holding provides the basis for what gradually becomes a self-experiencing being. Physical holding of the infant is a form of loving. (Physical and psychological are still one.) The good-enough parents allow and facilitate the process

of the baby inhabiting his own body. But they allow for the baby to depersonalise, to abandon the urge to exist for a moment. They facilitate a sense of security allowing for regression and dependence, especially for the sick infant.

Bonnie

Bonnie was referred to infant mental health service at eight months of age. She was in intensive care with a drug reaction which was the probable cause of fulminant liver failure. She looked very ill with severe respiratory complications and it was thought that she was so ill that a transplant might not be possible. A decision might be needed about treatment. But Bonnie seemed "positive and lively", despite being extremely ill. Looking back over her eight months of being extremely sick and in hospital, I had to ask when she was about to go home: "How has she survived?" It must be that Bonnie is a real "fighter".

Bonnie had been conceived somewhat unexpectedly, to a very young couple who had been together only four years, and already had one child, aged three years. He was as excited as his parents with the news of Bonnie's conception, and about her birth, at which he was present. He doted on her and followed every tiny movement of her tiny fingers and toes, eyes and mouth. However at about four weeks of age, a concerned maternal and child health nurse insisted on a rapid return visit when Bonnie's weight fell a little. Both parents became anxious when the nurse sent Bonnie to a paediatrician. Bonnie had become jaundiced. After an examination it was clear that she was sick. Her jaundice and poor growth were due to a very severe rare liver disorder. Subsequently she spent seven of her next eleven months in hospital—there was an attempt at a number of heroic medical treatments which saw only a little relief of her jaundice.

She was considered for liver transplant—for her it became the only way to be able to survive, but the difficulty was that she had to become bigger to be able to withstand the trauma of the operation and accept a piece of donated liver. There was to some degree a race against time—she had to grow quickly—and be lucky enough for a matching donor liver to be found.

What did we find on meeting them? Both parents were present, Bonnie lying on a pillow across her father's lap, he gently holding her fingers and occasionally stroking her head. She was small—the

size of a five-week-old baby and skin of a deep yellow hue, some jet black hair and deep open eyes. What was striking was her gaze. She looked, turned her head, and gazed straight into my eyes as I entered her room—she sought me out, fixed me with a powerful stare—it seemed neither fearful nor angry. It was as if she were saying to me, "Who are you? I am interested—and curious, but not too trusting. I am safe here on my father's lap, my mother also beside me." Can a pair of eyes say so much? She was after all only eight months old. I think so, and I think that the work of her extraordinary devoted parents played a critical role in her capacity to communicate. She could communicate fear as well—she withdrew her feet especially if anyone went to touch her.

Since her first admission to hospital one of her parents had been with her at all times, except for brief visits downstairs for lunch. They slept in the same bed. She had been physically close to at least one of them most of the time. "We could not imagine leaving her here alone", they said, although they did speak positively of the nursing staff, showing some trust in their care. Importantly they observed how well the nurses could play with Bonnie—despite her being so sick and incapacitated. It seemed to me her parents saw—and perhaps cultivated the nursing staff's acknowledgement of Bonnie's personhood while they did intrusive procedures to her: her parents (and Bonnie herself) convinced the staff that "someone was home"—Bonnie was there—alive—lively and responsive.

It is as if they all had accepted the fact of some intersubjectivity—that there was, from the beginning, communication (Trevarthen, 1974). This demonstrated intersubjective process seemed to be primarily a function of Bonnie's devoted parents responding to her reaching out for connection from birth. All that they did with her was responsive to and contingent upon her own behaviour. Some may have seen them as indulgent, but in the circumstances I think not.

Bonnie received a transplant at sixteen months but her problems continued. Just prior to her going home she had a serious drug reaction which reduced her capacity to respond to any sort of infection, but Bonnie continued to develop—in communication, differentiation, and demands. She has survived and thrived after leaving hospital ... but this seemed a consequence of her parents superhuman devotion as much as her medical and nursing care.

The mirror role of the mother

What does the baby see when he looks at his mother's face? The expression on the mother's face reflects what she sees in her baby. But when the mother is depressed, her face is a mirror to be looked at, not into (Winnicott, 1971, p. 112). Father and siblings too. This role of an alive mirror is very important—but it can be perturbed by the parents' feelings. In Bonnie's case the mirror role was the father's. He gave up his business to be the primary carer in the hospital, which was shared with his wife. If the parents are very cut off, this can be very problematic. We also have to help parents (and the staff) grapple with the sometimes disabling state of ambivalence (as with Frank's father).

Ambivalence

If ambivalence is "deep", does it abuse? The mother of eighteen-month-old Jessie said, "You doctors don't know anything—who do you think you are! Just doing this to a person—you've got no idea what it is like and what we have to go through—what sort of life is it for a child like ours and for us? Maybe you should ask us before you save lives—it may be better not to, you know!" Exhausted parents can wish for a peaceful end to their child's struggle and yet at the same time desperately hope for a miracle, a reprieve.

A paradox is that while the parents may be better able to see the baby's mind than us, but Jessie's mother, having voiced her anger, her fear, her resentment that her life already difficult, was turned totally on its head, it may be that she can then more readily see her baby as an autonomous person. This would be good for Jessie, although I expect it does not easily allow for regression. We may need to provide very active containment.

The infant's responses

The withdrawn baby may not be suffering a disorder in itself. How does the baby cope? What determines whether the baby's "shut down" is adaptive or pathological? It depends on the baby's inner resources including "temperament", the intrauterine experience, the parents' role and commitment (having two parents to share the dilemma means that one can be up, while the other is down).

Dissociation can be a useful defence. We need to consider the concepts of shutdown versus survival, whether the infant and family are experiencing post-traumatic stress disorder or an acute stress response, and to consider their resilience. All this is underpinned by neurochemical changes, including the pain experienced by the baby.

Is it unkind to overcome defences that may see the self of the very sick or terminally ill baby denied? Would it not be better to allow parents (and staff) to retain a clinical distance from their baby whose chance of survival is so remote, to allow him to die with minimal perturbation to his parents and carers?

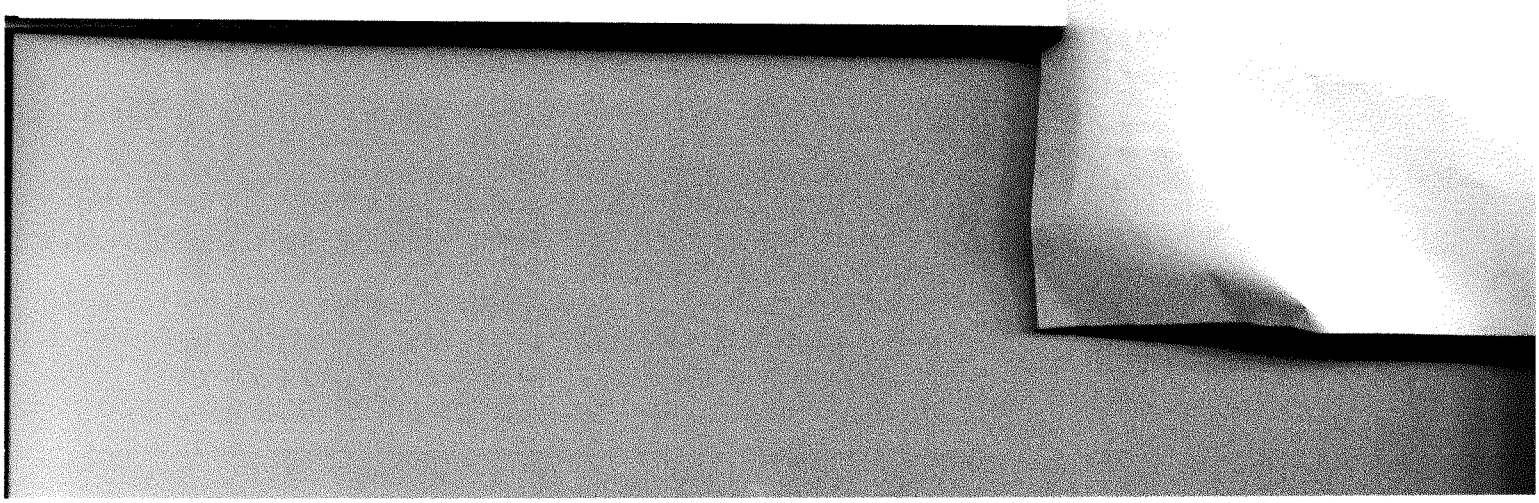
What can the IMH worker do with a baby?

The possibilities include infant–parent therapies, direct work with the baby in the presence of the parents and nurses, and work with siblings. Infants and their families may need brief serial therapies as a response in critical times (Stern, 1995). It can help that the IMH workers are not part of the core medical team; they can receive negative feelings.

The IMH worker facilitates the relationship between parent and baby and helps parents overcome some of the fear or resistance to seeing the baby there. Premature babies respond differently: it is harder to read subtle signals. There is a role for the baby as patient, who can also be a co-therapist for their mother and father.

Working with parents

In NICU/PICU parents often say how hard it is to talk to anyone (even their partner). How could they conceivably talk about their own doubt? "Why are you going on treating my baby?—such painful risky procedures! Cutting down into flesh to insert catheters!—restraining them in their humidicribs—painfully pricking their tiny heels to squeeze out tiny drops of blood." What can they say when they feel, "Enough! Why can't you stop it?" Or even, "Why can't you let my baby die?!" They fear that these words cannot be spoken to the nurses and doctors, lest they be taken at face value, consciously or unconsciously. It would be horrific if the staff acted as the parents' fought against fantasies. Just because their own courage seemed to be failing they did not really want their baby's death—but they do. So often, parents have to keep these poisonous secrets within themselves.



While every baby has a different story there is much in common, such as feeling a lack of support. It is part of the IMH worker's task to help at the appropriate time open up the feelings and phantasies especially in the confidential manner of one who is part of the baby's system of care but at the same time distant and apparently removed from decision-making processes. If ambivalence or hate can be spoken about, it loses some of its poison, especially towards the baby himself.

The effects of maternal depression

The effects of maternal depression may lead to problems in the parent–infant relationship, which may lead to later problems in infant development. Premature babies are more protected and can be close to their mother. But parents may be less "physical" with their infants who have to initiate more themselves. The mother's depression may constitute an ongoing trauma, affecting the sense of self for the child. Postnatal depression may also be thought of as a relationship disorder. Tracey (1991) showed that the depth of the trauma is often unresolvable.

Music therapy programme

One way of responding to distress in baby and parents is to facilitate music therapy. The music therapy programme (Chapter Five) is a music therapy intervention in NICU with babies with severe problems. The intervention is determined by the baby's state and response, a contingent intervention designed to facilitate her ability to calm and self regulate. A post discharge follow up found a positive sleeper effect for the baby so that there is a need to identify those who are most vulnerable (See also Malloch, 1999; Shoemark, 2004).

Other possible mental health roles in NICU/PICU

Minde (2000) has written about influencing the hospital ecology. IMH workers help parents and staff to clarify roles, explain behaviours of staff and parents to each other, help parents understand their feelings and regain control, and teach principles of child development.

The IMH worker needs patience in NICU/PICU, to "be there" to become known and credible. Credibility from service delivery is very important. The IMH worker needs to be there to respond to referrals,

attend ward rounds, and psychosocial meetings (along with art, educational and play therapists, chaplains), the nurses' group meetings and the nurse-run coffee morning meeting (PICU) and to consult with care managers and social workers regularly without the need for a referral. The IMH role with staff includes support, debriefing and collaborating in decision-making. Are there ethical questions in particular that they can be involved with?

Work with staff around "ECMO"

The staff who provide for children the lifesaving intensive heart lung machine, ECMO (Extracorporeal Continuous Membranous Oxygenation), are a close knit team. The individual team members can experience severe stress, when such a grave demand falls on the shoulders of a small team of specialists. The actions they take are under very close moment to moment scrutiny: it is a very delicate and demanding task to perform for the baby, the essential functions of human life. There are concerns over ethical and clinical decision-making. Powerful emotional attachments are formed with the infant and her family. Although up to seventy per cent of babies survive, when a baby dies the staff may also experience traumatic symptoms.

What are some of the problems of working with babies?

These include competing demands placed on the staff as people and on the skills of the staff. They need to have a special approach because the baby cannot talk and they have to avoid reducing the baby simply to a technical problem to be solved. It can be hard to identify with the baby.

There are countertransference issues for the nurses and IMH workers. We need to be careful not to demonise parents or vice versa—to ignore the baby herself, saying that it is too hard to enter her world. (See Paul, in Tracey, 2000, where there is a fuller discussion of issues of stress and countertransference.) Nurses talking about one infant who had been in the unit a long time, having been very sick and through many crises, vividly described the real person that they had come to know. "We were really upset; we could see how she pulled out her central venous line. She tears at her own skin as if she is distressed and wants to get it out." Their identification with her and her experience is deep and profound, and they were themselves traumatised by

her distress. A doctor described another infant, seeing him as having become sad and distressed. "You look into his eyes and he looks straight back at you. The look he gives is like he has just given up." It can be an intensely difficult task to allow an infant to die with dignity, as it is exciting and exhilarating to see those survivors go into the world; it is equally important to help those parents whose children do not go home to get to know their child as well as they can while they can.

Research

We need to show how our intervention works, and over what period of time. But any successful interventions are subject to the claim that this would have happened anyway. Large-scale clinical research is difficult, with the lack of specificity of a diagnosis and the rapidity of developmental change. Also while most studies look at acute loss of a baby, the impact of the death of a baby has been less studied.

Are premature babies prone to depression? Currently researchers are studying a matched small cohort of sick babies, carrying out an assessment of withdrawal and depression. But depression/withdrawal in such babies is hard to compare because of the diverse range of problems and severity experienced by them. Does the baby's depression persist or create ongoing difficulties? It may do so, although most premature babies can certainly do well developmentally. It depends on the degree of prematurity and whether there were major complications.

Conclusion

It seems that from the clinical experience which we have accrued working alongside very sick babies, their parents and our colleagues, there is an important role for keeping the mind of the baby as an important component of the narrative which unfolds. Although parents are severely stressed we believe that it is helpful for them to be able to relate to their baby as a person to whom they will have a lot to give. Developing this relationship, no matter how brief it might be, is critical for each baby and her devoted parents.

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