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An Occupational Therapy Parent Education Handbook: Parenting in the NICU

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An Occupational Therapy Parent Education Handbook: Parenting in the NICU

by

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This Scholarly Project Paper, submitted by Angie Laakso, MOTS and Olivia Donald, MOTS in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

Faculty Advisor

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Title: An Occupational Therapy Parent Education Handbook: Parenting in the NICU

Department: Occupational Therapy

Degree: Master’s of Occupational Therapy

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The authors wish to express our appreciation to our friends and families who have given us the support and guidance through those times we needed it the most, to our advisor for having confidence in us when we had none left and being so diligent in one of the hardest challenges we have endured in our lives and finally, to each other for being my best friend, the only one that truly understands what I have gone through and the one who if was not there I would not have made it.
ABSTRACT

Parents often feel overwhelmed by their premature infant’s fragile medical state and intimidated by the Neonatal Intensive Care Unit (NICU) environment. The birth of a premature infant is a stressful event for parents because they are coping with their newborn facing life threatening immaturity and its possible consequences, such as handicap or even death. Due to the premature infant’s fragile medical state parents often feel their infant does not belong to them but rather to the healthcare staff.

A parent’s lack of involvement in their infant’s care is a major source of stress, feelings of disempowerment and a lack of confidence in their parenting abilities (Franck & Spencer, 2003). The parental lack of involvement, in the initial weeks of the infant’s hospitalization, is a primary factor that can contribute to high-risk parenting. High-risk parents often demonstrate a hesitancy to develop a close relationship with their infant due to their difficulty in coping with their feelings and emotions related to their infant’s fragile medical state. This can have a significant impact on the early formation of a relationship between the infant and parents. “Failure to form an attachment during the first few weeks and months, or disruption of the attachment process, leads to a
higher risk of abuse and neglect of the dependent infant” (Aucott, 2002, p. 303).

Both the parents' and infant's quality of life is dependent upon the parents' confidence in their parental roles, adaptation abilities and their positive relationships with the healthcare providers of their premature infant. It is essential that the parent be involved, be provided resources and be informed about each step in the care of their infant.

According to Hurst (2002) "families spend a median of 20 hours in the first week after birth seeking information, the equivalent to a part time job. Families desired more information than was provided” (p. 42). The purpose of this scholarly project was to create a resource for parents of infant's born prematurely within the NICU setting. An Occupational Therapy Parent Education Handbook: Parenting in the NICU is offered in an easy to read format focusing on psychological, physical and emotional components of having an infant in the NICU.

The methodology used includes: a review of the literature, observation in a Neonatal Intensive Care Unit (NICU) environment and discussions with parents who have experienced having an infant in the NICU. The researchers also met with therapists who currently work within the NICU setting and toured the NICU environment while meeting the various staff who work within this area.

Based on the information gathered there is a need for additional resources to be provided for parents of premature infants in the NICU.
The following results were discovered after extensive research:

➢ There is a lack of resources available for new parents of infants in the NICU

➢ There is a lack of information and resources available to parents during the infant’s transition home and into early infancy

➢ There is a lack of education of NICU parents regarding what their infant is going through and what they can expect during this difficult time

There is a need for a resource to be available to parents’ who have infants born prematurely in the NICU setting that is offered in an easy-to-read and accessible format. *An Occupational Therapy Parent Education Handbook: Parenting in the NICU* is designed to be a guide and offer support to ease the stress and overwhelming feelings new parents experience when their infants are born within the NICU setting.
CHAPTER ONE

INTRODUCTION

An infant born prematurely is a stressful event for parents. They find themselves trying to cope with their newborn facing life threatening immaturity, possible handicapping conditions or even death. Parents and the parental role is not often remembered or can be disregarded in the NICU due to essential focus that is needed on the infant’s critical medical status. A parents’ lack of involvement in their infant’s care is a major source of stress, feelings of disempowerment and a lack of confidence in their parenting abilities (Franck & Spencer 2003).

The parental lack of involvement, in the initial weeks of their infant’s hospitalization, can also lead to factors that contribute to high risk parenting (Aucott, 2002). High-risk parents demonstrate a hesitancy to develop a close relationship with their infant due to their difficulty in coping with their own feelings and emotions related to their infant’s fragile medical state. “Failure to form an attachment during the first few weeks and months, or disruption of the attachment process, leads to a higher risk of abuse and neglect of the dependent infant” (Aucott, 2002, p. 303).

It is crucial for NICU staff to develop and implement strategies
that are designed to enhance the parents' involvement in their infant's caregiving (Ward, 2001). These strategies need to support the ongoing development of parental competence while transitioning the role of parent/caregiver from the medical team to the parent. Communication and collaboration between the parent and treatment team are essential to support the infant's growth and development.

The review of literature consistently supports the need for early intervention efforts between parents and healthcare providers and for additional resources to be provided for parents of premature infants in the NICU. Intervention efforts can decrease stress and depression of the mother or caregiver, and increase self-esteem both of which positively contribute to improving the healthy functioning of the family (Meyer, 1994). One such intervention effort is education.

Education would be beneficial to help the parents feel more comfortable when: handling their infant; recognizing the signs and symptoms of their infant's sensory needs; and helping the parents deal with the emotional stress of the situation. Parents of premature infants born within the NICU would benefit from a resource that provides valuable information both throughout their infant's hospitalization and transition home.

*An Occupational Therapy Parent Education Handbook: Parenting in the NICU* is based on a review of the literature, observation in a Neonatal Intensive Care Unit (NICU) environment and discussions with parents.
who have experienced having an infant in the NICU. This handbook has meant to be a guide to increase understanding and provide an educational tool for parents with an infant born prematurely. It is our intention for parents to use this handbook as a resource to care for their new infant and cope with stress as effectively as they can.

The occupational therapy model used in designing the Occupational Therapy Parent Education Handbook: Parenting in the NICU is the Occupational Adaptation Theoretical Frame of Reference also known as (OA). OA is a process that emerges from the interaction between the person, and occupational environment in response to occupational challenges. Within this project the occupational challenge for the parent is caring for an infant both in the NICU and throughout their transition home. The occupational role encompasses the parent or caregiver of the premature infant. An important principle of OA is the client’s ability to internally adapt to occupational challenges they may encounter.

The key concepts and primary terminology used in the scholarly project are identified in the following section. This terminology was adapted from many different sources and is referred to and referenced later in this document:

**Terminology**

**Developmentally Delayed / Disabled** - A term used to describe infants and toddlers who have not achieved skills and abilities which are
expected to be mastered by children of the same age. Delays can be in any of the following areas: physical, social, emotional, intellectual, speech and language and/or adaptive development, sometimes called self-help skills, which include dressing, toileting, and feeding. Many developmental delays can be overcome with early intervention programs.

**Developmental Milestones** - Major and minor social, emotional, physical, and cognitive skills acquired by children as they grow up.

**Environmental factors** - are a combination of external physical conditions. These environmental factors can affect and influence the growth, development, and survival of your premature infant. The infant is bombarded by environmental factors in the NICU such as: noise, light, and the type of interactions with caregivers.

**Incubator/Isolette** – An isolette or incubator is a clear, plastic, enclosed bassinet used to keep premature infants warm. Premature infants often lose heat very quickly unless they are put in a protected thermal environment due to the infant’s inability to regulate their body temperature. The temperature of the isolette can be adjusted to keep the infant warm regardless of the infant’s size or room temperature.

**Kangaroo Care** - This is a technique that focuses on skin-to-skin contact between the parent and infant. Kangaroo care offers many advantages for the infant such as: helping him or her maintain body warmth, helping him or her regulate heart and breathing rates, gaining weight and finally, decreasing crying so she or he can be more quiet and alert and show an
increased desire to breastfeed.

**Motor Skills** - Gross motor skills are the movements that use the large muscles in the arms, legs, and torso to move, roll, run and jump. Fine motor skills are the small muscle movements used to grasp and manipulate objects, like picking up a Cheerio, holding a finger or using a crayon.

**Physiological Factors** - Physiological factors are normal functions of the body, which include breathing, heart rate, digestion, reflexes, and movement of muscles.

**Premature Infant** - An infant born three or more weeks before their due date.

Research shows there is a need for additional resources to be available to parents’ who have an infant born in the NICU. An Occupational Therapy Parent Education Handbook: Parenting in the NICU will provide quality information for parents and help to bridge the gap between the NICU medical staff and parents. By using this handbook parents’ will feel better prepared and have increased confidence when caring for their premature infant.

Chapter Two will provide a review of the literature, which guided the creation of the final product. This chapter will share information of current research and provide strengths and limitations of various aspects of the NICU. Chapter Three introduces and explains the methodology that was used to gather the information for the development of the
parent educational handbook. An overview of the product is provided in and its relationship to the current literature. Chapter Four: *An Occupational Therapy Parent Education Handbook: Parenting in the NICU* is in its entirety. Chapter Four contains an introduction, significance of the product and addresses the need for this resource. Chapter Five is a summation of information, limitations and recommendations for further development and research.
CHAPTER TWO
REVIEW OF LITERATURE
INTRODUCTION

Prior to birth, the intrauterine environment provides the infant with a snug world of darkness, warmth and rhythmical movement. The infant is protected from external stimuli through the amniotic fluid in which the infant is surrounded. The infant, in utero, experiences the mother's rhythmic heart beat, sleep patterns and temperature regulation. After birth, the infant's whole world changes, as does the world of the parents.

The infant, who is premature, has a central nervous system that is capable of protected intrauterine life but not adequately developed to adjust to and organize the overwhelming stimuli and demands of the NICU. Infants, born prematurely, must deal with the extrauterine environment while their organ systems are still undergoing major development (Blackburn, 1998). The premature infant spends his or her last weeks or months of gestation in an environment of bright lights, constant loud sounds, temperature variations, painful procedures and equipment that comprise the NICU environment.

"The neonatal intensive care unit (NICU) is a complex and highly
specialized unit designed to care for infants who are born prematurely or are critically ill" (Case-Smith, 2001, p. 637). The focus of healthcare professionals, in the NICU, is on interventions to assist the immature infant to adapt to the extrauterine world (Blackburn, 1998). This means that the parents and the parental role is not often remembered or disregarded.

Parents often view the NICU as very powerful and feel that their infants' do not belong to them but rather to the healthcare staff. A study by Franck & Spencer (2003) found that when parents feel a lack of involvement in their infant's care they experience significant stress, feelings of disempowerment and a lack of confidence in their parenting abilities. Additionally, Caretto, Topolski, Linkous, Lowman, & Murphy, (2000) found that parents who often feel inadequately prepared to care for their infant, have specific unmet needs and high levels of concern related to caring for their infant after discharge.

It is crucial that the NICU staff develops and implements strategies to enhance the parents' involvement in their infant's caregiving. Education, communication and related resources are essential to help the parents feel more comfortable when handling their infant to: recognize the signs and symptoms of their infant's sensory needs and; deal with the emotional stress of the situation.
Based upon the information shared in the introduction, a comprehensive review of literature was conducted to: 1) present the circumstances that the parents find themselves in with an infant born prematurely, 2) present the needs of the parent, and 3) identify current, relevant and applicable information available to meet the parent's psychosocial needs during these times of stress.

**The Experience of the Infant**

Ideally the NICU environment should meet the infant’s physiologic or neurobehavioral needs, provide a supportive milieu in which the infant can respond without undue stress, support the infant’s emerging organization, and foster growth and development (Blackburn, 1998, p. 282).

The NICU environment is often not an ideal environment and can actually be a major source of stress for the infant born prematurely. Constant monitoring and procedures are required to care for the infant in his or her critical condition. Advances in technology have resulted in the infants being exposed to an overwhelming abundance of continuous bright lights and loud noises. These conditions impact their ability to sleep due to repeated interruptions often with frequent invasive and painful procedures that can impact their ability to grow and develop.

"Concerns about the environment have lead to suggestions that it may be a major contributing factor in the persistent incidence of behavioral and learning problems among pre-term infants" (Blackburn, 1998, p. 288). There are three components to the NICU environment
that have the most discerning impact on the development of the infant born prematurely; the sound and light in the environment, as well as caregiver interventions. These are presented in the following sections in more detail.

**Sound**

The sound level within the NICU has been directly related to: 1) sleep interference, 2) increased heart rate, 3) increased intracranial pressure, 4) decreased oxygenation, 5) agitation, 6) crying and 7) irritability. Excessive exposure to loud sound can be harmful to the premature infant’s auditory development. It is important to speak softly in a calm voice to decrease the level of stress on the premature infant and allow the infant to recognize the parent and family member’s voices.

**Lights**

Bright lights can be damaging to infants who are still developing their vision. Bright lights can increase the risk of a variety of visual problems including: retinal damage, strabismus and amblyopia (Blackburn, 1998). Studies have shown “decreasing sound and light for 12 hours at night resulted in improved weight gain and increased time sleeping” (Aucott, 2002 p. 301). Measures are also taken to decrease lighting through the use of isolette covers and minimizing light exposure (Aucott, 2002).
Caregiver Interventions

Medical professionals’ primary focus is meeting the infant’s survival needs. This means relatively little time is spent for social interaction with the infant. Due to the infant’s immature systems, adverse physiological consequences have been associated with handling the premature infant such as: 1) hypoxemia, 2) apnea, 3) bradychardia, 4) hyperventilation, 5) increased intracranial pressure and 6) behavioral distress (Blackburn, 1998; Brown, 2000; Lawhon, 2002). ‘Because of the fragility of the pre-term infants, most NICU’s have adopted a minimal handling and stimulation approach for very immature and/or sick infants’ (Ashbaugh, 1999, as cited in Aucott, 2002, p.301).

As stated previously, the focus of the NICU is on the health and constant monitoring of the infant. The information regarding the experiences of the infant is often not shared with the parents. The NICU staff may not have explained to the parents why they can not hold their infant. Also, the parents may not have been educated on the various aspects occurring within the NICU.

The Experience of the Parents

The birth of a premature infant is a stressful event for parents because they are coping with their newborn facing life threatening immaturity and its possible consequences, such as handicap or even death. Initially, parents of premature infants often feel isolated, alone,
and guilty; “I feel like I had done something wrong, like I should have done more during my pregnancy” (Hurst, 2006, p. 257).

The NICU is an overwhelming environment for the parents, which leads to feelings of disempowerment, lack of confidence in parenting abilities and difficulties bonding with their infant. The parental lack of involvement, in the initial weeks of the infant’s hospitalization, is a primary factor that can contribute to high-risk parenting. High-risk parents often demonstrate a hesitancy to develop a close relationship with their infant due to their difficulty in coping with their feelings and emotions related to their infant’s fragile medical state. This can have a significant impact on the early formation of a relationship between the infant and parents. “Failure to form an attachment during the first few weeks and months, or disruption of the attachment process, leads to a higher risk of abuse and neglect of the dependent infant” (Aucott, 2002, p. 303).

“The early mother-infant relationship has been pointed out as one of the factors that may exacerbate or ameliorate the impact of the pre-term birth” (Forcada-Guex, 2006, p. 108). A study by Kersting (2004) found that mothers of premature infants, “reported traumatic experience values significantly higher than those of mothers of term infants” (p.475). Mothers of infants born prematurely, have ongoing feelings of stress with the day-to-day impairment or delay of the infant’s development.
Forcada-Guex (2006) states, "previous research has shown mother's anxiety during the neonatal period, has a strong correlation to the perceptions of their child's vulnerability even long after the child has fully recovered" (p. 113). "Studies have shown that maternal sensitivity and responsiveness represent potent antecedents to toddler engagement and cooperativeness in the mother-child relationship and to later language and social competencies" (Forcada-Guex, 2006, p. 113). The mothers of premature infants born within the NICU environment are developing symptoms associated with depression and high levels of anxiety related to the significant stress of the situation.

**Parental Essentials**

Both the parents' and premature infant's quality of life is dependent upon the parents' confidence in their parental roles, adaptation abilities and their positive relationships with the healthcare providers. It is essential that the parent be involved, provided resources and informed about each step in the care of their infant.

**Involvement**

This is a very stressful time for the parents due to changes in their parental role, uncertainty of the infant's health, medical and developmental future and possible communication difficulties with their infant's health care providers (Ward, 2001). It is essential for the parents
to feel needed throughout the care of their infant during this overwhelming and often frightful time in their lives.

"The NICU staff needs to promote a positive parent-infant interactional style by providing parents with opportunities to handle, care for and observe their pre-term infant. This increases parental feelings of self-confidence and competence in reading the infant's cues and responding appropriately to the infant's behavior" (Forcada-Guex, 2006, p. 113). This will directly impact the parents' abilities to provide basic infant care and maintain their own health to better care for their infant during this time (Ward, 2001).

Early intervention efforts can decrease stress and depression of the mother or caregiver, and increase self-esteem both of which positively contribute to improving the healthy functioning of the family (Meyer, 1994). In the midst of the intensive technology driven environment of the NICU, the interaction of supportive parents can enhance the premature infant's development.

**Informed**

Communication is essential for the parents to feel involved and active participants in the care of their infant. It is crucial that parents understand the role of each specialist, what procedures the specialists are performing and why. In addition, the parents need to be provided with resources to search out information about each health care
professional providing care to their infant.

The role of rehabilitation specialists in the NICU represents a highly specialized area of practice that requires trained, experienced, therapists with advanced knowledge and skills given the fragility of the infants, the vulnerable emotional status of the families and the intricacy of medical and social factors that affect the child and family unit as a whole (Limperopoulos, 2002, p. 58).

The objective of an interdisciplinary team approach is to support the ongoing development of parental competence while encouraging the parents to gradually increase their parenting role as the medical team's involvement decreases. This is accomplished through mutual interactive communication between the parent and treatment team to support the infant's development and ongoing medical needs (Blackburn, 1998).

The infants will receive care from a variety of rehabilitation specialists who are highly trained to work with premature infants and their families. The parent's relationship with the rehabilitation professionals, within the NICU, is essential for successful communication, understanding of needs and the overall treatment of their infant. The discipline of focus for this scholarly project is the role of occupational therapy in the NICU.

**Occupational Therapy**

"Families are best served by occupational therapists who are not only knowledgeable about infant needs, but also sensitive to family circumstances, priorities, concerns and cultural beliefs. The occupational therapist must seek ways to establish supportive, collaborative, and therapeutic relationships with family members
in order to foster the infant’s optimal development” (AOTA, 2000, p. 641).

The occupational therapy assessment is a vital part of the process of becoming knowledgeable and gaining an understanding of the premature infant’s needs, family’s needs, priorities, circumstances, concerns and cultural beliefs.

Assessment

There are two parts to the assessment: the infant and the parents/family unit. Assessing the needs of parents often begins with an informal interview with the parents regarding their feelings and thoughts on having an infant born within the NICU. The assessment will identify stress levels and coping strategies used by the parents. Occupational therapy will also identify the infant’s challenges in relation to age appropriate growth and development. Specific assessments will be performed based on the information shared in the interview.

Based upon the assessment results, the identified needs can be addressed in the interventions. “Once the individuals specific challenge areas are identified, interventions are provided to support their engagement in occupations and daily life activities” (AOTA, 2002, p. 611). The intervention process can then be client-centered, making it much easier to develop a collaborative and therapeutic relationship with the family.
**Intervention**

In the NICU, occupational therapy focuses on developing the parent-infant relationship, which directly affects the infant's development. This is vital in all aspects of treatment.

*Infant:* The focus of intervention for the infant is on the facilitation of healthy development. "An important role of the occupational therapist is to assist each family to foster their infant's optimal development, including participation in age-appropriate occupations or daily life activities, sensorimotor processes and neurobehavioral organization" (AOTA, 2000, p.641).

*Parents:* An occupational therapist is a knowledgeable professional who can assist the parents in managing stress through listening to the parent's needs and concerns and offering coping strategies. The focus of intervention, for the parents, is to identify and use healthy coping strategies, such as education and participation in the care of their infant. "Mothers who participate in the occupational therapy interventions have more positive feelings toward the infant and a better sense of the parenting role" (Feldman, 2002, p.17).

All of the information presented in this section is essential for the parents' well being. Feeling knowledgeable about their infant's condition and having a relatively strong understanding of what is occurring adds to the parents' level of confidence and decreases stress. Both the parents'
and infant's quality of life is dependent upon their confidence in parental roles, adaptation abilities and positive relationships with the healthcare providers of their premature infant. Based upon the needs of the parents presented, an educational resource guide was developed, titled: *An Occupational Therapy Parent Education Handbook: Parenting in the NICU.*

**An Occupational Therapy Parent Education Handbook:**

**Parenting in the NICU**

According to Hurst (2002) “families spend a median of 20 hours in the first week after birth seeking information, the equivalent to a part time job. Families desired more information than was provided” (p. 42). Upon their infant's birth and admission to the NICU, the occupational therapists will provide the parents with: *An Occupational Therapy Parent Education Handbook: Parenting in the NICU.* This handbook is designed to be a resource to guide them throughout their infant's hospitalization and throughout their infant's transition home. The choice to organize the information in a handbook is based on the belief that it has “a direct influence on the care that the child receives or does not receive” (Hurst, 2006, p. 258).

The parent education handbook includes pertinent information that is readily accessible and is understandable to the parent or caregiver. It addresses the essential areas identified in the literature and
provides information under the following headings:

1. Learning to Cope
2. What your Infant is Experiencing
3. Connecting with your Infant
4. NICU Medical Team
5. Occupational Therapy in the NICU
6. Preparing to Take your Infant Home
7. Summary
8. References
9. Appendix: Definitions of NICU and Related Term

Model

An occupational therapy model or frame of reference provides a specific focus and direction for intervention. The occupational therapy model used in designing the parent handbook is the Occupational Adaptation Theoretical Frame of Reference (OA).

Occupational Adaptation is a process that emerges from the interaction between the person and occupational environment in response to occupational challenges. Within this project the occupational challenge, for the parent, is caring for an infant both in the NICU and throughout their transition home. An important principle of OA is the individual's ability to internally adapt to occupational challenges they may encounter. According to Schkade and Schultz:

The Occupational Adaptation process consists of a series of actions and events that unfolds as an individual is faced with an occupational challenge that occurs as the result of person/environment interactions within an occupational role. This process exists to enable the individual to respond adaptively and masterfully, that is, to meet both self-produced (internal) role expectation and environmentally produced (external) role expectations (2003, p. 185).
Through the use of this handbook occupational therapists are addressing the parent's emotional, physical, mental and spiritual needs involved in having a premature infant in the neonatal intensive care unit (NICU). The hope is that this educational handbook will provide parents with an effective means to achieve a feeling of competency within their parental role. The handbook will also help the parents make necessary adaptations for relative mastery during their infant's transition home and through the developmental milestones their premature infant will experience.

Summary

It is essential for parents to feel needed in the care of their infant throughout this overwhelming and often frightful time. Parents, can often feel disempowered, a lack of confidence in their parenting abilities and difficulty bonding with their infant. The parents' and infant's quality of life is dependent upon their confidence in their parental roles, adaptation abilities and positive relationships with their infant's healthcare providers. *An Occupational Therapy Parent Education Handbook: Parenting in the NICU* is an excellent resource for parents to gain the necessary information and tools to care for their infant throughout their hospitalization and transition home.

Chapter Three presents a description of the process used to design and organize *An Occupational Therapy Parent Education Handbook*: 

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Parenting in the NICU. Additionally, an overview of the parent educational handbook is presented in relationship to the methodology used.
CHAPTER THREE

METHODOLGY

The methodology used in the development of the Parents Education Handbook includes:

1. A review of the literature
2. Tour and observation in a Neonatal Intensive Care Unit (NICU) environment
3. Discussions with parents who have experienced having an infant in the NICU
4. Discussions with therapists who currently work within the NICU setting
5. Meeting various staff that work within the NICU setting

Through these experiences and literature review it was found that there is currently an overwhelming need for resources to be available to parents during this difficult time.

The design of the *An Occupational Therapy Parent Education Handbook: Parenting in the NICU* is based upon many ideas from professionals and information gathered in the literature review, which suggests the following:
1. There is an increased level of stress and difficulties that parents face when their infant is born within the NICU setting.

2. There is a lack of resources available for new parents of infants in the NICU.

3. There is a lack of information and resources available to parents during the infant's transition home and into early infancy.

4. There is a lack of education of NICU parents regarding what their infant is going through and what they can expect during this difficult time.

The handbook is intended to address the issues listed above such as; providing a resource for parents during their infant's hospitalization and throughout their infant's transition home. An Occupational Therapy Parent Education Handbook: Parenting in the NICU is designed to be a guide and offer support to ease the stress and overwhelming feelings new parents experience when their infants are born within the NICU.
CHAPTER FOUR

PRODUCT

According to Hurst (2002) "families spend a median of 20 hours in the first week after birth seeking information, the equivalent to a part-time job and families desired more information than was provided" (p. 42). To ease this transition An Occupational Therapy Parent Education Handbook: Parenting in the NICU was created for the parents use throughout their infant's stay in the NICU.

This handbook is designed to be a resource, provided by the occupational therapists, for the parent or caregiver to use throughout this difficult time in their lives. For the sake of this handbook, "parent" will refer to mother, father, caregiver, guardian or others caring for the infant. The choice to organize the information in a handbook was made because research suggests such a resource has, "a direct influence on the care that the child receives or does not receive" (Hurst, 2006, p. 258). Parents will have a resource available to access at any time, which will assist them in questions they may have regarding the care of their infant.

The Parent Handbook includes pertinent information that is readily accessible and is understandable to the parent. It addresses the needs identified in the literature and specifically addresses the following:
Model

An occupational therapy model or frame of reference provides a specific focus and direction for intervention. The occupational therapy model used in designing this parent handbook is the Occupational Adaptation Theoretical Frame of Reference (OA).

Occupational Adaptation is a process that emerges from the interaction between the person, their role and occupational environment in response to occupational challenges. This project addresses the occupational challenge of caring for an infant both in the NICU and during their transition home and beyond. The occupational role consists of being a parent to an infant born prematurely. An important principle of OA is the parent’s ability to internally adapt to occupational challenges they may encounter. According to Schkade and Schultz:

The Occupational Adaptation process consists of a series of actions and events that unfolds as an individual is faced with an occupational challenge that occurs as the result of person/environment interactions within an occupational role. This process exists to enable the individual to respond adaptively and masterfully, that is, to meet both self-produced (internal) role
expectation and environmentally produced (external) role expectations (2003, p. 185).

According to Franck & Spencer (2003), a parent’s lack of involvement in their infant’s care is a major source of stress, feelings of disempowerment and lack of confidence in their parenting abilities. Parents often view the NICU as very powerful and feel their infants do not belong to them, but rather to the healthcare staff. In turn, a study by Caretto, Topolski, Linkous, Lowman & Murphy (2000) found that parents often feel inadequately prepared to care for their infants, have specific unmet needs, and have high levels of concern related to caring for their infant after the infant has been discharged. In response to this issue it is crucial that the NICU staff implement strategies to enhance the parent’s involvement in their infant’s caregiving.

Both the parent’s and infant’s quality of life is dependent upon their confidence in parental roles, adaptation abilities and positive relationships with their healthcare providers of their premature infant. Based upon the parents needs, identified in the review of literature, An Occupational Therapy Parent Education Handbook: Parenting in the NICU was developed and is presented in the next section in its entirety.
An Occupational Therapy Parent Education Handbook:

Parenting in the NICU

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Occupational Therapy
Introduction

The NICU can be an overwhelming environment for you and your infant. You may feel like you have little to no control, and/or no confidence in your abilities to meet the needs of your infant. Throughout this stressful time you will have many questions related to your infant’s health and well being, both while in the NICU and upon returning home. According to Hurst (2002) “families spend a median of 20 hours in the first week after birth seeking information, the equivalent to a part time job and families desired more information than was provided” (p. 42).

This handbook focuses on parents’ common areas of concern related to caring for their infant and strategies to cope during this stressful time in their lives. It is hoped that this handbook will answer many of those questions and provide you with the resources you need.

Both you and your infant’s quality of life are dependent upon: 1) your level of confidence in your parental role; 2) your ability to adapt; and, 3) the building of positive relationships with the healthcare providers who are helping your infant. It is essential that you feel involved as much as you can while still ensuring your infant’s medical needs are met. It is also important that you be provided with resources and information about each step in the care of your infant.

This handbook was created to meet the above-mentioned needs.

This handbook is organized into the following sections:
1. Learning to Cope
2. What your Infant is Experiencing
3. Connecting with your Infant
4. NICU Medical Team
5. Occupational Therapy in the NICU
6. Preparing to Take your Infant Home
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Learning to Cope
The section on coping offers you several specific coping strategies to help you during this difficult time in your life. There are several checklists on pages 11-13 to help you assess your stress level. The occupational therapists may help you go through each of these and then discuss the results after. Additionally, several general coping strategies are provided in this section and on pages 14-19. The occupational therapists may review these with you and assist you in finding strategies that are the most effective in coping with stress.

You have probably experienced a wide variety of emotions such as: sadness, guilt, joy, fear, anger and regret since the birth of your infant. There will often be triumphs and setbacks to cope with during your infant’s care. As you learn to cope with these feelings and adjust to having your infant in the NICU you will find ways to enjoy the experience of getting to know and love your infant. The following is a list of questions/statements and suggestions that may help you cope more effectively with this experience:

**Coping Strategy 1: Try to Find a Balance & Routine in Life**

It is important to try to establish a balance and routine in your life before your infant comes home. So when your infant finally does come home, you will be able to focus more clearly and effectively on meeting your
infant's needs.

Explore ways to balance all aspects of your life. Managing your stress and time will help you feel in control of your life, versus feeling out of control. Some suggestions for balance include:

- Spending time with other family members. Although you may feel uncomfortable leaving your infant's side, it is important to dedicate attention to the other family so they feel involved especially, other children.

- Taking time for you. The most important thing to remember is to take time for you. If you do not take care of yourself, you will be unable to effectively take care of your loved ones. The following is a list of suggestions to effectively take care of yourself:
  - Getting enough rest
  - Exercise
  - Meditation
  - Reading
  - See additional ideas at the end of this section on pages 14-19.

**Coping Strategy 2: Deal with Emotions**

It is important to remember that each person will react differently to stress. You may feel that if you let your emotions show you are not strong or you will not regain composure. It is important to let yourself cry, feel sorrow, fear, frustration etc., during this difficult time, and it is understandable. Sometimes you may be feeling overwhelmed which is also normal. Learning how to feel and talk about these emotions is a
healthy part of coping and coming to terms with your feelings.

When your infant has a setback, you may be feeling fear and anxiety, which is normal. When your infant is making progress, let yourself feel joy, hope and happiness. It is important to let your feelings out, both the positive and negative, to others during this difficult time. Ideas to deal with emotions include:

➤ Do not hold your feelings in or push them aside to try and put on a “brave” face. Acknowledge them to yourself, and share them with others, one solution may be journaling that will be discussed next in coping strategy 3.

➤ Learn to be flexible and adaptive so when schedules change, you don't feel like you are going to go over the edge.

➤ Make lists of what has to be done now; what can be done later and what someone else could help you with.

**Coping Strategy 3: Keep a journal or maybe a scrapbook**

By keeping a journal or scrapbook with your spouse or other children, everyone will feel a part of the process. A journal is a great way to express and reflect on your feelings during this experience. This suggestion can help you work through the feelings and emotions you are experiencing. A journal may help you increase your strength, hope and patience while reminding you of the progress your infant is making.
Scrapbooking is another wonderful activity that can encourage you to document your infant's growth and progress. Remember to scrapbook and journal about what is happening with the other family members as well. Keeping a scrapbook will also allow you to look back with your family and reminisce about this time in your lives.

**Coping Strategy 4: Ask for and accept the help of others**

During this difficult time it may be the little things that become overwhelming. Learn to ask for and accept help from others and realize you cannot do it all. Many do not know how to help you unless you tell them. Family and friends will assume you are doing fine unless you inform them otherwise. Express your feelings and needs openly when you are feeling overwhelmed, even if you simply need someone to listen. Areas you may consider asking for help with include: a) bringing a meal, b) running an errand, c) babysitting siblings or taking them to the park for a break.

**Coping Strategy 5: Create a bond with other NICU parents**

You share many of the same struggles and feelings as other parents' in your position. It is helpful to surround yourself with others who understand the experience of having an infant in the NICU whom you can learn from and feel supported by throughout this difficult time. It may help a lot to just take time to visit with the parents' who also have
an infant in the NICU or consider joining a formal group designed to provide support. Ask for assistance from the NICU medical team who can provide information and connect you with past NICU parents' or support groups or other resources.

The following section on pages 11-19 offers tools to evaluate the stress you might be feeling during this difficult time and strategies to assist you in dealing with stress. Time management skills are also provided in this section to help you with scheduling difficulties you may encounter.
STRESS SYMPTOM CHECKLIST

Mark the appropriate symptoms below that apply to your life at this time. The higher the number, the higher your stress is. Sometimes we are not aware that these symptoms could be related to stress. We may think they are related to a cold or flu.

___ 1. Buzzing or ringing in the ears
___ 2. Fatigue I can’t account for
___ 3. Dizziness
___ 4. Blushing
___ 5. Sweating (other than from exercise or caused by physical environment)
___ 6. Peculiar numbness of any part of body
___ 7. Unexplained heightened sensitivity of any part of the body
___ 8. Stiffness or pain of muscle or joints (not due to exercise)
___ 9. Intestinal disturbance
___ 10. Stomach complaints
___ 11. Breathing difficulties (not caused by disease)
___ 12. Itching (I can’t explain)
___ 13. Urinary problems or complaints
___ 14. Visual disturbances
___ 15. Pain (I can’t explain)
___ 16. Nervous mannerisms (e.g., flinching, “tics,” nail biting, drumming fingers)
___ 17. Restlessness
___ 18. Tearfulness
___ 19. Irritability
___ 20. Confusion
___ 21. Trouble concentrating
___ 22. Insomnia
___ 23. Diarrhea
___ 24. Headaches
___ 25. Fever blisters
___ 26. Hunger or lack of appetite
___ 27. Clumsiness, fainting, trembling
___ 28. Heart palpitations
___ 29. Forgetfulness
___ 30. Immobilization
___ 31. Constipation
___ 32. Excessive sleep
___ 33. Coldness of extremities
___ 34. Dry mouth
HOW VULNERABLE ARE YOU TO STRESS?

The following test was developed by Psychologist Lyle H. Miller and Alma Dell Smith at Boston University Medical Center.

Score each item from 1 (almost always) to 5 (never), according to how much of the time each statement applies to you.

1. I eat at least one hot, balanced meal a day.
2. I get seven to eight hours sleep at least four nights a week.
3. I give and receive affection regularly.
4. I have at least one relative within 50 miles on whom I can rely.
5. I exercise to the point of perspiration at least twice a week.
6. I smoke less than half a pack of cigarettes a day.
7. I take fewer than five alcoholic drinks a week.
8. I am the appropriate weight for my height.
9. I have an income adequate to meet basic expenses.
10. I get strength from my religious beliefs.
11. I regularly attend club or social activities.
12. I have a network of friends and acquaintances.
13. I have one or more friends to confide in about personal matters.
14. I am in good health (including eyesight, hearing, and teeth).
15. I am able to speak openly about my feelings when angry or worried.
16. I have regular conversations with the people I live with about domestic problems, e.g. chores, money and daily living issues.
17. I do something for fun at least once a week.
18. I am able to organize my time effectively.
19. I drink fewer than three cups of coffee (or tea or cola drinks) a day.
20. I take quiet time for myself during the day.

TOTAL

To get your score, add up the figures and subtract 20. Any number over 30 indicates a vulnerability to stress. You are seriously vulnerable if your score is between 50 and 75, and extremely vulnerable if it is over 75.
HOW TO TELL IF YOU ARE A STRESS-PRONE PERSONALITY

Rate yourself as to how you typically react in each of the situations listed below.
There are no right or wrong answers.

4 - Always 3 - Frequently 2 - Sometimes 1 - Never

___ 1. Do you try to do as much as possible in the least amount of time?
___ 2. Do you become impatient with delays or interruptions?
___ 3. Do you always have to win at games to enjoy yourself?
___ 4. Do you find yourself speeding up the car to beat the red light?
___ 5. Are you unlikely to ask for or indicate you need help with a problem?
___ 6. Do you constantly seek the respect and admiration of others?
___ 7. Are you overly critical of the way others do their work?
___ 8. Do you have the habit of looking at your watch or clock often?
___ 9. Do you constantly strive to better your position and achievements?
___ 10. Do you spread yourself "too thin" in terms of your time?
___ 11. Do you have the habit of doing more than one thing at a time?
___ 12. Do you frequently get angry or irritable?
___ 13. Do you have little time for hobbies or time by yourself?
___ 14. Do you have a tendency to talk quickly or hasten conversations?
___ 15. Do you consider yourself hard driving?
___ 16. Do your friends or relatives consider you hard driving?
___ 17. Do you have a tendency to get involved in multiple projects?
___ 18. Do you have a lot of deadlines in your work?
___ 19. Do you feel vaguely guilty if you relax and do nothing during leisure?
___ 20. Do you take on too many responsibilities?
___ TOTAL

ANSWER KEY

➢ If your score is between 20 and 30, chances are you are non-productive or your life lacks stimulation.
➢ A score between 30 and 50 designates a good balance in your ability to handle and control stress.
➢ If you tallied up a score ranging between 51 and 60, your stress level is marginal and you are bordering on being excessively tense.
➢ If your total number of points exceeds 60, you may be a candidate for heart disease.

STRESS: HOW TO HANDLE IT

1. **TALK IT OUT** – When tensions build up, try discussing the problem with a close friend or with the people involved.

2. **ESCAPE FOR A WHILE** – Don’t wait until you’ve lost control. Act while you are still able to decide for yourself.

3. **TAKE A BREAK** – A change of pace, no matter how short, can give you a new outlook on an old problem.

4. **EXERCISE REGULARLY** – Any sport will help you relax and let off steam.

5. How about swimming, tennis, bicycling, jogging – you can reduce stress while having fun!

6. **EAT PROPERLY** – Your nutritional needs increase when you are under stress. You need protein, vitamins, and minerals to repair damage caused by stress.

7. **AVOID STRESS** – Many changes at once can result in increased stress. When you can, plan to avoid too many big changes at the same time.

8. **PLAN YOUR WORK** – Tension and anxiety really build up when your work seems endless. Plan your work to use time and energy more effectively.

9. **POSSIBLE RESOLUTION OF STRESSFUL SITUATIONS** – Learn to be an effective problem solver.

10. **TAKE ONE THING AT A TIME** – When work seems endless, tension and anxiety really build up. Planning can help you reduce stress as you use your time and energy more effectively.

11. **SHUN THE “SUPERMAN” or “SUPERWOMAN” URGE** – Be realistic. People who expect too much of themselves can become tense if their plans don’t work out. Set practical goals.

12. **GO EASY WITH YOUR CRITICISM** – Too much criticism of others and of yourself can lead to frustration. Instead of criticizing, search for good points.

13. **ACCEPT WHAT YOU CANNOT CHANGE** – When a problem is beyond your control, learn to recognize and accept it. It beats
spinning your wheels and getting nowhere.

14. GIVE IN OCCASIONALLY – It’s not always urgent to be right. If you yield, others probably will too. Working out disagreements with others will help you reduce and even avoid stressful situations.

15. GIVE THE OTHER FELLOW A BREAK – Competition is contagious, but so is cooperation. Giving the other fellow a break can make things easier for you too.

16. LEARN TO RELAX – Everyone needs and deserves some relaxation. Just a few minutes of peace and quiet each day make a big difference! Try it!

17. GET RID OF YOUR ANGER – Anger is a normal emotion. You use it to combat attack. Anger becomes a problem only when it’s unreasonable – out of control. It not only hurts others but also you.

18. DO SOMETHING FOR SOMEONE ELSE – It breaks the stranglehold of your moodiness, and brings a feeling of strength.

19. THINK POSITIVE – CHANGE ATTITUDE – Be positive and optimistic.

20. LEARN HOW TO HAVE FUN – Learn how to play!

21. DEVELOP A SENSE OF HUMOR – Laughter is good for the soul!

22. QUIT FEELING SORRY FOR YOURSELF.

23. IF YOU NEED HELP, GET AN EXPERT – When stress gets out of hand, professional help is available to you in your community. People who handle stress well tend to have the characteristics listed below.

24. Strive to develop these characteristics.
   a. He/she views change as a challenge, not as a threat.
   b. The person feels committed to something he/she is involved with (in personal life, on the job, or both).
   c. The person feels a sense of control – realizes that he/she is ultimately in control of their own life and situations to be dealt with.
101 WAYS TO COPE WITH STRESS

1. Get up earlier
2. Prepare ahead
3. Avoid tight clothes
4. Avoid chemical aids
5. Set appointments
6. Write it down
7. Practice preventive maintenance
8. Make duplicate keys
9. Say “NO” more often
10. Set priorities
11. Avoid negative people
12. Use time wisely
13. Simplify meals
14. Copy important papers
15. Anticipate needs
16. Make repairs
17. Get help with jobs you dislike
18. Break down large tasks
19. Look at problems as challenges
20. Look at challenges differently
21. Unclutter your life
22. Smile
23. Prepare for rain
24. Tickle a baby
25. Pet a dog/cat
26. Don’t know all the answers
27. Look for the silver lining
28. Say something nice
29. Teach a kid to fly a kite
30. Walk in the rain
31. Schedule play time
32. Take a bubble bath
33. Be aware of your decisions
34. Believe in yourself
35. Stop talking negatively
36. Visualize winning
37. Develop a sense of humor
38. Stop thinking tomorrow will be better
39. Have goals
40. Dance a jig
41. Say hello to a stranger
42. Ask a friend for a hug
43. Look at the stars
44. Breath slowly
45. Whistle a tune
46. Read a poem
47. Listen to a symphony
48. Watch a ballet
49. Read a story
50. Do something new
51. Buy a flower
52. Smell a flower
53. Find support
54. Find a “vent” partner
55. Do it today
56. Be optimistic
57. Put safety first
58. Do things in moderation
59. Note your appearance
60. Strive for excellence, not perfection
61. Stretch your limits
62. Enjoy art
63. Hum a jingle
64. Maintain your weight
65. Plant a tree
66. Feed the birds
67. Practice grace
68. Stretch
69. Have a plan “B”
70. Doodle
71. Learn a joke
72. Know your feelings
73. Meet your needs
74. Know your limits
75. Say “Have a good day” in pig Latin
76. Throw a paper airplane
77. Exercise
78. Learn a new song
79. Get to work earlier
80. Clean a closet
81. Play with a child
82. Go on a picnic
83. Drive a different route to work
84. Leave work (class) early
85. Put air freshener in your car
86. Watch a movie and eat popcorn
87. Write a far away friend
88. Scream at a ball game
89. Eat a meal by candlelight
90. Recognize the importance of unconditional love
91. Remember stress is an attitude
92. Keep a journal
93. Share a monster smile
94. Remember your options
95. Build a support network
96. Quit trying to fix others
97. Get enough sleep
98. Talk less and listen more
99. Praise others
100. Stop a bad habit
101. RELAX. TAKE EACH DAY AT A TIME...YOU HAVE THE REST OF YOUR LIFE TO LIVE
TIME MANAGEMENT TIPS
by Gayle Webb

1. Keep an appointment book. (Find a book that has the hours listed if you have a lot of things to keep track of every day.)

2. Write a "to do" list every day.

3. Write your "to do" list into your appointment book.

4. Ask yourself what things do NOT need to be done. Then don't do them.

5. Throw things out, preferably the first time you handle them so things don't accumulate.

6. Do each task only once. If the task is too big to handle in one sitting, divide it into tasks that are no more than a half hour or an hour.

7. When you pick up a piece of paper or open a letter, handle it only once. Once you pick it up, do everything that needs to be done.

8. Make the most of one spare minute.

9. Make the most of transition times. While walking home from class, plan how you will spend the afternoon or evening. Think over the paper you have to write and narrow down the topic.

10. Learn to say NO. If you are asked to do something and you cannot see how it will help you meet your goals, don't do it. (Remember, it's okay to do things that you enjoy doing or that are fun, but keep them in balance.)

11. Control interruptions. Don't answer the phone and call people back later. When you are on the phone, keep the call short.

12. Nothing is worth doing perfectly. For the additional time that it takes, perfection may not be worth achieving. (However, if
you need to have an error free paper (spelling and grammar), keep on working.)

13. Spend more time in planning. The time you spend planning how to do something, may make it possible to spend less time doing it.

14. Ask the question "What is the best use of my time right now?"

15. Listen well. Make certain you understand the directions. There is nothing more time wasting than doing something wrong so that it has to be done again.

16. Build your will power. Time management is self-control.

17. Enjoy what you are doing right now. If you have decided to go out with friends, don't spend your time worrying about the studying you could be doing. Enjoy being with your friends.

18. Concentrate on one thing at a time. Decide what you are going to do right now and do only that.

19. Develop procedures for routine matters. If you have bills coming in throughout the month, decide that you'll pay them as they come in or that you will pay them on the first of each month, then leave them alone in between times.

20. Don't be afraid to make mistakes. Remember that successful people have made more mistakes than average. To be successful means you have to take some risks.

21. Break down tasks into 15 or 30-minute segments so that you can use the little times in your day.
What your Infant is Experiencing
Your Infant's Experience

There are wide ranges of complications that can occur with your infant when she or he is born prematurely. In general, the more premature the infant is, the higher the risk of complications. Some common complications include: the infant's inability to maintain their body temperature, apnea, which is when the infant stops breathing for 20 or more seconds and the infant's inability to feed/eat using the bottle or through breastfeeding.

The purpose of this section is to provide you with information on what your infant is experiencing physically in his or her environment and some of the possible complications. Your infant has gone from a warm, snug, dark environment (intrauterine) in which his or her basic needs were automatically met to a loud, bright and busy environment, which can often feel overwhelming to the infant. Your infant is experiencing many physiological and environmental factors, which will be explained in the following section.

Physiological Factors

Physiological factors are normal functions of the body that include breathing, heart rate, digestion, reflexes and movement of muscles. Your infant's body is going through many physiological changes as he or she learns how to live outside of the womb. The following are some of the
physiological factors your infant may experience:

- Your infant may lack the body fat needed to keep his or her body at a regular temperature, even when swaddled with blankets. Therefore, incubators or radiant warmers may be used to keep the infant warm.

- Your infant may not be prepared to feed from a breast or bottle due to an immature coordination of the suck and swallow movements she or he needs. That is why infants who are born prematurely are often fed through a tube that is placed in his or her nose or mouth transferring nutrients into the infant’s stomach. Tube feeding allows time for the coordination of these movements to mature with treatment by an occupational therapist.

- Your infant will have special nutritional needs because she or he will grow at a faster rate than full-term infants and their digestive systems are immature. The first nourishment your infant will experience are Intravenous (IV) fluids containing sugar and water. Within a few days time, your infant may progress to a more nourishing solution that contains protein, vitamins, minerals and other nutrients. Premature infants typically receive IV nutrition for several days to several weeks after birth.
Environmental Factors

Your infant is bombarded by environmental factors in the NICU such as: noise, light, and interactions with parents and NICU staff. Although these factors assist in improving your baby’s health and development, they can cause stress, as well. Fortunately, there are ways to decrease this stress. In the following information, each environmental factor is presented with suggestions to help decrease your infant’s stress:

➢ The NICU tends to have high noise levels related to the constant care from staff and the equipment used to care for your infant.
   • Loud noises can keep your infant alert, which interferes with his or her sleep cycle/pattern and lowers his or her energy levels.
   • Sudden noises from equipment or people can cause startling and/or crying, which can result in oxygen desaturation (decreased oxygen) and/or pressure changes within the brain.
   • Suggestions to lower noise levels may include: speaking softly, avoiding loud radios, minimizing the amount of movement around each isolette and closing the isolette covers gently.

➢ Your infant can be exposed to very high levels of light, especially if he or she has to receive light treatment for jaundice.
   • Bright lights can keep your infant awake, which can lead to sensory overload. Sensory overload means the infant is getting to much stimulation. Too much stimulation can cause the infant’s oxygen levels to go down (desaturation), his or her heart rate to increase and all of this physical...
activity can result in losing calories.

- Suggestions to decrease lighting include the use of isolette covers and lowering the amount of light within the NICU environment.

Your infant will be interacting with people during medical procedures, which can be uncomfortable and/or painful. These procedures need to be done for his or her physical health and well-being. This often means that there is little cuddling or social interaction. The NICU medical teams have discovered alternative ways to soothe, help relieve or minimize the pain and relax your infant. These can be accomplished through:

- Decreasing the levels of light, noise and the amount of handling of the infant
- Providing repetitive or rhythmic movement such as rocking or softly singing to your infant
- Swaddling your infant tightly with a blanket so she or he feels safe and comforted. Your nurse or OT can show you how to best swaddle your infant.
Connecting with your Infant
This section will provide you with information, suggestions and assistance on how to successfully connect and develop that special bond with your infant. While it may seem like there are many barriers (medical equipment, staff and your infant's fragile health) between you and your infant, there are also many ways to deal with these barriers. The following are suggestions to develop a healthy connection with your infant:

**Focus on your infant**
Let yourself enjoy special moments with your infant. It is normal to feel stressed, worried and anxious; but don’t let that get in the way of being with and enjoying your infant. Take pleasure in the time you have to hold and bond with your infant.

**Pay close attention and learn your infant’s cues**
These cues will help you in figuring out what soothes and/or irritates your infant. Some examples are:

- If your infant turns his or her eyes/face toward you, offer him or her eye contact and use a gentle soft voice.
- Your infant will let you know the position he or she
prefers to be held or when a change in position is needed.
If your infant arches his or her back a change of position may be needed to soothe the infant.

**If possible, decorate your infant’s incubator**
There are many ways to make your infant’s space more personal. Ask the NICU staff if the following items can be brought from home:
blankets, family photos, small toys or a recorded tape of your voice talking to him or her or singing a lullaby.

**Holding your infant**

- Don’t be afraid to hold and touch your infant. Touch is important to develop that special bond between you and your infant. The nurse or occupational therapist can help you to become more comfortable and confident with touching and holding your infant.
- Positioning: Positioning is very important to help your infant’s cardiac (heart) and respiratory (lung) systems develop. Proper positioning also helps in the development of the infant’s posture and motor (movement) abilities. Your occupational therapist and nurse can teach you about proper positions that help your infant.
  - Other positioning devices such as blanket rolls and
support wedges can also be used to position your infant. These are used to position your infant with the arms and legs flexed (bent slightly at the elbow and knee joints) and the hips are in neutral (not bent), which helps to reduce his or her stress.

➢ Stimulation: Attempts are being made to simulate some of the things your infant experienced in the womb/uterus. These can include:

- Vestibular stimulation: The rhythmic motions that can occur through the use of oscillating or rocking mattresses, or waterbeds.
- Teddy bears that make breathing or heart beat sounds can be placed within the isolettes to promote quiet sleep for the infant by simulating the sounds of the mother.
- Swaddling your infant helps mimic the secure feeling of the womb. It provides a secure position, keeps the body and head aligned and the arms and legs tucked close to the body.

➢ Kangaroo Care: This is a technique that focuses on skin-to-skin contact between the parent and infant. During kangaroo care:

- The infant is placed on the parent's chest, wearing only a diaper and sometimes a hat.
- The infant's head is turned to the side so the infant can hear the parent's heartbeat and feel the parent's warmth.

Kangaroo Care helps parents' learn how to recognize their
infant's behaviors. It offers many advantages for the infant such as: helping him or her maintain body warmth; regulating heart and breathing rates; gaining weight; decreasing crying so she or he can be more quiet and alert; and, increasing the desire to breastfeed. All of this occurs because the infant feels safe and comfortable. Kangaroo Care is effective, but is limited to infants whose condition is not critical.
NICU Medical Team
NICU Medical Team

It is important to have a good relationship with the NICU medical team, from the beginning of your infant’s hospitalization. As you get to know the healthcare professionals who are caring for your infant, you will feel more comfortable asking them questions and talking about your concerns.

You are the main advocate for your infant so it is essential to stay informed about your infant’s health and well-being. Keeping informed will help to ease your stress and anxiety during this difficult time. When important decisions need to be made, remember, you are a key member in the NICU medical team.

The following is a list of NICU medical team members who may provide treatment to your infant during his or her stay in the NICU. A brief description of each team member is included to help you better understand what they do and how you can use their skills while your infant is in the hospital.

Case Manager
The case manager can bridge the gap between the parents’ and other medical staff to provide valuable information regarding an infant’s health
status and care. Their role also encompasses: assisting the parents' with financial difficulties by communicating with insurance companies, as well as, making arrangements for your infant's discharge and follow-up care.

**Charge Nurse**

The registered nurse has general responsibility for coordinating the nursing care of all the infants in a unit for a particular shift. Nursing shifts may be either 8 or 12 hours.

**Hospital Chaplain**

A religious advisor who can provide spiritual support and counseling to assist families with coping with the stressors of having a premature infant in the NICU environment.

**Neonatologist**

A pediatrician who has received extended training beyond medical school in the care of infants' born prematurely or ill. The neonatologist is the person who is typically responsible for your infant’s care if hospitalization in a NICU is required.

**Neonatal Occupational Therapist**

The occupational therapist (OT) will work to assist you in learning how to help your infant reach his or her optimal development. The role of an OT is described in more detail on pages 34-38. The occupational therapist
works to establish supportive, collaborative and therapeutic relationships with you and your family members while considering the family’s priorities, concerns and cultural beliefs. The occupational therapist works with the infant using a developmental and holistic approach while incorporating your family throughout the treatment process.

**Physical Therapist**

A professional who is trained to work on the gross motor movements, which are the large muscles in the legs, arms and trunk. A physical therapist's role in the NICU includes: positioning and posture alignment, range of motion, strength developmental activities and endurance.

**Speech and Language Pathologist (SLP)**

This profession assists with speech and language problems. The SLP’s role in the NICU primarily involves assisting the premature infant with feeding difficulties.

**Social Worker**

The social worker provides a broad range of services from emotional support to follow-up services for the infant after discharge. Social workers may also provide family, individual or couple’s counseling to ease the stress of having an infant in the NICU.
Occupational Therapy in the NICU
Occupational Therapy in the NICU

This section will discuss the role of an occupational therapist in the NICU. An occupational therapist, who works in the NICU, requires specialized training and knowledge to care for the infants born prematurely. The OT is familiar with neonatal medical conditions, procedures and equipment, as well as, the unique developmental abilities of your infant.

The OT will complete an assessment/evaluation with your infant to determine his or her developmental needs. After the assessment/evaluation is completed, a treatment plan will be created that includes specific goals to help in meeting your infant's developmental milestones. The treatment plan is used to guide in your infant's treatment and promote success for your infant.

**Occupational therapists' goals can include:**

1. To change the infant's environment to make it easier for your infant to learn and grow. Examples of changes to your infant's environment may include: a) positioning equipment such as rolled blankets or towels around the infant to help them feel secure and achieve a calming position for the infant or b) specially designed toys. These toys can provide vibration and
weight that helps your infant keep calm and relaxed.

2. To promote your infant's ability to eat which helps in his or her growth and development. Treatment focuses on increasing your infant's strength in the mouth muscles so he or she has the strength and coordinated mouth/tongue movements to drink from the bottle and/or breast-feed.

3. To promote play is the most important activity for your infant. Play is where your infant learns to develop his or her social skills and to interact with family and others. At a young age, play includes just smiling or looking at you when you speak.

4. To build a bond between your infant and you. The parent-infant relationship is critical for your infant's development. The occupational therapist provides suggestions and gets you involved in aspects of your infant's care which all helps to develop that special parent-infant bond.

5. To strengthen the parents' emotional, physical, mental and spiritual needs throughout their infants stay in the NICU. The focus of treatment is also based on each individual parent's needs.

In the NICU the occupational therapist provides treatment to help your infant develop the following:

1. Motor control: motor control is the infant's ability to control his
or her muscles in order to move his or her body. An example of motor control is the infant's ability to hold his or her head up. Strategies to help your infant's motor control develop can include the way you carry or hold your infant; place him or her in a certain position and/or use adaptive devices for positioning as talked about previously.

2. Sensory modulation: the ability of the infant's body to have the senses work together. The senses include touch, movement, body awareness, sight, sound and to move with gravity and against gravity.

3. Adaptive coping: The infant's ability to cope within his or her environment. One example of adaptive coping for an infant is how he or she adjusts when moved from the incubator to being held by his or her parents outside the incubator.

4. Sensory-motor development: The senses and motor control work together in your infant. An example is when you speak softly and the infant turns his or her head toward your voice. Another example is when noises are too loud and the infant gets upset.

5. Social-emotional development: The ability of your infant to interact with you and others, without getting upset by the stimulation. The goal of social-emotional development involves your infant's ability to successfully interact with his or her
peers, adults and within various environments.

Occupational therapy plays a key role in the treatment of your premature infant. OT can assist in positioning, feeding and helping to ensure your infant meets key developmental milestones. In addition, occupational therapists use a holistic approach focusing on the infant, parents and family throughout the infant's hospitalization and transition home. The following section will discuss the preparation needed to take your infant home.
Preparing to Take your Infant Home
Taking your Infant Home

Your infant is ready to go home when he or she no longer needs an incubator to keep warm, can breast or bottle feed, is steadily gaining weight, breathing on his or her own and weighs approximately four pounds or more. As this day approaches, it is normal to feel overwhelmed and even doubtful of your abilities to care for your infant without the support of the NICU staff and equipment. In this section there are:

1. Ideas to prepare your home before your infant is released from the hospital.
2. Common concerns you might have after your infant has arrived home such as sleeping, crying or feeding.
3. A detailed explanation and a birth to 12 months chart of developmental milestones you will want to be aware of as your infant grows.
4. Lastly, there is a list of resources regarding breastfeeding, learning disabilities and parent support groups.

The following is a list of arrangements/suggestions to help you prepare to bring your infant home:
What to do Prior to taking your Infant Home

As you prepare to bring your infant home there are several things to do:

1. Prepare your home
   For your infant's health and safety it is essential to have a home that is clean to protect your infant from harmful environmental factors. This may also be a good place/time to ask for help.

2. Obtain essential items
   You will want to prepare by having items such as a car seat which is properly installed, crib, clothing, blankets, diapers, bottles, bath and breast pump.

3. Find a Pediatrician
   Find a pediatrician who is experienced in caring for infants born prematurely. Ask for a referral from the pediatrician who is taking care of your infant in the hospital. Make scheduled appointments with a pediatrician and other disciplines (OT, PT, SLP) for your infant's follow-up care.

4. Training
   Before bringing your infant home, make sure you are trained and feel comfortable with any equipment your infant requires after discharge home. Most hospitals also require you pass a Cardiopulmonary Resuscitation (CPR) exam prior to bringing your infant home. If they don't require this, it may still be

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something you want to consider just to help you feel more comfortable and prepared.

5. Emergency Information

Have phone numbers available to assist you with any questions or concerns you may have such as operating the equipment.

6. Family and Friends

Have a list of family and friends available who have offered to help you and be prepared to take them up on their offer.

7. Support Groups

The NICU team should be able to provide you with information and telephone numbers regarding past NICU parents and support groups available in your area. In remote areas, the internet can provide a valuable link to others, as well.

**Common Concerns after Bringing Your Infant Home**

After bringing your infant home you may have many questions and concerns regarding caring for your infant. This section discusses some common concerns and provides suggestions to help you.

**Feeding**

Follow the suggestions and guidelines provided by your healthcare team. It is common for infants who are born prematurely to have a decreased appetite for up to one year after birth. Although this may be stressful to
you, as the parent, do not try to force feed, as the child/infant’s appetite will increase with age.

**Excessive crying**

There is a common misconception that if you “just let the infant cry” he or she will learn to soothe him or herself and go to sleep. This is especially not encouraged for infants born prematurely. Excessive crying lowers blood oxygen levels and increases pressure in the abdomen, which is already common in infants born prematurely. Always respond quickly to your infant’s cries as crying wastes his or her energy and his or her oxygen level is already compromised.

The infant gains many physiological benefits from sleeping close to his or her parent. The immature central nervous system, cardiorespiratory system and digestive system can mature more rapidly when sleeping close to the mother. Make sure the infant is placed near you in a room that is dark and quiet to encourage optimal sleep. Be aware of the risks associated with placing your infant in bed with you. Equipment is available to allow you to safely have your infant sleep near you.

**Stress**

The infant will display unique signals of stress. The infant’s body language can help in letting you know when your infant is feeling contentment or stress. It is also important to note that your infant may
also be able to sense increased levels of stress in you, the parent, which
will increase his or her stress level.

The signs of contentment include:

- the infant’s face is relaxed
- slowly moving arms and legs as though playing or reaching
- hands are partially open (not clenched in a fist) and the fingers are
  relaxed

The signs of stress include:

- crying
- clenched fists
- arms and legs flailing with jerky movements
- frown or grimace
- arched neck and back with possible skin color changes
Developmental Milestones

As a parent you may have questions about your infant’s progression through the typical developmental milestones. Keep in mind that all infants, pre-term or full-term, progress at different rates and skill development.

When considering your infant’s achievements, in reaching their developmental milestones, always keep in mind your infant’s gestational age instead of his or her chronological age. For example full-term infants typically sit unsupported at approximately six months of age. When considering your infant’s gestational age he or she may not sit unsupported until eight months of age because your infant was born two months premature. The following chart may help you understand the developmental milestones your infant will be progressing through.
<table>
<thead>
<tr>
<th></th>
<th>2 months</th>
<th>4 months</th>
<th>6 months</th>
<th>9 months</th>
<th>12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gross motor</strong></td>
<td>Lifts head slightly</td>
<td>Lifts head more</td>
<td>Lifts head to 90 degrees and scans environment</td>
<td>Sits briefly by self Needs help to stand yet supports</td>
<td>Crawls Pulls self up to stand Cruises, holding onto furniture Takes a few steps Walks assisted</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Stands supported</td>
<td>most of weight on legs</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Fine motor</strong></td>
<td>Hands remain in tight fists</td>
<td>Visually tracks parents Unfolds hands Briefly grasps toys</td>
<td>Embraces and reaches with both hands Holds toys longer Brings toys toward mouth</td>
<td>Transfer toys from one hand to the other Has more accurate reach and grab</td>
<td>Picks up objects with thumb and forefinger Points to toys Feeds self, holding bottle or cup to drink</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social and language</strong></td>
<td>Smiles occasionally Startles, turns toward sounds</td>
<td>Coos, squeals Holds eye contact, studies face</td>
<td>Laughs Enjoys social gesturing (flapping arms to be picked up) Tracks moving objects Engages in more eye contact</td>
<td>Imitates facial gestures Looks at mirror image Begins babbling</td>
<td>Waves bye-bye Babbles more, may begin to say words (“ma-ma and da-da”) May say a few intelligible words (“ba” for ball) Points and gestures for help Recognizes and points to familiar persons at the sound of their names</td>
</tr>
</tbody>
</table>

What to do when your baby is born prematurely by Garcia-Prats and Simmons Hornfischer pages 325-331 (2000).
Resources

These are a list of primary resources for you. You can access these resources to learn even more.

Breastfeeding
➢ La Leche League International (LLLl)
  (800) 435-8316
  www.lalecheleague.org

Learning Disabilities
➢ Learning Disabilities Association of America
  Pittsburg, PA
  (412) 341-1515
  www.ldanatl.org

Loss & Grief
➢ Compassionate Friends
  Oak Brook, IL
  (630) 990-0010
  www.compassionatefriends.org

  ➢ When Bad Things Happen To Good People. By: Harold Kushner.

Special Needs
➢ Family Support Network
  Chapel Hill, NC
  (800) 852-0042
  www.med.unc.edu/commedu/familysu/fsnframe_main.html

General Information
➢ American Association for Premature Infants
  Cincinnati, OH
  (513) 522-8040
  www.aapi-online.org

  ➢ For Parents of Preemies (Answers to Commonly Asked Questions)
    www2.medsch.wisc.edu/childrenshosp/parents_of_preemies/index

Support Groups
➢ Parent Buddy Programs: a program available in some NICU’s to assist parents in connecting with other parent’s of premature infants. For information and availability of a Parent Buddy Program within your infant’s NICU contact the NICU medical staff.
- www.preemiemagazine.com a free publication and online community for parents of premature infants.
Summary
Summary

This handbook is meant to be a guide to help you gain a better understanding of what is happening to your infant and you during this period in your lives. The handbook is designed to serve as an educational tool/resource to assist you in transitioning your infant home. During this challenging time, let this handbook guide and help you to care for your new infant. Remember to take time for yourself and family so you can effectively care for and enjoy your newborn infant.
REFERENCES


Franck, L.S. & Spencer, C. (2003). Parent visiting and participation in
infant caregiving activities in a neonatal unit. *Birth, 30*, 31-35


Appendix
Definitions of NICU and Related Terms

A neonatal intensive care unit (NICU) is a specialized nursery for premature and newborn infants with severe medical complications. The length of time the infant remains in the NICU is dependent upon the severity of his or her illness, and/or the complexity of what his or her needs are.

The following definitions were adapted from Case-Smith (2002), Willard and Spackman (2001), and other sources, which are provided for you in the end of this handbook in the reference section. These terms have been adapted to remove the medical jargon. These are in alphabetical order in two sections.

Section I: NICU Terms - this section explains many terms you might hear the medical staff use while treating your infant. These terms describe and define various names, programs, equipment and tests commonly used in a NICU.

Section II: Diagnoses and Disorders – this section explains many diagnoses and disorders that result from an infant being born prematurely. These terms are important to be aware of in order to speak with the NICU medical staff in regards to your own infant’s health.
Section I: NICU Terms

**Adjusted Age**
Also known as "corrected age." This is your infant's chronological age minus the number of weeks he or she was born early. For example, if your 9-month-old infant was born 2 months early, you can expect him or her to look and act like a 7-month old. Usually you can stop age-adjusting by the age of 2 or 3. See page 46-47.

**Blood Gas**
This is a blood test that is used to evaluate your infant's level of oxygen, carbon dioxide and acid. This test is significant because it helps to evaluate an infant's respiratory status and helps the medical team in determining if your infant requires more or less oxygen as well as any adjustments that need to be made to the infant's respirator.

**Bradycardia (Brady's)**
This is when the infant has an abnormally low heart rate. Bradys are usually associated with apnea in premature infants. During these spells the infant will stop breathing for at least 15 seconds and the heart rate will start to slow, usually to less than 60 beats per minutes (bpm), which is also referred to as an "A&B spell." Gentle touching or other stimulation almost always restarts the breathing and increases the heart rate. Medications are often used to treat these spells in infant's born prematurely and newborn babies if needed.
**BROVIAC Catheter**
This is an intravenous tube that is used to give fluids and medications to infants or children. The catheter is placed in a major vein of the body during surgery. The BROVIAC® catheter is designed to stay in place over many months, if needed. The BROVIAC catheter is used for infants who require IV fluids (nutrients and medications) for more than a few weeks. Infants who are unable to eat for a significant period of time and infants requiring long-term antibiotics to fight infections are good candidates for the BROVIAC catheter. The use of the BROVIAC catheter eliminates unnecessary needle sticks for your infant.

**Central Venous Line**
The central venous line (CVL) is also called the central venous catheter (CVD). This is a type of intravenous tube used to give fluids and medications. The catheter is placed in a major vein of the body during surgery or by insertion through a vein in the arm, leg or head. Central venous catheters are used for infants that require intravenous fluids for more than a couple weeks or to administer medications that may be irritating to smaller vessels.

**Continuous Positive Airway Pressure (CPAP)**
This is when supplemental oxygen or room air is delivered, under pressure, through either an endotracheal tube (tube that goes directly into the infant’s lungs) or small tubes or prongs that sit in the nostrils. Delivering oxygen under pressure helps keep air sacs in the lungs open and also helps maintain a clear airway to the lungs. Nasal CPAP (NCPAP)
is commonly used immediately after removing the endotracheal tube to treat apnea and/or prevent the need for an endotracheal tube and ventilator.

**Crit**
This is the medical slang/abbreviated word for hematocrit, this is a test used to evaluate the percentage of red blood cells compared to total blood volume which determines the level of oxygen in the infant’s blood. A normal hematocrit level in infants is 40%. It is commonly used to test for anemia. It is significant in that it helps to show an infant’s ability to supply oxygen to his or her organs and tissues.

**Echocardiogram ("Echo")**
This is an ultrasound picture of your infant’s heart. This is a painless, non-invasive procedure that takes accurate pictures of almost all parts of the heart. An echocardiogram is used to evaluate the functions of your infant’s heart and diagnose infections, congenital abnormalities, clots and general heart disorders.

**Endotracheal Tube (ETT or ET Tube)**
This is a tube that is placed through the mouth or nose into the throat and the infant’s trachea (windpipe). This tube provides a secure pathway through which air can be circulated to the lungs. An ET Tube is used for infants's who cannot breathe on their own and require a respirator that delivers air directly into the infant’s lungs.
**Fontanelle**
This is the soft spot on the top of the infant's head. At birth, the skull has several plates of bone; it is not a single, solid bone. The spaces between the bone plates allow the skull to expand as the brain grows. Where four of these bony skull plates come together it forms a soft spot in the skull called a fontanelle. There are usually two soft spots in the skull of a newborn, the anterior (front) and the posterior (back) fontanelle; both usually close by about 18 months of age. Fontanels are closely evaluated and watched in premature infants for increased pressure, which may be a sign of hydrocephalus (see definition in Section II).

**Gavage Feeding**
Feeding a baby through a nasogastric (NG) tube is also called tube feeding. This is the second step in feeding your premature infant. Gavage feeding actually places nutrients into the infant's intestinal tract. This feeding technique is also used to supplement older infants who are already breast or bottle-feeding but need extra calories for growth.

**Grasping Reflex**
This is the newborn's reflexive grasp of an object, such as your finger, when it touches his or her hand. This grasp may be strong enough to support the infant's own weight, but does not last very long. This reflex normally lasts until an infant is 3 or 4 months old. Newborns have many naturally occurring reflexes.
**Hearing Screen**
A test to examine the hearing of all newborn infants born in the NICU.
Clicking noises are sounded through headphones placed on the infant’s ears. Brain waves are recorded through the use of electrodes attached to the infant’s head. This is a painless procedure and is done periodically to test the infant’s hearing.

**Individuals with Disabilities Education Act (IDEA)**
This provides grants to states to support services, including evaluation and assessment, for young children who have or are at risk for developmental delays or disabilities.

**Individualized Family Service Plan (IFSP)**
This is a written program for an infant or toddler. A team of people who have worked with the child and family develops it. The IFSP describes: 1) the child's developmental levels, 2) family information, 3) major outcomes expected to be achieved for the child and family, 4) the services the child will be receiving, 5) when and where the child will receive these services, and 6) the steps to be taken to support the transition of the child to another program.

**Incubator/Isolette**
An isolette or incubator is a clear plastic, enclosed bassinet used to keep premature infants warm. Premature infants often lose heat very quickly unless they are put in a protected thermal environment due to the infant’s inability to regulate their body temperature. The temperature of the isolette can be adjusted to keep the infant warm regardless of the
infant's size or room temperature.

**Lanugo**
This is the fine, downy hair that often covers the shoulders, back, forehead, and cheeks of a newborn that is born prematurely. Lanugo is replaced by more normal appearing hair toward the end of gestation.

**Low Birth Weight (LBW)**
Any baby with a birth weight under 2,500 grams (approximately 5 pounds) is a low birth weight infant.

**Meconium**
This is dark green, sticky mucus, which is a mixture of amniotic fluid and secretions from the intestinal glands that is normally found in infant's intestines. This is the first stool that is passed by the infant.

**Vital Signs Monitor**
This is a machine that displays and often records the infant's heart rate, respiratory rate, blood pressure and blood oxygen saturation. An alarm may sound if one or a number of these vital signs are abnormal. For example, normally the heart rate is usually between 120 and 180 beats per minute, blood pressure should be between 50 and 70, and oxygen saturation should be above 90%. False alarms are common, and are often caused by abrupt movements of the infant, which can cause the monitor to register inaccurate readings.
**Moro Reflex**
This is a normal newborn reflex. It is the automatic response to loud noises or sudden movements, which may cause the newborn to extend his or her arms and legs, arch his or her back, and sometimes he or she will cry out. Newborns can have this reaction even during sleep. This reflex no longer occurs after a few months.

**Motor Skills**
Gross motor skills are the movements that use the large muscles in the arms, legs, and torso to move, roll, run and jump. Fine motor skills are the small muscle movements used to grasp and manipulate objects, like picking up a Cheerio, holding a finger or using a crayon.

**Nasogastric Tube (NG Tube)**
This is a narrow, flexible tube inserted through the nostril, down the esophagus, and into the stomach that is used to give food to the infant or to remove air or fluid from the stomach. NG tubes are used for gavage feeding and can be placed in the infant's nose.

**Oximeter**
This is a machine that monitors the amount of oxygen in the blood. A tape-like cuff is wrapped around the infant's toe, foot, hand or finger. This machine helps the NICU staff to monitor the amount of oxygen in the infant's blood without having to obtain blood for laboratory testing.

**Premature Baby**
An infant born three or more weeks before the due date.
**Rooting Reflex**
This is a normal instinctive reflex in all newborn infants that causes them to turn their head to the side when their cheek is stroked. This reflex helps infants learn how to eat. By gently stroking the cheek, your infant will turn his or her head toward you with an open mouth ready to feed.

**Surfactant**
Surfactant is a soapy material inside the lungs of adults and mature infants that help the lungs to function. Without surfactant, the air sacs tend to collapse on exhalation (breathing out). Lung surfactant production is one of the last systems to mature in an infant. Infants who are born before the surfactant production occurs will have breathing problems. Surfactant is then used to treat respiratory problems in premature infants and it is one of the most important recent medical advances in pediatrics.

**Tone**
An increase or decrease in the resistance to movement of the extremities is called tone. Normally infants give only a moderate amount of resistance to you when you move their arms and legs. The amount of tone present is one way of assessing the condition of the nervous and muscular systems in an infant. Infants with too much tone, and who resist movements, are called hypertonic. Infants with decreased tone, and who have no resistance to movements, are called hypotonic. In many cases, hypotonia can mean simply low muscle tone and increased
flexibility or laxity of ligaments. An infant who experiences hypertonic or hypotonic may have trouble or be unable to sit up, crawl, walk, or eat correctly.

**Tonic Neck Reflex**
This is a normal newborn reflex that resembles a fencing position. When your infant's head is turned to the side, one arm will straighten, the opposite arm will bend at the elbow, and often one knee will significantly bend at the knee. This reflex usually disappears between 5 to 7 months of age. Infants vary in the degree to which this reflex is obvious.

**Ventilator ("Vent")**
This is a machine that helps your infant to breathe. Lung immaturity in premature infants is the most common reason for a newborn to require a ventilator. The ventilator is removed from your infant when the medical team determines your infant can breathe on his or her own without assistance.

**Very Low Birth Weight (VLBW)**
A birth weight of less than 1,500 grams (about 3.3 pounds). About 1.3% of all births result in infants with a very low birth weight.

**Warmer**
This is a bed that has radiant heaters above the bed to keep the infant warm. Generally, an infant progresses from a warmer to an isolette to an open crib before leaving the NICU. A warmer is used because premature infants cannot regulate their own body temperature.
Section II: Diagnoses and Disorders

The following diagnoses or disorders do not occur in all premature infants.

Anemia
A common blood disorder in which the level of healthy red blood cells (RBCs) in the body becomes too low. This can lead to health problems because components within RBCs carry oxygen to the infant's tissues. Anemia can cause a variety of complications including fatigue and stress on the infant's organs.

Apnea
This is when the infant stops breathing for 20 seconds or longer. Also, known as an apneic episode or apneic spell. It is common for premature infants to stop breathing for a few seconds. They almost always restart on their own, but occasionally they need stimulation or drug therapy to maintain regular breathing. Apnea gradually becomes less frequent as premature infants mature and grow. There is no relationship between apnea and sudden infant death syndrome (SIDS).

Cerebral Palsy (CP)
Cerebral palsy is a term used to describe a group of chronic conditions affecting body movement and muscle coordination. It is caused by damage to one or more specific areas of the brain, usually occurring during fetal development; before, during, or shortly after birth; or during infancy. Thus, these disorders are not caused by problems in the
muscles or nerves. Instead, faulty development or damage to motor areas in the brain disrupts the brain's ability to adequately control movement and posture. "Cerebral" refers to the brain and "palsy" to muscle weakness/poor control. Cerebral palsy itself is not progressive (i.e., it does not get worse); however, secondary conditions, such as muscle spasticity, can develop which may get better over time, get worse, or remain the same. It is not a disease and should not be referred to as such. Although cerebral palsy is not "curable" in the accepted sense, training and therapy can help improve function.

**Developmentally Delayed / Disabled**
A term used to describe infants and toddlers who have not achieved skills and abilities, which are expected to be mastered by children of the same age. Delays can be in any of the following areas: physical, social, emotional, intellectual, speech and language and/or adaptive development, sometimes called self-help skills, which include dressing, toileting, and feeding. Many developmental delays can be overcome with early intervention programs.

**Developmental Milestones**
Major and minor social, emotional, physical, and cognitive skills acquired by children as they grow.

**Early Intervention Program**
The planned use of physical, occupational and speech therapy in the first few years of a child's life to enhance the child's development.
Gastroesophageal Reflex (GER)
This is when the contents on the stomach come back up into the esophagus. This happens when the junction between the esophagus and the stomach is not completely developed or is abnormal. GER is very common among premature infants. In some infants, reflux can irritate the lining of the esophagus and cause a form of "heartburn" which causes them to become irritable and uncomfortable. It is necessary to evaluate how severe the GER is and whether or not it requires treatment.
Treatment of GER may include keeping the infant upright, thickening of the feedings, giving medication to reduce stomach acid, and sometimes giving medication to increase the ability of the stomach to contract.

Heart Murmur
This is when a noise is heard between beats of the heart. These are common noises, which are harmless in infants and toddlers.

Hydrocephalus
This is an abnormal accumulation of cerebrospinal fluid within the ventricles of the brain. It is sometimes known as "water on the brain."
Within the center of our brains each of us has two fluid-filled areas called cerebral ventricles. Cerebrospinal fluid is made within these ventricles and distributed over the surface of the brain and spinal cord. When the normal circulation of cerebrospinal fluid is interrupted, fluid can accumulate within the ventricles. This fluid puts pressure on the brain, forcing it against the skull and enlarging the ventricles. In infants, this fluid accumulation often results in bulging of the fontanelle (soft spot)
and abnormally rapid head growth. The head enlarges because the bony plates making up the skull have not yet fused together. In premature infants the most common cause of hydrocephalus is intraventricular hemorrhage (see definition). Hydrocephalus is treated by removing spinal fluid using a spinal tap method. A more permanent drain called a shunt can be placed into the ventricles of the infant's brain and allows fluid to flow away from the brain and be absorbed elsewhere in the body.

**Intracranial Hemorrhage/Intraventricular Hemorrhage**
This is when there is bleeding within the skull. Bleeding most often occurs within the ventricles of premature infants, but it can occur anywhere within or on the outside of the brain. Rapid changes in blood pressure can alter the pressure and blood flow within the blood vessels of the brain causing a bleed into the surrounding tissue. Medications can help prevent hemorrhage and maintain a steady flow of blood to the brain.

**Intrauterine Growth Retardation (IUGR)**
This is a condition in which the fetus does not grow at a normal rate while he or she is in the uterus. These infants are small for their gestational age, and their birth weight is below the 10th percentile. IUGR can be caused by decreased blood flow to the placenta, maternal hypertension, drug use, smoking, poor weight gain, dieting during pregnancy, pre-eclampsia, alcoholism, multiple fetuses, abnormalities of the cord or placenta, prolonged pregnancy, chromosomal abnormalities,
or a small placenta. Premature infants that are below the 10\textsuperscript{th} weight percentile for his or her age in weeks are classified as IUGR.

**Jaundice**
Jaundice is caused by an accumulation of a natural waste product, called bilirubin. Bilirubin has a yellow color, and when the levels are high it stains the skin and other tissues. A little jaundice can be expected in all newborns. If the jaundice is higher than usual, it can usually be treated with phototherapy (special lights). Premature infants may have elevated bilirubin levels for several weeks.

**Meconium Aspiration Syndrome (MAS)**
When meconium passes within the uterus, before birth, it can be a sign of fetal distress. The meconium is very irritating to the lungs and can cause meconium aspiration syndrome when infants inhale meconium or meconium-stained amniotic fluid into their lungs. The infant can have mild to severe respiratory distress depending on the amount of meconium breathed and the length of time before delivery.

**Periodic Breathing**
This is when an infant has an irregular breathing pattern that has pauses for as long as 10 to 20 seconds. This is common in both premature and full-term infants and does not usually mean there is a problem.

**Tachycardia**
A faster than normal heart rate of 220-230 beats per minute.
**Tachypnea**
A faster than normal respiratory rate because extra fluid in the lungs is present. This condition normally lasts for 24-72 hours. Signs of tachypnea include rapid, labored breathing of more than 60 breaths per minute. The infant’s respiratory rate is monitored until oxygen levels remain normal.
CHAPTER FIVE

SUMMARY

According to Hurst (2002) "families spend a median of 20 hours in the first week after birth seeking information, the equivalent to a part time job. Families desired more information than was provided" (p. 42). The purpose of this scholarly project was to create a resource for parents of infant’s born prematurely within the NICU setting.

The experience of having an infant born prematurely can become stressful and confusing for parents. An Occupational Therapy Parent Education Handbook: Parenting in the NICU is designed to be a guide and offer support to ease the stress and overwhelming feelings new parents experience when their infants are born within the NICU.

It is recommended for the implementation of this product that occupational therapists use this handbook as a supplemental guide to educate parents and family members. Therapists who distribute this manual should document the effectiveness of having a handbook for additional parent education. Future development ideas could incorporate a survey completed by parents who have utilized the handbook to help them cope with their experience and share their
recommendations of the strengths and limitations of the handbook.

Scholarly project limitations are as follows:

1) It was found there were areas that could have been further
   investigated such as the long-term effects of premature infancy
   and early intervention efforts from occupational therapists.

2) A lack of evidence-based research was found on various
   interventions for premature infants born in NICU.

3) The product was limited by the various diagnoses and disorders
   in which an infant may experience while in the NICU and the
   specific implementation of occupational therapy interventions
   available to each circumstance.

In conclusion, the product is based on current literature and aims
not only to help infants born in the NICU but also to help the parents
cope with extreme changes in their lives.
REFERENCES


