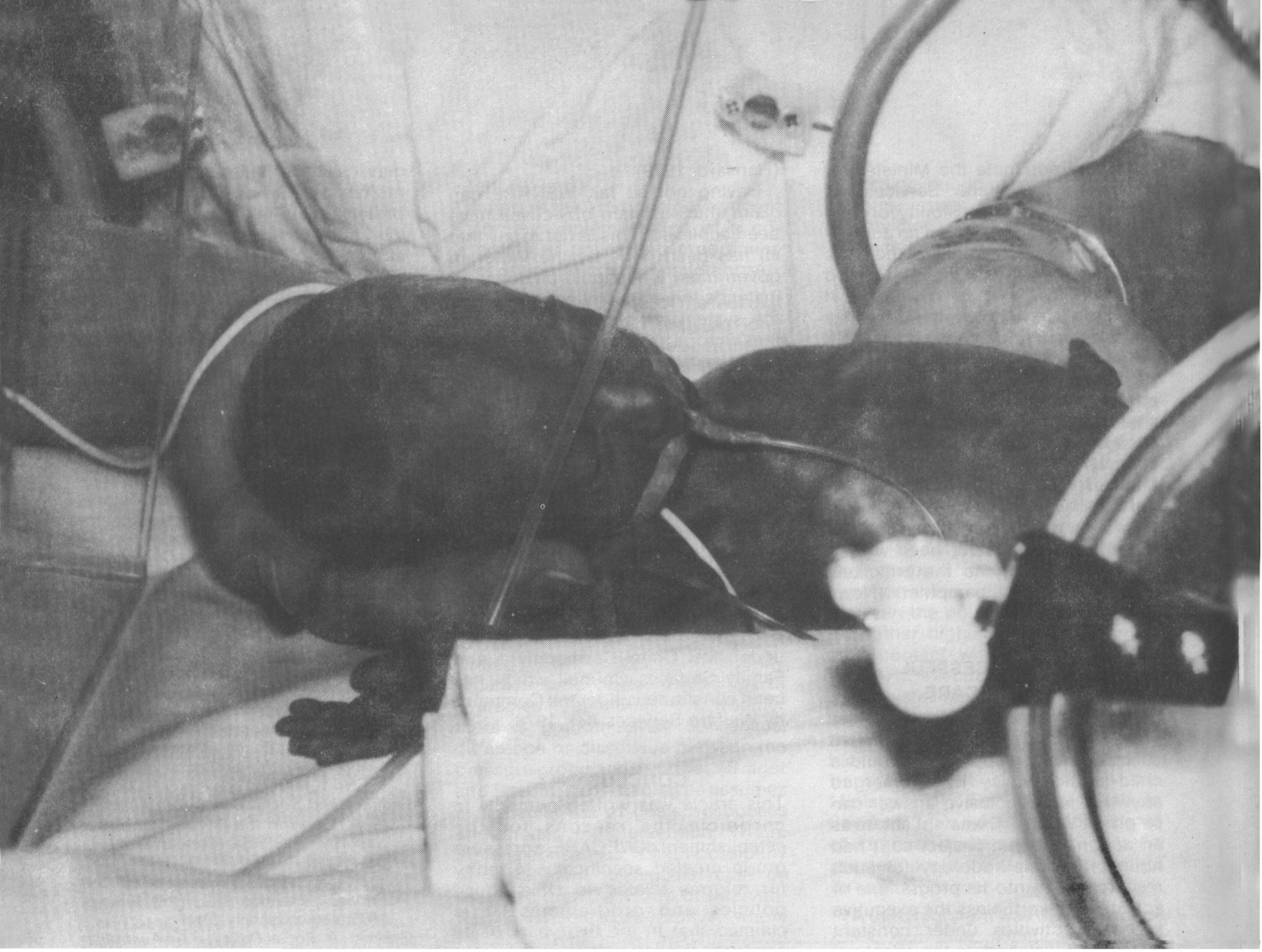


"Our Preterm Baby" photo taken by the child's father.

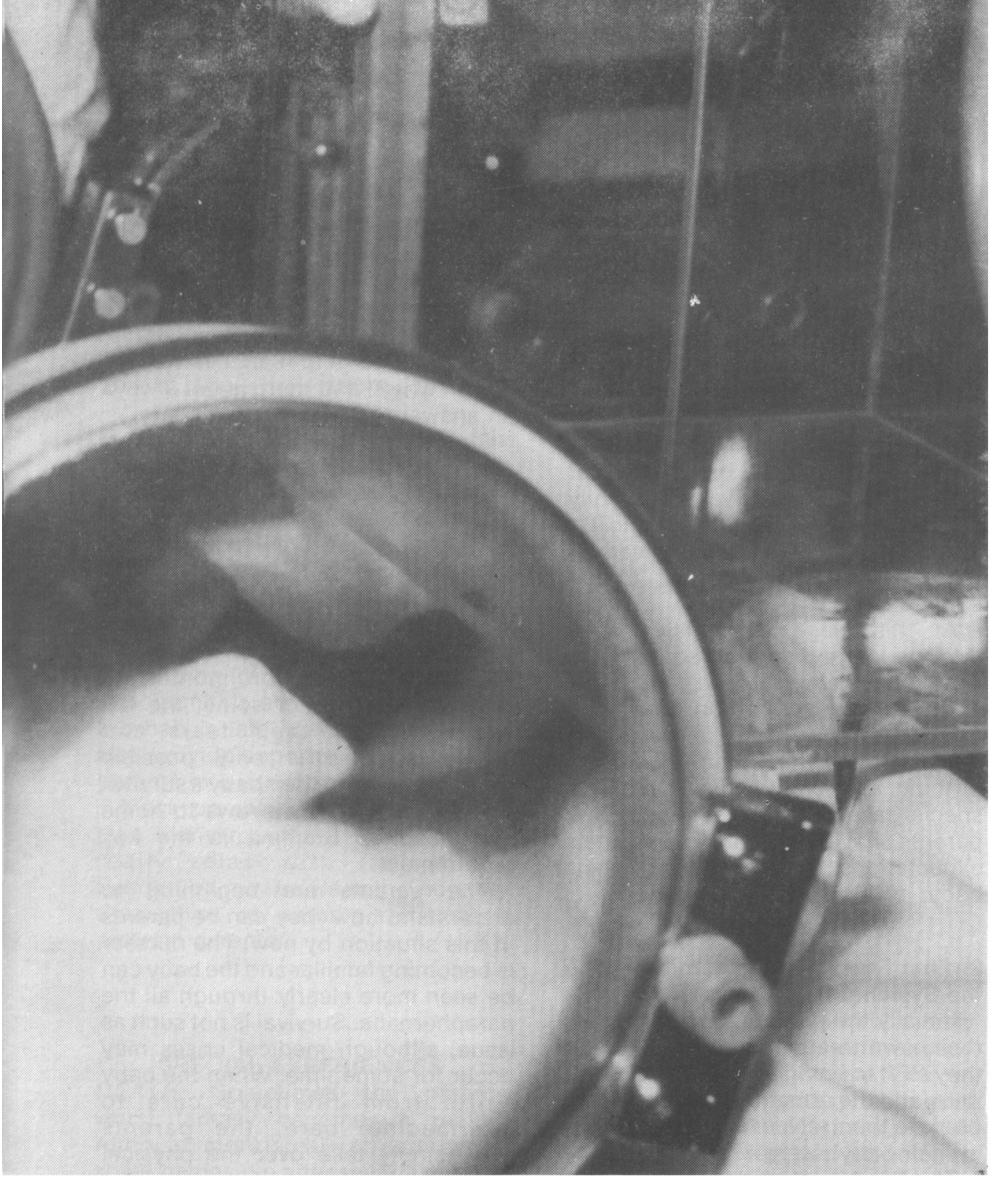
PRE TERM FAMILIES — visitors or colleagues

LIBBY LLOYD

Libby Lloyd was until recently Deputy Chief Social Worker at King Edward Memorial Hospital for Women, Perth, where she established a fulltime Social Work Service in the Department of Newborn Services.

Preterm birth is a crisis for both baby and family. The long term outcome for both will be greatly influenced by the families' ability to move from the grief and impotence associated with the loss of expected full-term parenthood through to active involvement as a preterm parent and eventual acceptance of parenthood.

The families' experience of the crisis is described for both normal and special situations. The implications for staff and family of more active participation of the family are discussed and some methods of involving the family are described.



PRETERM FAMILIES — VISITORS OR COLLEAGUES?

Preterm babies were exhibited in "child hatcheries" at fairs in America and Europe during the 1920's. Pioneer American neonatologist, Martin Cooney, then set up a permanent exhibit at New York's Coney Island, where he "raised" 5,000 babies over nearly four decades. He thoughfully gave each mother a free pass to the exhibit so that she could visit her baby! Unfortunately he was also involved in child placement, since many mothers refused to take home their baby after the few months in the "hatchery". (Klaus and Kennell, 1976).

Special Care Nurseries today are rather more conscious of the social and emotional consequences of their highly skilled work. Staff are aware that the quality of the home environment is crucial in determining the outcome for the infant after discharge. Follow up services increasingly take account of the family's reaction to the infant's birth and development.

These nurseries are situated in maternity, childrens and general hospitals and take care of the more than 5% of babies who have been born with a low birth weight i.e. less than 2500 grams. Some of these babies are born up to 16 weeks early and weigh less than 1000 grams. It is necessary for them to remain in their technological womb for several weeks or months, depending on their weight and medical condition! Most are discharged home at 2500 grams and long term physical and intellectual problems affect remarkably few of the survivors. A great deal more needs to be known about the babies psychosocial development.

The preterm birth is a crisis for the family as well as the baby; the family too have been "born" before their time and will need extra supports before they can continue "normally". Pregnancy involves the gradual development of a new or expanded family as well as the growth of a baby (Notman & Nadelson, 1978). How effectively the family copes with the crisis will be a major factor in the outcome for the baby as well as the total family. Such a crisis can integrate or disintegrate a family.

A SHIFT IN FOCUS

Until the mid 1970's the focus of the literature in this field tended to be almost exclusively on the physical needs of the baby. Since then there has been increasing attention on the social and emotional needs of both the baby and the family. This has raised issues to do with the system of care for these tiny babies. Are they to be visitors, grateful for the medical miracle and passively waiting to take their baby home? Are they to be colleagues, respected team members with a unique and important contribution from the beginning?

The reasons for this shift in emphasis are multiple. Key factors are:

a) Historical — neonatalogy has mastered enough of the technical problems of physical survival to be able to concern itself also with psychosocial survival.
b) Political — consumerism as a social movement has led patients and their families into taking more responsibility for their health services.
c) Technical — a more holistic approach to evaluating treatment outcomes has revealed significantly high rates of parenting problems such as child abuse and nonorganic failure to thrive amongst low birth weight babies. (Elmer & Gregg, 1967, Klein & Stern 1971, Smith & Hanson, 1974).

Before exploring the implications of this shift in the role of the preterm family in their baby's care, it seems important to understand the nature of the family's experience of the crisis. It will be argued that the family will cope most effectively with the crisis if they are offered a potent role during their baby's hospitalization.

THE PRETERM FAMILIES EXPERIENCE

The birth of a baby is a crisis for which we have some preparation in our culture. Even the anxious and

inexperienced new parent has some expectations of cuddling the new baby, feeding and changing, introductions to family and friends and going home (or staying home) with the new baby.

When a preterm baby is born that gradual preparation for the new family member is suddenly accelerated and they are expected to cope with a totally new situation. All the common experiencces and ways of relating don't seem to apply and the family is confused and anxious. The crisis surrounds both grieving the loss of full term parenthood and also learning the new role of preterm parenthood.

The issues at each stage of adjustment to the crisis seem to be common for all preterm families. Each family's experience of the issues will of course be different depending on the meaning of the events to them, their internal and external supports and the coping mechanisms they choose. (Aguilera & Messick 1974).

1. Pregnancy & Birth — Loss and Potential Loss

Even with preparations there can be a sense of unreality about a preterm birth, especially if it is by caesarian section. When beginning Stage 2 of her labour, one mother protested, "but I'm supposed to be at work this morning!". A feeling of incomplete or interrupted preparation was behind another women's complaint that "I didn't even get to wear my maternity clothes". More significantly there can be a deep sense of loss and failure.

Difficult obstetric histories are common and contribute to real or imagined fears. Long antenatal inpatient admissions or dramatic last minute transfers to specialist hospitals can mean separation from familiar supports and therefore increased dependency. Sometimes mother and baby are even in separate hospitals or towns.

The key issue for all families at this stage is "will our baby survive?". With uncertain prognosis, a strange environment, and information coming from a variety of sources it is a time of intense anxiety as the family struggles to comprehend this situation. Men are often torn between husband and father role, and their own reactions and needs can be pushed aside. Prior knowledge or experience of a successful preterm birth makes the situation much less frightening.

Some families seek to protect themselves from the potential loss by moving into anticipatory grief. "I won't get too attached, in case the baby doesn't survive". This is a key situation for staff intervention to help the family move through this withdrawal phase into a more active involvement with the baby. Whether or not the baby survives, the family already has some attachment and it is important that this is recognised by them if they are to adjust to the situation.

At this stage all families need information and support so that they can begin to accept the reality of their baby's birth and condition. They need opportunities to express their reactions to the nature of their birthing and baby. This is really a special case of the adjustment all new parents have to make from their expectations to the reality of their baby.

2. First Few Days — Learning the System

Initially the parents are focused on their own reactions, but gradually they shift to being able to relate to the baby and the nursery. In this way they prepare themselves for an active role in their baby's care.

This is a vital period for all new parents as the bonding process is most intense at this time. For the parents of a preterm baby there seem to be many physical and psychological obstacles to this process. It demands special parenting skills. Many do not feel the baby is "theirs" until they take it home. Simply visiting their baby in the nursery can be difficult when recovering physically from the birth. The woman in the next bed with her baby may intensify the sense of loss. Making contact is more complex when in a separate hospital; phone calls and photos are small compensation. Touching the baby, breast feeding and showing the baby to friends and relatives all have to be done in a different way. Cuddles may not be possible for days or even weeks.

The sights, sounds, smells and language of the nursery are bewildering. The baby can look unattractive and is covered in monitors and tubes and is initially unresponsive. Staff seem to offer so much more to the baby and many parents feel impotent at this stage. Friends and relatives can help or hinder by their reactions and all have their own coping methods to share with the parents. Joy and wonder mix with grief and guilt. Families want to know "why?" and there is not always an answer.

Parents at this stage need support and information to gradually move into an active role in the nursery system.

3. Visiting the Baby — Being a Preterm Parent

Having left hospital sadly empty handed, the family then faces the routine of weeks or months of hospital visiting. For some, the full expression of their fears and disappointments is only possible when the crisis of their baby's survival is over. The world narrows to home and hospital. Stamina is the key requirement.

The parents are beginning to understand how they can be parents in this situation by now. The nursery is becoming familiar and the baby can be seen more clearly through all the paraphernalia. Survival is not such as issue, although medical crises may occur for some time. When the baby shifts from intensive care to intermediate care, the parents increasingly take over the physical care of the baby, especially the feeding and bathing.

Most parents can visit daily, sometimes travelling long distances and juggling the conflicting demands of other children, home, job and baby. Expressing milk for weeks is a tiring but a rewarding contribution and a great disappointment for some who cannot sustain a supply. The baby's siblings need special attention at this time if they are to cope with tired and often absent parents. Marriages are affected by the strain and the varying way each partner copes with the situation.

When visiting becomes a routine, the slow build up of stress can be overlooked. Parents can present a smiling face in the nursery and go home to sleeplessness, tension and loneliness. One mother whose baby had become ventilator dependent felt that she was competing with machines as to who was the best parent. Some feel the baby belongs to the hospital.

Rural mothers are often faced with agonising choices of staying with the

baby or their other children and husband at home. They may be strangers in the city and travel is expensive.

Families need emotional and practical support and opportunities to learn how to care for their baby and how to juggle their priorities.

4. Baby goes Home — Being a Parent

Eventually the time for full responsibility comes and with a mixture of excitment and anxiety the family welcomes the baby into their home. Mothers value an opportunity to live in with the baby for a few days as a transition to full responsibility. The baby will still be small and demanding frequent feeds. Follow up appointments are offered to monitor the baby's later development. They also provide opportunities to support parents in a variety of ways.

Most parents of preterm babies take many months before they can really relax with their baby. Resolution may be when they identify themselves as parents rather than preterm parents.

SPECIAL EXPERIENCES

DEATH: Sometimes the parents worst fantasy becomes a reality. Although more usually an early event, some babies die after several months of hospitalization. Grieving the loss of a preterm baby is made more complex because the identity of the baby and parents is so intermingled. Parents need opportunities to be parents to their dying baby in what ever way is meaningful for them.

HANDICAP: A few babies have long term physical and/or intellectual handicaps associated with their preterm birth. This may not be able to be diagnosed for some time after discharge when later development is assessed. This situation will face the family with another crisis and unresolved issues from the birth and hospitalization will emerge.

OVERPROTECTION: Occasionally a parent becomes overprotective as a result of guilt or unresolved fears of loss during the birth and hospitalization. The baby continues to be seen as preterm and needing special attention long after this is required. Other family dynamics will probably be relevant too.

CHILD ABUSE: Various studies indicate 15-40% of child abuse and non-organic failure to thrive are low birthweight babies. This is significantly high in a group that are 5-8% of births (Nichol, 1979). The reasons for this high incidence appear to be multiple and are still being researched. Two main sets of factors are relevant:

1. Common socioeconomic factors in the population at risk for preterm birth and parenting problems, e.g. young teenagers have twice the risk of preterm birth and aboriginal mothers have three times the risk (Reid and Stanley 1977). Factors linked with child abuse — social isolation, family history of abuse and neglect, serious marital problems, inadequate child care arrangements, apathetic and dependent personality styles and inadequate child spacing (Hunter, et al 1978) may also relate to poor antenatal care and very young or grand multipara motherhood which are linked with preterm risk (Reid and Stanley 1977).

2. Consequences of preterm birth can be inadequate bonding and parenting skills. A preterm birth may tip the balance of an already vulnerable situation. Separations, an initially unrewarding baby, feelings of impotence and family stress may all contribute to a depleted parent who finds a demanding small baby more than they can manage. In addition, the negative reactions towards the baby are extremely difficult to express openly during hospitalization and may not emerge until later.

As these risk factors are identified (including infrequent visiting or limited interaction with the baby during visits), extra services can be offered these families (Lynch & Roberts 1977).

THE FAMILY'S ROLE

How then can the family and the hospital system interact most effectively? The choice for the parents is not simply between visitor and colleague role. There seem to be occasions when both roles are relevant. Each situation may require a slightly different balance although the movement during the period of hospitalization needs to be towards greater parental responsibility.

The Family's Perspective

The preterm family is faced with the task of resolving the crisis of their baby's birth and progress in a way which mobilises their parenting role as soon as possible. They are in fact being parents even as they cope with the loss of expectations and struggle to adapt to the new situation. The most nurturing choice they have initially as preterm parents is to allow other people to care for their baby in ways they are unable to through lack of expertise or through stress of the crisis.

Yet the parents themselves may experience this early phase with a sense of impotence, failure and dissatisfaction. They may assign themselves the role of passive visitor — "How can I possibly offer my baby anything?"

The shift from passive visitor to active colleague does not really come until the parents *themselves* value their contribution. They begin to realise that they are the most consistent caregivers to their baby in an environment of frequent staff changes. They begin to accept that the worrying, the stroking in the humicrib, the expressing milk are all ways of loving that are special to the family. From about 29 weeks gestation, the babies do actually respond significantly to their mother (Minde et al 1978). The reward of a response from their baby — even just open eyes — can reinforce the parents efforts more than any other factor. When parents can actually hold and bath and feed their baby — they begin to feel he or she is *their* baby.

The difficulty for caregivers, be they friends or hospital staff, is to decide when to be parent-focused and when to be baby focused. In other words how to balance the parents' needs for space to react to their baby's birth and condition, with the baby's needs for active loving parents.

The Staffs' Perspective

The staff in a critical care unit are highly skilled and work under considerable stress. It is interesting to note that one sign of a blurring of the interface between givers and receivers of health care is the increasing recognition of the emotional needs of the staff. Conferences on "Nurse Burn-Out", and staff groups for ventilation of feelings are becoming more common. Accepting the needs of the family in crisis will involve accepting the needs of the staff. This is difficult

and it is tempting to return to the security of rigid boundaries.

Some staff feel sensitive about what they see as family intrusions into their territory. Issues of power and control can be disguised as technical issues. The blurring of roles between staff can also increase insecurities which affect the family/staff boundaries. A flexible system requires negotiating skills and assertiveness.

There are many ethical dilemmas in neonatology which require some clarity about the differences between staff and family responsibilities. How much information do parents want or need in order to be effective parents rather than treatment decision makers? How can parents be involved in decisions about treatment of their severely damaged baby? Just who is responsible for the baby during hospitalization? When are we protecting parents from pain and when are we depriving them of their parental opportunities?

Most staff are keen for families to be involved and worry when families do not visit or phone. Sometimes it is hard to accept when a parent copes with fears and inadequacies by withdrawal or anger. It is demanding on staff to be both technically and interpersonally skilled. Staff need support and training to be able to respond appropriately to families.

SERVICE IMPLICATIONS

What are the ways that families can be mobilised into an active caring role for their baby during and after hospitalization?

1. Training and supporting staff to understand the needs of the families so that the pace and nature of involvement can be suitable for each family.
2. Allocating staff such as social workers expressly for the needs of the family.
3. Developing physical resources for the family in the nursery. These would include a family room where all family members can relax, take refreshment and talk informally. Child care facilities and childrens gowns help siblings be included. Local accommodation for rural families is vital.
4. Maximise information sharing with the parents about their baby and the nursery system. Booklets, videos, groups and individual contact can all be used.
5. Preparation for the role of preterm parent or supporter of such parents through education programmes for the public and for health professionals.
6. Research into dynamics of parenting disorders and their links with low birth weight babies.
7. Develop self help systems for parents and encourage the involvement of the families social network.

CONCLUSIONS

The birth of a preterm baby is a crisis for both the baby and the family. How effectively the family adjusts from their initial experience of loss and impotence to an active parent role, will greatly influence the outcome for both baby and family. The parents' task is to move from the role of 'parent' to 'preterm parent' and eventually to 'parent again'.

The implications for both staff and families of a shift in role from visitor to colleague are discussed and some ways of maximising family involvement are described. ■

REFERENCES

KLAUS, M and KENNELL, J (eds) 1976): *Maternal Infant Bonding:* Mosby & Co.

NOTMAN, M and NADELSON, C (eds) (1978): *The Woman Patient; Medical and Psychological Interfaces:* Plenum Press

ELMER, E & GREGG, G (1967); "Developmental Characteristics of Abused Children", *Paediatrics* 40.

KLEIN, M and STERN, L (1971): "Low Birth Weight and the Battered Child Syndrome", *Am. J. Diseases of Children,* 122

SMITH, S.M. and HANSON, R (1974); 134 Battered Children: A Medical and Psychological study", *Br. Medical J.* 3.

AGUILERA, D and MESSICK J. (1974); *Crisis Intervention: Theory and Methodology:* Mosby Co; page 63.

NICOL, M (1979); "Behavioural Variations associated with the degree of mother-infant neonate contact in the early post partum period": Unpublished honors thesis, University of W.A.

REID D and STANDLEY F (ed) (1977); *The Epidemiology of Prematurity:* Urban and Schwarzenberg.

HUNTER, R et al (1978): "Antecedents of Child Abuse and Neglect in Premature Infants; A Prospective Study in a Newborn Intensive Care Unit": *Paediatrics,* 61

LYNCH, M and ROBERTS, J (1977); "Predicting Child Abuse: Signs of bonding failure in the maternity hospital": *B.M.J.* 5,

MINDE, K. et al (1978) "Mother-Child Relationships in the Premature Nursery: An observational study: *Paediatrics* 61, 3

Our Preterm Baby (1979) video: Audio Visual Dept. Queen Elizabeth Hospital, Shenton Park W.A. Made by Social Work Departments of K.E.M.H. and Dept. of Child and Community Health, together with Preterm Infants Parents Association.

"THE MUMS' CHUMS