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**CARING FOR AT-RISK INFANTS:
THE EXPERIENCES OF PARENTS WITH INFANTS
ON HOME APNOEA MONITORS**

**BARBARA LOIS MACLEAN
1994**

**Caring For At-Risk Infants:
The Experiences of Parents With Infants
On Home Apnoea Monitors**

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of the requirements for the degree of Master of Arts
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ABSTRACT

Home apnoea monitoring for infants considered to be at risk for sudden infant death syndrome (SIDS) has been available in New Zealand since 1978. In light of the fact that the efficacy of home monitoring is unproven (Krongrad and O'Neill, 1986; Phipps and Drotar, 1990) an understanding of the impact of monitoring on families is essential.

In the present study, descriptive case studies (as described by Yin, 1984) are presented of six New Zealand families undertaking the home apnoea monitoring of their infants. Indepth interviews, conducted over a three month period, prospectively explored the experiences of one or more caregivers. Analysis of the data confirmed many of the reported findings from previous (mainly American) studies. In particular, parents perceived their infants to be "at risk" whilst monitored, and tended to become socially isolated because of their reluctance to leave their infants with other caregivers. The false alarms were a serious problem, causing negative arousal in the parents. When the alarms sounded parents found it very difficult to determine whether or not the infant was, or had been apnoeic. The monitor itself became the best indicator of the child's risk status and parents sometimes relied on the monitor to the detriment of other treatment regimes and of surveillance of the infant's condition for problems other than the risk of apnoea.

The present study used a systemic family nursing perspective to frame the participants' experiences. It was thus considered essential to take into account the family context in which monitoring was undertaken. Parents in the present study who, for example, had previously lost infants to SIDS, spoke of the ongoing grieving processes underpinning their monitoring experiences of

subsequent infants. When the youngest child was no longer monitored, the focus of attention shifted from the risk status of the infant to the prospect of a normal childhood.

Parents increasingly made their own decisions about how and when to use the monitor, based on their perceptions of their own ability to cope without it, rather than on the medical indications for its use or discontinuance. Mothers, especially, expressed strong needs for support from knowledgeable health professionals who could provide an integrated, holistic approach to the care of their infants, for monitoring supervision and for general parenting advice and support. The concept of a community-based nurse case manager is suggested as an appropriate means to meet their needs for a coordinated professional support service.

PREFACE AND ACKNOWLEDGEMENTS

As a nurse working in a Level II neonatal unit, I became aware that nurses had very differing interpretations of the alarms emitted by apnoea monitors (similar models to those used at home by parents). Without the digital display readouts available on the more sophisticated cardiorespiratory monitors, nurses would respond to apnoea monitor alarms by checking whether or not the sensor pad was appropriately placed. If not, the sensor placement would be adjusted, the alarm reset and no concern was expressed. However, if there was no problem detected with the sensor siting, nurses then made judgements as to whether the infant was apnoeic, or breathing too shallowly or too deeply to register the respirations on the monitor. What one nurse would consider "shallow breathing" another would call "apnoea".

This phenomenon led me to think about what it must be like for parents at home caring for infants on apnoea monitors. How did they cope with alarms in a home setting far removed from the neonatal unit where a second opinion was always available and alternative monitoring equipment on hand for times when apnoea was diagnosed?

From there I widened my field of possible investigation to incorporate a consideration of the effects of home apnoea monitoring on family functioning. Neonatal nurses are increasingly becoming aware of the importance of nursing the whole family, rather than just the infant with parents in attendance.

The result has been the undertaking of the present study where six families' experiences of caring for an infant on a home apnoea monitor have been explored.

My thanks for assistance and support for this study go to firstly, the participants who gave of their time so willingly and shared with me their

experiences and secondly, to the staff of the Department of Nursing Studies, Massey University (now renamed the Department of Nursing and Midwifery), especially to Professor Julie Boddy who supervised and encouraged the writing of this thesis.

Barbara Maclean

Key to Editorial Style Used in Quotations From Transcripts:

... material omitted

..... pause

(number/number/number) following an excerpt from a transcript refers to Case Study Number/Interview Number/Page Number of transcript.

[] Pseudonym used or omission of name to ensure anonymity of participants, or insertion of material not in original transcript to clarify the meaning.

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INTRODUCTION

In 1988, Dr Shirley Tonkin and Belinda Hutton (from the Cot Death Division of the Child Health Research Foundation) wrote that New Zealand's cot death rate was appallingly high by international standards (5:1000 births in New Zealand compared with less than 1:1000 births in Japan and Sweden). They went on to state that the survival rate of infants past the neonatal period could be achieved by two means. The first is to institute population-based strategies of identification and supervision; and the second is to target very high risk groups of infants and to safeguard them through infancy by such means as the use of home apnoea monitoring.

In New Zealand both these strategies have since been implemented. What is now known as the New Zealand Cot Death Study (Mitchell et al., 1991) has identified major risk factors for cot death, four of them modifiable; prone sleeping position, cigarette smoking, not breast feeding, and bed-sharing with the infant. The study was a three year multicentre case-control design and covered 80% of the country, comparing 485 cotdeaths with 1800 control infants. Commencement date of the study was 1st November, 1987, conclusion was 31st October, 1990. The researchers concluded that the four main risk factors could account for 82% of deaths from SIDS and that the rate of SIDS in New Zealand could fall to less than 0.7:1000 births if all infants in the country were breastfed, were not exposed to cigarette smoke, and were lain supine or on their sides to sleep in their own beds. The subsequent fall in the cot death rate has been attributed to the changes in parenting practices which have been promoted as a result of these findings (e.g. Scragg, Mitchell, Tonkin and Hassall, 1993).

Home apnoea monitoring for infants considered to be at high risk for sudden infant death syndrome (SIDS) has also become increasingly common over the last decade. Monitoring has been available in New Zealand since 1978 and organised programmes for their use have been developed across the country from the early 1980s (Tonkin and Hutton, 1988).

The hypothesis that led to the introduction of apnoea monitors was that babies dying from SIDS have cessation of breathing movements for 30 seconds or longer before death or irreversible brain damage has occurred (Milner, 1985). However, the Taskforce on Prolonged Infantile Apnea for the American Academy of Pediatrics pointed out in 1985, that knowledge regarding the aetiology and optimal management of prolonged infantile apnoea and its relationship to SIDS is only tentative. Five years later, Davies, Milner, Silverman and Simpson (1990) concluded that public awareness of SIDS has increased but the precise mode(s) of death in SIDS remain uncertain and unrecorded. Despite the rise in publicity and parental demands for the use of respiratory monitors at home, the efficacy of home monitoring is unproven. Large-scale controlled studies evaluating the effectiveness of home monitoring in decreasing the mortality and morbidity associated with infantile apnoea would raise serious ethical concerns (Rowland et al., 1987).

Several overseas studies have examined the effects of home apnoea monitoring on families but to date there have been no such studies reported in New Zealand. It is however recognised in New Zealand that for families undertaking home monitoring, the stresses are great and that support from health professionals is necessary, particularly when the time comes for monitoring to be discontinued (Moloney, Norton and White, 1987; Tonkin and Hutton, 1988).

The supervision of home apnoea monitoring in New Zealand is typically undertaken by Community Paediatric Nurses who follow up infants whose parents have been issued with monitors after consultation with a paediatrician. A number of parents of their own volition, hire monitors from local branches of the Cot Death Society. Alternatively, some purchase monitors of their own if they fail to meet the criteria for the provision of a rented monitor from an established programme (Moloney, Norton and White, 1987). Guidelines for the recommendation of apnoea monitoring vary according to the region. Auckland hospitals, for example, use a

protocol (written after consultation with Dr Tonkin in 1989 and updated in 1991) which lists the following infants as worthy of consideration of home monitoring; those who have recently been weaned off oxygen therapy, or discharged home on oxygen; infants of drug-abusing mothers; infants who have had an apparently life-threatening event in hospital; infants with respiratory obstruction (for example, from Pierre Robin Syndrome, a congenital condition in which the infant's tongue may fall back and block the airway); those with abnormalities of tone contributing to feeding and swallowing difficulties; apnoea of prematurity persisting beyond 37 weeks gestation; those with apnoea following surgical procedures; infants who are siblings of babies who died from SIDS and who have additional risk factors; and finally, infants of parents who are in an extreme state of anxiety, such as those with a poor obstetric history.

Plunket Nurses¹, Public Health Nurses² and Practice Nurses³ are all involved to some extent with families with monitors, as are hospital nurses in neonatal units and paediatric wards who may well be part of the after hours support/referral service for parents experiencing problems with monitoring. To increase the understanding of the issues involved, for nurses and other health professionals who seek to provide families of at-risk infants with assistance and support, the current investigation uses the family systems approach as a framework to explore the experiences of parents undertaking home apnoea monitoring.

1. Registered Nurses who are employed by the Royal New Zealand Society for the Health of Women and Children Incorporated (Plunket Society) which is a voluntary organization receiving considerable financial support from the government in addition to funds raised by its members. They provide parents and children (0 - 5 years) with preventative, supportive, advisory, and educational health services.

2. Nurses who provide predominantly family-centred preventive, supportive, and educational care to at risk groups in the community.

3. Nurses who are employed by doctors in general practice or in health centres. Their salary may be paid by a government subsidy to the doctor. They provide general nursing and delegated medical services in doctors' surgeries, health centres and in clients' homes.

CHAPTER ONE

Literature Review

The literature on home apnoea monitoring for infants will be discussed under three broad headings; the identification of those infants considered to be "at risk" and therefore in need of home apnoea monitoring; the technical aspects of the monitoring procedure; and families' responses to monitoring considered in conjunction with the relevant family nursing literature.

The Identification of Infants At Risk of Apnoea

Sudden Infant Death Syndrome is a poorly understood entity. Krongard and O'Neill (1986) point out that although the use of apnoea monitors to prevent this fatal syndrome is widespread, many questions have been raised regarding the adequacy or efficiency of what they term "this preventive-therapeutic modality"(p. 811). They go on to say that no test is available to indicate with a reasonable predictive value, that any one infant is at risk of sudden infant death and therefore in need of cardiorespiratory monitoring.

Krongrad (1991) comments that the search for infants at high risk for SIDS (candidates for apnoea monitors to safeguard them through infancy) has been based on parental observations and on epidemiologic risk factors. Both of these criteria are problematic. Infants considered to have high risk status (such as siblings subsequent to infants who died of SIDS (subsibs) and infants with reported periods of prolonged apnoea) have failed to demonstrate any specific physiological parameters, consistently and over time, that are different to those of the control group infants. Krongrad points out that parental observation which has been the cornerstone of the current definition of high risk is fraught with considerable error. The data collected by Kelly (1983) for example, which has been used extensively to estimate the incidence of prolonged apnoea in subsibs, relied heavily on

parental reports of apnoea. Davies et al. (1990) providing an update on monitoring and Sudden Infant Death Syndrome, concluded that the currently known epidemiological and physiological risk factors for SIDS are not "significantly sensitive or specific, even in combination, to identify infants for particular intervention" (p.238).

The uncertainty about the efficacy of home apnoea monitoring is demonstrated in the following advice given in 1985 to medical practitioners by the Task Force on Prolonged Infantile Apnea (p.129);

Physicians must evaluate and treat each case individually. Those who believe there is a relationship between prolonged apnea and SIDS and/or that home monitoring may be helpful should prescribe monitoring; those who do not are not obligated to prescribe monitoring and should not feel pressured to do so. All should recognize and communicate that monitoring cannot guarantee against SIDS.

Technical Aspects of Monitoring

The most commonly used model in New Zealand is the Graseby MR10 Respiration Monitor which is activated by abdominal movements detected by a sensor pad taped to the infant's abdomen. Davies et al. (1990) reiterate the shortcomings of this model - no data storage facilities are incorporated for event analysis, false alarms occur if the sensor pad is dislodged from the abdomen and more importantly, there is an inability to identify apnoea due to airway obstruction. Because no cardiac monitoring is incorporated, when an infant struggles against an obstructed airway, the body movements or bradycardic heartbeats may be picked up by the monitor as breaths. Caregivers may thus have unrealistic expectations that the monitor will always alarm if the infant suffers an episode of prolonged apnoea.

The false-negative problem, or failure to alarm is a major consideration with the MR10 monitor because as Davies et al. (op cit) point out, apnoea during apparent life-threatening events may be central (caused by failure of the central respiratory drive); obstructive (where there is some impedence to the flow of air from the nares to the alveolae) or a mixture of the two. Tonkin (1985) does however report that central events often become obstructive before normal respiration is re-established and that obstructive events can soon lead to central apnoea.

Recent suggestions for the improvement of home monitoring devices have included the use of oxygen saturation monitors to detect hypoxia (Davies et al., 1990) and the addition of an auditory stimulus to the alarm function to normalize the breathing pattern of the infant and thereby reduce the incidence of SIDS (Stewart and Stewart, 1991). Peeke and Levett (1992) write of the benefits of the use of event recorders incorporated into home cardiorespiratory monitors (these were not respiration detection only monitors such as the Graseby MR10 model). Event recorders enable computerized printouts to be made of heartrate and respiration patterns when an alarm is triggered. They also document caregiver compliance with instructions for the use of the monitor.

A number of studies have demonstrated that there is very little correlation between parents' reports of apnoea episodes and hard data obtained of cardiorespiratory activity from event recorders attached to the monitor. A recent study by Steinschneider and Santos (1991) confirmed the earlier findings by Krongrad and O'Neil (1986) and Weese-Mayer et al. (1989) that true biologic events were not reflected by parental reports of apnoea in the vast majority of recorded instances. Steinschneider and Santos monitored 155 "at risk" subsibs and with an attached event recorder, found that of the reported 1051 "true" apnoea episodes and 422 bradycardia episodes, none had a confirmed cardiopulmonary event that could be considered life-threatening. Anxious parents had made hundreds of attempts at stimulation or cardiopulmonary resuscitation (CPR) apparently needlessly.

Occasional reports have been documented of what appear to health professionals to be deliberately falsified apnoea histories. Rowland et al. (1987) encountered three such cases in a five year period of monitoring 211 infants, from 1981-1986 in Massachusetts. Light and Sheridan (1990) surveyed 127 apnoea monitoring programmes and found an incidence of this phenomenon, known as Munchausen Syndrome by Proxy and Apnoea (MBPA) of 0.27%. In such instances, management involves verification of symptoms with event recordings and therapy for families to break the link between the reporting of symptoms and receiving help. Light and Sheridan (op cit) appreciate the difficulties for clinicians presented with an infant who supposedly suffered apnoea, to tread the fine line between too much and too little suspicion of parents' reports.

Several issues arise from this literature review. Firstly, the value of monitors which alarm but provide no event recordings for the parents to compare, must be questioned.

Secondly, parents may be putting their infants at risk by relying on the monitor to detect any of the three types of apnoea, in time for the infant to be successfully resuscitated. Concern has also been expressed (McIntosh, 1990) that parents could regard the monitor as a safety net and rely on it inappropriately, sometimes unintentionally neglecting other physical aspects of their child's care.

Thirdly, there is risk to the monitored infants who are resuscitated unnecessarily. Rowland et al. (1987) warned that administered CPR does not necessarily mean required CPR. Clearly, the reported extent of the initial resuscitation of an apnoeic infant is not a reliable indicator of the event.

Fourthly, the reactions of the parents to the monitor alarms should be seriously considered. False positive alarms which are interpreted as real events are a potent source of stress for parents. Mothers have told of feeling threatened and upset when health professionals have questioned them about apnoeic episodes in a non-supportive, insensitive manner (Nuttall,

1988). Steinschneider and Santos (1991) observe that there are no published studies examining the influences of experiential and psychological factors on parental responses to monitor alarms.

Family Responses to Monitors

Families with home apnoea monitors are a specific population but share many of the attributes of other families experiencing the stress of having a child with a chronic illness (Geary, 1989; Sweeney, 1988; Wasserman, 1984).

Risk Perception of the Child

Wasserman (1984) in comparing and contrasting monitoring with the experience of living with a chronically ill child, states that although home monitoring is a time-limited experience (unlike truly chronic illnesses) its constant presence does not allow the family any denial of the fact that the child may die at any time. Constant vigilance required by the electronic surveillance programme thus leads to stress and emotional and adjustment problems similar to those reported in parents of children with chronic illnesses.

Shapiro (1983) in a review article of family reactions and coping strategies in response to the physically ill or handicapped child, describes the effects of a chronic or life-threatening illness on the family as profound, with the depth of the family response being directly related to the parents' perceptions of the severity of the risk to the child. She reports that if parents mistakenly identify their children as being at risk from, or suffering from some serious physical condition, then dysfunctional family responses such as overprotection of the child which occurs in the "vulnerable child syndrome" may result. The vulnerable child syndrome was first described by Green and Solnit (1964) who identified parents' reactions to the threatened loss of a child. Shapiro (1983) cites a follow-up study of misdiagnosed infants (Carey, 1969) which found that years afterwards, the

misdiagnosed children were still perceived differently and treated differently by the mother. Phipps and Drotar (1990) emphasise the importance of understanding the impact of the monitor on the parent-child relationship considering the undocumented nature of the preventive value of home monitoring.

In light of the recent findings by Krongrad (1991) and Steinschneider and Santos (1991) the question arises - are parents of monitored infants suffering needless anxiety because of a mistaken perception of the risk status of their infants? Certainly, Black, Hersher and Steinschneider (1978) point out that the alarm rates of monitors became important determinants of parents' convictions about the severity of risk to their infant.

Family as Context and Recipient of Care

The reciprocal relationship between the family and chronic illness is recognised by nurses and other health professionals who adopt a family systems approach as a framework for clinical practice. In the family nursing literature, authors such as Wright and Leahey (1984); Leahey and Wright (1987); Gillis (1991); and Shaw and Halliday (1992) emphasise interventions deliberately and consistently designed for the family unit, rather than for individuals in the context of the family. According to Woods, Yates and Primomo (1989) the entire family experiences the effects of demands generated by the disease and its treatment. Wright and Leahey (1990) advocate family systems nursing which concentrates on the interconnections between illness, the individual and the family; as life threatening illness affects the individual and family, the behaviour of family members, in turn, influences the course of the illness.

Rankin (1989) developed a framework to assist nurses and other health professionals to appreciate the diversity, complexity and plasticity (the capability of considerable alteration over time) of families. The framework melds two traditions, that of psychosocial transitions (based on the work of Parkes, 1971) and family development theory (Duvall, 1977). Rankin

emphasises that although consideration of common psychosocial transitions helps to reveal important tasks of families during certain phases in their histories, the unique context and perspective of each family must be taken into account. Developmental theory has been synthesized by Stainton (1989) a nurse advocate of the family as the unit of care. She emphasises the importance of a new mother's relationships with her "significant others" and her mate (p 201) and lists a set of four developmental tasks for her to accomplish within the family context. Families experience transitions in different ways and their resources and their abilities to cope must be taken into account when the needs for intervention are assessed. Family situations in which home apnoea monitoring is undertaken would thus both affect and be affected by the monitoring experiences.

The indications for the use of the monitor have been found to influence parents' reported levels of stress. Black, Hersher and Steinschneider (1978) found for example, that anxiety levels in their study's participants were higher in parents whose child had a diagnosis of sleep apnoea and in those who had had a previous child die from SIDS.

An understanding of the long-term effects of the loss of a child, is necessary to put into context the experiences of monitoring a subsequent child. Weinstein (1978) writing specifically about the responses of families to the loss of a child from SIDS, points out that the parents of the dead infant are left with the knowledge that their child died inexplicably, perhaps because of something they unwittingly had done or failed to do. They look for a reason to explain the death, partly to expunge the sense of guilt and feeling that others may consider that some neglectful action on their part caused the child to die. Bugen (1977) recognizes that the intensity of the grieving reaction is related to the preventability of the death. However, with cotdeath, the parents do not know what could have been done to prevent it. Family nursing authors, McClowry, Gillis and Martinson (1989) reject the traditional model of bereavement and instead describe how the pain of grief is ongoing and becomes integrated into the person the bereaved person has become. Monitoring parents who have lost a child thus cannot be assumed

to have passed through a series of predictable stages in the grief process and have successfully or unsuccessfully "resolved" their grief. McClowry et al. (1989) advise that bereavement is difficult and mourners are subject to a variety of ongoing emotional sequelae.

Demands of Monitoring: Anxiety and Social Support

Vohr, Chen, Coll and Oh (1988) used standardised questionnaires to compare the maternal stress perceptions and social support levels of ten mothers of preterm infants on apnoea monitors; ten mothers of full-term infants on home monitors; and ten mothers of non-monitored term infants. Monitored infants' mothers experienced significantly more stress than those whose infants were not monitored. Preterm infants' mothers reported more favourable responses to monitoring, however, than did the mothers of their full-term counterparts. The authors comment that parents of preterm infants are exposed to apnoea monitors in the neonatal care of their infants before hospital discharge. They postulate that the increased levels of pre-existing stress in mothers of preterm infants, because of the effects of the premature birth and its sequelae, contribute to the lower stress levels reported when monitoring at home.

The adjustments in family lifestyle necessitated by the birth of a premature infant were investigated by McHaffie (1990). Although McHaffie did not look at the monitoring experiences of parents of premature infants, her study is reviewed here because it provides an insightful exploration of the parenting of one group of 'at risk' infants who often are monitored at home for apnoea. McHaffie (1990) prospectively studied the perceptions of 21 mothers of very low birth weight infants, conducting six in-depth interviews with each mother from one week after delivery to three months after the baby's discharge from hospital. Extra data were supplied by diaries kept by the participants and by the administration of the standardised Neonatal Perception Inventory. She identified six phases in their experiences of the premature birth and subsequent home-coming, each characterized by certain critical factors related to the mother's emotional

state, her perceptions of the baby and family responses. The mothers who felt ready to take the infant home from hospital coped with the baby's ongoing care more effectively than those who felt unprepared for discharge. Both studies (Vohr et al. 1988; and McHaffie, 1990) conclude that strong levels of support for mothers diminish stress. McHaffie adds that professionals can help mothers to overcome their feelings of inadequacy by giving them the opportunity to talk frankly about their concerns without fear of censure or advice.

A number of studies have examined the relationship between home apnoea monitoring and emotional stress for families. Whilst there is general consensus that monitoring makes demands upon parents, there is considerable controversy as to whether monitoring significantly increases or decreases parental anxiety levels (Andrews, Nuttall, and Neilson, 1987). Initial studies were retrospective and descriptive in nature (Black, Hersher and Steinschneider, 1978; Cain, Kelly and Shannon, 1980) and presented generally positive pictures of the monitor as anxiety-reducing. Black, Hersher and Steinschneider (1978) obtained descriptive data from 31 monitoring families, through questionnaires designed after intensive interviews were conducted with 18 mothers and 15 fathers. They concluded that monitoring had a significant but temporary impact on family life. Many patterns of daily living were altered to accommodate the demands of monitoring and the technical limitations of the machine severely aggravated parents' problems. Most parents believed the monitor was ultimately an anxiety reducer and worth the inconvenience.

Wasserman's (1984) study used a prospective design to follow up 14 families of monitored infants for a period of five years from the time of initial contact. Each family received at least three "psychiatric" interviews and two other follow-up contacts. Wasserman reported that monitoring caused substantial distress manifested in depression, fatigue and anxiety in many parents, especially mothers, who had the largest burden of care. Cain, Kelly and Shannon (1980) conducted an exploratory study of 133 parents' perceptions of monitoring (74 families). Each parent was interviewed once

only in a structured interview lasting one hour. A self-administered graphic rating scale was used to supplement the data. The researchers found that fathers and mothers did not necessarily share the same perspective of the seriousness of the monitoring and that mothers tended to report higher levels of anxiety and insomnia, especially in the first month of monitoring.

A controlled prospective study of the impact of monitoring on mothers was undertaken by McElroy, Steinschneider and Weinstein (1986). Fifty-six mothers of monitored infants were studied at several periods following the infants' births; at 6 weeks, 12 weeks and one year. A battery of questionnaires was administered to these mothers and to 56 mothers of non-monitored infants in the control group. Very few statistically significant differences were found between the two groups and the authors conclude that a home monitoring programme, which includes an 'aggressive and readily available support system, does not impose a marked health hazard to mothers' (p.780).

Phipps and Drotar (1990) conducted a comparative study of three groups each of 30 mothers; mothers of infants who had suffered an apnoeic episode and who were being home monitored; mothers of infants with mild congenital heart lesions; and mothers of normal healthy infants. Measures were made of parenting stress, family resources and support, family coping activities, health locus of control, and maternal coping style. Mothers of monitored infants reported slightly increased levels of stress, their infants were perceived as more demanding, and the mothers reported less attachment to the child. Acute distress was engendered by monitoring in the first month but these effects were transient. Their findings were in line with those of Cain et al. (1980) but contrary to those of Nuttall (1988) and Williams and Williams (1990) who found no evidence with the passage of time, of an attenuated effect on mothers, particularly in families lacking cohesion and where low self-esteem of the mother hampered help-seeking behaviours. Phipps and Drotar (1990) suggested that family resources, including the availability of social/emotional support appear to be the crucial determinants of parenting stress. The study by Williams and

Williams (op cit) was of 25 mother/child pairs who were discharged home from hospital with apnoea monitors. Data were collected retrospectively from mothers using standardised instruments, including the Receptive-Expressive Emergent Language Scale; Home Observation for Measurement of the Environment; Family Coping Strategy questionnaire; Family Adaptability and Cohesion Evaluation Scales; and the Functional Social Support Questionnaire.

Another retrospective comparative study was conducted by DiMaggio and Sheetz (1983). Twenty-nine mothers of monitored infants were compared to mothers of normal infants. Monitoring mothers in this study felt socially isolated because of a lack of people who were willing or able to babysit and they experienced resultant emotional tension. They tried to maintain usual household routines despite the additional demands imposed by monitoring. These mothers expressed the need for networking with other monitoring parents as well as support from professionals.

In discussing the potential costs of home monitoring on families, McIntosh (1990) cautions that parents may react to the stresses of monitoring by becoming very demanding or withdrawn. The cumulative effects of the strains of monitoring can lead to social isolation and loss of social support as friends and family distance themselves.

Geary (1989) a clinical nurse specialist, emphasised the intensity of mothers' concerns arising from the impact of monitoring on a lifestyle that has already changed to accommodate a new baby. Discussing the findings of her qualitative study of 20 monitoring mothers, Geary warns that nurses must not overlook mothers' needs which become submerged in the process of caring for the baby. The prolonged stresses of monitoring may limit the amount of energy available to mobilise support. She identified frequently-used coping strategies such as denial or minimising the negative and emphasising the positive aspects of monitoring.

Selected findings from Geary's study were previously reported in 1986 by the same author (published under the name Dean). Dean categorized the stresses experienced by mothers as the need for constant watchfulness; feelings of confinement; lack of personal time; and limited time with other children in the family.

Maternal responses to home monitoring were described by Nuttall (1988) in a retrospective study of 74 mothers. Using semi-structured interviews, Nuttall found mothers reported family disruptions from the monitoring and a distressing lack of support from friends and relatives who were reluctant to assume any responsibility for the monitored infant. Monitoring also seemed to have precipitated fears in the mothers about the vulnerability of their babies. Nuttall describes home monitoring as a prototype for other medical technologies now being used in the home. The responsibility for 24-hour technological care is undertaken by the parents. Andrews et al. (1987) assert that education of families and supportive care by collaborative multidisciplinary health teams are vital for home monitoring to be an acceptable alternative to hospital care.

Compliance With Monitoring Protocols

Wilson, Stevens, Becker and Klinghagen (1990) point out that studies of family responses to monitoring have not provided data regarding how the parents used the monitor. In an investigation of 35 families in the South Dakota area, they interviewed caregivers in a home apnoea monitoring programme and found that only 8% of respondents followed the monitoring protocol advocated by the programme. Non-compliance and premature termination of monitoring were common with the result that many babies in the sample would not have received prompt attention if apnoea had occurred. The authors conclude that a mother's compliance with procedures is an indication of how vulnerable she perceives the child to be.

Cultural Considerations

Cultural considerations in the use of home monitors have been largely ignored. Bushy and Rohr (1990) emphasised the importance of providing meaningful and efficacious care to ethnic populations. Their work with the Plains Indians also revealed "non-compliance" of families with the monitoring protocols, which they attributed to cultural influences such as the role of the extended family in caring for the infant and the incongruency of technological monitoring with traditional health beliefs. Light and Sheridan (1989) reported that Hawaiian families who failed to use monitors were often from minority ethnic groups such as the Vietnamese, Koreans, Samoans or Blacks, suggesting cultural factors are involved in the acceptance or rejection of monitors. No New Zealand studies of Maori people's responses to monitoring have been published.

Summary

The role of apnoea monitors in preventing SIDS is unproven, but there was no dramatic decline in the incidence of SIDS victims reported when monitors were introduced over a decade ago. The apparent inability of parents to distinguish which alarms are associated with genuine apnoea and bradycardia episodes, is a major concern, as is the unrealistic expectation of parents that monitors will always alarm if the infant suffers a life-threatening episode.

Understanding the impact of home monitoring on families is considered essential when evaluating the costs versus the benefits of monitoring (Phipps and Drotar, 1990). It is noteworthy that several of the studies reviewed above have investigated only the mothers' perceptions of the stresses involved in monitoring. Most authors agree that monitoring represents a significant stressor for the family but there is a lack of consensus of opinion regarding the severity and temporal effects of monitor-related distress. Further study of the impact of monitoring is recommended. No such studies have been reported in New Zealand to date and the present

study was undertaken with the intention of providing insight into the experiences of home apnoea monitoring parents (both mothers and fathers) in a New Zealand context.

CHAPTER TWO

Method

Introduction

Descriptive case studies as described by Yin (1984; 1993) have been selected as an appropriate methodological approach to answer the question, in a New Zealand context:

What are the experiences of parents who care for infants on home apnoea monitors?

In addressing this question, a family systems perspective was used to explore:

- (a) What is the family context in which monitoring is being undertaken?
- (b) What are the parents' beliefs about the efficacy of monitoring?
- (c) How do parents respond to monitor alarms?
- (d) What are the parents' perceptions of the degree of stress involved in apnoea monitoring?
- (e) Are there cultural issues that parents believe should be taken into account by nurses and other health professionals supervising apnoea monitoring?
- (f) How do parents decide how long apnoea monitoring is necessary for their infants?

- (g) Ways in which nurses and other health professionals can assist and support families through the period of home monitoring.

Selection of the Descriptive Case Study Method

Case Study or Case History?

Hutchinson (1990) presents a useful overview of the case study and case history approaches for nursing research. She points out that the case study as a scientific research method is not widely used in nursing and that a preview of nursing research texts revealed little, if any, reference to the case study method. One exception is the chapter by Woods and Cantanzaro (1988) which discusses the case study method as an example of hypothesis-generating research. This chapter draws heavily on the work of Yin (1984) who wrote most definitively on the subject of case studies.

Hutchinson outlines the usefulness of case studies for the building of theory for nursing practice. For nursing research to be useful it must speak to practising nurses who deal with individual clients and their unique needs. The case study method uses a systematic, holistic approach to research and illuminates human experience and real-life problems. Particulars are then used to build theory for nursing practice. Such theory will ultimately involve generalizations that are "exploratory, predictive and useful" (Hutchinson, 1990, p. 177).

Yin (1984, p. 23) defined a case study as 'an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident and in which multiple sources of evidence are used'. Hutchinson (1990) recognises the distinction made between case studies and case histories by Strauss and Glaser (1970) - a distinction which Yin (op cit) does not make. Instead, Yin described three types of case studies (descriptive, exploratory and explanatory) for which the choice of research strategy is dictated by the type of research question posed. For example, 'what' questions may indicate an exploratory study (what are the ways in which an effective unit is

operated?); 'How' and 'why' questions are more explanatory (how does a community successfully thwart a proposed project?). Descriptive case studies have description as their main objective but must still have theory to determine priorities for data collection (Yin, 1993, p. 21).

Theory is important to case studies, not only for analyzing empirical evidence, but to also guide the selection of cases to be studied in the first place; to specify what is being explored; to define a complete and appropriate description in descriptive case studies; to stipulate rival theories and in some instances, to generalize results to other cases (Yin, 1993, p.4).

In this respect descriptive case studies (the method of choice for the present study) differ from some qualitative approaches such as grounded theory, favoured by nurse researchers, which require an atheoretical stance prior to data collection (Lijphart, cited by Hutchinson, 1990). They also differ from case histories, as described by Strauss and Glaser (1970) which aim to provide detailed data that may or may not be linked to theory. Lijphart (op cit) considers the term 'atheoretical' inaccurate because theoretical ideas inevitably guide the study, even if they are unarticulated. Yin (1993), elaborating on the use of theory in descriptive case studies, states that a descriptive theory covers the scope and depth of the case being described. It would specify what should be included or excluded in the study and where the description should start and end. In effect, it guides the design of the descriptive study.

Corbin and Strauss (1988) refer to case histories as cases with a temporal aspect or story line, the purpose being to 'exemplify a set of interpretations or ... to give an evolving picture ... with perhaps only implicit interpretations of the case history' (p. 19). Case studies, in comparison, aim to describe, generate or verify theory and thus do not focus on a complete story. Corbin and Strauss (1988, p. 19) state that the narrative line in case studies is 'subordinated to abstract purpose' but that case histories tend to be lengthy, because of their need to present the fullest possible story.

Anguish: A Case History of a Dying Trajectory (Strauss and Glaser, 1970) is the classic example of a case history. It presents an account of a 54 year old woman who is dying of cancer in a hospital setting. The authors give three chapters of description and at the end of each section present a brief 'theoretical' analysis of the chapter. However, the theory they apply to the case is what they call 'substantive' (p. 5). It appears to consist mainly of a summary and reframing of the story to derive recommendations for changing practice in the care of the dying. The authors do not systematically use formal theory nor previous research findings to assist in analysis of the case history.

For the present study, the descriptive case study method was considered more appropriate than the case history. An extensive review of the literature preceded the formulation of the series of research questions which guided the study. Participants' stories were subsequently presented in sufficient detail to describe their experiences with home monitoring but without the rich description associated with case histories. Pattern matching was used in the analysis of the data (as recommended by Yin 1993, p.21). Themes emerging from participants' stories were compared to the patterns revealed in previous studies of home monitoring and to those in the relevant literature of home care of at-risk infants. A family nursing framework was implicit throughout the study.

The descriptive case study method was selected because of its particular strength in permitting;

- (a) the investigation of a wide variety and large amount of information about the phenomenon of home apnoea monitoring;
- (b) a focus which is contemporary rather than historical;
- (c) naturalistic study within a real-life context;

- (d) the identification and description of the complexity of the phenomenon of home monitoring as it evolves over time under real life conditions;
- (e) an in-depth investigation of a particular unit of analysis, in this instance, the family.

(Barnard, Magyary, Booth and Eyres, 1987; Woods and Catanzaro, 1988; Yin; 1984).

Case Study Designs

Yin (1984) describes four types of case designs, derived from a 2 x 2 matrix:

	Single-Case Designs	Multiple-Case Designs
Holistic (single unit of analysis)	Type 1	Type 3
Embedded (multiple units of analysis)	Type 2	Type 4

Figure 1 - Basic Types of Designs for Case Studies

Source: Yin, R. (1984) *Case study research: Design and methods* (p.46). Beverly Hills, CA: Sage.

A single case design refers to one where only one case (e.g. a family) may be studied, whereas a multiple case design would study more than one case (e.g. several families).

Single case designs are appropriate where:

- (a) a critical case is presented, testing a well-formulated theory
- (b) an extreme or unique case is documented or
- (c) a revelatory case is presented of a phenomenon previously inaccessible to scientific investigation.

Multiple case designs, rather than being considered a different "methodology" from single case studies are included under the same broad framework (Yin, 1984, p.48). The evidence from multiple cases is often regarded as more compelling and the overall study thus more robust.

Multiple case designs employ a replication logic. This is not a sampling logic such as is used with the selection of multiple subjects within an experiment, but instead, multiple cases are considered as multiple experiments in themselves.

After an analysis of each case study, based on descriptive theory, a cross-case analysis is done, looking for patterns, both new and those previously identified in the theoretical framework derived from the review of relevant literature sources.

The units of analysis of case study may also be single or multiple. Yin (1984) describes as holistic those units of analysis which cannot be divided into components. Woods and Catanzaro (1988) use as an example, a case when an investigator studies a family, collecting data only at the level of the total family. However, in an embedded case study, multiple units of analysis are used, studying individuals in the family; dyads; and the family as totality.

The two dimensions on the matrix may be crossed, producing the following options:

- Type 1 Single-case holistic;
- Type 2 Single-case embedded;
- Type 3 Multiple-case holistic; or
- Type 4 Multiple-case embedded designs

A Type 4 multiple-case embedded design was considered appropriate in the present study as one in keeping with a family nursing perspective which acknowledges the interconnections between health and illness experiences, the individual and the family (e.g. Wright and Leahy, 1990).

Selection Procedure for Study Participants

A convenience sample of six families with infants currently on home apnoea monitoring was selected in the Manawatu area. Permission to recruit participants was obtained from:

1. The Paediatric Service Manager for the Manawatu-Wanganui Area Health Board, the institution which administered the local home apnoea monitoring programme.
2. The Ethics Committee for the Manawatu-Wanganui Area Health Board.
3. The Human Ethics Committee for Massey University.

Access to the families was with the assistance of the Paediatric community nurse who maintains contact with families using home apnoea monitors.

Criteria for inclusion in the study included:

- (a) A willingness to participate in the project over the three month period.
- (b) Ability to speak English and to be sufficiently literate to maintain diary records.
- (c) "Family" groups composed of two or more members, including the infant. Informants could be both parents, either parent, or a single parent or principal caregiver.

The Paediatric Community Nurse herself was not recruited as an informant. Although her knowledge of the topic is broad and her input into the recruitment of participants invaluable, anonymity could not be assured in view of the fact she is the sole nurse employed in the region to work with these families.

No attempt was made to select a sample of participants that was homogeneous in any respect other than the undertaking of home apnoea monitoring and fulfilling criteria (a), (b) and (c) as above.

Three participating families had had previous cotdeaths and were monitoring subsequent infants; two families had infants born very prematurely; and one family had a full-term infant who was thought to have suffered an apnoeic attack. Each case study presented contains a demographic profile of the participating family.

Data Collection

A multiple case study design was used with six families participating in the study. Data were obtained from transcripts of tape-recorded in-depth interviews, conducted monthly over a three month period. Interviews were held with both parents in all but one family (case study four) where the

father was unavailable. A paid caregiver (case study two) was also interviewed. With the exception of case study six, interviews were held with each parent separately. This was for several reasons. Firstly, mothers preferred to have their time with the researcher during the day, when most fathers were not home. Secondly, individual parents were able to speak freely about their experiences (including their partner's role in the monitoring) without the constraining presence of their partner. Thirdly, individual interviews were a means of obtaining data at the first of the five levels of questions set out by Yin (1984) for case studies. Responses to questions asked of individual interviewees were later able to be considered in the context of the family situation and the other caregiver's responses.

Diaries kept by participants over this time were used as prompts for the parents when recounting their experiences since the previous interview. Diaries were not used by the researcher in the data analysis. Instead, they remained in the possession of the participants, who had in some instances used them to record details of the baby's developmental progress as well. Entries covered not only the monitoring information but details such as sleeping patterns, vaccinations, physical milestones such as rolling over and records of days when the baby cried excessively. Diary entries were generally brief; information about parents' responses to the monitoring was forthcoming in the interviews.

Data Analysis

Yin (1984, p.72) sets out five levels of questions to be answered in multiple case study designs, and which assist the researcher in preparing the case study report.

Level I questions are asked of specific interviewees (each caregiver in the present study was asked open-ended questions about their perceptions of the home monitoring experiences).

Level II questions are asked of the individual case (individual family members' responses are considered at the level of the family unit).

Level III questions are asked of the findings across multiple cases (cross-case comparisons and pattern identifications are carried out).

Level IV questions are asked of an entire study (information beyond the multiple case is considered, literature that has been reviewed is used in data analysis).

Level V asks normative questions about policy recommendations and conclusions.

Levels I and II questions were addressed in the data collection phase of the present study, and are reported in individual case reports, numbered 1-6. Each case presents a family profile, a precis of the individual participants' accounts of their monitoring experiences and a discussion section which examines the family's experiences in light of the reviewed literature.

Levels III, IV and V questions are addressed in the final section of the report which makes cross-case comparisons, compares them with the literature, then suggests policy recommendations and other areas for future research.

Issues of Reliability and Validity

Construct Validity

Hutchinson (1990, p.201) states that the "construct validity in case studies that use pattern matching... refers to how closely the framework (in the literature or "discovered" in the data) fits the people, event or program that was studied". In the present study, there was a high degree of overlap between the accounts of home monitoring experiences of the participants and those described in previous studies in American settings (Black, Hersher and Steinschneider, 1978; Wasserman, 1984; Nuttall, 1988; and

Geary, 1989). Parents also confirmed the reports of Steinschneider and Santos (1991) that caregivers have difficulty in differentiating false alarms from apnoea.

Construct validity can be checked by asking participants if the written report accurately portrays their experiences and their world (Hutchinson, 1990). The six participating families were given this option but exercised their right to decline to do so.

Internal Validity

Woods and Cantazaro (1988) point out that in exploratory designs the investigator does not exert a great deal of control over variables that are studied, therefore the accuracy of the relationship between the variables is difficult to establish. Internal validity is not considered a concern of descriptive case studies as no attempt is made to make causal statements (Yin, 1984).

External Validity/Replication

Yin (1984) answers the critics of descriptive case studies (who decry their lack of generalizability because of their basis on one event, or one or few people in a particular time or place) by pointing out that case studies have analytic generalizability. In analytical generalization the investigator attempts to generalize a particular set of results to a broader theory.

In conjunction with the pattern matching carried out between the current findings and those in the previous literature on the impact of home apnoea monitoring, in the present study the family nursing literature relevant to the home care of at-risk or chronically ill children has been used. For example, a consideration of the frameworks derived from previous qualitative studies of the experiences of parents of very premature infants (McHaffie, 1990) and of chronically ill children (Cohen, 1993) found useful parallels with the findings of the present study.

Living with "sustained uncertainty" as Cohen (1993) labelled the life styles of parents of truly chronically ill children was an apt description of the experiences of the parents of the present sample of parents of monitored infants, albeit for a limited rather than indefinite period of time. Similarly, the stories of monitoring parents of infants born prematurely demonstrated several areas of common experience. Thus, findings from the present study were congruent with those of previous research studies about the caregiving experiences of at-risk children in a variety of situations.

Yin (1984) adds the rider that analytical generalization should go on to lead to testing of a theory in a second or third setting. If the results are then replicated they would be acceptable for a much larger number of similar settings. The replication logic he is describing here, is the same as used in the selection of multiple rather than single case designs.

Reliability

Guba (cited in Hutchinson, 1990) emphasises that in qualitative studies, certain types of reliability must be violated to gain understanding in different settings. Unique questions must be asked of different subjects, for example and the researcher's approach adapted to the style of the informant. Nevertheless, in multiple case designs it is possible to achieve a sense of the reliability of the study by looking at the range of responses given by the informants within the study. If informants gave vastly differing accounts of what it is like to live with a monitored infant, then obviously questions would need to be asked as to why this was so and no assumptions could be made that if the study was replicated, that there would be common experiences. In the present study, informants' stories not only demonstrated congruence with the reported experiences of other monitoring families in the literature, but also showed similarities with each other in many areas. Chapter nine, which presents cross-case comparisons identifies these in more detail.

Ethical Considerations

The rights of participants were protected in the following ways:

1. Informed consent was obtained (sample consent form appended) after full explanation of the purpose of the research was given and data-collecting procedures outlined.
2. Times for interviews were negotiated with participants, to minimise intrusion on family life. Interviews were held in the participants' homes.
3. Participants were advised of the right to decline participation, to withdraw from the study at any time or to withhold any information they felt unwilling to share. The option was given for participants to review transcripts of the interviews to check their validity. This option was not taken up but one father asked to read a copy of the completed thesis.
4. Anonymity was assured with code numbers not names used on data transcripts. Audiotapes were erased at the completion of the study and diaries remained the property of the participants. Participants were advised that every effort would be made to ensure that identifying details such as names and occupations would be disguised in the final thesis document.
5. The researcher informed participants that her involvement with the family would be focused on the research questions. Advice or solutions to problems were not offered, but if the researcher was concerned about the well-being of the infant or caregiver she suggested the opinion of the Paediatric Community Nurse, family doctor or Paediatrician be sought. This action was considered necessary because the researcher, as a Registered Nurse with experience of working in a Neonatal Intensive Care Unit, may have been viewed by participants as

a health professional qualified to give advice on home monitoring, a role inappropriate in this investigation.

It was acknowledged that the purpose of the study was not to evaluate the efficacy of home apnoea monitoring, but to examine the experiences of parents who care for infants on home apnoea monitors. Particular care was thus taken to ensure that the researcher did not discourage any participant from using a monitor, recognizing that the responsibility for advising parents on the necessity of their use must rest with the competent medical authority.

6. At the completion of the study, participants were invited to attend a debriefing session which would address any unresolved concerns and convey the preliminary findings of the study in a comprehensive form. However, none of the participants felt they needed to accept this invitation, preferring to leave the opportunity open to ring the researcher to discuss any aspects of the study that they wished to have explained.
7. Prior to recruitment of subjects approval to undertake the study was obtained from:
 - (i) the Massey University Human Ethics Committee;
 - (ii) the Ethics Committee of the local Area Health Board; and
 - (iii) the Manager of Paediatric Services for the local Area Health Board.

Summary

This chapter has outlined the methodological issues concerned with conducting case studies. The rationale for the choice of the descriptive case study approach using a multiple case embedded design has been presented along with details of recruitment of participants and data collection and analysis. Issues of reliability and validity and of ethical concern have been identified and addressed.

In the following chapters (chapters three to eight inclusive) each of the participants' experiences with monitoring an infant at home will be presented and discussed. Chapter nine will draw the threads of the stories together making cross-case comparisons. Conclusions will be drawn in chapter ten with suggestions made about the implications of the findings for nursing practice and for further research.

CHAPTER THREE

Case Study One

Family Profile

Jane and Sean are a European couple, in their mid to late thirties. Married for four years, they have two children, Ashleigh, aged 20 months and Andrew aged 12 weeks at the time of the first interview. Jane's teenaged children from her previous marriage also live with them - her son Johnny (13 years) and daughter, Kim (15 years). Their natural father lives overseas and does not keep contact with them nor contribute financially to their upbringing.

Sean, at the age of 37, is nearing retirement from the Armed Forces. The family was awaiting confirmation, when first contacted, of a transfer to a base near a major New Zealand city. Both Sean and Jane saw this a convenient move as employment opportunities for Sean would be greater than in the small rural town where the family had lived for the last two years. They were considering starting a small business with the money payable to Sean on his retirement. The older children were also looking forward to living in a large city.

Baby Andrew had been on a home apnoea monitor for three weeks at the time of the first interview. He had been born at full term, weighing 3kg and had appeared to be healthy on discharge from the maternity unit. Shortly afterwards he had developed a "rattly" sound in his chest and at the age of nine weeks was thought to have had an apnoeic episode. Following one night's hospitalisation, he was sent home with a Graseby MR10 monitor.

Jane's Story

Jane was never quite certain what had happened to Andrew the evening he had apparently stopped breathing. She had been concerned for some time about the noisiness of Andrew's breathing and described it as a rattly noise in his chest, as though he had phlegm in his upper respiratory tract that he was unable to cough up (1/1/5). On that particular evening, Jane was busy in the adjoining room to where Johnny and Kim were entertaining Andrew. Johnny was using his foot to rock Andrew fairly vigorously in the bouncinette, when he suddenly noticed that Andrew was having difficulty breathing. He called out urgently to his mother to come quickly. As Jane described it:

...he was all red and his arms were back like this [arms stretched out tightly at his sides] and he'd stopped breathing. It was as if he was fighting for breath

(1/1/1).

Jane picked him up out of the bouncinette "in one foul swoop" (1/1/2) and found his breathing resumed and colour returned to normal almost immediately. Jane contacted the doctor who advised her to take the baby to the hospital, thirty minutes' drive away, and Andrew was admitted for overnight observation. The Paediatricians, Jane said, had checked him over carefully and recommended that they used a monitor. Before Andrew's discharge the next day, Jane, Sean, Kim and Johnny were all shown how to do CPR and they were given a written sheet with step-by-step instructions for infant resuscitation.

Although Jane had completed two years' nursing training in her late teens, she did not feel competent to do CPR and for the first few days of monitoring she kept Johnny or Kim home from school to act as a support person who could phone for assistance if another crisis situation occurred.

Jane continued to be uncomfortable with the monitoring throughout the three month period that the family was involved in the study. In the first

three weeks they had called on each set of grandparents to come and stay in the house with them. Sean's mother was trained in the St John's Ambulance services and they found her presence reassuring. In fact, they stated that she was one of only two people with whom they would leave the baby, the other person being Jane's father who had been involved in the military medical corps. However, the grandparents lived six to eight hours' drive away and were unable to stay for more than a few days at a time.

From the beginning of monitoring, Sean and Jane used the monitor only at night. This was for two reasons. Firstly, neither Ashleigh nor Andrew slept much during the day and secondly, because Jane was not comfortable with monitoring whilst Sean was out at work during the day. Typically, Andrew would be put to bed in his cot, in his parents' room about 6pm with his monitor on. Jane did not feel it was necessary to use it when travelling in the car as Andrew could easily be observed when sitting in his carseat.

Although Jane described monitoring as "fine" (1/1/8) this description appeared to contradict the account she gave of its impact on her daily life. She and Sean both believed that to monitor the baby effectively, there needed to be two adults in the house. Jane was unsure if she would awaken if the alarm went off at night. Having had busy days caring for two little children who did little more than "catnap" for ten minutes at a time during the day, then with her evenings taken up with completing household chores and spending time with her teenagers, she was often exhausted at night. She felt she could sleep soundly if she knew that Sean was there to attend to Andrew if he woke or if the monitor alarmed.

Jane was unable to face the thought of a night in the house alone with the monitor. She became so distraught when Sean's turn to be on call at night "on base" was imminent that the Armed Services staff allowed Sean to sleep at home and instead be available by phone. Jane believed that if this concession was not made, she would have had to stay awake all night keeping guard over Andrew.

There were very few alarms with Andrew's monitor. On the occasions the monitor did alarm, they found it was because the sensor had come unstuck or the sensor lead was kinked. Jane admitted that she became blasé about the alarms. Although she would respond to them if they occurred before she went to sleep at night, she didn't really expect to find anything but a mechanical fault.

As the weeks went on, Jane became more aware of the restrictions on their social life which resulted from their decision not to entrust Andrew's care to any babysitters other than the grandparents whilst he was monitored. She found it frustrating not being able to go out anywhere with her husband without taking the baby as well and stated that her older daughter, Kim, could cope with babysitting if there was no monitor. Indeed Kim often minded other people's children to earn spending money.

Jane's sense of isolation with caring for the two younger children was evident. When Andrew was five months old she admitted to feeling "fed up" with the monitor and stated she would be quite happy to give it back:

I've said to [Sean], "You've never had them [Ashleigh and Andrew] on your own - you wouldn't know!" He thinks it's easy. But I never get any time to sit down by myself. Five months without a break...I'm getting cranky alright. I'd say, "I've had enough of this!"

(1/2/6).

Jane felt that the burden of caring for the children was mainly hers. Although Sean did put Andrew to bed in the evening with the monitor on, and did tend to him if he woke in the night, he had not been left alone with Andrew without Jane there as a back-up.

She believed that Sean regarded the monitor as essential. Although she herself knew it was important for Andrew to use it, she reported that paradoxically she would leave the baby with someone else or stay in the house at night by herself with Andrew, if the monitor was off:

I think if I turned the monitor off I'd be alright. It's just that it's there.....it doesn't usually worry me if [Sean]'s there, but if I start to listen to the damned thing, I'm terrible! It's like it's always reminding me that something might happen...With a monitor you wouldn't go out at night. That makes it hard unless my mother-in-law's here. Isn't it awful, but if they asked for it back, I think I'd just go! It doesn't make sense. With the monitor there, there's always that threat hanging over him.....I'd be happy to give it back. But [Sean] might say it's my fault if something happened to him and I'd made the decision to do it

(1/2/4).

The decision to stop monitoring had not been made by the time Andrew was five months of age. Jane's feelings of frustration with the monitor were partly because she was unsure what had caused the initial apnoeic episode. She wondered if the rocking movements had dislodged a plug of mucus in Andrew's chest and caused him to choke. If that were so, she believed that as he got older the likelihood of this happening again was small. Yet she sometimes had vivid dreams of having to resuscitate the baby. One night she woke up Sean in the middle of the night having had one of these dreams, and asked him to go to the lounge and check that the CPR instruction sheet was still displayed on the wall unit.

The financial aspects of monitoring were of concern to Jane. With only Sean's income to support the family, she budgeted very carefully. A major family upset had occurred shortly before Christmas, when Johnny had been tinkering with the monitor and accidentally dropped it. Very conscious of the contract signed when the monitor was issued, which stated that accidental damage must be paid for, Jane was furious with Johnny:

We said to [Johnny], "It's all your fault!" Poor [Johnny] they've never seen me so mad! I said, "Right, that's Christmas gone! That's it, you're not having Christmas, no money left!" I was imagining all the dollars it was going to

cost. I thought, "That's all we need"...We don't have much money - I don't get maintenance from the older children's father...

(1/1/6).

Johnny took the full brunt of their anger and anxiety, which turned out to be unwarranted as the monitor needed only minor repairs.

The anticipated shift to another part of the country caused additional concerns about the financial aspects of monitoring. There had been recent publicity about a family in another city who had to pay to rent their monitor and Jane was worried they would not be able to afford the rental. When Sean investigated the cost of purchasing their own, the price was prohibitive and out of the question for them. They wondered whether to just take their present monitor with them when they moved and to return it when they had finished with it.

Support services were available to Jane and Sean if they had chosen to use them. Jane had telephone access to the Paediatric Nurse who supervised the monitoring programme and had received two or three visits in the early weeks of monitoring. She had been given the names of two other families in their rural area who also were monitoring, but felt no inclination to contact them.

What Jane did find disappointing was the lack of contact with the Plunket Nurse in her area. She found the Plunket Nurse knew little about monitoring and on the few occasions the nurse had seen Andrew, she had carried out a routine assessment of the child rather than met Jane's felt need for information about current childrearing practices:

They [Plunket Nurses] are so busy these days. I think when it's your fourth baby they're a bit casual. You just sort of go for the weight. But every baby's different. There're a lot of things I'd like to ask, probably quite stupid things! Like I couldn't remember about mashed bananas - you're not

supposed to give them that too young, or avocados, you know?

(1/2/7-8).

Jane found that the person who provided her the most emotional support was her mother-in-law. She reassured Jane that her mothering abilities were more than adequate and spoke to Jane of how Sean, too, had slept very little when he was small and of how she appreciated the amount of energy required to care for the two younger children. She understood how Jane found the presence of the monitor frightening and Jane told of how she took comfort from her mother-in-law's words:

As his [Andrew's] grandmother said, "You can't do the impossible. You can only do your best". And she loves her grandchildren...

(1/1/8).

and later:

She said, "You can only do so much. You can give them all the care, but... [trailed off].

(1/2/4).

Sean's Story

Sean's story focussed more on the everyday use of the monitor, than did Jane's. Sean did not speak at any length about the restrictions to their social lives, although he commented:

We've hardly been out since [Andrew]'s had the monitor. We wouldn't leave him with a babysitter or anything like that

(1/3/4).

Sean felt that if monitors were reasonably priced and readily available they should be used by all parents, up until their babies were six months old, or at least old enough to roll themselves into a position where they could clear

their airways if they were obstructed. He believed that Andrew's "nasal problem with phlegm down his throat" affects other babies as well and monitors would let parents know their babies were experiencing difficulty:

I think it would be a good thing, if they could be a lot cheaper than they are, if everybody could have them. They should be routine for babies up to six months old. To give the parents a greater sense of safety

(1/3/1).

He was very aware of the need to listen for the monitor alarm and like Jane, believed there needed to be two adults in the house:

[Jane] gets really tired and she could easily sleep through it. Like an alarm clock. They do say the monitor sounds like this thing and that thing - but there's one ad on TV - the first time it came on, [Andrew] was in bed and [Jane] and I both thought it was the beeper going off. I went racing out to the hallway...you're always conscious of that noise...You can be outside and hear the microwave and you rush in...you're always conscious of it

(1/3/4).

Sean described his typical response to an actual alarm as:

Panic! Basically, give him a shake to make sure he's still breathing. Check to make sure. Then when he's alright, check what's set the monitor off...

(1/3/5).

then, despite his assertion all babies should be monitored:

Oh, it's been an experience that I wouldn't wish on to anybody!

(1/3/5).

As Sean was the parent who put Andrew to bed with the monitor on, he spoke of the technical aspects of monitoring. He had discovered by trial and error, that alkaline batteries were needed so the battery charge would be

constant rather than gradually wearing down. Sean found that as Andrew got older, he was tending to pull on the sensor lead, disconnecting it from the monitor and also lifting it from the tape which held the sensor onto the skin. This had caused skin irritation and he was now trying a belt to hold on the sensor instead. He observed that supplies of spare sensor leads were difficult to obtain for them, not living in the city area, and proposed that stocks should be kept by Plunket Nurses and chemists to avoid the need to make a special trip to the hospital to obtain them. Sean noticed that kinks in the sensor lead caused alarms to occur:

A bit of education about these things is what parents need. Now we've got the belt, we've got to put a loop under the nappy, like this to stop it getting a kink

(1/3/8).

He commented that although they had the monitor for Andrew, they still checked him far more often than they had checked Ashleigh at that age and were more conscious of avoiding the known risk factors for cotdeath. The monitor provided him with a sense of security that they would be warned if Andrew was experiencing any difficulty with his breathing. He was surprised when he was asked if he was ever concerned that the monitor would not alarm when it should and replied that the thought had never crossed his mind (1/3/5).

Sean was relieved to find Andrew was "growing out of his rattliness in his chest" (1/3/8) and attributed the cause to a local allergen:

When we took him to the hospital, they weren't concerned about his rattling. Three of them [doctors] - none of them was bloody well concerned about it. We pointed it out and they sort of said, "Oh, yeah". But I think it's probably because they realise it's a [district] problem. But people who are not from the area don't realise it.

(1/1/9).

His assessment of the risk status of the baby appeared to be related to Andrew's ability to cough up any obstruction. He believed that by six months of age most babies were capable of clearing their own airways but was unsure how long to continue monitoring Andrew. No mention was made of obtaining a medical opinion about the necessity for continued monitoring. Rather, he commented:

You can't put an age on it - it's up to the parents to decide
(1/3/1).

The dilemma about what to do about retaining the monitor when they moved from the area was very real. The financial costs of monitoring were mentioned several times but the need to keep the baby safe was paramount:

The cost involved is not important. You can't say, "I can't afford a monitor". It should become your first priority when your kid's life is involved

(1/3/7).

Sean, recognising his own dependence on the monitor, concluded:

We're used to having it there as security. I'd still like about a year - but then I think I'll probably go out and buy my own one! [laugh].....It's a good thing to have...

(1/3/4).

Discussion

For Jane and Sean, home apnoea monitoring compounded the levels of stress already experienced by a family undergoing several of the five areas of transition identified by Parkes (cited by Rankin, 1989, p.175) as requiring major reorganisation of life space, namely:

1. changes in personal relationships
2. changes in roles and status
3. changes in familiar environment

4. changes in physical and mental capacities, and
5. changes in loved possessions.

The family, because of the nature of Sean's employment, was anticipating their third relocation in the four years that Sean and Jane had been together. Their social support networks were not well developed and they did not have easy access to the grandparents, the only people they trusted to help them with monitoring.

The shift to a large city, in itself a major undertaking, was to be the first step in a series of changes for the couple. Sean was to leave the relative security of his long-term position in the Armed Forces and needed to plan for his future. The decision to set up a family business would mean that Jane's role would need to change from full-time mother and homemaker, to an active partnership in the business. Although the family was looking forward to living in the new area, there was a certain amount of uncertainty about their futures - for the older children for example, there was the prospect of new schools and friends, and for Sean and Jane, the practical details such as the need to purchase their own home when the rental housing supplied by the Armed Forces was no longer available.

The prospective move accentuated the couple's need to decide whether the monitoring was still necessary. They faced the dilemma of whether to act dishonestly and take their hired monitor out of the district, or to return it and take the chance that Andrew would not have another apnoeic episode. Alternatively, they could hire a monitor in the new area for some unknown sum, a financial commitment they were unwilling to undertake.

Financial considerations affected the family's lifestyle in several ways. An underlying tension was detectable about the financial strain felt by six family members living on one modest income. The fact that Jane's previous husband had absconded from his parenting responsibilities was mentioned several times. Day to day living within their limited budget required careful management and the episode with the broken monitor was seen as a crisis

situation. The possibility of insurance cover for the monitor was not discussed.

The births of the two younger children had necessitated changes in the structure of the newly established blended family unit. Sean had had no previous experience of parenting and Jane believed that he did not appreciate how demanding it was caring for the two little ones all day within the confines of their home. Jane expressed no lack of confidence in her ability to care for her teenaged children but it was evident that at times she found the responsibility for the care of the younger children overwhelming. Neither Jane nor Sean had made reference to the way in which monitoring might have impacted on the older children, Johnny and Kim. Although Jane spoke of how she had kept them home from school on occasions to act as resource persons and been so angry with Johnny for breaking the monitor, she was more aware of the impact on her own lifestyle and that of her husband, rather than of any indirect influence on other family members.

It was noteworthy that Jane did not take up the offer of contact with other monitoring families in the area but that she expressed the need for reassurance about her parenting abilities and practices. She was dismissive of the Plunket Nurse's role, regarding the Plunket Nurse as someone too busy to be concerned with the apparently trivial issues which bothered her.

Sean's mother, on the other hand, was able to play a supportive role for the family. Her credibility was established by her training in first aid, and her ability to give practical assistance and vital reassurance was appreciated. Jane was especially heartened by her mother-in-law's comments that Jane was doing everything practicable to ensure the baby's survival. This affirmation of her parenting skills by someone who also had an emotional tie to the baby, was a positive experience for Jane. Wright and Leahey (1987) recommend this same strategy of commending and reaffirming family members' competence as an effective nursing intervention in situations where low self-confidence and self-esteem are evident.

Similarly, Williams and Williams (1990) caution health professionals dealing with monitoring families that they should not assume that parents most needing help will ask for it. They advise that particular attention should be paid to the self-esteem of the child's caregiver and that the monitoring experience be positively reframed to support parents through what can be perceived as a long-term ordeal. It has been well recognised that monitoring can lead to parents feeling less confident to manage their child's care (Wasserman, 1984; Nuttall, 1988; Williams and Williams, 1990).

For Jane, particularly, the need to have the opportunity to confide her feelings of anxiety and frustration was evident. She did not have a wide circle of friends in the area and like monitoring parents described by McIntosh (1990) she reacted to the demands of parenting a monitored infant by withdrawing from social contact with others. As McIntosh (op cit) pointed out, social isolation for monitoring parents can occur at the very time support is most needed.

Dean (1986) in a qualitative study of the social support for monitoring mothers, concluded that health professionals needed to develop ways to facilitate mothers' contact with the outside world. The focus on the well-being of the baby can otherwise result in the needs of the mothers becoming submerged, and the impact of the monitoring on their lifestyle being underestimated. Geary (1989) advises health professionals to be alert to coping mechanisms used by monitoring mothers, such as denial of anxiety and emphasising the positives and minimising the negatives of monitoring. Geary found that mothers attempted to construct their own reality about monitoring and often gave mixed messages to support persons when they would describe monitoring as non-problematic, but then proceed to cite examples of the monitor's negative impact on their daily lives.

Jane's use of these coping strategies was evident and her descriptions of her feelings of reluctance and ambivalence about monitoring reflected also those reported by parents in studies by Dean (1986) and Black, Hersher and

Steinschneider (1978). Dean, for example, found that the presence of the monitor intensified feelings of responsibility for the child, particularly to keep the child alive. Black, Hersher and Steinschneider (1978) wrote of how parents described monitors as "necessary evils". Without the monitor, there would be much guilt if anything adverse happened to the child, yet its very presence was a reminder of the threat of the child's possible sudden death. Geary's respondents (1989) reported simultaneous intensity of watchfulness for the baby and emotions such as "You can't tell me anything is wrong with the baby - s/he looks too healthy".

The same dissonance was evident in Jane's story. She spoke of how she didn't expect the baby to be apnoeic when the alarm sounded and was "blasé" in her responses to the alarm, yet she was unable to be left alone with the monitor, somehow illogically perceiving the child to be more at risk with the monitor than without it. The presence of underlying anxiety was also evidenced by her repeated dreams of having to perform CPR on the baby.

Sean and Jane reacted differently to monitoring. Sean spoke several times of his immediate reaction to sounds similar to the monitor alarm and of his reluctance to discontinue monitoring despite his statement that their baby was old enough to clear any respiratory obstruction. Wasserman (1984) in a five year study of monitoring families found many parents continued to respond to noises similar to the alarm even years after the monitoring was discontinued. Wasserman's findings were that many babies were monitored far longer than was medically advised and that in subsequent interviews up to 2 1/2 years after monitoring, parents reported that monitored children were "spoiled". These findings raise concern that this group of children is indeed at risk for the "vulnerable child syndrome" (Shapiro, 1983).

Andrew had very few alarms overall, and no observed episodes of apnoea while he was monitored, yet Sean, like parents in the study by Black, Hersher and Steinschneider's (1978) admitted that he responded to alarms

by stimulating the baby before he checked for breathing. McIntosh (1990), writing about home monitoring in infants with obstructive apnoea, acknowledges that false alarms cause the parents to experience negative arousal and may lead to a distorted view of the risk status of the baby. Sean was unaware of the limitations of the Graseby MR10 monitor in cases of obstructive apnoea, and McIntosh suggests that as part of informed consent for use of the equipment, education about the limitations of the monitor should be included.

Jane and Sean used the monitor only at night despite the fact the initial "apnoea" occurred in the daytime. It was noteworthy that they regarded it as their own responsibility to make the decision about how long monitoring should be continued. Many studies have described how parents adapted the monitoring into their lifestyles (Black, Hersher and Steinschneider, 1978; Wasserman, 1984; Dean, 1986; Andrews, Nuttall and Neilson, 1987; Nuttall, 1988; Geary, 1989; McIntosh, 1990). It appears that in doing so, parents made decisions about the use of monitors which could be viewed as non-compliance with recommended monitoring policies. Inconsistent behaviour with the monitoring was investigated by Wilson, Stevens, Becker and Klinghagen (1990) who reported only 8% of babies were monitored in a way that would ensure that life threatening apnoea would receive an immediate response by the caregiver.

Sean and Jane attributed Andrew's "rattly" breathing to an allergy, yet there was an element of uncertainty about the exact nature of this medical condition. Sean was evidently dissatisfied with the level of attention paid by the doctors to their expression of concern about Andrew's noisy breathing and had made his own judgement about the seriousness of the condition. Part of Jane's ambivalence about the need for monitoring appeared to arise from the vagueness of her understanding of the diagnosis.

A recent publication by Cohen (1993) provides some relevant insight into the experiences of parents of chronically ill children. She reports that parents and doctors experience the event of diagnostic certainty quite

differently. The physician makes a diagnosis, then institutes formal therapies selected from a limited number of medically indicated choices. The parent however, only views the diagnostic certainty as an answer to the question, "What is wrong with my child?" No sense of closure is experienced, and the parent typically feels fear as countless unanswerable questions spread to every aspect of family life. The parent is faced with uncertainty and fear of the unknown.

To deal with their sense of fear and uncertainty, Sean and Jane had developed several of the strategies that Cohen (1993) found parents of chronically ill children used, namely transforming information, keeping a constant vigil over the infant and managing their awareness of the problem.

Because they had difficulty understanding the diagnosis of the baby's "noisy" breathing and supposed apnoea episode, they modified the "probabilistic diagnosis" (Cohen, 1993, p 90) by gathering information they felt was relevant. By attributing the cause to a local allergen, they limited their sense of uncertainty about the condition.

To deal with the threat to Andrew's safety, Sean and Jane needed to maintain a vigil over the infant and the monitor played an important role in their achievement of this. Sean took the responsibility for waking at night in response to the monitor's alarms and Jane kept a close watch over the baby in the daytime hours.

Cohen (op cit) describes the "management of awareness" as one of the cognitive strategies parents use to lessen their awareness of the threat of uncertainty. Parents make deliberate efforts to not think about the illness and to push it to the back of their minds. Jane clearly used this coping strategy - she did not want to be reminded that her apparently healthy infant was at risk. Unfortunately, the presence of the monitor hampered her attempts to normalize her life and to ignore the unpleasant possibility that Andrew might die of apnoea.

Cohen (1993) points out that the ability of the family to manage the stress of sustained uncertainty is likely to have long-range implications for the well-being of all the family members and quality of their family life. The conclusion of many studies of the effect of monitoring on family life is that monitoring is indeed stressful but that its negative impact can be moderated by a high level of social support (Wasserman, 1984; Dean, 1986; Nuttall, 1988; Geary, 1989; McIntosh, 1990, for example).

Sean and Jane did not have ongoing support from family and friends living locally, and would perhaps have benefitted from more professional support and intervention.

CHAPTER FOUR

Case Study Two

Family Profile

Baby Sarah was born to Diane and Alan, a well-educated professional couple in their mid-thirties. Diane and Alan insisted that an apnoea monitor be provided by the hospital from the time of Sarah's birth - in fact, Diane refused to give consent for the Caesarian Section delivery of her infant until a monitor was located and ready for use. Monitoring continued until Sarah was fifteen months old.

Sarah was the couple's third child. Their elder daughter, Amy, was nine years old at the time of the study. The second child, a son, had died from cot death four years earlier at the age of five months. At that time the family had been living in the South Island and the parents felt the cold weather in the district was a contributing factor to the death of the baby.

Diane and Alan employed an assistant, Cathy, to help with various tasks in their home. Cathy spent half her working hours doing office work for Diane, who was self-employed and worked from home, and the other half assisting with household chores and childcare. The three adults were all involved with Sarah's care and each agreed to be interviewed about their experiences with monitoring.

Diane's Story

Diane is an attractive, well-groomed woman who spoke confidently and articulately. She talked at length about the loss of her son who had been a bonny, healthy little boy and died during his afternoon sleep having shown no signs of anything being amiss. However, two days prior to his death he

had been given his routine vaccinations and on the day he died his daily schedule had been altered so that he had missed his usual morning nap. He had been put down to sleep in the prone position, as was the recommended practice at that time and Diane found him lifeless an hour later. Attempts at resuscitation were unsuccessful and the ensuing autopsy showed nothing conclusive. In retrospect, Diane felt he had been an infant at risk of cot death because he was a male child, residing in a cold climate, possibly overtired because of his disrupted routine and most importantly, because his older sister Amy had experienced two "near-miss" apnoea episodes in her first four months of life, episodes which were discounted by the family's doctor at that time.

Diane described how she coped with the grieving and how for her, accepting the loss involved undergoing therapy for being "traumatised" by the sudden death. The therapist had told her that being traumatised involved being left with irrational fears about loss. Diane found that for her, it resulted in:

Just a feeling that on any day with no reason at all, your life is suddenly going to disintegrate. And that's hard. So, for me, that has taken the form of.....like, I sent my little one down to the store to get some biscuits. What would happen to me was that I would have this irrational fear that something would happen to her in those five minutes. That someone would snatch her off the street or she'd get run over

(2/1/4).

She consciously made the decision not to dwell on the question, "What have I done or not done to cause the baby's death?" (2/1/5). Although at one level she needed to know why the infant died, she also knew quite clearly that there was:

...no way I wanted my baby to die. There's nothing I knowingly did to cause that

(2/1/5).

An experience with meeting a father who was still consumed with grief and anger eight years after losing his daughter in a road traffic accident made Diane determined to move on from focussing on the unfairness of the loss and to make a conscious choice about the sort of life she wanted to live.

Diane's pregnancy with Sarah was unplanned initially, but when confronted with the dilemma of whether to continue with the pregnancy, Diane thought the issues through carefully and made her decision to do so. She knew that if the pregnancy continued she would be faced with the prospect of caring for an infant on an apnoea monitor. This was of some concern as she had looked at parents who were using monitors and felt that they were "worriers". Their parenting style clashed with her own which she described as "really relaxed and confident. I didn't worry or fuss too much" (2/1/9).

The pregnancy continued to full term despite being complicated by Diane's high blood pressure. The baby was in a breech position and the decision was made by the Obstetrician to deliver the baby by Caesarian Section. Alan and Diane, at this point, requested an apnoea monitor be ready for the baby from the time of birth, and were informed that monitors were not issued until mother and baby were ready to be discharged home. Diane sarcastically described her reaction to this:

And I thought, "What's the rationale behind that? Is there some miraculous thing about the air in the hospital so nothing's going to happen there?"

(2/1/10).

She refused to give her consent for the Caesarian Section until the hospital staff procured a monitor for them. She felt the only reason they acquiesced to her demands was because the delay in her giving her consent for the operation was holding up the operating theatre staff. Later on, when talking about the anxiety induced by "self-start" monitor alarms, Diane referred back to this incident and said:

The short self-start alarms were very anxiety-producing in the beginning. But nothing like the anxiety I experienced when I thought I wasn't going to have a monitor in the hospital. The whole idea of being left in a room with this baby was just a nightmare! I was thinking, "How long can a human being stay awake and stay sane?"

(2/2/10).

Diane reported that "alarms" started very early on, in fact from the very first day of home apnoea monitoring. She distinguished between "self-start" and "bad alarms". Bad alarms were the ones when "we had to fling ourselves at the cot or actually wake her" (2/1/12) whereas self-start alarms were when "the alarm stopped before we got there" (2/1/17). At first she kept records of the frequency of alarms. The pattern most easily identifiable in the early days was an alarm at five am each morning which Diane attributed to a shift in sleeping pattern and which she considered to be most "dangerous":

She would alarm and it would restart her but not wake her. And then you'd usually get three alarms in a row over a twenty minute period and her colour would gradually change. And what I took to doing was, if I'd had a series of alarms within ten minutes of each other, I'd wake her... I always felt those were quite dangerous - that she was drifting down and down - yeah.....I used to sometimes sit and watch the alarms...

(2/1/11).

Failure to rouse and change of colour were two of the cues she used to decide whether or not an alarm was serious:

What she does is, what I've found is, that if I pull her lip down, she's put her tongue up and covered her airway through her mouth. It's like she's stuck her tongue onto the roof of her mouth. There's no way air can get through there. And I look at her ear colour. That's my gauge

(2/1/17).

Bad alarms could occur as frequently as four or five times in a two-week period. In a "good" week, there could be as few as three alarms overall. However, in the worst weeks as many as eight alarms could occur within the space of twenty-four hours. Diane said she knew of other people who reported only two alarms in nine months.

She attributed Sarah's very high rate of alarms to a "genetic breathing pattern" in the family. Her older daughter, Amy, often held her breath during sleep and a grandmother did the same thing. After her son's death, Diane found she was continually checking on Amy:

to see if she'd die in the night, even though I knew she wouldn't. And one of the things about that, that was completely heart-stopping, was that she holds her breath. I've actually counted to twenty-five with [Amy] before I've seen any kind of breath at all

(2/1/13).

At the time of the first interview, Diane was asked what the Paediatric medical opinion was about Sarah's "alarms", to which she replied that the baby was not currently under a Paediatrician's care and had seldom been seen by the family's General Practitioner (G.P.). She had, however, asked the visiting nurse to organise an appointment at the Paediatric clinic later that week. Further probing about the reasons for the absence of medical supervision to date, elicited the following responses:

- (a) As a precaution against cotdeath, Sarah had not been taken to the G.P. for routine vaccinations, because the previous baby had died shortly after receiving vaccinations. Sarah's general health was good and she suffered no illness which had necessitated medical intervention.
- (b) An appointment for the baby to be seen by a Paediatrician, had not been made, nor suggested by the health professionals who issued and supervised the use of the monitor.

- (c) The parents were not aware of anything that the medical profession could do to either prevent the alarms or treat the apnoea episodes and they were reluctant to submit their baby to any unnecessary medical procedures which in themselves would pose a threat to the infant's well-being.
- (d) The responsibility for keeping the baby alive was perceived to be that of the parents, with emotional support from the visiting Paediatric Nurse.
- (e) The general health of the infant in the early months of life was closely supervised by the Plunket Nurse. Diane kept a graph of Sarah's weight and was quick to take action to feed her more if any weight loss was evident. However, as Sarah got older contact with the Plunket service ceased as Diane felt their new nurse knew little about home apnoea monitoring and was too busy to be of any help anyway.

Diane used several different types of monitor in the fifteen months she monitored Sarah. She soon obtained an alternative model to the Graseby MR10 monitor issued by the hospital. This was partly because of technical problems with keeping the sensor attached to the baby's skin and partly because the audible clicking sound could not be muted:

What happens, I find, with those kinds of little clicks, is that you start to listen to the click and I found I'd hear the slowing down of the breathing and be anticipating the alarms...if you're going to listen for it, it's pointless

(2/1/14).

Although she accepted that anxiety caused by "self-start" alarms was stressful, she trusted the monitor to alarm if a problem arose with the baby's breathing:

I thought it was going to be an emotionally very, very anxious time - that I'd be living on adrenalin all year - have

that sort of.....gut-wrenching kind of fear sitting in the top of my chest all year.....I was so very scared. But there was a point at which I'd had to say, "that is the technology available - it is the monitor's job to give me the warning"

(2/2/8).

The family's lifestyle was dramatically affected by the monitoring. Diane spoke of the need to have someone actually in the house listening for the alarm to sound. This, of necessity, restricted noisy activities to times when at least two people were in the house. If one was listening to music, for example, the other listened for the monitor. Out of the house activities such as gardening or working in the garage could only be undertaken if someone was inside listening. On occasions Amy was persuaded to stay indoors and read and to notify Diane or Alan if the alarm sounded. They found that with two adults in the house, each could assume the other was listening for the monitor and both could wander out of earshot of it. The solution to this problem was to report to each other, "I am listening for the monitor now" (2/2/13).

Finding babysitters was a major problem. Potential babysitters were very few as their criteria for a suitable sitter included willingness to take responsibility for a child who could become apnoeic, and possession of knowledge of infant resuscitation methods. In addition, the person needed to be someone Diane and Alan felt would be honest enough to admit it if they did not feel competent to care for the child. Although Cathy was available weekdays to help Diane with Sarah's care, time out for the couple on their own throughout the year was limited to only one or two evenings. In Diane's words:

The stress on everyone in our immediate family and on our relationship was enormous...It's that unrecognised stress over a period of time...One day we were talking about that and it's a very different kind of stress to being.....When [baby son] died, it was very obvious that we needed help and everyone sympathised. And in this circumstance you need

help! But because you're not weeping and you don't have an empty crib, people don't see it in the same way. But you need help! People get bored with the idea that you're needy over such a long period of time. And I don't want to ask for help...

(2/2/12-13).

Although Diane was aware of the existence of support groups for parents of infants on home apnoea monitors and had limited contact with members over the year, she found the groups' input was unhelpful for her, personally. She was unwilling to surround herself with people who had had recent similar losses and who were still working through their own grief - "they were the 'walking wounded' basically" (2/1/15).

When Sarah was eventually seen by the Paediatrician, the consultation appeared to be the trigger for the decision made by Diane and Alan to stop monitoring. The Paediatrician, Diane said, confirmed their belief that theirs was a particularly high alarm rate. He offered to monitor Sarah for a time with sophisticated recording equipment which would give hard data about Sarah's cardiac and respiratory status. When examining Sarah, the Paediatrician detected a heart murmur which he indicated was of doubtful significance but should be followed up by further investigations.

When asked how the decision to stop monitoring was made, Diane responded:

...our technology started playing up. Both our mattress monitors kept alarming all over the place. And I don't know if that's because of springy floorboards in the older house, or the baby's weight, or what...And the difficulty in attaching the monitor [sensor] to her meant we were risking actually waking her and making her overtired and much more vulnerable...[Alan] was ready long before me...I'd been away and he'd stopped monitoring during the day.

However, when I got back, she went back on the monitor - because I was here! [laugh]...One night, I just said, "Let's try it tonight!".

(2/2/1-2).

She went on to explain her view that monitoring needed to be done day and night to be effective - her son had died during the daytime hours. Her decision to agree to stop monitoring was partly because of her belief that night-time only monitoring was futile and partly because of Alan's desire to be "technology-free" and rid of his constant irritation at the alarms. Alan, she stated was a lot more optimistic than she was herself:

I am always more cautious, more prepared to believe the possibility of disaster

(2/2/3).

A noticeable reduction in the number of alarms was reported after the visit to the Paediatrician and Diane debated whether to proceed with the on-line monitoring offered:

So I rang Dr [] and I said, "Look, what do you think?"
And he said, "It's not worth it".

(2/2/7).

Although Sarah's monitoring was discontinued by the time she was fifteen months old, her parents did not return the monitor immediately. Diane felt she needed to keep a monitor in the house for another couple of months and would not hesitate to use it again if Sarah was overtired or unwell with an infection such as a cold or an earache.

When asked how they were coping without the monitor, Diane replied that they were managing surprisingly well and that she was a lot less anxious than she'd expected to be. Her assistant, Cathy, she felt, had found the adjustment much more difficult, needing to check the baby every few minutes at first.

Diane stated that although Alan had found the monitor irritating - "bloody irritating at times" - she accepted that the irritations were "part of the package, basically" (2/2/10). Although Sarah had never required cardio-pulmonary resuscitation (CPR) there had been occasions when Diane had found she had needed to be held up in the air and shaken to restart her breathing.

There's no doubt in my mind, that for us, I don't think we would have [Sarah] now, if she hadn't been monitored

(2/2/9).

Her belief that their three children all suffered from a genetic breathing pattern that made them susceptible to apnoea meant that any amount of stress from monitoring was worth it:

I'd rather have that to catch the big one!

(2/2/10).

Alan's Story

Alan's experiences with home apnoea monitoring of Baby Sarah, like Diane's, were strongly influenced by the unexplained death of their baby son, four years previously.

Coupled with the perception of the high risk status of Baby Sarah, was an underlying lack of confidence on Alan's part, in the competence of health professionals, especially doctors.

Alan emphasised that the recent publicity drive to encourage parents to lay their babies on their sides or their backs to prevent cotdeath, contradicts the medical advice that he and Diane followed when they were taught to lie their baby son prone, much to the opposition of their own parents:

Our parents said we should lie baby on its side or back and we said, "No, no! Plunket Nurses say medical opinion says you've got to do it this way". And at no point has anyone

from Plunket or the medical profession said, "We are at fault for wrongly advising people". They just haven't fronted up and accepted that responsibility...it is one of the things that makes you feel anger...Anger is one of the feelings I've had in relation to this, 'cos it was so unexpected and so unfair

(2/3/3-4).

Alan believed that the health professionals with whom the family had contact, took a very casual approach to the monitoring. He found there was a lack of understanding of the feelings of parents who had lost a previous baby through cotdeath:

...we really had to make a fuss to have the baby monitored after the birth. I guess the professionals in the hospital didn't realise the emotional state we were in over the baby being safe - the need for the baby to be monitored. You did get the sense you were being treated as slightly - you know - a fusspot...A number of cotdeaths occur early in life and there didn't seem to be any awareness of that or any effort to accommodate our anxiety

(2/3/1).

The attitude projected, in his opinion was "...ordinary baby, ordinary parents - get out there and get on with it!" (2/3/1).

The need to keep the baby safe was of paramount importance. Alan stated that the monitor, at one level, gave him a sense of security, in that he was confident it would alarm if the baby stopped breathing. Yet, he also had a strong sense of the vulnerability of all people, especially little children (2/3/4) and the monitoring of Baby Sarah emphasised this:

There's a sense of responsibility for the life of this child - which every child has - but with a child on a monitor, it is magnified a hundred times. That sense of, "If we do this and the baby dies, how will we feel having done that?"

(2/3/11).

He admitted to a shared sense of guilt over the death of their baby son and still questioned whether the child would have died if they had lived their lives differently. Alan and Diane had tried to give Baby Sarah the "most stress-free year that a child could have" (2/3/10). Long journeys, aeroplane trips and holidays were avoided, and the daily schedule was adhered to as much as possible to avoid "stressing" the child. Looking back on their lifestyle, after monitoring had been discontinued, Alan stated that seeing other people living their lives in an ordinary way, made him realise the restrictions they had been living under. When monitoring was stopped, he stated, his fear that the baby would die of cotdeath faded and merged into the:

more general fear about how vulnerable children are, anyway. You know, being hit by cars, bitten by dogs, ripped off by a stranger, pouring hot water over themselves - to me it's kind of taking place within that range of accidents that can happen to children

(2/3/13).

Living with the monitor, for Alan, was very stressful. "It was like having a ball and chain around your leg, really. You can't leave it" (2/3/8). The need to be within earshot of the alarm was a considerable imposition on their lifestyle, "constantly listening and constantly watching" (2/3/8).

The relationship between the parents was strained by the monitoring for several reasons. Firstly, the fact that obtaining babysitters was such a problem meant they had virtually no time out together as a couple. Secondly, the inability to tell whether alarms were genuine apnoea episodes or not led to some debate between them. Diane was more inclined to fear the worst and Alan would deliberately "play the alarms down" to compensate for her reactions. His reasons for doing this were partly to reassure Diane, whom he felt was over-responding, and partly to convince himself that they were not real - "I just didn't want to believe that the baby was having this number of real alarms" (2/3/9). Thirdly, alarms occurring at

night meant the family suffered sleep disturbance. Alarms regularly sounded at 5am but not uncommonly they also sounded three or four times a night. At such times, Alan said, the parents could be awake for up to an hour from the time they'd leapt out of bed to respond to the alarm, because the baby would then be roused and needed to be changed and breastfed before resettling to sleep.

Alan's typical response to an alarm sounding was to go to the baby as quickly as possible. If the alarm stopped sounding by the time he reached Sarah, he would check that she was still breathing. If the alarm was still ringing, he would shake her until she stirred or gave a "startle" response. Although he had never had to resuscitate the baby with CPR he did believe that at times she had stopped breathing. On many occasions it was difficult to tell whether or not it was a false alarm.

When questioned about his reasons for not seeking medical advice about these episodes, Alan, like Diane, did not know of anything that could be done for Sarah. The problem was seen as a developmental phenomenon which could only be dealt with by time. He had been unaware of the on-line recording equipment which was available to investigate the alarms and regarded hospitals as dangerous places for infants. The message that Alan felt had been conveyed by the hospital staff, was that:

...this is just a baby on a monitor. You know, the monitor's going to go off sometimes and sometimes it's not. There wasn't a sense that if it went off, this is a medical emergency

(2/3/6).

Like Diane and Cathy, Alan distinguished between bad and self-start alarms rather than between alarms and apnoea. Although there was discussion among the adults about what had happened when the alarm sounded, more often than not, they could not tell whether an apnoea episode had occurred or whether a mechanical fault was to blame.

His decision to stop monitoring was associated with some ambivalence. Although he was unwilling to risk taking her off the monitor, he was aware that monitoring had to stop sometime. The monitor alarms were tending to wake Sarah up and causing her to lose sleep and she was at an age when she could disconnect the monitor herself, setting off an irritating series of alarms. He reached the stage where he was aware of the intrusion of the monitor into the family relationships:

You want to have an ordinary child. An ordinary relationship with your child - it really gets in between you and the baby. Twenty-four hours a day.....

(2/3/17-18).

Alan believes counselling should be available for couples before discontinuing monitoring, to enable them to talk through issues such as, who would be blamed if they took the baby off the monitor and the baby subsequently died. He and Diane did talk it through between themselves but he felt they would have benefitted from the opportunity to have had formal counselling. Although he was checking Sarah frequently in the first few days the monitor was not used, he found they "adjusted really rapidly to her being off it - we just check her like a normal baby now" (2/3/13). He feels that support of parents with babies on apnoea monitoring needs to be provided by professionals who have time to spend with the family. Although they were visited by the Paediatric District Nurse and previously by the Plunket Nurse, he found these services were not geared towards families under a great deal of stress.

The consultation with the Paediatrician confirmed his belief that "you never know where you stand with them" (2/3/13). When Sarah was found to have a heart murmur, Alan described it thus:

"Oh, she's got a heart murmur". And you go, "Oh my God, a heart murmur! What does that mean?" It would never occur to you that your child would have a heart murmur! And then they say, "Oh, it's alright, it's quite normal, it's nothing to worry about...We're going to check it out, just in

case". So, you get this whole raft of mixed messages where you simply don't know whether to worry or not worry...But I think they simply haven't got to grips with the idea that they simply have to share information with people. They've got to have some faith in people's ability to respond to information and people tend to take things much better if they know what's happening...It may be nothing, it may be something.....

(2/3/13-14).

Cathy's Story

Cathy is the mother of three children, two teenagers and an eleven year old. She has been employed as a personal assistant to Diane since Sarah was eleven weeks old. Although her time is paid as half for office work and half for childcare assistance, she finds the tasks are mingled throughout the day. Her own children had never suffered from apnoea attacks or anything similar.

When her employment was confirmed, Cathy was instructed in CPR by the Paediatric Visiting Nurse and felt confident she could carry this out if the occasion arose when it was needed. She found the burden of responsibility for caring for someone else's child was heavy. The first few weeks she found the "bleeping" sound of the monitor reassuring and chose to station herself outside the door of the room where Sarah was sleeping, so she could hear the monitor.

Although the alarm went "many, many times" (2/4/3) Cathy found having it there was "really good". She stated that the monitor did the work for her, telling her that the baby was alright. If the alarm went off she would run to the baby and usually found it had stopped sounding by the time she reached it. If it was obvious the baby was breathing, she would press the reset button, but if there was any doubt she would give Sarah a shake. Several times

Cathy believed the monitor had alarmed simply because the baby was taking "a perfectly normal twenty second breath" in between a big sigh and the next breath.

Cathy's belief was that monitoring made parents more attentive to their babies, especially during sleep. She acknowledged however, that parents could become dependent upon them and described an incident where she was asked to briefly hold a six-week old infant at a social function:

...I thought, "This is weird, this is weird - I can't hear anything". It felt quite strange...I think I'd really prefer to have a monitor...It would be strange without one

(2/4/7-8).

Her perception of the "danger" Sarah was in altered when the monitoring stopped:

We always reported to each other what had happened. When [Diane] came in from training, I'd tell her, "She had an alarm at ten to twelve". We'd keep each other informed. It was really good. When I'd arrive in the morning, I'd say, "How did she go last night?" And [Diane] would say, "Well, she had three alarms". And so we'd know she's still not out of danger

(2/4/7).

Although occasional alarms were sounding up until the time monitoring was discontinued, Cathy was able to confidently state two weeks later, that Sarah was now out of danger. She found it difficult at first, caring for Sarah without the monitor. Very conscious of the responsibility she had in caring for someone else's child, she checked Sarah at least every six minutes for the first few days. Thereafter she found she could relax a little more and checked her less frequently until it reached the point where she cared for Sarah more like she had cared for her own children:

I checked my children as much as I check [Sarah] now she's been off the monitor a while

(2/4/5-6).

Her position of employee, albeit a trusted one, meant that she did not make the decision to not use the monitor, but followed the instructions of the parents. Although she couldn't make the decision for them, she experienced a sense of relief for Alan and Diane when they did so:

I was relieved for both of them. They had such disturbed sleep. Yeah.....

(2/4/7).

She considered her own role to be that of supporting Sarah's parents:

I just feel I'm doing a real service and helping people get on with their own lives as well. You know, they could be driven batty being around this thing all day

(2/4/12).

As well as being involved with the monitoring Cathy helped Diane and Alan carry out measures they felt could be influential in preventing cotdeath. Acting on information supplied by her employers, Cathy would wash the baby's clothing separately from the rest of the family's washing, using hot water and no soap powder. Disposable napkins were used at night to ensure the baby did not become cold and wet as alarms tended to sound when this happened. Frequent visits were made to the Plunket Nurse to check Sarah's weight gains were steady in the early months:

[Diane] would say to me, "They shouldn't be losing weight. They should be gaining weight".....She knew all the signs to look for and I thought, "Oh dear, we've got problems here". There was nothing better than when the Plunket Nurse would say, "She gained 200 [grams] this week", and I'd say, "Oh brilliant! That's what I want to hear!"

(2/4/11).

If Sarah failed to gain weight steadily, Cathy would buy yeast to boost Diane's milk supply and the baby would be offered solid foods as well.

Cathy, like Alan and Diane, believed Sarah would not have survived without the apnoea monitor. Viewing it as a "lifeline", she summarised it thus:

With the amount of alarms we did have, I don't think she would have survived. Since they've already lost one baby, you just can't take the risk...

(2/4/12).

Discussion

The death of their baby son from cotdeath had had a profound effect on Diane and Alan. Although the infant had died several years before the time the interviews were conducted, the grieving of the parents was still very much in evidence. McClowry, Gillis and Martinson (1989, p.219) write of the devastating effect on families of the death of a child and quote Schiff (1977) who described it thus; "When your parent dies, you have lost your past. When your child dies, you have lost your future".

McClowry et al (1989) warn against the dangers of viewing grief as a hierarchical series of predictable stages, with the expectation that grief should be completed at some specific point in time (e.g. Lindemann, 1944; Kubler-Ross, 1983). They cite the findings of the Committee for the Study of Health Consequences of the Stress of Bereavement (1984) which showed that for some individuals the pain of loss may continue for a lifetime. The Committee found that a variety of emotions can be experienced simultaneously rather than in stages, and special occasions such as the deceased child's birthday can trigger off feelings of profound sadness.

Bugen (1977) notes that the intensity of the grief reaction is determined, to a large extent, by the preventability of the death. When a diagnosis of

cotdeath is made, it is by exclusion of any recognizable cause of death at post mortem, hence parents are not told how they could have prevented the death. Weinstein (1978) writing of families' responses to SIDS, stated:

They ask the logical question - "Why did my baby die?" They look to their physician for answers and he does not have them. They want to make sense out of the nonsense and put the pieces together in a way that will enable them to see a cause and effect...The autopsy is a procedure that says to parents, "We have looked and found no other known cause of death"...The atmosphere of not knowing the cause generally leads parents to dwell on their own doubts or doubts suggested by others and to blame themselves for doing - or failure to do - something that led to the death. "If I..."

(p.832).

When their baby son died, Diane and Alan shared the uncertainty of the cause of death, that parents of other SIDS victims feel. At the time the baby died, the giving of routine vaccinations, the cold climate and a disrupted routine were considered as possible causes and resulted in a certain amount of guilt in both parents. Weinstein (1978) described guilt as the "common denominator of SIDS parents" (p.832), which combined with the grief and lack of knowledge constitutes major emotional stress for the couple. However, for Alan especially, this sense of guilt was compounded three years after the death of their son, by the release of the findings of the New Zealand cot death study (Mitchell, Scragg, Stewart et al, 1991) which reported a high correlation between prone sleeping position and SIDS. When they looked again at the preventability of the baby's death, they found it was advice given by health professionals which had, in all probability, resulted in the loss of their son. The ensuing anger, bitterness, blame and sense of unfairness (all emotions listed by Bugen (1977) as to be expected in such instances) were accompanied by an understandable distrust of health professionals, especially medical personnel.

Despite the fact the prone sleeping position was considered a major factor in the cause of death of their son, Alan and Diane did not feel that their next child, Sarah, would be "safe" if she was merely lain in a different sleeping position. Instead, Diane's interpretation of the problem was sleep apnoea, a condition she felt was a hereditary problem which had not been taken seriously by their GP at the time their older daughter had experienced the "near miss" apnoea episodes. Thus, Diane expected Sarah to suffer from sleep apnoea even if the known risk factors for SIDS were avoided.

The apnoea monitor itself, in this situation, became the parents' best indicator of the risk status of the baby. When the alarm sounded, the parents did not assume that a mechanical fault was the likely cause, but treated each episode as an "apnoea" - either self-correcting, or needing stimulation to restart Sarah's breathing. Their inability to distinguish which episodes were genuine apnoea meant that Sarah, rightly or wrongly, was regarded as having numerous life-threatening events and was treated accordingly. Black, Hersher and Steinschneider (1978) found similar problems in families with monitors and reported that some of the "hazards of overmanagement were negated by the fact that parents' anxieties tended to be related to the feedback that the monitor itself provides" (p.685). Significantly, in their study of 31 families, they found anxiety levels were especially high in parents whose child had a diagnosis of sleep apnoea or who had previously lost a child from SIDS. The monitor alarm, whilst inducing negative arousal in the parents, also enabled parents to feel that they had some control in the situation.

Diane and Alan used the monitor for Sarah, not only to enable them to resuscitate her if she became apnoeic, but also to warn them of risk situations. If the monitor alarmed when she was cold and wet, for example, they could use disposable napkins to prevent this occurrence. Monitoring enabled the couple to keep an intensive watch over Sarah, to ensure her survival over the most "dangerous" months, without the intervention of medical staff. The onus was on the parents to keep her alive, and the high alarm rate meant all three caregivers needed to be constantly vigilant.

Baby Sarah's risk status for SIDS was perceived by the parents as a threat, for which various psychological coping strategies were employed. Shapiro (1983) posits the need for control as a basic human drive - in the situation where the risk of sudden death is present, an important coping task is to regain a sense of control over the uncontrollable. Thus, parents would attribute blame, even to themselves, rather than "confront the helplessness of having nowhere specific to lay blame" (p.917). Shapiro (op cit) points out that issues of vulnerability and the fragility and transitoriness of life are raised when a life-threatening situation is encountered and certainly both Diane and Alan mentioned the sense of vulnerability of their children was increased whilst Sarah was monitored. In an attempt to gain a sense of mastery in an overwhelming situation, it appears that Diane and Alan used cognitive coping strategies listed by Shapiro (1983, pp.917-918), namely:

obsessional hypervigilance, or the effort to be in active control of all aspects of the disease and its treatment; dysfunctional denial and avoidance; and control through thinking, in the sense of accumulating information...in an attempt to obviate one's essential helplessness...; intellectualization and denial of affect.

It was apparent that Diane was attempting to put her feelings about the loss of her son behind her and to consciously and rationally go on with her life. She watched avidly for any information about ways to avoid cotdeath, but it was ironic that the attempt to give Sarah a "stress free" year to minimise the risks meant that tension was produced in the household in other ways. The sound of the alarm disturbed the parents' sleep at night, and also actually wakened Sarah from sleep at times. The number of occasions she was stimulated to breathe again were stressors in themselves. A certain amount of marital discord was evident over the significance of the alarms, when Alan was unwilling to accept they were all "real". Although Sarah was not subjected to the stress of travel and disrupted routines, she was exposed to the underlying anxiety of her parents in their everyday caretaking roles. It was only in retrospect, when monitoring had finished, that they were able

to recognise the intrusiveness of the monitoring on their lifestyle. As Diane implied, the first year of Sarah's life was a time when they needed much emotional support from friends (family not living locally) yet were unwilling to be seen as needy over an extended period of time. To a certain extent, the role of the caregiver, Cathy, was instrumental in providing support.

The decision to stop monitoring eventually was an impulsive one. The parents were given the opportunity to have recordings made of Sarah's apnoea but instead of willingly accepting the offer to have their observations validated by a non-invasive procedure, they used the consultation with the Paediatrician to reconsider the need for monitoring. The diagnosis of the heart murmur appeared to shift their focus of attention from the possibility of apnoea to a potentially significant heart defect. Although the monitor had alarmed many times in the past, when it did so after the visit to the Paediatrician, Diane attributed the alarms to various causes such as "springy floorboards", or the "baby's weight", rather than to apnoea and from there made her decision to discontinue monitoring. Even then she experienced some ambivalence and expressed the intention to use it again if she felt it was necessary. Mothers in studies reported by Dean (1986); Geary (1989) and Wasserman (1984) had the same problems with discontinuance of monitoring, with some parents monitoring for extended periods of time and others weaning the baby off the monitor and using it again when s/he was unwell. All three caregivers were surprised by the speed of their adjustment to discontinuance of monitoring and commented on how they soon began to check Sarah like parents of 'normal' children would. It appeared that once the monitor was no longer in use, their perceptions of her risk status changed. Thus, they were able to look back on the 15 months of monitoring, accept that the monitor had had a significantly negative impact on their lifestyle, but at the same time they derived a sense of achievement from the belief that without the monitoring and their vigilance over that time, Sarah would not have survived to be a robust, apparently healthy toddler.

CHAPTER FIVE

Case Study Three

Family Profile

Christine and Mike became first time parents of twins in 1985. Liam, the male twin was delivered first and weighed just over 1kg. He was slow to resuscitate and was taken away to the Neonatal Unit for treatment just as his twin sister Jenny was born, weighing almost three times his weight. Liam required intensive care for several weeks but Jenny's progress was uneventful. The twins were discharged home, apparently fit and well. At the age of thirteen weeks, Jenny died in the night, unexpectedly, of cotdeath (Sudden Infant Death Syndrome). Mike was the one to find her in the morning. An ambulance was called but Jenny was beyond resuscitation.

Home apnoea monitors were issued to the couple for the surviving twin, Liam, then for their subsequent children, Susan, Rhianne and Carl. At the time of the first interview, Carl was being monitored with a Graseby MR10 monitor. Christine and Mike made the decision to discontinue monitoring when Carl was nine months of age.

Christine's Story

Christine is a vivacious, outgoing young woman in her late twenties, the mother of four surviving children aged seven years, five years, three years and six months respectively, at the time of the first interview. Of very slim build, Christine moved and spoke rapidly and like Mike, tended to smoke heavily and drink endless cups of coffee during the day. Christine had lived in the area for several years and had parents and siblings nearby and a wide circle of friends her own age, many with young children as well.

Before being able to focus her story on how monitoring was going with Baby Carl, Christine needed to talk about the loss of her daughter, Jenny. The events of the day of her death were still clearly imprinted in her mind. She had woken up "feeling something was wrong" (3/1/11) and when Mike had found the baby dead in the bassinette Christine had become hysterical. Mike had restrained her from going to the baby and had called an ambulance but the baby was not able to be resuscitated.

When reviewing the order of events of the fateful day, Christine tried to identify where the blame for the baby's death should be lain. She blamed herself for not waking in the night:

Why didn't I get up? Every other ruddy night I got up!
(3/1/11).

She blamed Mike for not instituting CPR:

Why did he ring an ambulance? Why didn't he say to me, "Snap out of it, woman - ring an ambulance!?" I don't know why he didn't do CPR

(3/1/11).

Christine felt bitter because she had seen that Jenny was pale the day before she died and had mentioned the fact to the nurse who had visited them that day. The nurse had advised her to take no action other than to proceed with the appointment she had already made to see the Paediatrician the next day at the hospital. The baby died before the Paediatrician saw her.

Christine suspected that Jenny suffocated because she was lying face down near a little pillow which contained a music box, a gift from the baby's grandmother:

Once again, lying the babies on their tummies is not the right thing to do! If she'd been on her back, I doubt very much whether she'd have suffocated...My auntie came, and she said, "For God's sake, get those babies off their stomach!" But I went by the book, y'know? I let them sleep on their

tummy...I made one mistake, that's how I feel, I made one mistake and my baby was taken from me...It's so unfair...If we'd had a monitor we probably never would have lost her
(3/1/12).

Christine had been told by someone that if her baby had been blue when found, she could not have been revived. If her colour was pale, that would have indicated that she had only just stopped breathing and CPR could possibly have saved her. The thought tormented Christine, that her baby might have been still alive if Mike had let her go to Jenny immediately she was found apnoeic, instead of trying to protect her from the horror:

And I keep asking [Mike], "What colour was she?" And he said, "She was pale but with one blue line on her face". And I said, "Well, then, why didn't you do something?" And all these horrible feelings keep coming back...I needed to know if she was just pale. For God's sake, I could have done something...It is hard. They say time heals. But how much time? How long?

(3/1/10-11).

She had found Jenny's death especially hard to deal with because during the twins' hospitalisation after birth, she had not expected Liam to live. Christine had formed an immediate close bond with Jenny, but had distanced herself from Liam during the time he was unwell:

...now he'd got a needle in his head and in his leg. It was just so horrible. And it was my way of coping. I really thought he was going to die...

(3/1/14).

Jenny's ashes were kept in an urn in the lounge of their home, displayed next to a studio photograph taken of her shortly before her death. Christine stated that she believed Mike was not ready to release the ashes for burial as he still felt guilty for not attempting to resuscitate Jenny. He had learned CPR since the time of her death and had actually done mouth to mouth

resuscitation on Rhianne when she was found to be apnoeic after the monitor alarmed.:

She wasn't breathing, she was as white as a ghost...I said to myself, "Keep calm". [Mike] was doing mouth to mouth...I heard [Mike] say, "Please, I couldn't bear to lose you"...When [Mike] found her, he shook and shook before the ambulance came. When I tried to take [Rhianne] away, he couldn't let her go

(3/1/17-19).

Rhianne spent the night in hospital under observation and was home again the next day, apparently well.

Monitoring of Baby Carl was comparatively uneventful for Christine and Mike, in that he suffered no severe apnoeic episodes and there was only one time that Christine felt he might have stopped breathing. The monitor had alarmed:

...and as we got to him, he sort of jumped and took a deep breath. So we don't really know if he'd stopped breathing

(3/1/2).

Carl tended to be a heavy, noisy breather and generally there was no difficulty in deciding whether or not the monitor alarms were due to a mechanical fault.

The false alarms, however, were a constant source of stress for the couple. Christine described how, on one particular night, the monitor alarmed incessantly, waking the parents who slept in the same room as the baby:

...it constantly went off and [Mike] said, "I've had enough of this!" and he turned it off. And I just lay there thinking, "Oh my God, he might be going, right now!" And I just couldn't handle it. I got out and changed the sensor lead, changed the battery, changed his pants and it started up again...But I just

couldn't bear to have it turned off.....[Mike] said, "He doesn't need the monitor on - I can hear him!"

(3/1/2-3).

Christine found that she needed to use the monitor both night and day. She had tried turning it off during the day but had worried that something would go wrong with the baby. She used a portable intercom system to relay the sound of the monitor and took it with her wherever she went, in the house or garden needing to be able to hear the clicking sound of the monitor, whenever the baby was out of her sight.

When friends and relatives visited with their own infants, Christine would not check on the sleeping infants unless they had an apnoea monitor. She spoke of an occasion when several babies were sleeping in the bedroom with Carl:

Gail had her baby on the monitor and there was clicking from two monitors but there were two babies in there without. You know our two are okay, but I don't know about those other babies, y'know? So scary...

(3/1/5).

Although the presence of the monitor gave Christine a certain amount of reassurance that her baby was breathing, she still liked to physically check him frequently. She had an underlying fear that the monitor might not alarm if the baby was apnoeic, either because of a malfunctioning machine, or because a cat might sit on the infant and trigger the sensor mechanism so that it would not alarm. When the family were travelling in the car they did not use the monitor as they reasoned that the movement of the car would simulate the baby's breathing movements and prevent the alarm from signalling that the baby was apnoeic. Instead they would listen out for the baby's noisy breathing and look at him every time they slowed down at an intersection.

Christine described herself as "a panicker" (3/1/8). She mentioned several incidents where life-threatening events had happened to other people's children, such as when a friend's young child had choked on a small object and Christine had successfully managed to dislodge the obstruction. Being prepared to carry out first aid was important to her and she was constantly on the alert to prevent accidents or illnesses:

I'm a panicker. I like to get things checked. And that costs a lot of money, running backwards and forwards to the doctor all the time

(3/1/18).

It disturbed her to think that despite all precautions taken, children could still die. Her brother had died of injuries sustained in a traffic accident, aged 21 years, and another young friend had died of asthma. The most distressing death, she felt, was teenage suicide:

Babies die of cotdeath, kids get hit by cars and what-not and that's an accident and that's hard enough to cope with. But then, at fifteen, for a child to decide he doesn't want to live any more, that's one hell of a thing to fit in!

(3/1/16).

She worried about leaving the monitored baby with babysitters and trusted only two people to care for him; one was a friend who had done a CPR course and the other one was her mother. Outings without the baby were very few and when she left Carl with her mother, to attend a wedding, she was anxious about leaving him and concerned that her mother took the monitoring so casually. Having shown her mother where all emergency supplies were, she felt that:

She just wanted to kick me out of the house and I didn't feel comfortable with that. I like her to know what to do. I've got a card in the bedroom by the phone, not just for people who don't know, but for myself, if I go in there and something's wrong and I do panic

(3/1/7).

The decision to stop apnoea monitoring was preceded by a number of events in the household. Carl, who had had several episodes of bronchitis in the first six months of life, had been diagnosed as having asthma, at the age of eight months. His chesty cough had developed at the time he was "grizzly" with teething and increased monitor alarms were causing the parents to become frustrated. Christine said:

And it started going off all the time and needed another sensor. And I didn't have enough money to pay for it

(3/2/1).

I was getting tired and ratty running to the alarm - I was sick of it and I said, "That's it! He's coming off it!"

(3/2/6).

She justified her decision by rationalising that Carl had never had an apnoeic attack, despite his illnesses, and that other "sick babies out there needed the monitor" more than he did (3/2/1). Her understanding of the asthmatic condition that Carl suffered from was that mouth to mouth resuscitation would be of no benefit (3/2/6) so the monitor had a very limited role in the treatment of the asthma:

I mean it's bad enough thinking I could have to do mouth to mouth. Well, with asthma, that's not going to do much, is it?...And he doesn't seem like a little baby now - he's more like a little boy

(3/1/6-7).

The decision to stop monitoring was affirmed by the Paediatric Nurse when Christine phoned and spoke to her. The nurse's comments that the baby was at an appropriate age to stop monitoring, and that stocks of monitors were low and theirs would be needed for another baby reassured them that they had done the right thing.

Christine continued to have a degree of anxiety about the risk of cotdeath, for another two or three weeks after returning the monitor. She did not

attribute the previous rise in alarm rates to any risk to the baby, but rather to the need for yet another new sensor lead. Carl's developing ability to pull the lead and chew on it was indicative that the baby had outgrown the monitor. For the first week, the parents woke frequently during the night and checked he was breathing well, but gradually felt more relaxed about it. Christine stated that at first:

I thought we'd never get over it. I kept thinking to myself, "I only checked him five minutes ago"....[Mike's] a lot better with him off the monitor. He started telling me off. "You've only just checked him a minute ago. Sit down!" So, it still sort of worries me...I really don't think I could live with myself now if anything happened to him; 'cos we've taken him off the monitor. 'Cos we did have the chance to have it

(3/2/4-5).

Christine and Mike did not make any effort to contact the Cot Death Society or monitor support group even though they were aware of the groups' existence. However, a high level of interaction with health professionals was evident. Christine took her children to visit the G.P. as necessary and had regular contact with the Public Health Nurse who had been visiting the family since Jenny's death seven years earlier. Christine found the Public Health Nurse's services invaluable. The continuity of care given by the same nurse over the seven years' span meant there was a high degree of trust involved and the nurse assisted her with accessing services for all family members. Appointments were needed for the older children for treatment of Ear, Nose and Throat conditions, for example, and for Christine herself for gynaecological and dental treatment. The Public Health Nurse provided support for Christine whilst she was monitoring Carl, but referred any specific problems with the baby to the Paediatric clinic at the hospital.

The family's wide circle of friends and relatives also provided emotional support for the parents, although generally they were not entrusted with

babysitting Carl whilst he was monitored. Christine was able to leave Carl with her mother without any qualms by the time monitoring had been discontinued for three weeks.

Mike's Story

In telling his story of what it was like caring for a baby on a home apnoea monitor Mike was keen to focus on the present rather than think back to when Baby Jenny died. He believed that Christine still grieved for her, more than he did himself:

Like, I'd never ever forget it, sort of thing, it's there all the time. But I try to keep going, keep going with life...I remember it, but I don't mention it...I don't believe in things being reactivated all the time...Like, we'll never forget [Jenny]. She's in that little box up there, in the cabinet there and everything. They all understand. But, no doubt, one day she'll get put to rest in the ground somewhere.....

(3/3/8-9).

Mike talked about the importance of knowing how to do CPR. which he had learned since Jenny's death. Because his present employment involved the risk of electric shock, on-the-job teaching and revision of CPR techniques were carried out six monthly. He felt confident that, if the need arose, he could "jump in straightaway" to resuscitate someone (3/3/3). His experience with doing mouth to mouth resuscitation on Rhianne when she was monitored was another unpleasant memory he tried to forget. He described how they found her pale and apnoeic and how he revived her before she was taken off to the hospital in an ambulance:

I was shaking and what-not...But if we didn't have the monitor we just can't say how long it would have been before we went in there to check her ourselves

(3/3/5).

For this reason he thought it was important that all babies had monitors if they were available. Although he found the alarms very frightening, the warning they gave that something was amiss meant the parents had a chance to do something before it was too late (3/3/2).

The monitor alarms, in one sense gave him a feeling of control, in that action could be taken before the baby died, but in other ways they were the main disadvantage of monitoring, especially at night:

The initial thing when it goes off is the fright. What are you going to find? How long has it been going off before you've heard it, has it just gone off? They're terrifying but they're good!...I always thought it might be like [Jenny]. After you've lost one, you sort of think, "Christ, is this another one?"

(3/3/2).

When Carl was cold at night, Mike believed he breathed too deeply for the monitor to register the breaths. On such occasions the sleep disturbance was a problem:

It might squeal for a couple of seconds then the alarm would go off and the light would be flashing. So.....just reset it, check him and cover him up and go back to bed. Just get back to sleep and - wham! Off it goes again...And your initial reaction - your eyes are not even open - is your feet hit the floor and you're off - you know - in the direction of where it is

(3/3/4).

Mike and Christine coped the best way they could with sleepless nights. They tried taking turns at getting up to the monitor but Mike found he would wake up anyway, that he could not sleep through the noise. They were unwilling to switch the monitor off when it alarmed frequently even though the baby was obviously breathing well:

You just gotta deal with it. It's something that's a responsibility that you've been given by putting that

monitor on your child and you've just go to cope with it. You've put it there for a reason, so if you want to ignore it, you might as well not have it.....You get used to the noise it makes, the light, the clicking. You do adjust to that. But you never adjust to the sound of the alarm when it goes off..

(3/3/12-13).

On the one occasion he had turned it off in desperation in the early hours of the morning because a faulty sensor lead was causing it to alarm unnecessarily, he lay there awake until morning, listening to Carl's breathing until it was time for him to get up and go to work.

Mike's ear was "tuned in" to the sound of the alarm and he responded automatically to similar noises. He described how a television advertisement used the same sound and how he'd "motor" out of the lounge to the bedroom to check Carl before Christine could tell him it wasn't the monitor.

With Carl, there was little difficulty in telling whether or not he was breathing. Mike would respond to the alarm by pressing the reset button on the monitor and looking for breathing movements. If he was unsure he would prod the baby until he squirmed and the monitor started clicking again. He was not prepared to wait for the monitor to go through another twenty second cycle to see if it alarmed again.

Like Christine, Mike had some anxiety that the monitor would not alarm when it should do so. He cautioned that parents could get to rely on the audible clicking rather than physically check their babies were breathing. He described how he was always a little "on edge" with the monitor, wondering if it was going to ring off or whether it would fail to alarm. He used the same example that Christine had, that a cat might be keeping the monitor going. It had been Mike's discovery that the monitor was ineffective on car journeys:

It took me a while to work that out. But I actually tried it, you know. A couple of bumps in the car will actually set it off. So, to me, they weren't much chop in the car

(3/3/6).

The edginess that he felt about monitoring was with him the whole time he was in the house with the baby, but he experienced a sense of relief when he could walk out to go to work, knowing the responsibility for the child was on someone else; Christine. "If you're there yourself, it's on you" (3/3/6). The older children were not directly involved with the monitoring other than letting their parents know when the alarm was sounding.

Mike's policy of dealing with problems independently, if possible, was evident. He did not want any counselling after the death of their baby, nor did he want assistance from support groups. His lack of faith in doctors was revealed in his statements that he never consulted one for himself and disliked the practice of "feeding Carl up" on Ventolin medicine to treat his asthma because it would lower the baby's natural "immunity" to deal with the asthma himself. He was sceptical about theories of the reasons for cotdeath. His reaction to recent advice about preventing cotdeath was:

You think, "Is it right or is it wrong? Have they got it sorted out, or what?"...Still, I'm not a doctor! [sarcastically]. Babies can quite easily suffocate themselves lying on their tummies but also sleeping on their backs. It's all a worry. Sleeping them on their sides they could do the same thing - twist their necks around or anything. You're always looking for an answer - if I'd done this, if I'd done that....

(3/3/15).

Mike's opinion was that parents needed to assess for themselves the usefulness of advice given by health professionals. The responsibility for the child's welfare was ultimately that of the parents thus their judgement of what was best for their child was of prime importance:

A lot of them advise you to do this and do that...I'll listen to what they say but whether or not I'll do it is my decision. Some of the them are too pushy. A lot of people are susceptible to being bloody taken over by them - you know? I don't agree with that, myself

(3/3/16).

This reasoning was evident in his account of how he and Christine had decided to stop monitoring Baby Carl. Mike pointed out to Christine that monitoring needed to be done during every sleep time or not at all. "He's either on it, or off it" (3/3/7). Over a period of a month or so, they assessed whether Carl was having any problems with apnoea and decided:

Okay, he seems to be doing alright...there's got to be someone else who needs the monitor more than he does at this stage

(3/3/7).

After a period of three weeks of feeling nervous with Carl off the monitor, Mike felt confident that Carl would be safe without it. He told himself that the problem was one that existed only in his own mind and decided "You've got to rely on him to breathe" (3/3/8). Mike thought it unlikely that Carl would stop breathing now that Carl was so mobile, crawling around and within three weeks of monitoring being stopped, Carl was moved out of the parents' bedroom and into his own. The intercom was plugged in so Mike and Christine could listen out for him at night.

When Carl was ten months old and had been off the monitor for a month, Mike was able to say:

The worst is gone. Well, perhaps not so much the worst is gone. There are other dangers now - like putting things in his gob, choking, falling out of windows - but they're just everyday occurrences that you have to deal with. But we're careful...He's into a different phase now - he's never really past the risk of cotdeath, but like I said before, he's dealt with

most things by himself...I feel quite confident to say he is over it, but I suppose you just don't know.....

(3/3/14).

Discussion

Although a time period of seven years had elapsed since their twin daughter died, to Christine and Mike, the loss was still a painful memory which was seldom far from consciousness. Jenny's death was unexpected - her twin brother, Liam had been seen as the more vulnerable of the two. Christine, in particular, had been mentally prepared for Liam, not Jenny, to die. Liam had been underweight, had suffered an almost overwhelming infection and Christine had coped with the prospect of his death by distancing herself emotionally from him and devoting a disproportionate amount of her love and attention to Jenny.

When Jenny died, Christine was devastated. Rando (1991) described something of the emotion communicated by Christine about her daughter's death:

This comes...also from the loss of part of each parent's self in relationship with the child...When the child dies, that special part of the parent dies too, notwithstanding the fact that there may be other surviving children whom he or she is still called upon to care for

(p. 239).

Christine and Mike still had the surviving twin to care for, his presence an unavoidable reminder of his twin's absence, but neither parent spoke of their feelings for him. Rather, their stories focussed on the death of Jenny and the monitoring of their subsequent children.

Rando (1991) summarizes the documented outcomes for the parents who have experienced an unanticipated loss of a child (see case study two)

namely, a sense of helplessness and threat, prompting enormous efforts to regain a sense of control by finding meaning in the death and determining who is to blame.

To this end, Christine had agonized over the sequence of events on the day of Jenny's death and attributed responsibility for the failure to resuscitate Jenny, to her husband Mike. She had almost convinced herself that Jenny would not have died if Mike had taken the appropriate action. She also blamed herself for lying the babies prone to sleep, despite family members' advice to the contrary and blamed the nurse who had reassured her that Jenny's pallor the day before her death was of no significance. Jenny's ashes, kept in a prominent position in their lounge, perhaps served as a punishment to Mike, a conspicuous memorial to her death. At the time of discontinuance of their youngest child's monitoring, the parents were beginning to anticipate a lifestyle without an "infant" in the house and were considering the possibility of releasing Jenny's ashes for burial. Their experiences of parenting, to date, had involved constant anxiety about the threat of infant death and had been accompanied by the stresses involved with monitoring as well. When monitoring was no longer regarded as necessary, the youngest child was perceived as a "little boy", rather than a baby, and the need for extra protective measures was no longer emphasized. The cessation of monitoring in one sense, heralded Carl's transition to toddlerhood and directed the parents' energies towards the normal developmental processes involved with child rearing, rather than on the possibility of the child's death. This optimistic outcome is one denied to parents of children with truly chronic illnesses. As Wasserman (1984) stated, home monitoring (and with it the perception of the infant's high-risk status) is a time-limited experience. The restrictions which monitoring had imposed on their lifestyle were soon eased. Within three weeks of stopping monitoring, Christine and Mike were able to feel comfortable with leaving Carl with a sitter so they could spend time together alone. The intense sense of responsibility for ensuring the child's survival faded as their perception of his risk status decreased.

The couple accepted the responsibility for monitoring was theirs and recognized that this in itself created tension in the caregivers. Mike spoke of the sense of relief he experienced when he left the house for work each day. He could then abdicate responsibility for monitoring until his return in the evening. Christine was unable to have this opportunity for respite and the pressures of monitoring were with her both day and night. Sleep loss from false alarms at night was something they felt compelled to cope with and like parents in previous studies (e.g. Black, Hersher and Steinschneider, 1978; Wasserman, 1984) they were unwilling to disconnect a malfunctioning monitor so they could sleep and would stay awake to keep guard over the baby if necessary. Despite the high rate of false alarms at night, Christine and Mike were aware that in certain circumstances, the Graseby MR10 monitor might not alarm if the baby was apnoeic. They had reasoned for themselves that movements other than the baby's breathing, would keep the sensor clicking, hence they checked the baby even when the monitor was in use. Christine was aware that respiratory distress from asthma would not be picked up by the monitor.

Mike, especially, preferred to sift through information supplied by health professionals and decided for himself which advice should be heeded. He and Christine debated between themselves whether or not to use the monitor both day and night and made their own decision about when monitoring was no longer necessary. Having done so, they then presented their decision to the Paediatric Nurse for her validation. In light of the comments made by Christine about not being able to live with herself if anything happened to Carl when monitoring was stopped, it appears that a thorough medical check-up of the baby and counselling for the couple would have been appropriate before discontinuing monitoring, particularly to minimize any further blaming and feelings of guilt if their worst fears were realized.

Although Carl did not have any apnoea episodes observed during the time he was monitored, his parents assumed he had a high-risk status for apnoea because of the family history. Statistically, Carl's chances of dying from

cotdeath were low (Krongrad, 1991) yet Christine and Mike took it for granted that a monitor was a necessity. Their emphasis on avoiding other known risk factors for cotdeath was minimal. Both parents smoked in the house, for example, despite an ongoing publicity campaign advising to the contrary, and the fact that Carl suffered from episodes of bronchitis and asthma. The baby was formula-fed and no attempt had been made by his mother to breastfeed.

Christine and Mike were fortunate to have family and friends available for support over the time they were monitoring Baby Carl. Although they seldom took up offers of babysitting, they invited and encouraged people to visit them at home and at least one other friend had a monitored child as well. They talked freely and openly to others about their experiences with losing Jenny and their concerns about Carl and their sense of vulnerability of all children.

Support services from health professionals were coordinated by the Public Health Nurse who had visited the family regularly since Jenny's death. Christine had lost faith in the nurse who had previously visited her when the twins were discharged home and who had discounted her concern over Jenny's pallor. Smialek (1978) writing about parents' reactions to sudden infant death observed that this was a common reaction. Her experience was that parents did not appreciate subsequent visits from such people and would likely respond by saying:

"What good is she now? She can't bring my baby back. She's the one who told me my baby was well"

(Smialek, 1978, p161)

The Public Health Nurse who took over the family's care was not implicated in the "wrongful" advice and over the seven year period her input was invaluable to Christine in providing help, reassurance and information, particularly to access services from other health care providers for Christine and the children. Although Mike did not express the same

need for professional input, it is noteworthy that he was not the parent who was primarily involved in the routine care of the children.

Several authors have reported that marital discord results when there are disparate views of the parents of the seriousness of the monitored child's condition (Cain, Kelly and Shannon, 1980; Wasserman, 1984; Nuttall, 1988). In this family, Mike did not deny that Carl was at risk of cotdeath but he did downplay the asthmatic symptoms displayed by Carl and preferred the child to cope with them without medical intervention. He compensated for Christine's "panicking" and ongoing expressions of grief for Jenny, by speaking gruffly at times - as quoted:

"You've only just checked him a minute ago. Sit down!"

(3/2/4-5) and

"He doesn't need the monitor on - I can hear him!" (3/1/2-3).

Mike appreciated that monitoring was "terrifying" but essential for ensuring their infants survived the first few months of life. His willingness to depend on the monitor decreased as the baby grew and his emphasis on self-reliance resurfaced when he felt monitoring was no longer necessary; "You've got to rely on him to breathe" (3/3/8). Cain, Kelly and Shannon (1980) found that fathers in their study of monitoring parents deliberately minimized the extent of the anxiety they expressed, in comparison to the mothers who described themselves as "very" or "extremely anxious". Fathers expressed more concrete concerns about monitoring difficulties and rather than dwelling on possible apnoea, they addressed such issues as potential monitor failures. When viewed from a systemic perspective, these fathers appear to have contributed to the family functioning at a time of stress by taking a complementary role to that of the mothers. If the mothers appeared overly concerned with possible negative outcomes, the fathers indirectly provided them with support by deliberately presenting an alternative perspective. The desired effect would be a stabilizing one on the threatened family system.

With Christine and Mike, the same cybernetic process (Wright and Leahey, 1984) was evident. Although Christine was the main caregiver of the monitored child, Mike was involved in making the decision about how long monitoring was necessary. He compensated for her anxiety by emphasising the infant's ability to cope for himself, whether it be with the risk of apnoea or his bouts of asthma. By taking a leadership role in the decision about discontinuing monitoring, Mike was able to focus their attention towards a future with four healthy children who had survived the risk of cotdeath.

CHAPTER SIX

Case Study Four

Family Profile

Lynda's husband, David, is a long-distance driver and spends most of his time away from home. He drives five nights a week and returns home to sleep on the two nights he has off work. For Lynda, this means the responsibility for the day to day caring for their five children, rests on her shoulders. Their youngest child, Simon, was aged fourteen weeks at the time of the first interview and was being monitored with a mattress-type monitor. It was not feasible to interview David because of his travelling but Lynda agreed to share her experiences with home apnoea monitoring.

Lynda and David had had seven children, two of whom died in infancy. The firstborn child, a daughter, had been born slightly prematurely and had a birthweight of five pounds. She was kept in hospital for three weeks after her birth and appeared to be progressing well, when the hospital staff found her dead in her crib the evening before she was to be discharged home. A son and daughter were subsequently born full term, of good birthweight and no problems were experienced with their health. The next-born child was another daughter, Kylie who was again, only five pounds in weight, and she died at home of cotdeath at the age of seven weeks. Lynda used home apnoea monitors for each of her children born after Kylie, two daughters and a son, Simon.

Lynda's Story

Lynda is a woman in her mid thirties, a thin, reserved person who prided herself that she had inherited her mother's ability to conceal her emotions. She spoke in a matter-of-fact manner and tended to give a brittle laugh

when talking of events that were painful for her to recall. Lynda had been in the house alone when her fourth child, Kylie, had died and remembered the events of that day as if they were part of a bad dream. Because Kylie had been seven weeks old, Lynda felt she had known her better than the firstborn daughter who died:

...'Cos I never really knew her. Like they kept you in hospital for three weeks in those days and she died in hospital. I knew her but I didn't know her like I knew [Kylie], if that makes sense...[Kylie] sort of lived her first six months in the first six weeks. She was crawling up the cot, and smiling, and she knew everyone about by four weeks. She was incredible...

(4/2/7).

After Kylie died, Lynda grieved for her in her own way, only allowing herself to cry when others were not present. She had refused an apnoea monitor for her next baby, at first, somehow linking the need for a monitor with responsibility for the baby's death:

When I had [] - she's the one I had after [Kylie], I didn't really want one [monitor]. I sort of wanted to prove to myself that I didn't need it, that I didn't do it, that I didn't contribute to it. Yuh...After the first couple of weeks I needed one, 'cos I was such a mess [laugh]

(4/1/3).

Lynda's brother and his wife had lost a twin baby from cotdeath and her observations of how the monitoring of their surviving twin had taken over their lives, made her determined not to become too reliant on the monitor with her own children. She used Graseby MR10 monitors with the two girls born after Kylie, and because of the technical difficulties in keeping the sensor pad securely attached to the infant, had found a very high stress level had resulted from the false alarms:

You know, it was just going off all the time. And they were alright. It stopped ringing when you moved the sensor

closer. Yeah, they hadn't stopped breathing or anything like that

(4/1/6).

For this reason, she returned the second Graseby MR10 monitor to the hospital and then used a Vickers mattress monitor for that daughter, and for Simon, her youngest child. Because the monitor had an electrical power source, the mattress monitor was only used when the baby was home in bed.

None of Lynda's monitored infants had required active resuscitation for apnoea, but at times Lynda found it difficult to determine whether or not Baby Simon was breathing. On occasions, Simon would appear to be in a deep sleep when the monitor would alarm. When this happened, Lynda would give the baby a "shake-up under the chin" (4/1/6) and wait for the green light on the monitor to flash again, the signal that all was well with the baby. For several weeks, Simon's monitor alarmed regularly at the same time, an hour before he was expected to wake up. Lynda became accustomed to this alarm, reporting:

I don't panic half as much now if it does go off. The green light usually flashes again soon

(4/1/9).

The green light on the monitor reassured Lynda that the baby was still breathing and also provided sufficient illumination in the room at night for her to see the baby in his cot and for her toddler to find her way into Lynda's bed if she was unsettled. Lynda used the green light to help her "wean" the baby off the monitor. She had made the decision early on that she would only use the monitor over the cold months of the year and said:

It was always planned that I'd just have it for a couple of months otherwise you could get yourself addicted to it...if he hadn't got that cold, it would have gone back a month ago

(4/2/9).

Lynda decided that the best way to gradually wean the baby off the monitor was to have the alarm switched on only during daytime naps, and switched off at night. This meant that the green light would flash with each respiration at night but no alarm would sound if the baby was apnoeic. If Lynda woke at night she could see the infant and be reassured that the green light was still on. The Graseby MR10 monitors did not have this facility available, of being able to have the respiration detector function on, with the alarm function off. With the Graseby monitor, the only options were 10 or 20 second time delay settings and on/off switches. The mattress monitor had several different time delay settings, from 5 to 20 seconds, a fact Lynda had discovered one night when her toddler altered the setting to the 5 second delay. The monitor had alarmed persistently overnight and Lynda, unaware of the altered settings, had spent a sleepless night:

I got sick of it. I got up and switched it off for about half and hour. Then I thought, "No, don't be stupid, you can't do that! But the kid's breathing!"...Of course, it was just going and going.....

(4/1/7).

Baby Simon was monitored for six months overall, the weaning process interrupted by episodes of illness. When Simon was unwell, catching colds from the older children in the family, Lynda was reassured by the presence of the monitor. At the time of the final interview the monitor had been returned for three weeks and Lynda was worried that Simon would catch chickenpox from his older siblings, one of whom had been very ill with the disease. She was wondering half-heartedly whether she should ring the hospital and ask for the monitor back again.

The decision to return the monitor, in this case, had been made by Lynda. In the early weeks after Simon's birth Lynda found her husband was "really pushing" for her to use a monitor (4/1/10) but when the baby grew older and she was wanting to discontinue monitoring, her husband allowed her to make the decision to stop it:

He agreed it's up to me. He's never here at night anyway
(4/2/3).

Her older children had been anxious about the monitor going back and had challenged her about it:

"Why're you taking Baby's alarm back? What if he stops breathing?"... [oldest son] was really upset
(4/2/3).

She had reassured them that the monitor was only really needed over the cold months, when cotdeaths were most common.

When asked about other risk factors for cotdeath, Lynda spoke of how Kylie had smothered herself by crawling up to the corner of her cot, and lying flat on her face on her sheepskin rug. She did not use sheepskin rugs for any of the subsequent children but was aware that she was not avoiding other known risk factors. For instance, she knew about the current medical advice to lie babies on their sides or supine but disregarded this:

Well, he's on his stomach now. Started off on his back. Then he got a bad cold and he was coughing all night, choking on his back. So I turned him round on his tummy and he was sleeping like a log
(4/1/5).

She went on to add that she had been unsuccessful with breastfeeding her other children and was bottlefeeding Simon, although she knew breastfeeding was reportedly one defence against cotdeath.

...And I smoke...[laugh]...nothing will stop me from smoking!
(4/1/11-12).

Lynda's need to be self-reliant with the upbringing of her children was evident. She had lived in the region for only three years and although her extended family network had close links they did not live locally. She tended to take her children with her to visit her family out of town and did

not leave Simon, with his monitor, with a babysitter. Because her mothering responsibilities were in many ways similar to those of a solo parent, Lynda's lifestyle did not include many social occasions where she would go out without the children, with or without a monitor.

The family's GP had become a family friend and she obtained much support from the doctor with the care of her children, both emotionally and for their physical care. Lynda believed that support specifically for the monitoring was available from the nurses who supervised the home apnoea monitoring programme but that Plunket Nurses were unavailable when she needed them for advice:

Well, I find [the Plunket Nurse] is never there - you even just ring for an appointment - she's either at some other village or you get told to ring tomorrow or make an appointment next week. Well, that's useless to you, when you're panicking at that time, isn't it?

(4/2/10-11).

During the time Simon was monitored several significant events happened to the family. Lynda's father died suddenly then her uncle died shortly afterwards. Lynda was involved in supporting her family through their grief and then she was notified that she herself had abnormal smear results following a recent colposcopy and would have to be admitted to hospital for surgery. To add to the stress, the family moved house for the second time within a year. Lynda coped with these events, outwardly managing well:

Mum reckons I'm like her - I put a wall up. If someone hurts me or I get hurt, I put a wall up. No-one ever sees me cry, Mum's the same...I should have had counselling when [Kylie] died. But I was alright, I thought...Whereas, I didn't think it had affected me that much. But when I look back now, yeah...it had - something terrible

(4/2/14-15).

Her worry about her own health made her admit she was irritable in her day to day interactions with her children and felt edgy and anxious about their future well-being:

No - nothing can happen to me! I've got too many kids to look after [laugh]...it just can't happen. Not too many people want to look after five!

(4/2/16).

She spoke about availing herself of counselling services some time but was unable at this stage to project far enough into the future to set up an appointment. With apnoea monitoring finished, her attention was focussed not on the possibility that Simon might die of cotdeath, but on more immediate concerns:

Yeah - maybe once we're over all these hurdles - when the chickenpox are finished and Mum's been to her little bed [in hospital] in another three weeks - I'll come out and find I've got nothing left inside - that would be alright - there'd be no more babies...Nuh, don't want no more.....

(4/2/20).

Discussion

Lynda's experiences with monitoring Baby Simon obviously took place at a time when Lynda was under considerable stress. She had almost sole responsibility for five children, including the monitored infant, three of the children still preschoolers. Lynda had lived in the region for only three years and with her young children to care for at home she had had only limited opportunities to make friends. Her own family of origin lived out of town and over the time Simon was monitored, Lynda not only lost her father and uncle but was faced also with the prospect of her own upcoming surgery and probable diagnosis of malignant disease. She was forced to deny her own needs for support and comfort so that she could provide caring for her children and for her recently bereaved mother and aunt.

The two adult family members' deaths were unexpected - both men died from cardiac disorders - and the family had also experienced the sudden unexplained deaths of three infants; Lynda's daughters and her brother's daughter, one of twins.

Rankin (1989) suggests the concept of psychosocial transitions developed by Parkes (1971) is appropriate for use by nurses in understanding changes within a family's boundaries. Psychosocial transitions are:

those changes in the personal world of the individual or family that are lasting in their effects, are of short duration, and affect a large part of the family's or individual's "life space"...

(Rankin, 1989, p. 174)

Of the five types of transition identified by Parkes as requiring major reorganization of life space (see case study one) changes in personal relationships (such as the birth of a child or death of a loved one) are seen as having the greatest potential for creating family disequilibrium. Such events can overwhelm the family's ability to cope and supportive intervention from outside agencies may be necessary.

Lynda's method of coping with the enormous demands on her personal resources was to deny to herself and to others that she needed help. She needed to be able to manage independently and tried to block from her mind the thoughts which would threaten her ability to do so. She was unwilling, for example, to face the possibility that her own health would deteriorate and that she would not be able to care for the children.

Her statement about initially not wanting a monitor for the baby born after Kylie's death, reflected the same need for self-reliance and for denial that something she had done had caused Kylie's death. She had reasoned that if she could cope without a monitor for the subsequent baby and the baby survived, it would "prove" not only that her mothering skills had not been

lacking with caring for Kylie, but also that she was not emotionally vulnerable after losing her baby. However, Lynda was forced to admit she was a "mess" after two weeks without a monitor and resorted to asking for one, despite her concerns about becoming reliant on it.

For Lynda, it appears that the presence of a monitor was an anxiety-reducer, even taking into account her reports of a high false alarm rate with her first two infants. Her awareness of how monitoring could adversely affect parents' lifestyles resulted from her observations of how her brother and his wife had coped with monitoring their surviving twin. She thus identified the risk factor for cotdeath which she considered the most significant - cold weather - and aimed to use the monitor only over this "dangerous" period. By specifying in advance the time period for which she would need the monitor for Simon and by using a monitor model which had proved in the past to be reliable and to have a low rate of false alarms, she was able to retain a sense of control over the monitoring and not fall into what she had implied was the trap of becoming dependent upon it.

"Weaning" Simon off the monitor appears to have been more a process of weaning the mother of her need to have him monitored. Lynda used the green flashing light to reassure herself that Simon was breathing. By leaving the alarm off and having only the respiration light on, she would not have been alerted if Simon became apnoeic when she was asleep. Indeed the same effect could have been achieved by placing a night light near his cot so that if she woke in the night she could see him breathing. Her inability to switch off the monitor when it alarmed all night because of the incorrect time delay setting correlates with the reactions of other monitoring parents in similar situations (Black, Hersher and Steinschneider, 1978; Wasserman, 1984) who saw the alarms as an indication that the baby was in danger despite the obvious malfunctioning of the machine (see case study three). The feedback from the monitor was also the standard by which Lynda had measured whether or not Simon was breathing, if the alarm had sounded. If the green light flashed after she had given him a "shake-up under the chin", then this was seen as a reliable

indicator that the baby was breathing again. The difficulty in determining whether or not true apnoea or bradycardia has occurred is one that exists when the type of monitor used has no data storing facility for the parents to compare (Krongrad and O'Neill, 1986; Steinschneider and Santos, 1991). This drawback is a feature of both the mattress and the Graseby MR10 monitors.

Lynda had made her own decision about when the monitor should be returned, again, without medical advice as to whether or not the infant was at risk of dying from cotdeath. The reasoning appeared to be that if she could cope without the monitor, the baby was no longer in need of it, except perhaps if he became ill with a communicable childhood disease. Because Simon was exposed to the minor illnesses of his older sibling he did suffer from a number of upper respiratory tract infections and was consequently monitored for six months rather than the intended two months. His father's involvement with the decision to stop monitoring, and indeed with monitoring itself, was minimal, although he had been insistent that Simon needed to be monitored in the early weeks.

Lynda's older children realised the importance of the monitor for the baby and when the oldest son (perhaps fulfilling the role of the absent father) challenged her about returning it, she defended her action by replying that the main risk factor, the cold weather, was now past. She knew that lying babies prone was a strongly discouraged practice, as was smoking near the baby, yet she persisted with these practices, again denying their risks. It could be argued that this behaviour is another example of her attempt to prove to herself that her actions were not responsible for Kylie's death. Kylie had been sleeping prone when she died and her mother had smoked in her presence. If Simon could survive infancy when the same conditions were present, then it would be evident that they did not cause Kylie to die.

Lynda's needs for support were met by her family doctor, to some extent, but clearly the needs of the mother in this family, were submerged by the needs

of those she cared for. Geary (1986) expressed concern that the focus of health professionals involved in monitoring programmes, is usually on the baby rather than on the mother, with attention mainly directed to monitoring and the infant's apnoeic episodes. Lynda knew that she could obtain support from the monitoring service nurse for issues directly involving the monitoring, but it is evident that she had a need for an opportunity to have more support from someone who could see through her protective "barrier". The well-being of all the family members was threatened by the existence of the many stresses Lynda was dealing with almost singlehandedly.

The family doctor was the one person who was able to have a broad view of the simultaneous problems confronting the family. Whilst services were provided by Plunket (well baby checks); monitoring programme staff (home apnoea monitoring); and the gynaecological clinic (cervical, cancer screening/treatment for the mother); supportive intervention for the family as a unit was limited. Health professionals were involved in providing efficient but fragmented care to the individuals in the family.

Lynda's account of her experiences with monitoring revealed a need for a more coordinated service, one which recognized that personalized care of individuals not only acknowledges that the family is a significant context for the health of its members, but that the family is the necessary unit of service (Gillis, 1989). Monitoring of Baby Simon, whilst in itself a significant stressful experience, was undertaken in a family context where several areas of psychosocial transition were occurring. Monitoring did impact on the family but, when viewed from a systemic family nursing approach, it is essential to recognize that the experiences of sole parenting, social isolation, loss of family members, and threat of serious illness had a reciprocal effect on the way Lynda coped with caring for her monitored infant.

CHAPTER SEVEN

Case Study Five

Family Profile

Mary and Peter, a European couple in their early thirties, live on a dairy farm twenty minutes' drive from the nearest city. They have four sons, the youngest of whom was born at twenty-six weeks' gestation and was hospitalised for three and a half months before being discharged home on a Graseby MR10 apnoea monitor.

The family, at the time of Baby Tyler's premature birth, was in the process of selling one farm and moving to another larger property. When Mary showed signs of premature labour at twenty-five weeks' gestation, she was transferred from the local Maternity Unit to a major New Zealand hospital, two hours' drive away, where Level III neonatal unit care was available. When talking about the events surrounding Tyler's early birth, Mary and Peter described a time of upheaval for the family. Peter was left with the responsibility of caring for their three older boys, aged ten, eight and four years respectively, and with the task of shifting both household and farm possessions, including stock, to the new property. Extended family members were called in to help with the shift and with milking, calving and with childcare so he could travel down to spend time with Mary and the tiny newborn baby in hospital. In addition, the family was experiencing financial difficulties and because they did not have a Community Services Card, were presented with an account for \$500 for Tyler's hospital care.

Tyler was transferred back to the local hospital when he was a week old and remained there until his discharge fourteen weeks later.

Mary's Story

Mary is fiercely protective of Baby Tyler, describing him as "very special" to her. Because Tyler is their fourth son, she finds it hurtful when people who do not understand the circumstances of Tyler's birth, tactlessly say, "Oh no, you poor thing, four sons!" (5/2/9). She is proud of the fact that Tyler has survived despite adverse circumstances:

We wouldn't give him back for the world, would we? He's not our favourite but he's very special

(5/2/9).

He's so special - he's beaten the odds and he's made it! Then they say, "Oh, that's okay then!" You can just about see them thinking.....

(5/3/18).

Tyler's progress in hospital was slow. He was oxygen dependent until shortly before discharge and suffered numerous episodes of bradycardia and apnoea, associated with his prematurity. He was born with quite a marked facial palsy and a heart murmur which was of doubtful significance. When Mary and Peter brought him home from the hospital he was on a monitor because he was still "at risk" of having recurrent apnoea and bradycardia (5/1/1).

At times Tyler's monitor alarmed persistently but at other times seldom alarmed. Mary described it as "nerve-racking", when in the first few days at home it "continually went off" (5/1/2):

Um - it just went off all the time. Twenty times in an hour would be nothing! I'd be trying to cook tea and I'd be just continually rushing to the room. I questioned whether it was the monitor and [nurse] checked it out. It was okay. We changed the batteries, got new leads and it wasn't that. It was all him. She [nurse] came to the conclusion it was him breathing too shallow to register

(5/1/4).

When Mary realised that alarms did not always mean something bad, she coped better with the monitoring, but reported that she would usually give Tyler a shake if the alarm sounded, even if it was not really needed (5/1/2).

As the weeks went on she became more comfortable with the monitoring and made the decision to use the monitor only at night, to give her a sense of security while she slept. This decision was made when she recognised that the alarms were disrupting their family life to an unacceptable extent:

And it was too much - it was ruling my life to too big a degree

(5/1/2).

Although Mary had discussed this course of action with the nurse she was initially reluctant to admit that she was not using the monitor in the way prescribed by the hospital:

I'm probably not very good saying I'm not using it during the day but I have to be honest, eh?

(5/1/5).

In the first few weeks at home, Mary had found it very frustrating having to stay within earshot of the alarm. She bought a portable intercom at considerable expense so that she could listen for the alarm whilst she was in the carshed, or pegging out washing, reassured by the clicking sound of the monitor through the intercom. The range of the intercom was 100 metres but Mary was aware that if she was to move that distance away from the baby, and the alarm sounded, it would take her too long to return to the baby to initiate resuscitation measures.

In daytime hours, when the monitor was not being used, the older boys were involved in physically checking the baby:

It's sort of become a real family thing - [Tyler] breathing? Check him and you know, it's not a frightening thing to say to them...It's just part of [Tyler] "Go and see if [Tyler's]

breathing". And they know.....and if they don't know, they say so

(5/1/6).

The boys had been trained in CPR and Mary was confident the older two could use it if the occasion arose.

Mary's perception was that Tyler was at greater risk of apnoea at nighttime. She spoke of how she would not be able to sleep at night without the monitor (5/1/3) and how, on the occasions when the monitor alarmed incessantly, she could not turn it off. On one memorable night:

The alarm went every minute. I lay back down, turned the light off and it would go again. It was just dreadful...I think it is too dangerous to turn it off. I felt like turning it off. I felt like throwing it, but I didn't do either. I just put up with it!

(5/1/8).

On nights when the monitor alarmed often, Mary would keep vigil over the baby, tending to the monitor whilst she read a magazine, so Peter's sleep would be undisturbed. Peter, she said, was tired enough with getting up at 4am to milk the cows then putting in long days working on the farm.

Mary would reposition the sensor leads, try new leads and batteries and various types of adhesive tape for the sensor lead and even tried, at one stage, to hang the monitor up in case it was "losing power from the sensor" (5/3/2).

The alarm rate decreased after the first six weeks at home and the false alarms assumed less significance in their lives as Tyler succumbed to a series of illnesses. He suffered numerous upper respiratory tract and ear infections and had needed to be hospitalised twice for bronchiolitis by the time he was six months of age. Mary found it comforting to have the monitor to use

when Tyler was unwell, particularly because she relied on it to alarm if anything should be amiss with his breathing.

Caring for Tyler at home was primarily Mary's responsibility and contact with health professionals was a major part of the daily activities. The Paediatric District Nurse kept contact with the family and Mary needed to take Tyler regularly to the hospital for routine progress checks by the Paediatrician. The developmental therapist visited them occasionally and advised Mary about therapy for his facial palsy. In addition, Mary also had to take Tyler for audiology and ophthalmology checkups at clinics at the hospital, because of his extreme prematurity.

Interspersed with routine checkups were visits to their G.P. or the emergency after-hours doctor, for Tyler's acute illnesses. Mary found that visits from the Plunket Nurse were seldom forthcoming:

Plunket! Who gets that? What's that? I think, to be honest, and I'm very for Plunket, it's disgusting! [Tyler]'s supposed to be getting what they call red-star treatment - because he's prem he's supposed to have extra attention!

(5/3/12).

She went on to describe how the Plunket services did not allow for the prematurity of the infant and how the nurse had not visited her between the times Tyler was six to nine months of age, when his age was only three to six months corrected for gestation. The reasons she felt she needed Plunket Nurse contact were that she wanted the baby weighed regularly, and she needed up to date information from the nurse about current childcare practices. Although she knew she could get medical advice and treatment from the doctor, she said:

I'd like that contact with the Plunket Nurse - it's good. Things have changed - with every baby you have, things have changed. And I like the information they give you. It's a pity their resources are so knocked around

(5/3/12).

Mary and Peter did not have family members living locally but Mary's mother lived an hour's drive away and her sister visited as often as she could. Mary generally did not leave Tyler with anyone, but took him with her when she had to go out. She was unwilling to ask friends to care for Tyler so she could have time out as she believed friends were "scared":

One friend, she wouldn't like the responsibility in case something happened. But I think they're happy to nurse and cuddle him while I'm here, but you know, it's just that little thing at the back of their minds. I'd hate to inflict that on them too. Not that I think anything would happen to him in the daytime, I don't

(5/2/7-8).

Mary was proud of her ability to cope with Tyler's illnesses as they arose. Tyler, she said, had developed "asthma" and was often chesty and wheezy, needing to be nebulised at the doctor's surgery several times between the ages of six and eight months. She was considering buying a nebuliser because of their distance from the nearest city, but was hesitant to do so, not only because of the expense, but because she believed that if it was used too often it could lose its effectiveness when it was needed for a severe asthmatic attack. Her approach was to analyse information and to take action according to what she felt was necessary:

I've tended to do what I wanted to, anyway!

(5/2/11).

On one occasion Tyler was wheezy and unwell and after the doctor on call had arranged for a chest xray to exclude pneumonia, Mary had asked that he not be admitted to hospital but be cared for at home. She sat up with him reading when he was really distressed then felt she could sleep because the monitor would let her know if his condition deteriorated:

...Sometimes he really does go blue and he's struggling for breath. That's when - say, I put him down at night, at least I

know that if he gets any worse the monitor will let me know.

(5/3/6).

When questioned further about this, Mary showed no appreciation of the limitations of a Graseby MR10 monitor in such situations. Instead, she associated Tyler's asthma with the risk of cotdeath, something she realised she had not done when her older son had had asthma in his first year of life:

The monitor will actually tell me if he's got problems with his breathing so the monitor's actually doing two jobs for me

(5/3/7).

Mary intended keeping the monitor until the baby was over a year old, so that it would be used to tide him over the cold winter months when he would, in her opinion, be at increased risk. Although, they were still experiencing intermittent times of high unexplained monitor alarm rates, and she admitted that she lost a considerable amount of sleep from false alarms, she was able to say when Tyler was nine months old:

The clicking of his monitor doesn't bother me at all - it's almost harmonious. I think, "that's good, the monitor's clicking, I can go to sleep"...He is erratic with his breathing. His lungs are stiff, Dr [] said and that will improve with time and so will his breathing...I just look at him and I think, I just couldn't bear to lose him! So it makes me think it is worth it.....

(5/3/19-20).

Peter's Story (one interview)

Peter did not have the direct involvement with Baby Tyler that Mary did and saw his role in the family as the support person for Mary and breadwinner for the family. He pointed out that this situation was not only

because of Tyler's prematurity but had been the family model when their older boys were infants as well.

Even after Tyler had been transferred back to the local hospital at one week of age, Peter's contact with him had been very limited. Tyler's birth had coincided with a very busy period on the farm with calving and milking to be attended to. Although family members had been available to assist initially, the responsibility soon fell back on his shoulders, for the day-to-day running of the farm. Peter had needed to make a conscious effort to make time and energy available to go into the city and visit Tyler regularly. He found the heat in the neonatal unit oppressive and had never stayed long enough in the unit to participate in the baby's care. Thus, he did not have the same familiarity with the monitoring equipment that Mary had and he preferred to leave the management of Tyler's care to her when Tyler was discharged home.

It was at Peter's insistence that Tyler slept in their bedroom at night so that Mary could keep close watch over him. Knowing that he had to rise early in the morning to start milking, meant that he developed the ability to "switch off" at night and ignore the monitor alarms.

His perception of the most at-risk time for Tyler was during the months of five to eight months of age (corrected for gestation) and he was emphatic that the baby would be staying on the monitor over this "dangerous" period no matter what the false alarm rate was.

Like Mary, Peter saw the monitor as essential for Tyler when he had asthma:

When he had asthma, he could hardly breathe one day - he
was just about blue

(5/3/6).

Mary described Peter as a "worry-wart" (5/3/10) and laughingly said that even if she decided that she didn't want to use the monitor any more, Peter would insist that she did so.

Peter admitted that he would not be happy looking after Tyler for an evening if Mary wanted to go out. He commented:

Well, I don't think I could handle it!

(5/3/15).

then added:

Plus I have to do everything myself now [on the farm] and I keep quite busy, don't I?

(5/3/16).

Mary stated that Peter was quite "happy to do his thing" with Tyler as long as she was there as a back-up resource person, a statement that Peter did not deny.

Peter expressed his opinion that the monitor had a high degree of reliability. The number of alarms they had had convinced him that, without the monitor, Tyler would not have survived the first month at home. His ear was tuned in to listen out for Tyler's breathing and it was part of his daily routine to check up on Tyler at 4am when he rose for the day.

The expense of Tyler's care was considerable. The family had medical insurance and found this was essential with the number of medical bills incurred and prescription costs for the numerous courses of antibiotics Tyler was given for ear infections. The monitoring itself meant costs of \$10 for sensor leads which lasted one to two weeks and \$6 per week for disposable batteries. Both Peter and Mary emphasised that despite their current difficult financial situation they would pay anything for Tyler and they would put no price on Tyler's life. Peter was taught CPR by the Paediatric District Nurse but otherwise the dealings with health professionals were part of Mary's role. He would encourage Mary to consult a doctor, for example, if Tyler was unwell and would take them there in the car, but the actual consultation with the doctor would be Mary's task.

Discussion

Mary and Peter had had three normal full-term infants before the birth of their fourth son, Tyler, at twenty six weeks' gestation. The premature birth had constituted a crisis for the family, particularly occurring as it did, in the middle of winter, when the family was in the process of shifting farms, and was financially stretched. The couple had responded to the challenge of coping with the premature birth and Mary was determined to give her "special" baby the best possible start in life.

McHaffie (1990) in a qualitative study of the perceptions of mothers of very low birthweight babies identified six phases through which the woman passed. The first three occurred when the infant was hospitalized:

1. Anticipatory grief. Mothers mourned the loss of the expected perfect baby and acknowledged that the baby might die.
2. Anxious waiting. The survival of the child was reasonably assured and the focus shifted to worries about possible lasting disabilities.
3. Positive anticipation. Mothers actively and positively planned for baby's homecoming but expressed misgivings about the baby's vulnerability and their own ability to care for him/her.

After the infant's discharge home, mothers experienced:

4. Anxious adjustment. A blend of excitement at having baby home and insecurity about coping adequately were felt.
5. Exhausted accommodation. The new baby took up much attention and energy and strained relationships with other family members resulted.
6. Confident caring. Rewards were found to exceed the demands imposed by the care of the baby, and tiredness and anxiety lessened.

At the time of the first interview Mary and Peter were at the stage of anxious adjustment. They had not long since taken Tyler home from the hospital's neonatal unit and were learning to cope with caring for Tyler without the ever present support of the neonatal unit staff. Mary had been involved with Tyler's care before this discharge, but always with back-up assistance available.

Hence, when Tyler was taken home Mary was forced to quickly move to the stage of confident caring and to make her own decisions about what to do with monitoring problems. The household routine needed to be maintained as much as possible, with the farming tasks to be carried out daily and the older children to be taken to school or preschool. At first, the apnoea monitor alarmed incessantly and disrupted Mary's ability to carry out her household chores. Cooking meals, for example, became problematic. The Graseby MR10 monitor did not have the same features as the monitor used in the hospital, so Mary could not look at a visual display screen and read it for an explanation of why the alarm had sounded. She would thus use her own problem-solving skills to identify the problem and try various solutions such as different adhesive tapes or monitor positions. After seeking advice from the Paediatric Nurse, Mary tolerated the high false alarm rate for a certain time, then made her own decision to monitor Tyler only at night-time. By this time she had passed the stage of exhausted accommodation and was feeling confident enough to take assertive action to address the problem.

Cohen (1993) describing how parents cope with the care of a chronically ill child, gives a similar description of how parents assume control of the child's care:

Early in the course of the illness, parents fear the possible consequences of varying from the prescribed schedule of treatments and hence adhere rigidly to medical directives. As they become more confident in their own abilities to assess their child's status, they begin to test the boundaries of

therapy. They may, for example, try forbidden foods... Such actions, if uneventful, tend to decrease parents' dependence on professionals and provide them with a sense of mastery. By being able to vary the therapeutic regimen and predict the consequences of their actions, parents are able to decrease their uncertainty in this dimension

(Cohen, 1993, p.92).

Mary's approach to monitoring was a practical one and she felt comfortable with her decision to stop monitoring during the daytime. Even though she was reluctant to admit it initially when interviewed, she felt that the baby was not in enough "danger" to warrant the disruptions to the household from the false alarms. Wilson et al. (1990) postulate that a mother's behaviour with the monitor may reflect how vulnerable she perceives her child to be. Mary and Peter had had no experience of previous cotdeath and did not appear to link the necessity for the monitor with Tyler's history of apnoea and bradycardia of prematurity. Rather, they spoke of the monitor as a preventative tool for cotdeath.

Although it is a positive step for parents to reach the stage of "confident caring" (McHaffie, *op cit*) and rewarding for health professionals to see them taking assertive action in decisions about their infants' care, it is essential that parents are given full information on which to base their decisions. Mary (the primary caregiver for the child) ignored the reality that many instances of SIDS occur during the daytime hours and that if Tyler was at risk of apnoea he needed to be monitored continuously.

Similarly, her unrealistic expectations about what the monitor would do when Tyler had bronchiolitis or asthma further illustrate the need for education about the limitations of this type of monitor. The Graseby MR10 monitor detects breathing movements. If the infant is hypoxic from partially obstructed airways and is tachypnoeic to compensate for the lack of oxygen, then obviously the monitor will not alert the caregiver that the infant is in respiratory distress. No oxygen saturation measurement

facilities are available with this monitor and Mary had a false sense of security that the monitor would "do two jobs" and alert her to the fact that the baby was either apnoeic or hypoxic. McIntosh (1990) recognizes this problem; that monitoring may give parents an unwarranted sense of complacency that may lead them to neglect some other aspects of the infant's treatment and thus effectively increase the child's risk of obstructive apnoea. She advocates that parents need "thorough preparation and continuous logistic and professional support if they are to carry out this monitoring" (McIntosh, 1990, p.125).

McHaffie (1990) recommends that mothers be allowed to gradually assume the dominant role in their premature infant's care before the baby is discharged home. Mary had had the benefit of this preparation for Tyler's homecoming but her knowledge deficit about the limitations of the monitor meant that she would base her judgement about the seriousness of Tyler's illnesses on the feedback from the monitor itself rather than on the baby's clinical condition.

Mary and Peter adopted the traditional nuclear family roles. Peter was responsible for the running of the farm and for decisions to do with financial concerns. Mary, on the other hand, was responsible for the running of the household and care of the children. It was her task to stay awake and care for Tyler at night if he was unwell or if his monitor was alarming for no apparent reason. Mary believed that it was important for Peter to obtain enough sleep so he could carry out his farming tasks the next day, and she was prepared to go without sleep herself.

Her belief that nothing would happen to Tyler in the daytime did not extend to night-time hours. Although she could happily not monitor Tyler during the day, she could not turn off the monitor if it alarmed unnecessarily at night (cf Black, Hersher and Steinschneider, 1978; Wasserman, 1984; cited in case studies three and four). Again, the feedback from the monitor was taken as reliable despite visual evidence to the contrary. If the baby had "asthma" and the alarm did not sound, then Mary

was reassured that Tyler was safe. If the baby was obviously breathing and the monitor alarmed then Tyler was regarded as being in danger.

Peter's comments about the reliability of the monitor expressed the same belief. Because the monitor had alarmed often, Tyler must have been at risk and "might not have survived the first month at home".

Mary's high level of interaction with health professionals for Tyler's care was noteworthy. Although she had access to a Paediatrician, a Paediatric District Nurse, audiovisual testers, a developmental therapist and a range of doctors, she still expressed a need for contact with the Plunket Nurse for reassurance about the infant's general progress and about her own mothercraft skills.

Vohr et. al. (1988) who compared stress perceptions of mothers of monitored preterm infants with those of mothers of monitored term infants reported that the preterm infants' mothers demonstrated high pre-existing levels of stress, resulting from prolonged hospitalization of the infants. Preterm infants' mothers tended to view monitors as having a beneficial impact on their home environment but their coping abilities were very much affected by the strength of their social support systems. Mary's experiences with monitoring were likewise reported as being mainly positive but her social support network was limited. She relied on her husband and to a small degree, the older children, to help her with monitoring. Extended family members helped when they were available. Assistance from friends was only minimal, with some people finding it difficult to accept that Tyler, despite his stormy beginnings, was a loved and wanted member of the family. The Plunket Nurse's visits perhaps could have provided Mary with much needed support. Regular routine visits to check up on Tyler's normal developmental progress would have provided an opportunity for Mary to discuss mundane, rather than medical concerns, and have reassured her that her monitored infant, whilst "special" still shared many of the attributes of normal babies born at full-term.

CHAPTER EIGHT

Case Study Six

Family Profile

Megan and Greg are devoted young parents of Baby Laura who had been born by emergency Caesarian Section at twenty-five weeks' gestation. Laura was not expected to survive as she was small for gestational age as well but after sixteen weeks of hospitalisation she was discharged home, feeding and growing well and with a Graseby MR-10 monitor.

Megan and Greg were living with Greg's parents and sister when Laura was ready for discharge from hospital. They were not satisfied with this arrangement, particularly as Greg's family were heavy smokers and they were concerned that the cigarette smoke would adversely affect Laura. Two months after Laura's homecoming, Megan and Greg were allocated a Housing Corporation two-bedroomed unit and they were happy to be able to establish themselves as a family in their own home.

Greg was unemployed at the time of Laura's birth and for the year following. He spent most of this time at home with Megan, caring for Laura. He was anticipating acceptance into a training school which would lead directly into full-time employment and appreciated the opportunity meantime, to be fully involved in his daughter's care, including the apnoea monitoring.

Megan's Story

Megan comes from a family of fourteen children born to a Maori mother and Pakeha father. Megan, who was twenty years of age when Laura was born, left home when she was seventeen and returned to school as an adult

student. She then went on to complete a training course so she could work as an auto-electrical mechanic. Megan was the tenth child in the family; she had three younger sisters, and a younger brother and she was determined to break out of the family's accepted lifestyle.

She emphasised that education was very important to her and that she would do everything within her power to raise her daughter to have high aspirations for the future. She had broken contact with her family, feeling she had little in common with them:

They [Megan's family] don't have a lot of time for children. Children are to be seen and not heard. Whereas, I'm quite different from the family. I'd like to spend a lot of time with her and get her out to socialise. Education's very important to me, whereas it's not to my family

(6/3/11).

She associated herself with the European rather than the Maori side of her ancestry and was not willing to acknowledge any specific aspect of the Maori culture as relevant to her present lifestyle. Megan had been devastated by the news of her pregnancy, feeling that her own career plans were now thwarted. She decided to continue with the pregnancy and in retrospect she was glad she did so as she would be able to have her children early then return to the workforce when they were of school age.

The pregnancy was complicated with toxæmia and at twenty-three weeks' gestation Megan was admitted to a small city hospital's maternity unit for bedrest. This was not successful in maintaining her blood pressure at an acceptable level so after two weeks she was transferred by plane to a major New Zealand city hospital supposedly for more rest there. On her arrival, instead of the expected admission to the antenatal ward, she was taken straight to theatre for the Caesarian delivery, and from there Megan was transferred to the Intensive Care Unit for two days and Laura was admitted to the neonatal unit. Megan knew that the medical intervention was necessary but was intensely resentful that the staff of the smaller hospital

had "misled" her about the seriousness of her condition. If she had known she was to deliver that day, she could have arranged for Greg to be there with her. As it was, he was in an isolated part of the countryside seeking labouring employment when the news was conveyed to him.

This experience influenced Megan's relationships with other health professionals and she made it clear that with Laura's everyday care, including monitoring, the parents' opinions were of prime importance and trust in health professionals was something they needed to earn. When Laura was ready to be transferred back from the Level III neonatal unit to a smaller one nearer home, she said, for example:

We wanted to come home to [city] but we wanted the best for her. We didn't know if they could look after her here

(6/1/11).

When Laura was critically ill initially and not expected to live, Megan had reacted by wanting to spend every possible moment with her, needing to know she had spent time with Laura if she "didn't make it" (6/1/11). Laura's progress was steady, however, and until she suffered a major infection shortly before discharge, she had only the usual number of apnoea and bradycardia episodes that were to be expected with her extreme prematurity.

When Laura's parents brought her home on the monitor, they were initially very anxious, despite the fact the monitor seldom alarmed. They were used to having Laura monitored in hospital and Megan described it as a "normal" part of her care (6/1/13). In the early days at home they "jumped" when the alarm sounded and their usual course of action was to silence the alarm then give the baby "a good shake" (6/1/12). As they became more accustomed to the alarms (and did not react so strongly to noises similar to the monitor alarm, such as the microwave oven) they became more confident in their ability to care for Laura. Within a month they had made their own decision to use the monitor only at night when they were asleep as it was not necessary during the day.

Partly this was because they felt that they closely observed Laura during the day as she spent most of her time in the living room with them, and partly because they saw her as only slightly more at risk of cotdeath than a normal fullterm infant:

But she's still got that little more risk than a newborn. The fullterm baby's lungs are fully developed at this stage. But hers will

(6/1/11-12).

Similarly, in the early weeks at home, they made their own decision, against the advice of the Plunket Nurse, to feed the baby solids and to give her a milk mixture usually reserved for older, heavier babies, because Laura was constantly hungry.

Although Megan reported initially that there were few problems with monitoring, there was a sudden increase in the alarm rates when Laura was six months old, and had been home for six weeks:

Monday last week she got really grizzly and was crying all the time...And that's when her alarms started going, every night...We couldn't see any reason for it...I wasn't sure what it was. It's hard to know, when the alarm goes off. And umm, you check her, reset the alarm, just check the lead's still stuck on her tummy...

(6/2/1).

For several days on end the baby was "grizzly" and the monitor alarmed at night. It alarmed:

at least six or seven times a night, from Monday till Thursday this week. I must admit, it did get to us. 'Cos when you're tired, you get grumpy...We were prepared to try anything just to keep that monitor quiet!

(6/2/5).

They found they had all sorts of theories to explain the alarms - baby too hot; baby kicked blankets off, so too cold; sensor lead lifted, to name a few:

We just didn't know what it is. And we have to check everything. That makes it more frustrating when it just happens again...I got up and she'd stopped breathing and the alarm was going off and - a lot of the time maybe she hadn't stopped breathing but was...um shallow breathing...Last time you [researcher] came, we were saying, "Oh no, not a problem! Doesn't stress us out". But now!....

(6/2/5-6).

Laura was checked over by the doctor several times during the periods of frequent alarms but no physical reason for them was identified. The alarms increased the anxiety level of the parents and with this, their perception of the baby as more vulnerable:

When the alarms weren't going off too much, I thought, "Oh, she's coping quite well. No apnoeas, nothing wrong"

(6/2/12).

Megan felt that it was a pity there was not equipment for them to test whether or not there was a fault in the monitor, lead or battery. They did notice a correlation between times of increased alarms and times when the baby was "grizzly" such as after her routine vaccination shots.

Both parents were very protective of Laura and never left her with a babysitter. Even when Greg's mother offered to mind the baby and gave them tickets to a show, they had refused, preferring to stay home with Laura. Very few people were actually permitted to hold the baby. Family members on Greg's side:

tend to drag her around like a little rag doll or teddy bear or something...We're really quite funny - where we go, she goes. We take her bottle, we feed her and we are even very careful who we give her to, to hold

(6/1/6).

As Laura got older, the episodes of frequent monitor alarms occurred intermittently, as before, most frequently when the baby was unsettled. Laura seemed to be constantly hungry and needed feeding every 2-3 hours to stop her "grizzling".

Crying at night would cause the alarm to sound because "sobbing then taking a deep breath" upset her regular breathing pattern (6/2/3).

Although the parents stated that they believed she no longer was at any real risk of succumbing to an apnoea attack, they would not be willing to give the monitor back to the hospital, nor discontinue its use when the alarm was sounding frequently for no apparent cause. When Laura was eight months old they stated that they regarded her prematurity as no longer of any significance, but the risk of cotdeath, as for any normal fullterm baby, to be more of a threat.

Greg's Story

Megan and Greg had not been living together on a permanent basis when Megan's pregnancy was confirmed. Megan had moved in to live with Greg's parents as she had cut links with her own family and Greg continued to move around the countryside seeking work.

Like Megan, Greg was angered that he had not been informed of the necessity to deliver the baby the day of her transfer by plane. Because he was expecting the delivery to be deferred for several weeks, he did not travel with her in the plane and consequently missed the birth.

Greg's reaction to the premature baby was one of rejection. He distanced himself from the baby, not even wanting to look at her because he was sure she was going to die and he didn't want to be hurt by this. As it became apparent the baby was going to live, he slowly became involved with caring

for Laura in the neonatal unit, saying laughingly it was a "case of having to, really" (6/3/10).

Greg stayed with Megan throughout the time she was recuperating in the major hospital, then when Laura returned to the smaller hospital, he and Megan both lived with his parents.

After Laura's discharge, Greg shared the parenting responsibilities equally, knowing it was a role not accepted by his family:

When we were kids, my father didn't change naps - if we had dirty naps they stayed on us until Mum got home
(6/3/10)

Megan trusted him to care for Laura as she would herself. They spoke of health professionals' surprise when they visited the house to check up on Laura and found Greg caring for her. As Megan said:

A lot of people are surprised I leave [Laura] with [Greg]. But he's a capable dad and I know he is! (6/3/10).

During the hours they spent at home together with the baby, Greg and Megan often talked about their lives together and the type of childcare they wanted for their children. They were emphatic that quality daycare would be preferable to having family members babysit for them and were determined to spend time with their children.

Greg was the person who followed Laura's progress on the height and weight measurement graphs and he was involved in the preparation and feeding of the baby's meals. In addition, he most frequently was the person to get up at night to respond to Laura's apnoea monitor alarms. He admitted to becoming frustrated when the frequent alarms started and had, at times, threatened to drop the monitor on the floor (6/2/4).

Greg shared Megan's difficulty in locating the cause of the alarms and had difficulty differentiating genuine apnoea from a mechanical fault:

We're not sure what's causing it. Whether it's her or the monitor

(6/2/5).

He mentioned several times that the monitor alarmed when Laura was uncovered and cold and thus breathing "faster and heavier" (6/2/6). Like Megan, he would not consider turning off the monitor when it alarmed frequently:

No! We might consider dropping it on the floor! Never turn it off!

(6/2/15).

As is common for babies born prematurely, Laura was "followed-up" by several different professionals. Ophthalmology and audiology checks revealed no abnormalities and Laura's general health was good. She did not have problems with ear infections or chest infections, indeed she had seldom visited the family doctor other than for a mild upper respiratory tract infection, vaccinations, and for check-ups when the monitor was alarming often.

The couple tended to laugh about routine visits from well-baby services as their policy was to make decisions for Laura's care according to what they felt was necessary, not what the nurses advised. Greg felt the Plunket Nurses were not really knowledgeable about monitors:

The only thing the Plunket Nurse notices is...she'll say, "Is that a bit of eczema on her tummy?" It's just red marks from the tape for the monitor. And she'll say, "Oh, that's right, she's on a monitor, isn't she?" They forget

(6/3/6).

Greg had learned CPR when he was in the army, previously and with the instruction given by the Paediatric District Nurse, felt he could use it competently. The nurse had offered to also teach his parents and sister but they were not interested in learning. The expense of the monitor did not

present a problem. Greg worked it out that using rechargeable batteries and replacing the sensor leads only as necessary, it cost only \$2.50 per week, a cost they gladly accepted "for the price of a baby" (6/1/13).

Greg recognised their reliance on the monitor for Laura and at times joked that she would be on it until she started school. When Laura was eight months old he concluded:

A couple of times I've been tempted not to put the monitor on. Sometimes with her teething she's been awake still at 10 o'clock at night...But we always end up putting it on, for safety. We really are quite confident we don't need it any more. But if the hospital board came around and said, "We need our monitor back" we wouldn't be keen to give it back. We wouldn't be likely to give it back!

(6/3/14).

Discussion

Megan's pregnancy with Baby Laura was not planned and occurred at a time when Megan was planning her own career. Her decision to continue with the pregnancy precipitated her commitment to a long-term relationship with Greg, the baby's father. Megan had severed the ties with her own family of origin, but she was able to obtain physical and emotional support from Greg's parents, who took her into their home and cared for her, even though Greg was not living at home much of the time.

Stainton (1989) summarizes the developmental tasks of pregnancy to be achieved by the mother:

1. to be concerned for the embodied infant as well as for herself;
2. to reconcile tensions with her own mother;

3. to feel positive toward herself in developing the role of the mother to this infant; and
4. to prepare physically and psychologically with her mate to incorporate another person into the attachment system.

(p.202)

A harmonious relationship with the partner and a reconciled mother-daughter relationship are thus considered important for the formation of secure attachment to the infant.

Megan showed a strong sense of purpose in her decisions made in young adulthood. She was determined to move out of the family mould from which she had come and so, reconciliation with her mother would have meant going back on the promises she had made to herself. For the benefit of her unborn child, she relinquished some of her independence by turning to Greg's family for help, until she and Greg could settle into their own home. Megan did not reject the infant because its conception had disrupted her lifestyle. Instead, she adjusted her plans to include parenthood before the establishment of her own career, rather than vice versa.

When the baby was born, Megan feared that Laura would die and responded by wanting to spend as much time as possible with her, to love her and care for her while she could. In this respect her response was different from those mothers in the Scottish study by McHaffie (1990) who initially reacted to their very low birth weight babies by distancing themselves so they could minimize their loss if the baby died. Greg's reaction was much more in keeping those of the Scottish parents and he waited until Laura's survival was reasonably assured before becoming involved with her.

Greg was then able to spend much time with Laura as he was not currently employed and he willingly took over some of her routine care. By the time Laura was discharged at the age of sixteen weeks both parents felt confident in their ability to care for her. They quickly adjusted to having Laura at

home and sharing the load, were soon at the stage identified by McHaffie (1990) as "confident caring" (see case study five). From there, they fast reached the point where they challenged the advice given by professionals and trialled various actions which they themselves thought more appropriate (a strategy used to increase parents' sense of mastery, identified by Cohen, 1993, cited in case study five).

Although Laura's monitor alarmed very infrequently in the early days at home, they had decided not to use the monitor in the daytime, preferring to keep her where they could observe whether or not she was breathing. However, when the night-time alarm rates increased they responded in the same way as did other monitoring parents (Black, Hersher and Steinschneider, 1978; Wassermann, 1984; also case studies three, four and five of the present study) and were unable to turn the monitor off. They found it difficult to cope with the lack of sleep and were tempted to damage the monitor so it genuinely would not work, rather than actually switch off and be held accountable if something untoward happened to Laura whilst it was not in use.

Megan and Greg did not perceive Laura to be at high risk of apnoea, in the early days and regarded her risk status as only slightly higher than that of a normal full-term infant. As she grew older, they perceived her to be more and more like a full-term baby but expressed ambivalence about discontinuing monitoring. Like most monitoring parents they were frustrated when the alarm sounded frequently and were unable to pinpoint the cause for its happening (cf Steinschneider and Santos, 1991). Hence as reported in previous studies the monitor itself provided the only tangible negative feedback about her risk status (Black, Hersher and Steinschneider, 1978). All routine checks of Laura's development were reportedly normal and after initial appointments at the hearing and audiology clinics, Laura's progress was then overseen by the visiting Paediatric Nurse, the Plunket Nurse, the GP and occasionally by the Paediatrician.

Well baby checks by the Plunket Nurse were opportunities for the parents to be given advice but they tended to disregard the nurse's input and instead did as Cohen (1993) described, "tested the boundaries" of therapy, for example, feeding Laura items which were considered inappropriate for a premature infant of her age.

Megan and Greg supported each other with caring for Laura on the monitor but were reluctant to use any offered opportunities for respite for time alone. They preferred to limit their social outings to occasions where they could take Laura with them. It was apparent that Greg's parents were willing to babysit for them but were not prepared to either learn CPR or to limit their cigarette smoking to where the smoke would not be inhaled by Laura. Their casual attitude about these things which were important to Greg and Megan meant that they were not entrusted with Laura's care, even for short periods of time. The couple had no formal contact with other parents of monitored infants, preferring to remain self-reliant as much as possible. Their very intense parenting style appears to reflect their perception that the need to care for their prematurely born infant was a challenge to them, as a young couple in a newly established family unit. Canam (1993) warns that unwary parents can become so involved with the child's needs that they neglect their own needs with resultant dysfunctional family relationships. Additionally, Shapiro (1983) notes that in some instances, the "special" or ill child, becomes the centre of attention and the hub of the family's existence. Parents may feel overprotective towards the child who is then placed at risk of the "vulnerable child syndrome".

Stainton (1989) describes the usual patterning of the prenatal family's experiences. Before the birth three major themes emerge - the pregnant woman as centrepiece, the infant as focal point and a narrowing of the social world. By the time of the birth, the family is a cohesive, tightly-knit group with energy directed towards the mother-infant unit. After the birth, in the first few weeks, the infant becomes the centrepiece of the family's focus with the mother as essential caregiver. Throughout this time, the mother gradually increases the infant's interaction with others and by eight weeks of

age the infant is made accessible to others in the wider family circle. The marital relationship then assumes a greater significance and the family "rounds off again" (Stainton, 1989, p.209).

Megan and Greg did not conform to this pattern. They had deliberately restricted the involvement of the grandparents and of other extended family members and were continuing to focus almost exclusively on the infant, unwilling yet to widen the infant's social world and to expose her to risk, however small.

Allowing for her prematurity, Laura's corrected age for her gestation at the time of the final interview with the parents was five months. Since her hospital discharge, Laura had not been left with any caregivers other than her parents. Regular contact with health professionals was maintained but Megan and Greg mentioned very little about ongoing social contact with friends, spending most of their time at home together, caring for their "special" infant.

CHAPTER NINE

Cross-Case Comparisons

It is apparent from the stories of the members of the six families who participated in this study that the impact of home apnoea monitoring cannot be appreciated without an understanding of the context in which it is undertaken. McElroy, Steinschneider and Weinstein (1986); Phipps and Drotar (1990); and Vohr et al. (1988); each commented that the designs of earlier studies about the effects of home apnoea monitoring on families, have precluded the possibility of separating the effects of home monitoring itself from those more appropriately attributable to other family variables, such as the reasons for parental and clinical concern (for example, history of parental reports of an apparent life-threatening event (ALTE) or the previous cotdeath of a sibling). To overcome this difficulty they suggest controlled studies using tools such as objective psychological inventories and homogeneous samples.

The present study however, undertaken to examine the experiences of parents caring for infants on home apnoea monitors in a New Zealand context, takes a systemic perspective of family functioning during the time of home apnoea monitoring and thus makes no attempt to separate the monitoring experiences from the context. The sample is small and there has been recognition throughout that a reciprocal relationship exists between the demands of the treatment of a perceived illness and the individual and the family both as the context for care and as the unit of systems care (Wright and Leahey, 1990). The aims of the present study were thus to examine the experiences of a specific sample of monitoring parents rather than to make controlled comparisons with non-monitoring parents.

Nevertheless a cross-case comparison of the six families' stories reveals several patterns consistent with those reported in both the family nursing literature and the literature dealing specifically with home apnoea

monitoring. These have been broadly categorised and will be discussed under the headings:

- The experiences of bereaved parents;
- Risk perception and anxiety levels;
- Monitor alarms;
- Adaptation of the monitor into family life;
- Social support: Friends and family;
- Social support: Professional;
- Discontinuance of monitoring;
- After monitoring: an optimistic future

The Experiences of Bereaved Parents

Although the families who participated in the present study made up a convenience sample, unexpectedly the three families (case studies two, three and four) who previously had lost infants from SIDS presented several common themes in their stories. The focus of the investigation was their current experiences with living with a monitored child, yet each parent felt the need to speak at length about the death of their previous child. The depth of emotion revealed in their accounts of the events leading up to and after the discovery of the lifeless infant left no doubt the loss of the child had had a profound and lasting effect on their lives.

Recent literature about the grieving processes undergone by bereaved parents (McClowry, Gillis and Martinson, 1989; Rando, 1991) describes many of the ongoing feelings that these participants shared. Several years had elapsed since the deaths of the infants yet the parents still felt the pain of the loss acutely. Each parent felt a sense of helplessness and frustration that their child had died despite their best attempts at being good parents. They needed to find reasons for the unexplained deaths, partly to assuage their feelings of guilt that they must have done something to have contributed to the infants' demise. Each parent had their own explanation of the factors that had led to the loss of the child and each, in their own way, ascribed

blame to themselves and to others, particularly to health professionals who had advised them to lay the babies in the prone position to sleep.

The bereaved parents spoke of a sense of vulnerability, of their children especially, but also of all people. Diane and Alan (case study two) recognized that this was happening. Diane spoke of her "irrational fears" about the safety of her older daughter, Amy. She mentioned her reluctance to let the child out of her sight (2/1/14) and how she would continually check on Amy at night, "to see if she'd die in the night, even though I knew she wouldn't" (2/1/13). Alan referred to his sense of responsibility for the life of the monitored baby but also of his more general sense of the frailty of life.

Christine and Mike (case study three) also reported a heightened sense of the life-threatening risks to children, Christine especially showing her fear that the unexpected could happen to children of any age, even teenagers who could counter all their parents' efforts to keep them safe by committing suicide! Lynda (case study four) attempted to deny her own sense of mortality and that of her children and to block out the possibility of further deaths in the family. Her comment "No - nothing can happen to me! I've got too many kids to look after [laugh] it just can't happen" (4/2/16) was an example of this coping mechanism.

These sets of parents showed their need to regain a sense of control over the threat of death. This need was met, to some extent, by rationalizing the events which led to the death and by attributing blame (Ranbo, 1991) but it was clear that the presence of the monitor contributed to their sense of mastery over the threat to their subsequent children. In this respect, the monitor was viewed by the parents as a necessity and an anxiety-reducer (positive views shared by bereaved parents in the study by Black, Hersher and Steinschneider, 1978).

Risk Perception and Anxiety Levels

In one of the first studies of the impact of the apnoea monitor on family life, Black, Hersher and Steinschneider (1978) reported that anxiety was greatest in those parents whose infants had a diagnosis of sleep apnoea or who had previously lost a child. Lower distress levels were found by Vohr et al. (1988) to be present in parents of monitored premature infants than in parents of monitored infants who had been born at full-term. (Their control group, parents of non-monitored infants, had the lowest measured anxiety levels overall). Certainly in the six participating families in the present study, the parents of the infants born prematurely had lower risk perceptions of their infants than did those who had had previous children die of cotdeath, or believed there was a family history of sleep apnoea.

The need for the monitor was not seen as quite as important for the parents of the two premature infants. Their focus was on the maturation of the infants and as the babies grew older their risk perceptions of the babies appeared to decrease, to the point where they regarded the babies as only slightly more at risk of cotdeath than a normal full-term infant. Jane and Sean (case study one) were unsure about the risk status of their son and of his medical diagnosis. The ambivalent feelings they expressed about the need for the monitor reflected this uncertainty.

Monitor Alarms

Despite their differing anxiety levels, all parents in the present study encountered difficulty with the monitors' false alarms. If the alarm sounded, parents reported a panic reaction and tended to over-respond to the alarm. The feedback from the monitor itself gave them an indication of whether or not the infant was breathing. So, in the situation when an alarm was sounded, the parents could respond by (a) stimulating the baby immediately (whether or not it was necessary); (b) checking visually to see the baby's chest movements with each respiration; or (c) looking at the

monitor to see if the respiration light was flashing and listening to the audible click which indicates a breath has since been detected. However, unless the infant is obviously still apnoeic, or the sensor pad dislodged, there is no immediate feedback to the caregiver as to why the monitor alarmed in the first place. This limitation of the monitor models used has been acknowledged (e.g. Davies et al., 1991) and creates anxiety and frustration in the parents. They are left unsure whether the infant suffered an apnoea attack which was self-correcting, whether the monitor was faulty, or whether the baby's breathing was too "shallow" or too "deep" to register on the sensor.

The inability to distinguish false alarms from real episodes of apnoea was a recurrent problem for the participants over the three month investigation period. Diane and Alan (case study two) showed the most extreme reactions to the alarms, classifying them as either "self-start" (when the monitor proceeded to show a flashing respiration light after an alarm) or "bad" when the infant required stimulation to resume breathing, rather than apnoea versus false alarm. Their responses are congruent with the findings of Steinschneider and Santos (1991) whose study confirmed earlier findings that parental reports of apnoea are unreliable.

Even the parents of the premature infants (case studies five and six) whose experiences with cardiorespiratory monitoring in the neonatal units meant they were familiar with dealing with an infant connected to various wires and machinery and had had experience of hearing numerous alarms, found episodes of frequent, unexplained alarms distressing. In the early period of hospitalization, very premature infants have cardiorespiratory and oxygen saturation monitors *in situ* routinely. As the infants progress, they typically have these monitors withdrawn and are instead nursed with respiration-only monitors. Hence, in the crisis period after the early delivery, the monitors used have digital readings and electrocardiograph and respiratory tracings on display screens to advise the caregivers when the baby is apnoeic, bradycardic, or hypoxic. Later, when apnoea monitors are used alone, the interpretation of the cause of the alarms is the responsibility of the

attendant. Parents who are performing many of the caregiving tasks, in preparation for the homecoming, have the back-up and support of the staff when the apnoea monitor alarms. Obviously, once the baby is discharged, the parents must learn to interpret the alarms independently.

Mary (case study five) experienced a lot of difficulty in the first weeks at home with the monitor alarming constantly, and the eventual diagnosis of the problem was shallow breathing by the infant. Megan and Greg found their series of frequent alarms occurred at a later stage. The initial period without alarms had led them to feel a sense of complacency that their daughter was not at risk.

As reported in the study by Black, Hersher and Steinschneider (1978) the monitor became the parents' only tangible negative feedback about the infant's risk status. Every family in the present study (as in the above-mentioned study) reported an inability to switch off a monitor that alarmed frequently. Despite the evidence that the infant was breathing, they reacted to the alarm by concluding that the infant was in danger. Thus, they would lose sleep because of the frequent alarms, rather than switch the monitor off, the only alternative being to stay awake to keep guard over the sleeping infant.

The monitor's presence, as Wasserman (1984) wrote, denied the parents any opportunity to put from their mind the awareness that their child may die at any time. Although it required constant vigilance in listening for alarms, it also provided reassurance that the parents would be warned if the baby required resuscitation. Five of the six families stated that they consciously put their trust in the monitor and did not consider the possibility that the monitor would not alarm when it should do. The fact that the monitor alarmed so readily when the baby was not apnoeic, led them to conclude that there was little possibility that it would fail to alarm. Christine and Mike (case study three) were the exception to this pattern. They had tested the monitor in the car, believed it to be ineffective and had thought of the possibility that something other than the baby's breathing movements

would keep the monitor clicking. In fact, Diane and Alan were the only parents (case study two) who did use the monitor in the car.

Adaptation of the Monitor into Family Life

Parents in the present sample did not always fully understand the medical indications for the monitoring. Lack of regular, ongoing contact with the monitoring programme staff, in some instances, had led parents in some instances to

- use the monitor inconsistently
- consider it their own responsibility to ensure their child's survival
- make their own decisions about discontinuing monitoring, based on their perceptions of their own ability to cope without it, rather than on the medical indications for its use or non-use

Wilson et al. (1990) who surveyed mothers' behaviour with home apnoea monitors found that very few of them (8%) used the monitor consistently so that their babies would have been responded to immediately if resuscitation had been necessary. Parents had adapted the monitoring into their lifestyles using it in ways considered inappropriate by the researchers.

In the current sample, only one family (case study two) used the monitor both day and night and when travelling. This family went to extraordinary lengths to avoid known risk factors for cotdeath and restricted their social activities so as to give the child a regular routine and stress-free environment (both factors were considered to have been neglected on the day their previous infant had died of cotdeath).

Of the remaining five families, three used the monitor at night-time only (case studies one, five and six) and two used it day and night but not when travelling. Wilson et al. (1990) concluded that compliance with recommended monitoring regimes reflected the parents' perceptions of

their child's risk status. Certainly, Diane and Alan (case study two) who monitored Sarah vigilantly, saw her as being in danger of dying at any time.

An alternative explanation for the sometimes inappropriate use of monitors is perhaps provided in the recent family nursing literature with Cohen's (1993) description of how parents cope with the strain of living under conditions of sustained uncertainty. Their increasing independence with making decisions about monitoring (appropriate or otherwise) were in line with Cohen's description of how parents manage the stress of the "sustained uncertainty" experienced when they care for children with chronic, life-threatening illnesses. They develop strategies to manipulate the stressors, the "known, the unknown and the unknowable" (p.85) and learn to cope with six interactive dimensions of daily life - time, social interaction, information, awareness, the actual illness and the environment. Managing the illness (or threat of apnoea) requires constant vigilance and effective handling of the treatment regime (in this instance, the monitoring). As parents become more confident in their own abilities to assess their child's status they independently vary the therapeutic regime and thereby achieve a sense of mastery and decrease their dependence on professionals' advice.

In the present study, parents' independent actions were evident in each of the six families. Most parents became increasingly confident that their child could be watched over at times without the monitor, and felt competent to make the decision not to use it during the day-time or in the car. The most "compliant" monitoring family (case study two) expressed very little faith in health professionals' abilities to convey accurate and full information. They avoided visiting a doctor, and considered it their own responsibility to keep their child alive. Lynda (case study four) continued with actions advised against by health professionals such as smoking near the baby and lying the child prone. Both sets of parents of the premature infants (case studies five and six) chose to increasingly make decisions and care for their infants independently of health professionals' advice, as did the parents, in case study three (Christine and Mike). Christine had negative feelings towards

the nurse who had reportedly ignored her concern about her daughter's pallor just before the baby died, but otherwise enjoyed a good relationship with health professionals. Her husband, Mike, was however, sceptical about medical advice and made no secret of the fact that medical opinions were not to be accepted uncritically.

Obvious knowledge gaps were revealed by parents. For example, Jane and Sean (case study one) were able to share with the researcher their opinions that their son's medical diagnosis was vague and that the medical indication for monitoring had not been clearly explained. They felt they had received inadequate information about their child's medical diagnosis and had no ongoing contact with the medical staff of the monitoring programme. Diane and Alan (case study two) were much more assertive people, but still felt that medical information was withheld from them. They had been unaware of the available facilities to investigate their daughter's apparently extreme high rate of apnoea episodes.

Parents' beliefs about the efficacy of monitoring were in some instances unrealistic. The participants in the study were unaware of the risk of obstructive apnoea which may not be detected by the Graseby MR10 monitors. The mother in case study five who relied on the Graseby monitor to alert her of respiratory distress in a child with asthma, did not have an appreciation of the limitations of a monitor that detected breathing movements only. She did not realise that the rapid respirations in an asthmatic attack were in themselves a sign of respiratory distress and that the monitor would only alarm if the breathing effort was absent for twenty seconds or longer. The weaning of the infant off the monitor using the green light (case study four) was another instance where a mother gained a sense of security about the infant's safety that was not reasonably warranted.

At the other extreme, the perceptions of the mother in case study one, that the infant was more at risk when the monitor was *in situ* were equally unrealistic. The mother was unable to be left in sole charge of the infant at

night when the monitor was to be used yet cared for him alone during the day when the monitor was not in use.

Technical aspects of monitoring included reports from parents that:

- adhesive tape caused skin irritation for the baby
- financial costs of replacement batteries and sensors could contribute to the decision to stop monitoring
- insurance cover for accidental damage to monitors was necessary
- "after hours" stocks of monitoring accessories could be held by chemists or other 24 hour service centres
- it was possible, in some instances, to predict when alarms would sound, e.g. an hour before waking in the morning, or when the infant was too hot or too cold, or had been unwell.

Social Support: Friends and Family

Support for the mothers (the main caregivers) of the monitored infants was provided mainly (with exception of Lynda, case study four) by their partners. Nuttall (1988); Geary (1989); and Phipps and Drotar (1990) all emphasized the importance of social support and resources for mothers who carry most of the burden of care.

It was noteworthy that of the six families interviewed in the present study, only one family had lived in the area for any appreciable period of time. The recent shifts in location meant the other five mothers had had limited time to build up a network of trusted friends to support them during the monitoring. The mobility of the families resulted in separation from extended family members who would otherwise have been available to help.

Each of the participants spoke of the lack of opportunities for respite from the care of the baby yet expressed unwillingness to either entrust their child to another person's care, or to impose the burden of care onto a babysitter.

In this respect their behaviour mirrored that of mothers in Geary's (1989) study of stress and social support for monitoring mothers, who also found it difficult to leave their babies even when they had capable, trained sitters available. Some fathers in the present study were willing to help with the baby only whilst the mother was there as a support person (case studies one, three and five). One father (case study four) was not involved in the baby's direct care, effectively leaving the mother to cope singlehandedly. However, two fathers (case studies two and six) did take responsibility for their babies care whilst the mothers were out of the house.

The desirability of having two adults in the house whilst the baby was monitored was a recurrent theme. Sean and Jane, for example, spoke of the possibility that one parent could sleep through an alarm (much like an alarm clock) and Jane preferred a second person there to help with CPR or to phone for an ambulance if needed. Alan and Diane found that it was all too easy to wander out of earshot of the alarm. Christine and Mike debated between themselves the significance of the alarms. Mike's comments about the sense of edginess which he felt when in the house with the monitored child appeared to reflect the intense feelings of responsibility to keep the child alive, which other parents in the study also experienced. Dean (1986) identified the same inability of parents to relax with their baby. Their need to provide constant watchfulness and twenty-four hour vigilance was a major category of concern for parents.

Social Support: Professional

Several authors have written of the importance of the availability of social support for parents of monitored infants (e.g. Vohr et al., 1988; Phipps and Drotar, 1990) and mention the value of support groups for parents. Inexplicably, support groups were not identified by the parents in the present sample as appropriate for meeting their needs. Instead, these parents repeatedly expressed their needs for support from knowledgeable health professionals, when caring for their monitored infants. They indicated a preference for direct contact with competent, yet approachable,

health professionals, such as Plunket Nurses who could provide information and reassurance about routine child care as well as about the issues specific to monitoring. Especially evident was these mothers' need for reassurance and affirmation of their parenting abilities and skills. Even mothers who had had several children expressed the need to have regular ongoing contact with the Plunket Nurse (case studies one, two, four and five). Mothers spoke in emotive language about the perceived unavailability of the service and felt the nurses were too busy to be bothered with their apparently trivial concerns.

An unwillingness to ask for help was apparent. Diane (case study two) confided that she needed help, as much during the monitoring as she did in the immediate bereavement period following the death of her son. She believed friends could not be expected to provide support over such an extended period of time. In the first few months of monitoring she had received considerable support from a Plunket Nurse who was knowledgeable about monitoring. When the new nurse had shown a limited understanding of the demands of monitoring, Diane found her input less helpful.

For the monitoring parents (case studies one, two, four, five and six) assistance from Plunket Nurses was only helpful if:

- (a) the nurse was readily accessible;
- (b) the nurse understood the reasons for their child having the monitor at home;
- (c) the nurse understood the stresses and technical difficulties experienced with monitoring;
- (d) the nurse was able to provide advice about well-baby care (dietary, general parenting skills) and convey this advice in a way that

demonstrated an understanding of the unique family situation in which the child is living.

Parents' comments (sometimes scathing) about the shortcomings of this support service indicate that an integrated, holistic approach to their child's supervision would be appreciated. A nurse, for example, who performs a routine physical check of the child and shows no acknowledgement that the baby is on a monitor, does not earn the trust of the parents. The one family (case study three) who felt their nurse (a Public Health Nurse) met their requirements, had built up a relationship with the nurse over several years. Her input to the family was invaluable in assisting the mother, especially, to access services from other health care agencies, for herself, the infant and the older children.

Services were provided for monitoring families by a variety of health care providers including hospital staff, Plunket, Public Health and District Nurses, and medical personnel. The parents of the premature infants had contact with an even wider range of health professionals, each dealing with a different aspect of the baby's care - audiology, ophthalmology, developmental therapy, well-baby checks, vaccinations, treatment of acute illnesses; to name but some of these. An integrated, coordinated service appeared to be lacking.

Discontinuance of Monitoring

It is not surprising, in light of this discussion, that parents' decisions to stop monitoring tended to be impulsive rather than based on formal medical advice that the monitoring was no longer necessary. Several participants (fathers in case studies one and three; caregiver in case study two) believed that ideally all babies should be monitored. They made these assertions despite their recognition that parents could become dependent on the monitors and that their presence created tension in the parent-child relationship. The caregiver's comments (case study two) that monitors are "essential" and that parents "could be driven batty being around the thing

all day" (2/4/12) demonstrated the ambivalence felt by parents both in this study and in previous studies (Wasserman, 1984; Nuttall, 1988).

When parents decided to discontinue monitoring, they approached the task in various ways. Lynda (case study four) "weaned" her infant off the monitor, using the green respiration light on the monitor to ease the transition. Alan and Diane monitored the child for fifteen months and made an impulsive decision in the end to stop monitoring and not follow up on an offer to have the supposed apnoea episodes investigated.

Both of these families verbalized their intention to recommence monitoring if the baby appeared to be again "at risk". Wasserman (1984) found that some parents continued to monitor for longer than was necessary (by medical criteria) and that many used it again if the baby became ill. Her study was conducted over a five year period and the parents' reported that they continued to respond to noises like the monitor alarm even years after the monitoring was discontinued.

After Monitoring: An Optimistic Future

In the present study, each of the three families who discontinued monitoring during the three months of the study's duration, was monitoring what was for them, a last child. Diane and Alan had not planned the pregnancy and were not intending to have further children. Christine and Mike, who had lost one of their first-born twins, had completed their family with the birth of Carl. Lynda, who had had several surviving children interspersed with two SIDS victims, was anticipating a hysterectomy, in the near future. These three families appeared to have shared the experiences of discontinuing monitoring of what was to be their last child, with some trepidation, each having lost previous infant/s from cotdeath. It was significant that although they felt considerable anxiety about the well-being of the baby for approximately three weeks after cessation of monitoring, that they then were able to focus their attention on the child's prospects of a normal childhood. Their perceptions of the risk

status of the child altered, from an infant "at risk" to that of an older infant approaching toddlerhood with the usual risks of mishaps.

Christine and Mike (case study three) had never had the experience of caring for an infant from the time of the child's birth, without the threat of sudden death. Their surviving twin had been very ill in the neonatal period and was monitored in hospital, then at home from the time of his sister's death. All their subsequent children were treated as also vulnerable to cotdeath and their infancies were all affected by home apnoea monitoring.

Alan (case study two) spoke of how the cessation of monitoring had made him appreciate the insidious effects of the monitoring ordeal and how his sense of Sarah's vulnerability had eased when they considered monitoring no longer a requirement to keep her alive. For each of these three families, the loss of their previous infant/s had underpinned their monitoring experiences. Whilst the child was monitored the parents' task was seen as ensuring the child survived the dangerous period of infancy. When the monitoring was stopped, it signalled not an end to the grieving for the lost child, but a new focus on an optimistic future for this subsequent child.

CHAPTER TEN

Conclusions and Implications for Nursing Practice

Home apnoea monitoring for infants thought to be at risk for apnoea has been available in New Zealand since 1978 (Tonkin and Hutton, 1988) yet to date, it is still unknown whether apnoea monitors do actually prevent infant deaths. Their usefulness in the lowering of the incidence of SIDS in New Zealand is limited partly because of the small numbers of infants who can be monitored at any one time. In comparison, it is thought (Mitchell et al., 1991) that larger numbers of infants' lives could possibly be saved if parenting practices were changed to implement the findings of the New Zealand Cot Death Study and the four modifiable risk factors avoided (exposure of infants to cigarette smoke, bed-sharing with adults, artificial feeding, and the laying of infants face down to sleep)

Parents' Beliefs about the Efficacy of Monitoring

It was apparent from the stories of the participants of the present study that significant knowledge deficits existed about the role of monitoring in the everyday management of their children's care. One parent, for example, used the monitor inappropriately for a child with acute respiratory distress. Another perceived the infant to be more at risk when the monitor was *in situ* than when it was not in use. None of the caregivers in the present sample had any knowledge about the different types of apnoea and they were unaware of the documented limitations of the Graseby MR10 monitor in detecting obstructive apnoea in time for resuscitation to be successfully carried out.

Stress perceptions and coping strategies adopted by parents were influenced both by the family's circumstances and resources, and by the reasons the parents perceived the monitor was initially issued for use by the family. A need was demonstrated for parents' perceptions of the infants' risk status to

be thoroughly assessed, taking into account that parents may well hold disparate views about the seriousness of the infants' risk status and that this can lead to marital discord (Geary, 1989).

Ongoing grieving processes clearly underpinned the monitoring experiences of parents who had previously lost a child to SIDS and it was evident that monitoring of subsequent children to a SIDS victim was especially anxiety-producing. Health professionals should be aware that the grieving of parents who have lost a previous infant can have profound effects on how they cope with monitoring a subsequent child. Time could profitably be spent with the family ascertaining their beliefs as to why their previous child died. Parents may attribute blame to themselves or to their partner for failing to provide proper care for their infant.

It can not be assumed that the information given by health professionals to monitoring parents will be accepted unquestioningly. Participants in the present study who had lost infants from cot death had all followed the advice of health professionals and had lain their infants in the prone position to sleep despite warnings to some from family members that it was a dangerous practice. Questions arise as to who should take responsibility for giving parents advice that may well have resulted in the the deaths of the infants. Accountability for information and advice given to clients is a hallmark of professional practice, yet as one participant in the study pointed out, medical and nursing personnel were not publicly accepting responsibility for advice that was, in retrospect, misguided.

Education about the reasons for, and the efficacy of monitoring should ideally be given to caregivers at the time the monitor is issued. Caregivers expressed the need for information about their child's condition to be shared fully and explicitly with them, especially by medical staff. Assessment of parents' perceptions of the reasons for the need for monitoring could well reveal beliefs about their infant's condition that may seem illogical to others. The family in the present study who attributed

their child's problem to an allergy, for example, had not been given this diagnosis by the Paediatrician but had drawn this conclusion themselves.

As Cohen (1993) indicated, the provision of a medical diagnosis is conclusive for medical staff but for parents it provides no sense of closure; instead it raises countless questions and fears and is only the beginning of a period of uncertainty affecting every aspect of family life.

Information-sharing and collaboration between the Paediatric medical staff who make the diagnosis and other health professionals who interact with the monitoring parents, is necessary to ensure consistent and accurate information is conveyed to parents. Regular contact between the staff of the monitoring programme and the infant's caregivers throughout the period of monitoring would provide opportunities for on-going education about the use of the monitor in the management of the child's care.

Responses to Monitor Alarms

Obviously, the limitations of the type of monitor used so prevalently in New Zealand, the Graseby MR10, led to many of the negative experiences reported with monitoring. Frequent false alarms continue to be reported with these respiration detection monitors, despite the technological advances since 1978. The levels of false alarms were one of the factors influencing the decision of most parents in the study to modify the recommended use of the monitor and to adapt it into the family's lifestyle. The participants in this study, like those in the earlier studies reviewed, reported that high rates of false alarms led to loss of sleep. False alarms caused negative arousal in the parents who became angry and frustrated when monitors alarmed persistently for no apparent reason at night-time, but were unable to switch off the monitor and go back to sleep. Their sense of responsibility for keeping the child safe meant they would rather stay awake and keep guard over the infant at such times. (cf Black, Hersher and Steinschneider, 1978; McIntosh, 1990).

In light of the difficulties reported with the use of this type of monitor, it would be appropriate for an independent review to be undertaken of the equipment available for monitoring at home. Because the Graseby MR10 is a respiration detection monitor, no information is given about the infant's heartrate. Data storage facilities are not incorporated into the machine, hence when the alarms sound, no information on the cardiac and breathing activity before, during and after the alarm can be recalled and there is often no obvious explanation for the origin of the alarm. Anxious parents are thus left uncertain how to respond to alarms and will stimulate the infant unnecessarily rather than run the risk of leaving a possibly apnoeic infant to sleep. More sophisticated cardio-respiratory monitors which have incorporated data display and storage facilities are not only cumbersome but their expense is prohibitive in times when cost containment is of prime concern in the health care system.

Wilson et al. (1990) raise some very relevant points for nurses and others who supervise monitoring programmes. They point out that it needs to be established whether the monitoring was prescribed because the infant is indeed in danger of apnoea or whether it was provided mainly for the peace of mind of an over-anxious parent. They emphasise that if the infant is truly at risk of dying if left unmonitored then ethically the monitoring programme staff have an obligation to ensure the infant is monitored consistently, not just as the parent finds convenient.

At present, it appears that risk status is vaguely defined. The participants in the present study were issued with their monitors by the staff of a supervised monitoring programme, but there are many other parents in New Zealand who independently obtain monitors for use from the Cot Death Society. Although apnoea monitors may be issued to very anxious parents with the intention of lessening their anxiety levels, it is apparent that the opposite effect may be unwittingly achieved, when the monitors used have high false alarm rates and cause the infants to be wrongly diagnosed as apnoeic. If the availability (by consultation with a Paediatrician) of on-line equipment and event recorders to investigate the

causes of frequent unexplained alarms is made known to parents then it may well be possible to prevent the experience of long-term acute anxiety in parents who, as a result of the only tangible evidence of apnoea (the alarm of the monitor) believe their child may die at any moment. Parents who undertake home monitoring of their infants, whether medically advised or self-selecting, clearly require on-going education and a vigorous support system to assist them through this stressful time.

Professional Support for Monitoring Parents

The need for structured professional support throughout the monitoring period was an important theme which emerged in the interviews with the participants in the present study. Acknowledgement of the influence of apnoea monitoring on all aspects of the child's care was shown by the parents to be essential, and unfortunately, it appears from the stories of the six participating families, that this tends to be overlooked when health care services are fragmented rather than integrated. The extension of the role of the Visiting Paediatric Nurse to incorporate that of a community-based nurse case manager for monitoring families would go some way to redress this problem.

Community-Based Nurse Case Managers

The concept of community-based nurse case managers as a model to meet New Zealand's changing health care needs has been discussed by Wade (1992) and although its implementation has been most often considered appropriate in the mental health field, the principles are equally applicable to the community care of at-risk infants. Wade defines a community-based nurse case manager (CBNCM) as a person who manages the total health care of a given group of clients over time.

The CBNCM role would include:

1. Assessing the client and family needs for assistance and resources,

2. Providing support and targeting suitable resources to achieve health status goals,
3. Ongoing monitoring of the clients' health care needs and treatment regime,
4. Collaboration with other health care professionals on behalf of the client and family,
5. Taking accountability for client outcomes in terms of quality and costs,
6. Promoting self-care behaviours and client/family responsibility for their own health

(Wade, 1992, pp.6-7).

Overseas experience with CBNM has shown the model to be effective in achieving integration between primary, secondary and tertiary health care services, and assisting clients to "negotiate the complex and fragmented health care system" (Wade, 1992, p.7).

Monitoring parents in the present study deplored the lack of support from the Plunket service and expressed their need for advice and reassurance about normal well-baby care as well as about the specific demands of monitoring and/or care of their premature infant. Mothers, particularly, would have benefitted from a co-ordinated professional support service. If, for example, one health professional had been involved in advising Mary (case study five) both about the management of asthma and the role of apnoea monitoring during asthma attacks, then it would be more likely that Mary would have more realistic expectations of what the monitor could and could not do. It is possible that Diane and Alan (case study two) could have been saved considerable anxiety if they had been made aware earlier of the non-invasive equipment available to investigate Baby Sarah's numerous apnoea episodes. A health professional with a case management focus

could have provided these parents with the relevant information or co-ordinated meetings with the Paediatric medical staff to resolve misunderstandings such as these.

The Visiting Paediatric Nurse currently has the opportunity to provide the supervision of the monitoring of the infant and instruction in carrying out CPR if needed. However, the role could be expanded to include more direct involvement with the families, spending time assessing their needs for information, education, counselling, or for other forms of assistance. In some instances the nurse could provide this assistance directly. In others, he/she could co-ordinate the provision of services from other health professionals (particularly for caregivers of premature infants who have contact with such a large number of health services). Collaboration between the Visiting Paediatric Nurse and other community agencies such as Plunket and Public Health services would be an integral part of the CBNM role. Information and education about apnoea monitoring would need to be given to all health professionals who have contact with the monitored child.

Professional support was seen as especially important for this sample of New Zealand parents perhaps because they tended to have a high degree of mobility, seeking employment opportunities. The frequent changes of location meant that these families could not be assumed to have an established network of supportive friends and family available to assist them. They were not interested in formal support groups and they could well have benefitted from extra contact hours with professionals.

Active promotion of opportunities for respite from their infants is an important task for nurses and others dealing with monitoring parents, who almost without exception, find it difficult to abdicate their monitoring-parent role for even short periods of time. The findings of the present study support the statements by Williams and Williams (1990) that monitoring can decrease mothers' self-esteem and confidence in their parenting abilities. It should therefore not be assumed that those most in need of help

will ask for it. The initiative can be taken by health professionals alert to the potential difficulties with monitoring, to systematically assess each family's ability to cope. There may well be a need to positively reframe the experience for parents so that the infant's normal development is emphasized and the baby is nurtured and enjoyed within the family.

Discontinuance of Monitoring

A crucial time for support to be provided for parents is the stressful period when monitoring is to be discontinued. The necessity of a medical opinion and for counselling for the family was evident in the stories of parents contemplating discontinuing the monitoring. Issues to be addressed included assessment of the degree of risk involved in removing the monitor and the need for parents to openly discuss concerns such as feelings of guilt and the attribution of the blame if the infant died subsequent to the return of the monitor. The duration of monitoring is acknowledged as a stressful time for parents and when decisions are to be made about cessation of monitoring, these ideally should be made in conjunction with medical opinion about the infant's health status and with both parents in a counselling-type situation. Haphazard, impulsive, uninformed decision-making about such an important part of the infant's care, could be avoided if close contact is maintained between the parents and the staff of the monitoring programme.

In the New Zealand sample, parents who were discontinuing monitoring, were looking forward to an optimistic future with a healthy child rather than with an "at-risk" infant. Although it is beyond the scope of this study to make predictions about the future well-being of these children, the possibility must be considered that monitoring has had a lasting effect on their development. Shapiro (1983) warned that children perceived by their parents to be at risk of a serious physical problem, may be still perceived and treated as vulnerable even years later.

Conclusion

It is of some concern that the findings of the present study replicate in many details the reported findings from previous (mainly American) studies which used similar methodology to look at the impact of monitoring on family life. It was noteworthy that even in the early study by Black, Hersher and Steinschneider (1978) parents, despite the fact that they were some of the first to undertake home apnoea monitoring of their infants, reported many similar experiences to those of parents in the present study. The question must be asked - why has so little been done in the interim to address the difficulties consistently identified by parents?

The studies by Black, Hersher and Steinschneider (1978); Dean (1986); Geary (1989); Nuttall (1988); and Wasserman (1984); used open-ended interviews to explore and to describe caregivers' perceptions of the monitoring. These authors recognised that a monitor is not a benign device - that its presence in the home impacts on families in far-reaching ways. Their respondents, like those in the present study, perceived their monitored infants to be "at risk" of dying, and were unable to leave them with babysitters, even if reliable sitters were available. Mothers tended not to actively seek support and assistance from others. They carried the greatest burden of the infants' care and had few opportunities for respite. The restrictions to their lifestyles and the need to be within earshot of the alarm meant they experienced social isolation at a time when social support was most needed (Wasserman, 1984; Nuttall 1988; McIntosh, 1990). The need for effective support by health professionals has been a recurrent theme in the present study and in those previously reported. Although apnoea monitoring causes varying degrees of distress to families, it is acknowledged that it is a time-limited experience, unlike for parents of truly chronically-ill children, who generally do not see the prospect of a permanent "cure" and must live under conditions of sustained uncertainty for indeterminable periods of time.

Limitations of the Present Study and Suggestions for Further Research

It is acknowledged that a small, non-homogeneous sample has been recruited to share their experiences of apnoea monitoring. The investigation explored the experiences of six families over a three month period. Within the constraints of this study design it has been impossible to draw conclusions about:

- (a) The efficacy of monitoring, rather than the psychosocial impact of its undertaking.
- (b) The cultural issues which could have been identified by participants from cultures other than New Zealand European. No conclusions about the cultural appropriateness of monitoring can be drawn from the present data.
- (c) The long-term effects of monitoring on infants who have been considered at-risk and placed perhaps at risk of the "vulnerable child syndrome" (Shapiro, 1983). These participants were involved in the present study over a three month period only.
- (d) Whether the presence of the monitor reduces or increases anxiety. Comparisons across cases have been made and patterns identified but no descriptive statistics can be used to make statements about such questions as increased or decreased anxiety levels, or temporal effects of monitoring on anxiety levels. Comparisons of responses of parents in larger homogeneous samples could perhaps reveal differences and similarities across monitoring families who have lost a child from SIDS, had a premature infant, or had an infant suffer an ALTE.

- (e) The phenomenon of Munchausen Syndrome by Proxy and Apnoea which would best be explored by the selection of one or more "revelatory" cases (Yin, 1984) rather than a more generalized investigation of the experiences of home monitoring parents.

In addition, the role of siblings of monitored children has been paid scant attention in this study. Parents tended to downplay older children's involvement with monitoring and permission to interview the monitored infants' siblings was not obtained.

Further research in the area of home apnoea monitoring could well address these important aspects of monitoring, which have been beyond the scope of the present study.

Concluding Statement

Multiple case studies have been undertaken to explore the experiences of caregivers of infants on home apnoea monitors, in a New Zealand setting. The present study was conducted prospectively (unlike many of the previous studies reviewed which were retrospective in design) and examined the experiences of both parents where this was feasible, rather than just those of the mother. In-depth interviews were held with the participants over a three month period and during this time three of the six families made the decision to discontinue monitoring. The prospective design enabled observations to be made of the changes occurring in the families over time. The maturational changes in the infants' behaviour and physiology contributed to the overall monitoring experiences as did the individual parents' psychological coping mechanisms, their perceived risk status of their infants, the feedback from the monitor itself, parents' levels of social and professional support, and their previous parenting experiences.

It is clear that in New Zealand monitoring parents are affected by many of the same difficulties experienced by their American counterparts. Health professionals involved with issuing and supervising the use of apnoea monitors, are alerted by the findings of the present study to the fact that a monitor, although often described as an anxiety-reducer, is not a benign device. The limitations of the design of the monitor most frequently used in New Zealand, the Graseby MR10, contribute to parents' negative experiences with monitoring.

An understanding of the stresses involved in monitoring is essential for effective intervention to be provided by health professionals who ideally would assess each family's unique situation and level of resources in order to provide an integrated support service to the family.

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APPENDIX 1

Massey University
Department of Nursing Studies

Informed Consent FormProject Title:

Caring for At-Risk Infants: The Experiences of Parents with Infants on Home Apnoea Monitors.

Investigator:

Barbara Maclean. Phone



I/We _____ understand the information sheet which was given to us and have had time to talk about it as a family. Our questions about the research project have been answered to our satisfaction. I/We consent to take part in the study.

Signed:

Address:

Phone Number:

Date:

APPENDIX 2

Massey University
Department of Nursing Studies

Information SheetProject Title:

Caring for At-Risk Infants: The Experiences of Parents with Infants on Home Apnoea Monitors.

Investigator:

Barbara Maclean. Phone 3569099, ext 7471. After hours ph [REDACTED]
MA student, Massey University

The purpose of this research project is to increase the understanding of nurses and other health professionals of the experiences of families caring for infants on home apnoea monitors.

Participation in this project would mean that you would be required to keep a daily diary record for three months, of your experiences with home monitoring.

In addition, over the three month period you would be asked to give three interviews in your own home, with the researcher, each of about one hour's duration. The interviews would be audiotaped and later transcribed into written form so the researcher can review and analyse the information on the tape. You will be given the opportunity to read and confirm the transcripts of the interviews. At the completion of the study, the diary records will remain your own property and all audiotapes will be erased.

Information from the tapes and diaries may be published but your name will not be associated with the research. You may withdraw from the study at any time if you decide you no longer wish to take part.

There will be no health risks to you resulting from your participation in the research, but nor will there be any direct benefit.

The researcher will answer questions you have. You will have time to think about participating in this study, and to discuss it as a family before signing the consent form. Your rights are in no way affected by signing the consent form. It is simply a record that on the basis of your present understanding of the project, you agree to take part.

Barbara Maclean
MA student
Nursing Studies Department