

SUPPORTING  
FAMILIES FOR  
**NURTURING  
CARE**

21

# THE CARE OF SMALL AND/ OR SICK NEWBORNS

**PART 1** SUPPORTING FAMILIES WHILE THE BABY IS IN THE  
NEONATAL INTENSIVE UNIT OR PAEDIATRIC HOSPITAL





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## **KEY MESSAGES - why is this topic important for you?**

With improved services and technology, more and more babies born prematurely and/or with medical conditions survive. However, many of these infants may require special care and/or can be at a higher risk of health and developmental difficulties.

The Module “The care of small and/or sick newborns” is intended to support home visitors in providing advice and support to parents and families of small and/or sick newborns before and after the discharge from health facilities. The module consists of two parts. Part 1 provides information about supporting families while the baby is still in the Neonatal Intensive Care Unit (NICU) or Pediatric ward, while Part 2 is focusing on the care for small and/or sick newborns when at home.

- Infants born prematurely or with health conditions make up an important group of infants that are considered high risk in all countries. The needs of small and/or sick newborns are very diverse and they change, as the baby develops.
- Having a baby born small and/or sick constitutes one of the greatest challenges for any family. It can affect parental health and wellbeing, the relationship of the parents/caregivers with the baby and each other, and the long-term outcome for the child and family.
- Many parents will go through a difficult situation when babies are placed in Neonatal Intensive Care Units. They need emotional support to cope with the separation, skills and knowledge to take care for their child during the stay in NICU and prepare for the discharge.
- Commonly, home visitors have limited contact with families during the time, when the child is placed in NICU, though they may be visiting another young child in the household, have followed the mother throughout the pregnancy, or might have already interacted with the parents in the clinic.
- However, should this happen to one of the families, home visitors can help them better cope in their daily lives, spend some quality time with their newborn in the NICU, if the conditions allow, provide breastmilk; and prepare for the discharge of the baby.
- Because home visitors will always keep the infant in mind, the wellbeing of the parents and their ability to cope with this situation will be a primary concern. These parents and caregivers need empathy, open mind and problem-solving skills. Home visitors can help them to understand that they will be able to cope better when they do not disregard their own wellbeing, even in this stressful situation.
- In your contacts with the family, you have a unique opportunity to observe and discuss levels of physical activity and sedentary time in the home, learn about sleep routines and patterns, and screen time. With your expert knowledge and position of trust, you can advise families on how to adopt daily routines that contribute to their children’s health and wellbeing.
- By supporting healthy lifestyles in the families you visit, you contribute to optimal child development and the prevention of non-communicable diseases throughout the life course.



## **LEARNING OUTCOMES**

Part 1 of the module will help you to:

- Gain a better understanding of the issues and challenges faced by sick and/small newborns, their parents, and families.
- Understand how you can support parents during the time the baby is in NICU and plan and support parents to prepare for their baby to come home.



## SELF-ASSESSMENT

1. Because of advances in medical care, the percentage of preterm births is around 4-5% in Europe and Central Asia. (True/False)
2. Almost all babies experiencing neonatal intensive care were born premature and with very low birth weights. (True/False)
3. Almost all babies born preterm will experience permanent cognitive, social-emotional and motor difficulties. (True/False)
4. Parent's presence, voice, scent, and touch can all impact the development of a pre-term baby in a positive way. (True/False)
5. Some of the characteristics of the family-centered neonatal care are the following: (Mark all that apply).
  - a. Support for breastfeeding of the baby.
  - b. A reduction of noxious stimuli and painful procedures to the extent possible.
  - c. Regularly informing parents about the condition of their child.
  - d. Sleep protection.
  - e. Reducing parent-child contacts to limit the risks of infection.

### Answers:

1. False. The rates across Europe vary widely from 6-13% and thus about one in 10 infants in a home visitor's caseload.
2. False. The group of babies that required NICU care is very diverse and may also include newborns born at term but who are sick (e.g. heart condition, cerebral palsy related to asphyxia, etc.). These babies have diverse medical needs that may also affect follow-up when they are discharged.
3. False. It is true that the more premature babies are at birth, the more likely it is that they will experience developmental difficulties. However, many premature babies can catch up with the peers with nurturing care by the time they reach school age.
4. True. Scientific evidence shows that parent's presence, voice, scent, and touch has the potential to enhance neurological and neurobehavioral outcomes of preterm infants. The early mother-infant contact and interaction helps bonding, reduces stress and stimulates development.
5. The correct answers are a, b and d. Family-centred care promotes partnerships with carers and empowers them to become more independent in planning and providing care for their newborn during admission to the health facility and in planning discharge. The eight principles for patient-centred and family-centred care for newborns in a neonatal intensive care unit are: parental access with no limitation due to staff shift or medical rounds, psychological support for parents, pain management, a supportive environment, parental support, skin-to-skin contact, support for breastfeeding and lactation and protection of sleep.

**SUPPORTING FAMILIES FOR NURTURING CARE**  
THE CARE OF SMALL AND/OR SICK NEWBORNS



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## GLOSSARY AND DEFINITIONS<sup>1</sup>

**Apnea.** Interruption in breathing for 15 seconds or longer. Premature infant may need medication or manual stimulation to maintain or restart a normal breathing pattern.

### **Birthweight**

Low Birth Weight (LBW)	Baby weighing < 2500 grams at birth
Very Low Birth Weight (VLBW)	Baby weighing < 1500 grams
Small for gestational age	Newborns smaller than average for the number of weeks of gestation

**Corrected/adjusted age.** The premature babies chronological age minus the number of weeks or months s/he was born early (corrected age for a 12-month-old baby, born three months prematurely, is 9 months).

**Bradycardia.** A slowed down heart rate often associated with apnea in the premature baby.

**Continuous Positive Airway Pressure (CPAP)** delivers oxygen through nasal cannula or endotracheal tubes to help the baby breathe and keep the air sacs of the lungs open.

**Developmentally supportive care.** Care that supports the infant's growth and development and reduces environmental and sensory stress, while allowing stabilization of physiological and behavioral functioning.

**Endotracheal tubes** are small plastic tubes that deliver oxygen via a ventilator through the baby's mouth or nose.

**Essential newborn care.** Key routine practices in the care of all newborns, particularly at the time of birth and during the first days of life, whether in the health facility or at home.

**Family-centred care.** An approach to care delivery that promotes a mutually beneficial partnership among parents, families and health-care providers, based on dignity and respect; information sharing; participation; and collaboration. It can be practiced in health facilities at all levels and in all interactions between parents and care providers. The eight principles for patient-centred and family-centred care for newborns in a neonatal intensive care unit are: parental access with no limitation due to staff shift or medical rounds, psychological support for parents, pain management, a supportive environment, parental support, skin-to-skin contact, support for breastfeeding and lactation and protection of sleep<sup>2</sup>.

**Feeding Tubes.** Inserted through the mouth or the nose to the stomach to provide food for babies who are not able to breastfeed or drink from a cup or bottle on their own.

**Gastroesophageal reflux** happens when the content of the baby's stomach comes back into the esophagus.

**Intensive newborn care.** Inpatient care (24/7) practices, usually provided in a tertiary level facility, i.e. a neonatal intensive care unit (NICU) for very small and sick newborns.

**Infant warmers.** Open beds with overhead heaters that keep the baby warm.

**Incubator.** Enclosed unit that provides controlled heat, humidity, and a clean environment.

<sup>1</sup> Adapted from: WHO (2019). [https://www.healthynewbornnetwork.org/hnn-content/uploads/Survive-and-Thrive\\_Final.pdf](https://www.healthynewbornnetwork.org/hnn-content/uploads/Survive-and-Thrive_Final.pdf) p. 3 USAID (2019). Nurturing care for small and sick newborns: [Evidence review https://www.everypremie.org/wp-content/uploads/2019/09/Nurturing-Care-Evidence-Review-and-Case-Studies-13Aug2019.pdf](https://www.everypremie.org/wp-content/uploads/2019/09/Nurturing-Care-Evidence-Review-and-Case-Studies-13Aug2019.pdf) National Association of Neonatal Nurses (2018). Baby Steps to Home. <https://babystepstohome.com>

<sup>2</sup> Roué JM, Kuhn P, Lopez Maestro M, Maastrup RA, Mitanchez D, Westrup B, et al. Eight principles for patient-centred and family-centred care for newborns in the neonatal intensive care unit. Arch Dis Child Fetal Neonat. 2017. 102: F364–8.

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**Intrauterine Growth Restriction (IUGR).** A baby growing more slowly than usual in utero and smaller than normal for gestational age at birth. Usually diagnosed during pregnancy by ultrasound.

**Intravenous (IV) or Infusion Pumps.** Provide fluids and/or medication into a baby's bloodstream.

**Jaundice.** Yellowing of the skin and eyes caused by a normal waste product called bilirubin.

**Monitors.** Attached on the baby with sensors to provide information about heart rate and rhythm, breathing rates, oxygen level, etc.

**Nasal Cannulas.** Keep the nasal passages open to provide the baby with oxygen or room air at a higher flow.

**Post-discharge care.** Care given to the infant at home post-discharge from an inpatient facility for up to 3 years of age

#### **Pregnancy duration and birth:**

- Average pregnancy duration. 37-42 weeks
- Moderate to late preterm birth. Baby born at 32 to < 37 weeks of gestation
- Very preterm birth. 28 to < 32 weeks of gestation
- Extremely preterm birth. < 28 weeks of gestation

**Radiant warmers.** Help premature babies maintain an ideal body temperature.

**Retinopathy of prematurity** is a scarring or abnormal growth of blood vessels in the retina. The retina does not mature until close to term.

**Sick newborn.** Newborn with any medical or surgical condition.

**Small newborn.** Newborn weighing < 2500 g at birth (includes preterm and low-birth-weight newborns).

**Special newborn care.** Inpatient care (24/7) practices provided by a health facility for small and sick newborns, including (but not exclusively) provision of warmth, feeding and breathing support; treatment of jaundice; and prevention and treatment of infection. Special newborn care may include the provision of intermittent positive-pressure therapy.

**Ventilators and respirators.** Help the baby in breathing when s/he is not able to breathe on his/her own.

## INTRODUCTION

According to WHO, the Lancet, and the European Foundation for the Care of Newborn Infants<sup>3,4,5,6</sup>.

- Across the globe, in 2014, 14.8 million babies were born prematurely (before 37 weeks of gestation), and 5-6% of these are born before 28 weeks of gestation. Preterm infants are at higher risk of neurodevelopmental impairments, stunting and non-communicable diseases.
- In 2014, the rates of preterm births varied widely across regions and countries, ranging from 5 to 18% globally. In Europe, the rates ranged from 6.3 to 13.3% of live births.
- Half or more of the infants placed in a NICU are born at-term, with low weight for gestational age and/or with medical conditions, most commonly respiratory problems, bacterial infections, hypoglycaemia (low glucose levels), pathological jaundice and asphyxia<sup>7</sup>.

In some cases, as with multiple births or with conditions detected during pregnancy, parents and families may be aware of a potential health condition at birth and prepare for their newborn to receive neonatal intensive care. Many families, however, are often unprepared for the birth of a baby with special health needs.

Babies born with a birth weight of less than 2500g (includes preterms and low-birth-weight newborns) as well as babies with any medical or surgical condition are treated under the label “small and/or sick newborns” in international guidance documents<sup>8</sup>. However, it should be noted that they are a highly diverse group with respect to the cause and severity of their conditions. What they have in common are the challenging conditions around their birth and first days or weeks of their life. These babies are often separated from their mother (and father, or caretaker) for long periods of time; they frequently experience noxious and painful medical interventions in a neonatal environment full of machines, noises, and lights; and receive care from multiple health providers. Children in this situation might feel more anxious or require more intense support than a child who was born under normal conditions and has been consistently nurtured by at least one care provider.

The diverse medical needs of small and/or sick newborn babies are managed by specialists in the neonatal care unit, and sometimes by rehabilitation specialists and pediatricians upon discharge. As the home visitor who accompanies the family on their journey from pregnancy through their child’s first years of life, you also have a role in helping families manage this situation; support them in bonding with their baby; and promote and monitor the health, development and wellbeing of their baby before and after discharge.



### IMPORTANT

Remember, the early days are critical for the growing architecture of the infant’s brain and for the development of the relationship with his/her parents or caregivers and will mediate the health, development, and wellbeing of the small and sick newborn over the life course<sup>9</sup>.

<sup>3</sup> The Lancet (2019). A new framework for managing extremely preterm births. 394, 1592. Chawanpaiboon S, Vogel JP, Moller A-B et al. (2018). Global, regional, and national estimates of levels of preterm birth in 2014: a systematic review and modelling analysis. *Lancet Glob Health*. (published online Oct 29, 2018). [http://dx.doi.org/10.1016/S2214-109X\(18\)30451-0](http://dx.doi.org/10.1016/S2214-109X(18)30451-0)

<sup>4</sup> WHO (2019). Survive and thrive: transforming care for every small and sick newborn. [https://www.healthynewbornnetwork.org/hnn-content/uploads/Survive-and-Thrive\\_Final.pdf](https://www.healthynewbornnetwork.org/hnn-content/uploads/Survive-and-Thrive_Final.pdf)

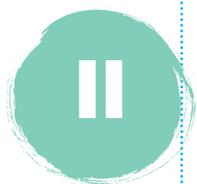
<sup>5</sup> The European Foundation for the Care of Newborn Infants, Definition and Epidemiology, 2019

<sup>6</sup> Lawn JE, Blencowe, H. et al (2014). Every newborn: progress, priorities, and potential beyond survival. *The Lancet*, 384, 189-205.

<sup>7</sup> *BMJ open* (2017). Term admissions to neonatal units in England: a role for transitional care? A retrospective cohort study. Retrieved from: <https://bmjopen.bmj.com/content/7/5/e016050.full?ijkey=dRMlpMjzNnlbfV1&keytype=ref>

<sup>8</sup> WHO (2020). Standards for improving quality of care for small and sick newborns in health facilities. Geneva. License: CC BY-NC-SA 3.0 IGO.

<sup>9</sup> WHO (2019). Survive and thrive: transforming care for every small and sick newborn. <https://apps.who.int/iris/bitstream/handle/10665/326495/9789241515887-eng.pdf?ua=1>



## SMALL AND SICK NEWBORNS IN NEONATAL INTENSIVE CARE

This section provides you with background information on small and sick newborns during their time in the Neonatal Intensive Care Unit (NICU). Parents and family members may have questions for you as you work in the community or the clinic. The section below summarizes important information and provides relevant resources that can help you feel confident when supporting families with small and sick newborns.

### 1. THE ISSUE

At birth, most newborns benefit from a basic package of “essential newborn services”. Additionally, according to WHO (2019), “up to 30 million newborns require some level of inpatient care each year”. This includes newborns experiencing complications from prematurity, intrapartum brain injury, severe bacterial infections and pathological jaundice, and those born with congenital conditions<sup>10</sup>. Depending on their conditions, small and/or sick infants may need more specialized treatment at the secondary or tertiary level of the health system, and often time in neonatal intensive care units (NICUs). Table 1 below<sup>11</sup> lists the types of services infants should be able to receive at different levels of the health system.

**Table 1. Inpatient care for small and sick newborns: requirements for care at different health systems levels**

Level	Type of care provided	Standards of care and evidence-based interventions
Primary	Essential newborn care	Immediate newborn care (through drying, skin-to-skin contact of the newborn with the mother, delaying core clamping, hygienic cord care); neonatal resuscitation (for those who need it); early intervention and support for exclusive breastfeeding; routine care (Vitamin K, eye care and vaccinations, weighing and clinical examinations); prevention of mother-to-child transmission of HIV; assessment, management and referral of bacterial infections, jaundice and diarrhoea, feeding problems, birth defects and other problems; pre-discharge advice on mother and baby care follow-up.
Secondary	Special newborn care	Thermal care; comfort and manage management; Kangaroo mother care; assisted feeding for optimal nutrition (cup feeding and nasogastric feeding); safe administration of oxygen; prevention of apnoea; detection and management of neonatal infection, detection and management of hypoglycaemia, jaundice, anaemia and neonatal encephalopathy; seizure management, safe administration of intravenous fluids; detection and referral management of birth defects.  Transition to intensive care: continuous positive airway pressure; exchange transfusion; detection and management of necrotizing enterocolitis (NEC); specialized follow-up of infants at high risk (including preterm).
Tertiary	Intensive newborn care	Advance feeding support (e.g. paternal nutrition); mechanical/ assisted ventilation, including intubation; screening and treatment for retinopathy of prematurity; surfactant treatment; investigation and management of birth defects; paediatric surgery, genetic services.

<sup>10</sup> WHO (2019). Survive and thrive: transforming care for every small and sick newborn, p. 2.

<sup>11</sup> *ibid*, p. 4.

Premature babies are babies born before completion of 37 weeks of gestation. Premature babies especially those born extremely preterm (before the 28<sup>th</sup> weeks of gestation), often have complicated medical needs and are at higher risk of short-term and long-term health problems. The severity of frequency of the health complications are higher for the babies with lower gestational age and lower birth weight. For children born in the first weeks the health complications may include breathing difficulties, feeding difficulties, heart problems, brain injuries, gastrointestinal and blood problems, retinopathy of prematurity, increase risk of infection due to immaturity of the immune system. In the long-term premature babies may develop cerebral palsy, vision and hearing problems, developmental delays and psychological and behavioural difficulties, chronic health conditions. Information Card 7 and 8 provide you with a brief summary on common health issues small and/or sick newborns might experience while receiving treatment.

A number of **risk factors** are associated with low birth weight (small-for-gestational age or born pre-term) or specific medical conditions of some babies. These include a prior preterm birth, multiple pregnancies (often due to reproductive treatments leading to multiple births), uterine or cervical abnormalities of the woman, infections and chronic conditions (e.g. urinary tract infections, bacterial vaginosis, sexually transmitted infections (STIs)), non-communicable diseases (diabetes, high blood pressure, asthma, renal or cardiac disorders), genetic factors, lifestyle patterns (under- or overweight, smoking, alcohol, stress), exposure to environmental contaminants, and no or late antenatal care. **Demographic factors** (the mother's age, socio-economic disadvantages, ethnicity) also play an important role in addition to the factors listed earlier<sup>12</sup>.



### **IMPORTANT**

Remember, as the family's home visitor, you can **contribute to reducing some of these high-risk births** by encouraging pregnant women to take full advantage of antenatal care when available, obtain treatment for health conditions and make positive lifestyle changes (encouraging good nutrition, engaging in daily physical activity, not partaking in smoking, alcohol or other substance ab/use). Reducing some or all of these risks will increase a woman's likelihood of carrying a healthy infant to term.

## **2. THE CARE OF SMALL AND/OR SICK NEWBORNS – IN A PERIOD OF CHANGE**

The role of empowered parents is key in the hospital setting and in transition from hospital to home.<sup>13</sup>

Sick and small newborns experience excessive and toxic stress from their separation with the mother and/or from receiving treatment in the days and weeks after their birth. Without the mediating factors of nurturing and developmentally appropriate caregiving, these stressors can affect survival rates negatively, increase the duration of the stay in the NICU, and increase the risks for health and developmental difficulties throughout the lifespan.

The first days of life constitute the period of greatest development of the infant's brain and the beginning of learning through human relationships and interaction. Therefore **all five components of nurturing care** must be addressed in the pediatric ward or NICU. In these environments, care needs to provide support for:

<sup>12</sup> European Foundation for the Care of Newborn Infants (FNCI), Causes & Risk factors, Home – EFCNI

<sup>13</sup> WHO (2019). Survive and thrive: transforming care for every small and sick newborn, [https://www.healthynewbornnetwork.org/hnn-content/uploads/Survive-and-Thrive\\_interior\\_2019\\_5-24\\_WEB-compressed.pdf](https://www.healthynewbornnetwork.org/hnn-content/uploads/Survive-and-Thrive_interior_2019_5-24_WEB-compressed.pdf)

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- **Health** – increasing the chances of survival by supporting the child’s growth and development and with the treatment of existing and prevention of future medical conditions
- **Adequate nutrition** – provision of essential nutrients, ensuring that the baby receives (in the following order of priority: the mother’s breastmilk, human milk, additional nutrients as needed, and special formula)
- **Responsive caregiving** through skin-to-skin contact (kangaroo care), touch, massage and responsive and loving interactions involving the mother, fathers and other primary caregivers
- **Security and safety** by reducing exposure to noxious stimuli, such as pain, excessive noise, light, rough and insensitive handling, as well as ensuring the child’s rights of non-separation from the primary caregiver; and
- **Early learning** by stimulating all senses in accordance with the developmental level of the infant.

To reduce toxic stress for these infants, countries and health facilities are moving from a medical to a **family-centered approach**, based on the principle that the child has a right to be with their family. This approach encourages health professionals to consider, “What are the very exceptional circumstances under which a caregiver(s) and baby should be separated?” instead of “Under what conditions can caregivers stay with their baby in the NICU?”.

Hospital staff that implement “family-centered care” provide an environment that enables the bonding of the mother with her newborn through skin-to-skin contact and early initiation of breastfeeding as soon as medically possible. The approach also highlights the role of the mother, father, and other primary caregiver as members in the team that provides early routine care for the newborn. The European Foundation for the Care of Newborn Infants, which is developing standards in Europe for newborns calls this “**developmentally supportive care.**” NICUs are expected to strive for providing an environment that reduces stress for the baby, family and providers; reduces unnecessary painful procedures (and seeks ways to make painful procedures more tolerable); and provides sensory experiences that meet the developmental needs of the baby.

In a **developmentally supportive care model**, the newborn is at the centre of a healing environment that includes the physical surroundings (for example, the facility or NICU) and the sensory environment (for example, temperature, touch, smell, taste, sound, light, vestibular and proprioceptive inputs). Interactions with health-care providers, parents and family affect the environment and can modify it to promote healthy development and minimize adverse consequences from hospitalization.

The actions associated with this model are vital to promoting healthy growth and well-being. They include the following:

- **Optimize nutrition** – Provide human milk; use cue-based, infant-guided feeding; involve parents in feedings to improve breastfeeding initiation and duration
- **Safeguard sleep** – Cluster care; assess and provide care to coincide with sleep and wake cycles; and minimize noise and light
- **Manage pain and stress** – Minimize noise and light; recognize signs of stress and pause intervention when possible; and use positioning and boundaries to provide containment
- **Position and interact** – Maintain head in midline with limbs and trunk flexed and tucked; handle with slow, gentle movements; and provide support during transfers
- **Protect skin** – Maintain humidity during skin maturation; monitor susceptible skin/mucosal areas for breakdown; and promote skin-to-skin contact.

From WHO (2019). *Survive and thrive: transforming care for every small and sick newborn*, p. 85-86.

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This shift in mentality and behaviour requires significant changes in the health care organisation (e.g. spaces for caregivers when staying around the clock with the baby to wash, sleep, and prepare food) and workforce skills and attitudes (i.e. accepting the caregiver's role and function in participating in the care of their baby, not only during limited visiting hours). These changes will take time to implement, and it is your role as a home visitor to advocate for these changes, as well as to help families to support their babies while in NICU and transition smoothly from the NICU to the home.



#### Video clip

The video clip by Dr. Arti Maria (2017). Family Centred Care at a Glance - Dr. Ram Manohar Lohia Hospital, New Delhi, provides a good summary of the principles of family centred care that has contributed to the development of Indian national guidelines.

<https://www.youtube.com/watch?v=ui7YcfTMd74&t=18s>

NIDCAP: One family's story. (25.06.2014) Prematurely born, medically fragile and in critical need of nurturing care. One family's experience with the life changing support of NIDCAP professionals as they navigate the necessary but often overwhelming early days of their infant's new life and their new life as a family. NIDCAP ensures that the 'voice of the newborn' is heard.

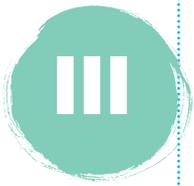
<https://www.youtube.com/watch?v=fBtZDjSs8GM>



#### Reflection and discussion

Where is your country or community in the transition to family-centred and developmentally supportive care? What have you heard from the families you are visiting about their experience in the care of their small or sick newborn? What questions and needs do they bring to you, as the family's trusted home visitor?





## SUPPORTING THE FAMILY WHILE THE BABY IS IN THE NICU OR PEDIATRIC WARD - WHAT HOME VISITORS CAN DO

Should you have contact with a family during the stay of their baby in NICU or Pediatric ward, there are the following primary actions you can take:

- Understand family's emotions and experience.
- Support the mother in providing breastmilk to her baby in the NICU or Pediatric ward.
- Support mothers and other family members to bond with the child and provide nurturing care.
- Help the family with planning so caregivers are better able to cope in their daily lives, including spending time with their newborn in the NICU or Pediatric ward.



### 1. UNDERSTANDING FAMILY'S EMOTIONS AND EXPERIENCE

Having a small or sick baby in NICU is extremely stressful for the parents. In the early stages while a baby is in the NICU, mothers, fathers and families may feel like they lack control over their child's condition and health outcomes. Research has reported high rates of depression and anxiety in parents following the NICU experience<sup>14,15,16,17</sup> in some cases with long-term effects. Parents may go through:

- Feelings of loss, as the anticipated birth of a healthy or term baby did not take place;
- Feelings of anger (why me?), guilt (what did I/we do wrong?), fear (what is happening with my baby?), helplessness (why can't I be with or do something for my baby?), disempowerment of the usual parenting role; confusion (it is not the parent who is in charge of the baby, but professionals: What are these people doing with my baby? What are all these machines doing to my baby?), abandonment (Where are they/we going with all this?);
- Mood swings: in the mother this may also be related to normal hormonal changes, i.e. the "baby blues" or peri-natal depression, and normal post-pregnancy tiredness, but fathers may also be affected;
- Helplessness and lack of efficacy by the inability to hold the baby, comfort the baby and protect him/her from pain and discomfort; and
- Stress that contributes to an inability to manage the daily life inside and outside the NICU, sometimes with the NICU in a distant location.

<sup>14</sup> Spittle A, Treyvaud K. The role of early developmental intervention to influence neurobehavioral outcomes of children born preterm. *Semin Perinatol* 2016. 40; 8: 542-548. <https://www.ncbi.nlm.nih.gov/pubmed/27817913>

<sup>15</sup> Ahlqvist-Björkroth, S., Axelin, A., Korja, R. & Lehtonen, L. (23.1.2019). An educational intervention for NICU staff decreased maternal postpartum depression. *Pediatric Research*. 85, 982-986. <https://www.nature.com/articles/s41390-019-0306-y>

<sup>16</sup> Carson, C, Redshaw, M, Gray, R & Quigley, MA (2015). Risk of psychological distress in parents of preterm children in the first year: evidence from the UK Millennium Cohort Study. *BMJ Open*. 5. <http://dx.doi.org/10.1136/bmjopen-2015-007942>

<sup>17</sup> Ahlqvist-Björkroth, S., Axelin, A., Korja, R. & Lehtonen, L. (23.1.2019). An educational intervention for NICU staff decreased maternal postpartum depression. *Pediatric Research*. 85, 982-986. <https://www.nature.com/articles/s41390-019-0306-y>

## SUPPORTING FAMILIES FOR NURTURING CARE

### THE CARE OF SMALL AND/OR SICK NEWBORNS

The health condition of a small or sick infant can frequently, improve and decline from day to day. Overtime, families may begin to feel overwhelmed by their child's constantly changing condition; and, combined with complications at home, work, finances, etc., many mothers, fathers and families may begin to experience harmful toxic stress.

Mothers often have greater access to the NICU and their babies than fathers, because they can provide their breastmilk. Fathers, on the other hand, can feel left out, anxious and even terrified when they see their tiny baby in the midst of high-tech equipment, but may not be able or willing to express their emotions, because it does not fit the cultural gender expectations. Paternal depression is often expressed as irritability, anger, and inability to find pleasure in anything<sup>18</sup>. Involving fathers is critical for giving the father the opportunity to bond with the baby and support the mother. You will see how active efforts to involve the fathers can shape his experience and feelings towards the baby in several of the video clips in this module. Involving both the mother and the father in discussion and planning and addressing their emotional needs during the time the baby stays in NICU or Paediatric ward is of great importance for the family wellbeing. Try to understand their feelings and needs, and listen to them with empathy.

From reviewing Module **“Parental Wellbeing”** and Module **“Caring and Empowering – Enhancing Communication Skills for Home Visitors”**, you know about the importance of listening with empathy, and you are aware of tools you can use to see if a caregiver is affected by depression (for example the Edinburgh Postnatal Depression Scales, a tool that has also been used with fathers).

*Strengthening parent skills and competence in caring for their small, sick or high-risk infant reduces stress and anxiety, and benefits the newborn's weight gain and neurodevelopmental progress. Parental skills continue to grow after discharge with the support of in-home visits, outpatient services and ongoing education<sup>19</sup>.*

WHO standards for improving the quality of care for small and sick newborns in health facilities<sup>20</sup> highlight the need to provide parents with psychological and emotional support to help them cope with the stressful experience and gradually assume responsibility for their newborn. Family-centred care promotes partnerships with carers and empowers them to become more independent in planning and providing care for their newborn during admission to the health facility and in planning discharge.

In this context, if you are visiting the family while their baby is in the NICU, you can do the following:

- Listen to families, their emotions and experiences with empathy.
- Use your knowledge and skills to respond to family questions and concern and be willing to help the family learn more, as needed.
- Use your skills to
  - support the parents to problem-solve on coping strategies and managing their daily lives,
  - encourage parents to also take care of themselves and each other, so they can be emotionally available to engage in the care of their baby, and
  - help families seek and accept help from their network and link them to relevant community services.

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<sup>18</sup> Carson, C, Redshaw, M, Gray, R & Quigley, MA (2015). Risk of psychological distress in parents of preterm children in the first year: evidence from the UK Millennium Cohort Study. *BMJ Open*. 5. <http://dx.doi.org/10.1136/bmjopen-2015-007942>

<sup>19</sup> WHO (2019). Survive and thrive: transforming care for every small and sick newborn, [https://www.healthynetwork.org/hnn-content/uploads/Survive-and-Thrive\\_interior\\_2019\\_5-24\\_WEB-compressed.pdf](https://www.healthynetwork.org/hnn-content/uploads/Survive-and-Thrive_interior_2019_5-24_WEB-compressed.pdf)

<sup>20</sup> Standards for care for small and sick newborns in health facilities. Geneva: World Health organization. 2020. [IRIS Home \(who.int\)](#)



### Video clip

Here are two videos, from UNICEF Serbia and from Best Beginnings, UK illustrating the importance of both parents in the NICU.

UNICEF Serbia (13.09.2019). The big touch of little heroes. This video illustrates the involvement of mother and father in caring and engaging in skin-to-skin contact with their premature twins. <https://youtu.be/BE4gqI64wMQ>

Best Beginnings (23.9.2014). Small wonders: CH5/5 – Father overcoming fears. Produced for the Best Beginnings 'Small Wonders' project - a DVD for the parents of premature and sick babies across the UK. <https://www.youtube.com/watch?v=080euOVx3e0>

## 2. SUPPORTING BREASTFEEDING

Fulfilling at least half of an infant's daily nutrition with breastmilk has been found to reduce the risk of infections<sup>21</sup>. As indicated in Table 2<sup>22</sup>, the mother's breastmilk, provides any baby, particularly sick and/or small newborns, with ample nutrients, protection against infections, and establishment of a healthy gut biome. This starts with the highly nutritious properties of colostrum, which begins generating as early as 16 weeks of pregnancy. Furthermore, breastmilk expressed following a preterm birth is similar to the mother's amniotic fluid in that it contains growth factors and immune cells that the baby needs to fight infections<sup>23</sup>. To share the multiple benefits of breastfeeding with your families, you can find a summary in Information Card 1.

WHO<sup>24</sup> recommends that low birth weight (LBW) and very low birthweight (VLBW) babies are fed their own mother's milk. If this is not possible, infants should be provided first safe donor breastmilk, then standard infant formula (or preterm infant formula) if safe donor breastmilk is unavailable. LBW infants should be put to the breast as soon as clinically stable, while VLBW infants should receive breastmilk via enteral or gastric route feeding, with supplements as per recommendations of the neonatologist. Cup or spoon feeding is the preferred mode of feeding infants that can be fed orally but are not breastfeeding.

NICUs have gradually begun to allow mothers into the facility making it easier for the mother to express and/or pump her milk whilst close to her newborn. However, due to hospital procedures and/or family constraints, not all mothers are able to stay together with their newborns for part or most of the time after the infant's birth. Therefore, it is important that you support mothers to express their milk also at home and take it to the hospital, as well as help mothers to start breastfeeding after the baby has come home. The techniques to teach a mother to start or restart lactation, using hand expression or a breast pump are the same, whether she is in the hospital or at home. (For more detail about breastfeeding techniques detail see Information Card 1 and Information Card 2). To understand when an infant is developmentally ready to coordinate the various skills to breastfeed, review Table 2 below.

<sup>21</sup> National Association of Neonatal Nurses (2018). Baby Steps to Home. <https://babystepstohome.com/nicu-discharge-module.pdf>

<sup>22</sup> Every Premie Scale. Safe and effective human milk feeding for small and sick newborns. [https://www.everypreemie.org/wp-content/uploads/2019/07/DNH\\_TechBrief\\_HumanMilkFeeding\\_7.9.19Final.pdf](https://www.everypreemie.org/wp-content/uploads/2019/07/DNH_TechBrief_HumanMilkFeeding_7.9.19Final.pdf)

<sup>23</sup> National Association of Neonatal Nurses (2018). Baby Steps to Home. <https://babystepstohome.com/nicu-discharge-module.pdf>

<sup>24</sup> WHO (2011). Guidelines on optimal feeding of low birth-weight infants in low- and middle income countries. [https://www.who.int/maternal\\_child\\_adolescent/documents/9789241548366.pdf?ua=1](https://www.who.int/maternal_child_adolescent/documents/9789241548366.pdf?ua=1)

Additionally, the following two videos will provide you with information about breastfeeding the pre-term baby and how mothers can establish a good milk supply.



**Video clip**

Best Beginnings. Breastfeeding your sick or pre-term baby. Babies may begin with taking milk feeds through a tube into the baby’s mouth or nose before they can suck at the breast. Breast milk is best for many reasons. This video clip follows four mothers and their premature babies. <https://www.bestbeginnings.org.uk/fbtb-sick-or-pre-term>

### 3. SUPPORT MOTHERS AND OTHER FAMILY MEMBERS TO BOND WITH THE CHILD AND PROVIDE NURTURING CARE

**Help parents understand the development of the preterm baby**



**IMPORTANT**

- Overall, development of preterm babies happens in the same order as it would have happened in the womb.
- Babies born earlier in their foetal development are likely to have experienced more health challenges and medical interventions in the NICU (i.e. experienced stress and pain), and they are at greater risk for health and development issues.

Aside from concerns with their baby’s survival and health, it is important for mothers, fathers, and other family members to understand what they can do to support their newborn’s development. To help you respond to these potential parent questions, Table 2<sup>25, 26</sup> provides you with basic information about the baby’s development during these weeks of prematurity. Keep in mind that greater prematurity and/or additional complications (e.g. heart conditions, congenital disorders...) can delay the baby’s developmental progression. Information Card 6 provides information about the key development milestones of the pre-term babies.

**Table 2. Development of the preterm babies**

Development from conception	What fetus/baby can do	What parents can do
13 – 16 weeks	<ul style="list-style-type: none"> <li>• The fetus can swallow and hear</li> </ul>	
17 – 20 weeks	<ul style="list-style-type: none"> <li>• Sucking reflex develops, and fetus may suck the thumb in the womb</li> <li>• Sleeps and wakes regularly</li> </ul>	
21 – 25 weeks	<ul style="list-style-type: none"> <li>• Lungs formed, but not yet able to function outside the uterus</li> </ul>	

<sup>25</sup> FAQ <https://www.acog.org/Patients/FAQs/How-Your-Fetus-Grows-During-Pregnancy>

<sup>26</sup> Premature baby development : 26 -36 weeks. <https://raisingchildren.net.au/newborns/premature-babies/development/premature-baby-26-36-weeks>

**SUPPORTING FAMILIES FOR NURTURING CARE**

THE CARE OF SMALL AND/OR SICK NEWBORNS

<p>26 weeks: baby is about 35 cm in length and weighs about 760 grams, can fit into a large hand</p>	<ul style="list-style-type: none"> <li>• Baby feels most comfortable in curled up position, supported and kept warm</li> <li>• Can sense light changes, opens eyes occasionally, but cannot focus; lights may be stressful and incubator may be covered</li> <li>• Lacks muscle tone, moves with jerks and twitches</li> <li>• Baby may have apnea – pauses between breathing</li> <li>• Is sensitive to sounds and noises, but ears and hearing system not completely formed</li> <li>• <b>Cannot yet breastfeed</b></li> </ul>	<ul style="list-style-type: none"> <li>• The baby’s sleep benefits from “nesting,” i.e. the baby is in a curled up position and has an enclosing surface to touch as in the uterus</li> <li>• Can be held, but skin is very sensitive and fragile</li> <li>• Mother can pump and provide breastmilk</li> </ul>
<p>26-28 weeks</p>	<ul style="list-style-type: none"> <li>• Baby can blink, but cannot focus and follow with eyes, grows eyelashes and eyebrows</li> <li>• Has no clear sleep and wake cycle, but shows brief active and alert periods</li> <li>• Starts responding to sound, and may start showing preference for certain sounds (voice)</li> <li>• <b>Can begin to suck, but cannot yet coordinate sucking, swallowing and breathing</b></li> <li>• Skin still sensitive and fragile</li> </ul>	<ul style="list-style-type: none"> <li>• The baby’s sleep benefits from “nesting,” i.e. the baby is in a curled up position and has an enclosing surface to touch as in the uterus</li> <li>• If medically stable, skin-to-skin contact can be initiated</li> <li>• Talk to the baby</li> <li>• Mother can pump and provide breastmilk.</li> </ul>
<p>28-30 weeks</p>	<ul style="list-style-type: none"> <li>• Muscle tone improves and baby starts to move and stretch</li> <li>• Periods of deep sleep (no movement) and light sleep (moves limbs and eyes), short alert periods</li> <li>• Sensitive to pleasant sounds, may become attentive to the caregiver’s voice</li> <li>• Rooting reflex – turns when touched at the cheek, may start sucking, but cannot yet breastfeed</li> <li>• Skin still sensitive to touch, but likes skin-to-skin contact</li> </ul>	<ul style="list-style-type: none"> <li>• The baby’s sleep benefits from “nesting,” i.e. the baby is in a curled up position and has an enclosing surface to touch as in the uterus</li> <li>• Look at the baby, or talk and sing to the baby, focusing on one action at a time to not overwhelm the baby’s sensory system</li> <li>• Skin-to-skin contact and gentle skin touch</li> <li>• Mother can pump and provide breastmilk and leave a cloth that smells of her breast at her baby’s side.</li> </ul>
<p>30-33 weeks</p>	<ul style="list-style-type: none"> <li>• Unless born with a health condition, born at this stage, the baby may have less needs of medical interventions</li> <li>• Movements become smoother</li> <li>• More alert periods, especially in dim light</li> <li>• May focus on face or other objects, might make eye contact</li> <li>• Responsive to voice and cuddling</li> <li>• <b>May start sucking rhythmically</b></li> <li>• May put hand to mouth to soothe</li> <li>• Still sensitive to touch and handling</li> </ul>	<ul style="list-style-type: none"> <li>• The baby’s sleep benefits from “nesting,” i.e. the baby is in a curled up position and has an enclosing surface to touch as in the uterus</li> <li>• Let baby smell and taste breastmilk, gently touch lips and inside of mouth to have baby get ready for the sensation of breastfeeding</li> <li>• Accompany actions (handling the baby) with talking or singing to the baby</li> <li>• Skin-to-skin contact and gentle touching</li> </ul>

## SUPPORTING FAMILIES FOR NURTURING CARE

### THE CARE OF SMALL AND/OR SICK NEWBORNS

33-36 weeks	<ul style="list-style-type: none"> <li>• Can move smoothly, bend arms and legs and move head to the side</li> <li>• Less likely to experience apnea</li> <li>• Clear states: quiet sleep, active sleep, drowsy, quiet and alert, awake and fussy, or crying, alert periods grow in duration and frequency</li> <li>• Able to interact more socially and to turn away when tired</li> <li>• Still sensitive to touch, but responsive to voice</li> <li>• <b>Can suck, swallow and breathe at the same time, criteria for breastfeeding</b></li> <li>• Begins to cry more with getting closer to term</li> </ul>	<ul style="list-style-type: none"> <li>• Skin-to-skin</li> <li>• Accompany routine care with talking, singing, gentle touching and stroking, gazing</li> <li>• Breastfeeding</li> </ul>
37 – weeks	<ul style="list-style-type: none"> <li>• If there are no health concerns, the baby may be ready to go home</li> </ul>	<ul style="list-style-type: none"> <li>• Breastfeed</li> <li>• Talk, sing and read to baby</li> </ul>



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### Reading a baby’s signs of communication

When born healthy and at term, infants have some capacity to “organize their neuro-behaviors.” This includes regulating their breathing, movement and muscle tone, their gastro-intestinal system, self-soothing or self-regulation, moving between different stages of sleep and alertness in clear transitions, and responsiveness to sound and visual stimuli.<sup>27</sup> Premature or sick newborns are more likely to display weak, and often “disorganized” neuro-behaviors, which tend to be more difficult for parents to recognize or understand. For example, when stressed, the breathing of infants may accelerate, and they may twitch; they might also reduce their eye contact and sustained gaze. When relaxed, their breathing will slow down. Premature infants are more sensitive to noise and touch, but may cry very little.

**Table 3. Signs indicating that premature infants feel overwhelmed or relaxed<sup>28</sup>**

Overwhelmed, uncomfortable, stressed	Relaxed
<ul style="list-style-type: none"> <li>• Wakes up or stays awake and is upset</li> <li>• Changes from being alert to being drowsy or fussy, or starts crying once bigger and stronger</li> <li>• Distressed look on face, a wrinkly forehead</li> <li>• Jittery or jerky movements of arms and legs, covers face with hands, or splay or fist his fingers and toes</li> <li>• Breathes faster, or has a faster heart rate</li> <li>• Changes skin colour to pale, red, mottled or blue</li> <li>• Yawns, sneezes, hiccups, gags or spits up.</li> </ul> <p>If these signs are present, the baby shall be covered and kept still. This should help the baby get back to balance.</p> <p>If the baby is in an incubator, the environment of the baby shall be changed. For example, the noise or the light in the room shall be adjusted or baby’s position changed.</p>	<ul style="list-style-type: none"> <li>• Has regular, relaxed breathing</li> <li>• Has a relaxed body</li> <li>• Moves in a less jerky and more gentle way</li> <li>• Is still and alert and might even want to look at you or something else.</li> </ul> <p>The baby might be very interested in looking at something (often a face), and her body will be quite still and her breathing slow. <b>This is the premature baby’s way of showing that she’s interested.</b></p> <p>As the premature baby gets older, they’ll be able to stay awake and engage for short periods. This is the time to play with the baby by talking, cuddling, singing, or making eye contact. Active play shall be replaced with quiet activities, like gentle holding and slow movements, if the baby shows signs of fatigue or distress.</p>

As the baby gets older, their state of alertness will be clearer, moving from deep sleep, light sleep, drowsy, alert, alert and fussy to crying and their signs may become easier to understand.

### Support for Skin-to-skin contact (Kangaroo Care)

With a few exceptions, such as parents with severe psychological problems, almost all parents are eager to take on KMC and learn very quickly. Even fathers find the experience overwhelming the first time they engage in skin-to-skin with their child. Something happens physiologically and psychologically during this activity. I believe toxic stress is reduced and that something changes in the brain connections.<sup>29</sup>

<sup>27</sup> McManus (2015). Integration of the Newborn Behavioral Observations (NBO) System into Care Settings for High-Risk Newborns. Zero to Three.

<sup>28</sup> Your premature Baby’s body language. <https://raisingchildren.net.au/newborns/premature-babies/connecting-communicating/premature-body-language>

<sup>29</sup> USAID (2019). Nurturing care for small and sick newborns: Evidence review <https://www.everypreemie.org/wp-content/uploads/2019/09/Nurturing-Care-Evidence-Review-and-Case-Studies-13Aug2019.pdf>

“Kangaroo mother care,” is defined as both continuous skin-to-skin contact of the infant with the chest of the mother (or another caregiver when not possible with the mother) and feeding exclusively with breast milk. Because skin-to-skin contact can reduce infant mortality and infection rates, enhance breastfeeding, and contribute to caregiver-infant bonding, it is gradually becoming the standard of feeding in countries globally<sup>30</sup>. In this respect, a study by WHO published in 2021 indicates the need for a global paradigm shift in the care of small babies with zero separation of babies from their mothers by having dedicated *Mother-Newborn Intensive Care Units* (ICUs). The study shows that starting skin-to-skin contact immediately after birth can significantly improve survival rates and health outcomes of small babies. “The best way to nurture the newly born low birthweight baby, including in high-income countries, is through ongoing skin-to-skin contact with the mother, in a mother-newborn couplet care unit that provides care and medical treatment for both,” said Dr Bjorn Westrup, of the Karolinska Institute, Sweden, and a technical expert for the study<sup>31</sup>. At present WHO is revising its recommendations on Kangaroo mother care, published in 2015, in light of the new evidence.

The protective effects of Kangaroo care are long-lasting for child development, the child’s brain volume, and behavioural adjustment and achievement. The length of skin-to-skin contact and father participation in skin-to-skin contact further strengthens these outcomes<sup>32</sup>. Mothers and fathers are generally instructed to be showered, with clean clothes (not exposed to cigarette smoke), and free of perfumes or scented lotions. Skin-to-skin sessions may last for 1-3 hours, with the baby placed by the NICU nurse on the bare chest of the caregiver, with the infant’s head up and covered with a blanket.

The benefits of skin-to-skin contact, just like breastfeeding, have contributed to the increasing acceptance of the role of the mother and more reluctantly other caregivers, i.e. the father, in the NICU, and the move to family-centred, and developmentally-appropriate care. As mentioned earlier, it can also significantly contribute to parental efficacy and bonding with the baby.

As a home visitor you can help families understand the importance of skin-to-skin contact and the implications and the advantages of such care for both the mother and the baby. Provide general information how to practice Kangaroo care: the position, feeding options, care in the NICU and later - at home, how to observe the baby, possible difficulties, etc. and answer any questions or concerns the family may have regarding this practice.

### Encourage families to stimulate child development – touching, massage, love, read, talk and play

From Modules “**Falling in love: promoting parent-child attachment**” and “**The art of parenting: love, talk, play and read**” you have learned how to support parents to bond with their child and promote development through talking, play reading, singing. These include touching, holding, gazing into the baby’s eyes, talking, singing, humming, reading, playing with the baby, and providing basic caregiving functions (e.g. changing diapers) in the NICU or paediatric ward. These interactions reduce stress in infants, stimulate their development and growth, and contribute to bonding and feeling of efficacy and ability in parents. Having this experience in the NICU is particularly critical for fathers who often feel left out and overwhelmed by caring for a small or sick infant.



#### **IMPORTANT**

Aside from breastfeeding, all activities that support the development of the baby can be provided by any of the primary caregivers.

<sup>30</sup> WHO (2019). Survive and thrive: transforming care for every small and sick newborn. <https://apps.who.int/iris/bitstream/handle/10665/326495/9789241515887-eng.pdf?ua=1>

<sup>31</sup> Kangaroo mother care started immediately after birth critical for saving lives, new research shows (who.int)

<sup>32</sup> WHO (2019). Survive and thrive: transforming care for every small and sick newborn. <https://apps.who.int/iris/bitstream/handle/10665/326495/9789241515887-eng.pdf?ua=1>

For preterm babies<sup>33</sup>, gentle holding, touching, and stroking can reduce procedure-related pain (e.g. heel sticks), enhance the immune function and pain tolerance, improve weight gain and child development, and reduce infections, hospital stay, and parental stress. When the infant is stable and enjoying touching and stroking, massage can be applied. NICU staff will show mothers and fathers what is developmentally appropriate for the baby. Information Card 4 provides some general information about the benefits of human touch and how to use it. In Information Card 5 you can also find some information about baby massage.

**However, be aware that premature babies quickly become overstimulated, and caregivers must be attuned to their baby, read the cues and signs during these times and respond appropriately.**

As a home visitor you can encourage and support parents to spend as much time as possible in the NICU with their child. Keep in mind that access to the baby in the NICU may still be limited, and the extent to which mothers and fathers can participate into the routine care of their baby stills varies widely from hospital to hospital and from country to country.



**IMPORTANT**

Remember, the more confidence mothers, fathers, or other caregivers acquire in their parenting role during the days in the hospital, the easier will be transition, when the baby comes home. Therefore, if you have the opportunity, encourage mothers and fathers to:

- Learn from professionals about their baby, ask questions about what the baby likes, how the medical providers know when the baby is hungry, feels well, feels pain...
- Participate in routine caregiving, skin-to-skin, cuddle, feeding, contact, touch, massage, learn about baby signs and signals, such as calming and soothing.
- Communicate with the baby (talk, read, sign to baby) – this helps baby learn, connect, learn about rhythm, sound of voice.

## 4. HELPING FAMILIES TO IDENTIFY SUPPORT

The ability of parents to cope with stressful times depends on many factors including the family's ability to remain resilient, the support they receive from their network, including family, friends and services, and of course— your home visits.

Sit down with the parents to develop a family ecomap (*see Module "The New Role of the Home Visitor"*) together. This will help to identify the strengths in the family and the resources (social networks and services) needed and available while the baby is in the hospital, and after discharge. Consider the following actions with the family:

- Help parents identify the strengths in their social networks and mobilize them to deal with challenges at home (e.g. friends and relatives could provide emotional support, transport, prepare meals, provide baby-sitting and help with daily chores...).
- Support parents to participate in the care of their newborn with breastfeeding, skin-to-skin and other routine and developmental care, when permitted (see the previous sections).
- Help parents to reach out to mental health and/or spiritual support services (i.e. to address depression and post-traumatic stress). Some families might like to meet other families that had an infant in neonatal intensive care.
- Suggest that parents use relevant apps and social media groups to communicate with family and friends in order not to have to provide the same updates over and over. Some parents may like to keep a journal to document their feelings and the baby's progress; and
- Help parents to see how they can set aside some time for sleep, rest and reflection without feeling guilty. How to establish helpful routines, not forego enjoyable activities while the baby is in the NICU and eat and engage in some exercise.

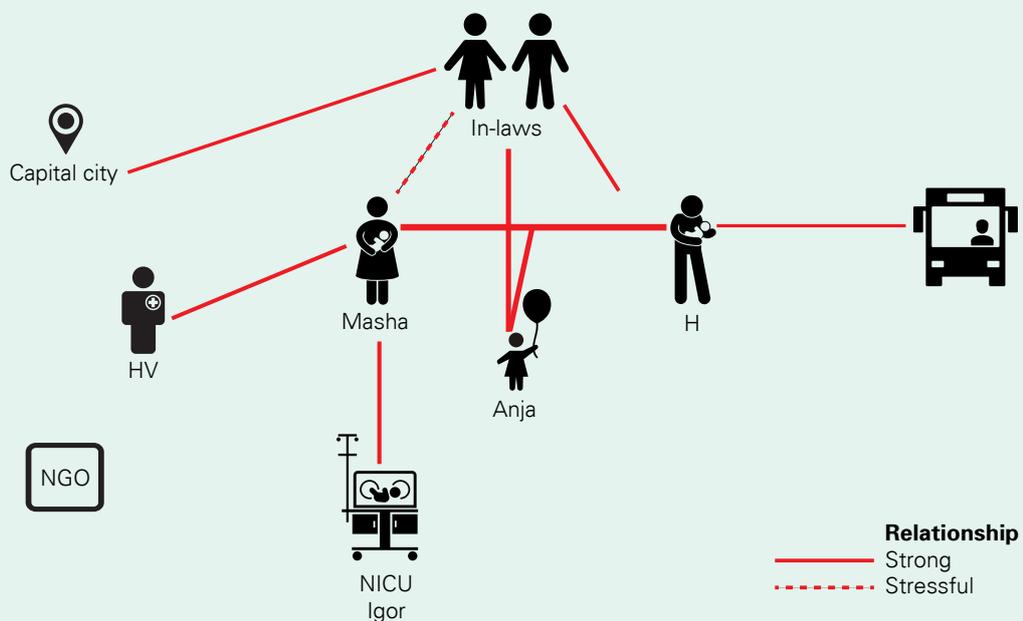
<sup>33</sup> Field, T. (2019). Pediatric Massage Therapy Research: A narrative review. *Children*, 6, 78.



### Reflection and discussion

Look at the attached example and the ecomap for the Masha and her family. On your own or with your colleagues, think of some possible actions and strategies you could explore.

Masha, 22 years, and her husband (H), a bus driver, are living with her in-laws in a small town about 30 minutes away from the capital city. They have a 2-year-old girl, Anja who is the centre of her grandmother's life. Masha's baby boy, Igor, was born 2 months prematurely. Masha was released yesterday. You (HV) received a call this morning from the hospital to visit Masha and her family. Masha is supposed to provide breastmilk for the baby as soon as possible. The hospital's visiting hours are twice a day for mothers, and you have heard that some fathers have also visited their newborns in the hospital's NICU in the recent months. You have also heard of an NGO in the capital that has provided equipment to families that have children with disabilities.



Here are some possible actions you could pursue with the family:

- Discuss the importance of breastmilk with Masha, her husband and mother-in-law and show Masha how to hand-express to get the milk flowing and how to store milk.
- Talk with the hospital or the NGO in the capital city to see if they can procure and loan a breast pump and bottles to store breastmilk for Masha and her baby.
- Help the family identify a way for Masha to get to the hospital once a day to drop off her breastmilk, engage in skin-to-skin contact, and bond with the baby.
- Discuss if the mother-in-law is willing to care for Anja during the time Masha is at the hospital.
- Involve the mother-in-law in ensuring that Masha gets sufficient rest and eats well so she can breastfeed and be emotionally available for her baby.
- Discuss if the husband's work schedule could be adjusted a couple of times a week with his supervisor to visit his baby and provide skin-to-skin contact.
- Discuss how members of the mother and father-in-law's mosque/church can help with transport or other essential tasks.

IV

## PREPARING THE FAMILY FOR THE DISCHARGE

The circumstances of families with respect to the conditions at birth and the home environment differ greatly. Mothers, fathers and families may have been separated from their baby - maybe for weeks or months - due to health system restrictions and access to the NICU, distance from the NICU, or other family circumstances. They may face more challenges with bonding, parenting skills, and confidence, and may be most in need of your support. Once you have an understanding of the family's home environment, you can help them prepare to bring their small or sick infant home after being discharged. The family's ability to adjust is influenced by how much experience they have had caring for their baby and confronting caregiving challenges to-date.



### Reflection and discussion

Review the discharge issues listed in the table below (adapted from the EFCNI<sup>34</sup>) that are important for families to consider. Mark how you feel about these topics and those for which you need more information. Most of these topics are discussed further in Information Card 3.

**Table 4. Discharge issues and questions**

Discharge issues	Confident	Learn more
Infant sleep: Safest sleeping positions; how to reduce risk of Sudden Infant Death Syndrome (SIDS)		
Daily care of their baby: skin care, nappy changes, washing and bathing		
Show parents how to give medication if needed (dosage, side effects, missed doses)		
Help parents in using medical equipment, such as apnoea monitor or oxygen. Understand whether the baby will be dependent on the equipment after discharge.		
Be able to show and advise mother on all aspects of breastfeeding. Start/restart lactation process, breastfeeding positions, frequency, methods to increase breastmilk production. Storing of breastmilk and handling of equipment and containers.		
If the family is bottle feeding, can you advise on preparing the baby's feeds, how to sterilise the bottles? How to feed responsively with the bottle? Feed by cup as a better alternative, if breastfeeding is not an option.		
Normal body temperature of the baby and how to monitor and control it		
Typical developmental milestones of the baby and how to support the baby's development		
Proper hygiene measures at home e.g. proper house cleaning and hand washing techniques		
Advising parents when and whom to contact in an emergency		
The routine follow-up care for these babies with respect to medical issues, growth, and neurodevelopment		
Vaccination for premature and sick babies		

<sup>34</sup> Adapted from EFCNI. Discharge from Hospital and European Standards of Care for Newborn Health

## SUPPORTING FAMILIES FOR NURTURING CARE

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The NICU or paediatric ward may have a standard list of what families should prepare. If not, Information Card 3 will provide you with a list of important issues to discuss with the family before the baby is discharged and a checklist for families. Use this information when you help these families in problem-solving on how to address these practical issues when they bring their baby home and during the first weeks at home.



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## ANNEX

### 1. INFORMATION CARDS



#### INFORMATION CARD 1: SUPPORTING BREASTFEEDING

##### Benefits of breastfeeding

Benefits to baby	Benefits to mother
<ul style="list-style-type: none"><li>• Decreased mortality</li><li>• Reduced neonatal sepsis, pneumonia, diarrheal diseases, meningitis, urinary tract infections, necrotizing enterocolitis, inflammation of intestine, sudden infant death syndrome (SIDS), lower rates of chronic lung disease and retinopathy of prematurity,</li><li>• <b>Preterm birth is similar to the mother's amniotic fluid and contains growth factors and immune cells the baby needs to fight infections</b></li><li>• Improved development of the immune system</li><li>• Cognitive development</li><li>• Later life: diabetes, heart disease, Crohn's disease, ulcerative colitis</li><li>• <b>Opportunity for skin-to-skin contact and bonding</b></li></ul>	<ul style="list-style-type: none"><li>• Reduction in post-partum bleeding</li><li>• Helps control glucose levels after birth</li><li>• Lower risk of breast, ovarian cancer, and type 2 diabetes</li></ul>

##### Supporting breastfeeding

Human milk, particularly the mother's breastmilk, provides the baby with the best nutrition and protection against infections. It is important for the baby to establish a healthy microbiome that contributes to health and development<sup>35</sup> and, therefore, critical for small and/or sick newborns.

The use of breastmilk starts with colostrum which can be expressed as early as 16 weeks of pregnancy, with its high anti-infection components. Furthermore, breastmilk expressed following a preterm birth is similar to the mother's amniotic fluid and contains growth factors and immune cells the baby needs to fight infections and thrive<sup>36</sup>. At the same time, breastfeeding, of course, has significant benefits for the mother.

For many reasons (related to hospital procedures and/or family constraints), many mothers are unable to stay with their newborns for most or some of the time. You should, therefore, be able to show mothers how to hand express or pump and safely store the milk at home until it is taken to the hospital. The techniques to teach a mother to start or restart lactation, using hand expression or a breast pump, are the same, whether the mother is in the hospital with the baby or at home.

<sup>35</sup> Every Preemie Scale. Safe and effective human milk feeding for small and sick newborns. [https://www.everypreemie.org/wp-content/uploads/2019/07/DNH\\_TechBrief\\_HumanMilkFeeding\\_7.9.19Final.pdf](https://www.everypreemie.org/wp-content/uploads/2019/07/DNH_TechBrief_HumanMilkFeeding_7.9.19Final.pdf)

<sup>36</sup> National Association of Neonatal Nurses (2018). Baby Steps to Home. <https://babystepstohome.com/nicu-discharge-module.pdf>



## INFORMATION CARD 2: STARTING/RESTARTING BREASTFEEDING AT HOME – TIPS AND RESOURCES

**Re/starting breastfeeding:** If the mother did not provide her breastmilk, you can help her to re/start breastfeeding. Most women are not aware that breastmilk production can be started manually, when they are ready, and that they can even breastfeed an adopted infant. What is important for re/starting breastfeeding are persistence and a good technique.

Show the mother how to stimulate milk production every 2-3 hours and at least once at night, when milk-producing hormones are the highest (at least eight times per day) manually or with a breast pump. Explain to the mother that the time it takes to produce milk varies greatly among women. Re-lactation can change her breasts, menstrual cycle and hormones, but that milk production is good for her body and the milk and sucking is good for the baby.

- Give tips to help both the mother and baby enjoy the time at the breast. This includes:
  - Use skin-to-skin contact, with or without breastfeeding.
  - Drip milk into the baby's mouth to increase the interest of the baby.
  - Hand-express first to get the milk started for the baby.
  - Provide breastmilk by spoon or cup.
  - See that the baby latches on correctly.

### Tools for breastfeeding:

- Association of Breastfeeding Mothers. Relactation – Restarting breastfeeding after a gap. 2- page pamphlet. <https://abm.me.uk/wp-content/uploads/ABM-relactation-breastfeeding.pdf>
- Best Beginnings. Overcoming challenges. <https://www.bestbeginnings.org.uk/watch-from-bump-to-breastfeeding-online>





## INFORMATION CARD 3: ISSUES TO DISCUSS WITH THE FAMILY BEFORE DISCHARGE<sup>37, 38, 39</sup>

*“It’s normal for caregivers to have confused feelings. There’s a lot to look forward to. But many parents also feel nervous about caring for their premature baby on their own for the first time, without the support of hospital staff. It might help to know that the hospital won’t discharge their premature baby until staff are confident that both parents and baby are ready.*

*This usually means that your baby no longer needs the hospital’s specialist equipment and medical care. For example, this might be when she’s steadily gaining weight and can breastfeed or bottle-feed at all feeds, has no breathing problems and can keep her body temperature steady in an open cot<sup>40</sup>. ”*

The following are important aspects to review and discuss with the family before the baby is discharged.

### Home environment

- The house should be clean, but it is good to not use toxic or harsh cleaning supplies.
- The baby should be protected from exposure to smoke and smoking (even smoke sticking to clothes) as this can affect the functioning of their lungs and increase the rate of respiratory and ear infections, bronchitis, pneumonia and Sudden Infant Death Syndrome (SIDS).
- Pets should be monitored and kept away from the baby’s sleeping area.

### Family and Friends

- The number of outside visitors should be limited. Visitors who are sick or have been exposed to respiratory infections should be asked to visit another time.
- It can help to involve the other children and family members to play a role in getting ready, so not all the attention is on the baby.
- It helps to prepare siblings of the baby, spend special time with them and involve them in the care as feasible.

**Baby’s Health.** Babies released from NICUs have higher re-hospitalization rates for conditions such as dehydration associated with vomiting or diarrhea, respiratory conditions, hernia complications, apnea or shunt repairs<sup>41</sup>.

- Review the discharge instructions provided by the NICU or pediatric hospital team with the family:
  - Will the baby continue to be dependent on the use of certain equipment (e.g. cardiac monitor, oxygen, ventilator)? How comfortable is the family in the use of this equipment? Have they been trained? Are they confident in the use and in handling malfunctions? Who is available at short notice to help?
  - Will the baby take prescriptions at home? How frequently? What dosage? What are the possible side-effects? Are the caregivers comfortable in measuring and administering the medication?
- Have the caregivers been educated about illnesses the baby may be at risk of, i.e. the danger signs requiring an immediate medical care? Does the family know what constitutes an emergency and when and whom to contact? Have they been trained in infant resuscitation? Do they have contact information for ambulance services, their pediatrician, the hospital readily available?

<sup>37</sup> AAP. Bringing baby home: Preparing Yourself, Your Home, and Your Family. [www.healthychildren.org](http://www.healthychildren.org)

<sup>38</sup> Going home with your premature baby. [www.raisingchildren.net.au](http://www.raisingchildren.net.au)

<sup>39</sup> Going home: A parent’s checklist. [www.PremieCare.org](http://www.PremieCare.org)

<sup>40</sup> Going home with your premature baby. [www.raisingchildren.net.au](http://www.raisingchildren.net.au)

<sup>41</sup> AAP. Bringing baby home: Preparing Yourself, Your Home, and Your Family. [www.healthychildren.org](http://www.healthychildren.org)

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- Does the family have follow-up appointments? Vision and hearing screening? Do the parents have a contact number for the NICU staff in case they have a question?
- Are the caregivers aware of the vaccination schedule and upcoming vaccinations? Have they been informed that family members and anybody in touch with the baby on a regular basis should be up-to-date on their vaccines?
- Are the caregivers aware of the back-to-sleep position and important sleeping arrangements for the baby?
- Has the hospital provided them with guidance on restricting visitors to the family and when the baby can be taken out for the first time?

#### Baby Nutrition and care

- Is the baby breastfeeding? If not, is the mother interested to re/initiate breastfeeding?
- Do caregivers know how to feed the baby? How long to feed the baby at any session? How frequently? How to tell when the baby has had enough food? Handle breast pumps, bottles, nipples and other equipment?
- Do parents know how to care for their baby (nappy change, bathing, skin care, and personal hygiene)?

#### Car Seat Safety

- Do caregivers know how to use a car seat when picking up the baby at discharge? When traveling in a car in a rear-facing infant car seat (position with seatbelt on a back seat and fastened with the seatbelt), very small babies need additional supportive padding to keep in position. This is something that caregivers may want to try out with the health care team prior to discharge<sup>42</sup>. In some countries, e.g. the U.S., NICUs may give the infant a "car seat test"<sup>43</sup> placing the infant in the car seat for about 90 minutes and monitor the infant for apnea, bradycardia and oxygen desaturation, as part of the discharge readiness.

#### Discharge check list

The check list will facilitate the discussion with parents on their preparedness for the discharge of the baby.

Discharge Issues	Know about it	Need more information/ instruction
Knowledge of the safest and most comfortable sleeping position? Informed about Sudden Infant Death Syndrome (SIDS) and how to prevent it?		
Knowledge of the daily care of the baby?		
Hands-on experience in nappy changing, skin care, and washing and bathing their baby?		
Instructed in giving medication if needed (dosage, side effects, missed doses)?		
Hands-on experience in the use of medical equipment, such as apnoea monitor or oxygen, if baby will be dependent on the equipment after discharge?		
Have the parents learned how to feed their baby, how much and how often the baby should drink?		

<sup>42</sup> EFCNI. Safe transport – Car Seat Safety. <https://www.efcni.org/health-topics/going-home/safe-transport/>

<sup>43</sup> Verywellfamily. 24.06.2019. 3 NICU Milestones that must be met before discharge. <https://www.verywellfamily.com/nicu-milestones-before-discharge-2748716>

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Discharge Issues	Know about it	Need more information/ instruction
Is the mother comfortable with breastfeeding? Does she know how frequently? Breastfeeding positions? And how much feeding is adequate?		
If the mother expresses her milk, does she know how to express and store the milk? How to sterilise the milk expression sets and the bottles?		
If the parents are bottle feeding, are they instructed in how to prepare the baby's feeds, how to sterilise the bottles. Have they been instructed in feeding responsively with the bottle? Have they been shown how to feed by cup as a better alternative, if breastfeeding is not an option?		
Knowledge of the normal body temperature and how to monitor and control it?		
Knowledge of the typical developmental milestones of the baby and how to stimulate development?		
Knowledge about proper hygiene measures at home e.g. proper house cleaning and hand washing techniques?		
Who to call (phone number) or where to go, when there is an emergency, a general health problem or other difficulties with the baby?		
Have the parents received resuscitation training?		
Information received about follow-up care appointments for medical problems, growth, and neurodevelopment? Has the first follow-up visit been scheduled before discharge?		
Knowledge about the baby's vaccine schedule and next appointment?		
Other issue identified by the NICU team		



## INFORMATION CARD 4: TOUCHING AND HOLDING THE BABY IN THE NICU – TIPS FOR PARENTS<sup>44</sup>



### Key messages

- Touch, holding and massage are great ways to care for your premature baby and bond in the NICU.
- When your premature baby is ready for touch, it's best to keep it simple and quiet.
- Pay attention to your baby's signals so you know when she's had enough touch.

### Touch and premature babies

Touch is the first of a baby's senses to mature.

Touching your premature baby will help him feel cared for and supported. Touch can be the **beginning of your relationship with your premature baby**, and it's a good way to bond with your baby.

Premature babies in the neonatal intensive care unit (NICU) have many people touching them in many different ways. A lot of the time, the touching can be stressful, uncomfortable and upsetting for them – for example, if they're having a heel prick or being ventilated.

But when you touch your baby, you do it to help your baby feel calm, cared for and loved. Your baby will get to know that you're the one who touches her in this special way. She'll learn that when you touch her, she won't be overwhelmed by sudden changes, rough handling or too much stimulation.

### Getting started with touch and holding for your premature baby

If your baby is very small or sick, you might not be able to hold him yet – but you can still touch him. Just like any baby, **your premature baby needs the comfort of human touch**. But touch can also overstimulate and stress a very tiny, fragile premature baby.

**Starting small.** It's a good idea to start with something simple, like holding your premature baby's hand or letting her hold your finger. It's also a good idea to do this on its own and not to talk or sing to your baby at the same time. This is because your baby might find both things together overwhelming. But it can help to **say something before you touch** your baby so she knows something is about to happen and that it should be pleasant.

As your premature baby grows and gets stronger, you'll be able to sing or talk to your baby while you touch or hold him.

**Comfort holding.** You could also try deep touch, or comfort holding. To do this you pretend that your hands are like the walls of the uterus. Place cupped hands on your baby's head, feet, bottom or back and keep them there with constant pressure. Watch your baby's monitors to see how she's coping with this new stimulation.

Your baby might be happy with comfort holding at some times and on some days, but not others. Watch to see whether your baby likes one kind of touch better than others.

**Being careful.** It's a good idea to avoid stroking, patting or using your fingertips across your premature baby's skin. After a while, this can be slightly painful for new preemies. As your baby gets older and his skin isn't so sensitive, he might enjoy patting, stroking and massage.

<sup>44</sup> From <https://raisingchildren.net.au/newborns/premature-babies/connecting-communicating/touch-massage-in-the-nicu>

Just relax with your baby. Feel her breathing. **Your rewards for sensitive touching and holding will come later** – with a close, loving and physically relaxed relationship with your baby.

Try not to use perfume or scented deodorant when you're holding your baby. These can interfere with his recognition of your smell.

### **Skin-to-Skin or Kangaroo care for premature babies**

Kangaroo care is simply **holding your premature baby in an upright position, skin to skin, on your chest.**

Your baby's nurse will place your baby on your chest and cover her with a warm blanket. Then you can sit back, relax, listen to your baby breathing and feel her relax into you. It's as if you're making a **protective mini-pouch** for her.

Your baby's nurse will help you work out how long to give your baby kangaroo care. To start with, it might just be a few minutes, building up to several hours as your baby grows.

Quiet humming or singing during kangaroo care is a great combination if your baby can cope with multiple forms of stimulation.

You'll need to **check with your baby's nurse or doctor before doing kangaroo care.** Some very tiny or ill premature babies can't have kangaroo care if they need lots of monitors and other equipment. Kangaroo care also won't do as much good if your baby is stressed.

Most hospitals encourage kangaroo care. But in some hospitals the staff might not suggest it, so you might need to ask your baby's nurse. It's a good idea to work with your baby's nurse to have kangaroo care as part of your baby's care plan.

Kangaroo care can help you become sensitive to and understand your premature baby's signals. This is **all part of bonding with your baby.** It can also help you adapt to the premature birth experience.

Kangaroo care can help premature babies control body temperature, improve blood oxygen levels, keep heartbeat and breathing stable, sleep better, get started with breastfeeding, improve weight gain and motor development, cry less and go home sooner. It also has long-term physical and behavioural benefits.

Kangaroo care can also be done by the father or other adult caregiver, and you can continue to do it at home, for example, when you baby seems to be cool or cold to get back to a normal temperature or when you would like some quiet time with your baby.



#### **Video clip**

The following clip demonstrate skin-to-skin contact: Best Beginnings. (2.12.2010). Daddy Kangaroo care.

This short film is an early clip from footage shot for the Best Beginnings 'Small Wonders' project - a DVD for the parents of premature and sick babies across the UK. It features a father holding two of his three pre-term triplets in skin-to-skin contact. Research shows that through skin-to-skin, touch and voice, expressing and giving breast milk, parents can play a vital and beneficial role in their babies' care. We are following the stories of ten families in neonatal units that are centres of excellence across the UK. The resulting DVD will be given free to the parents of premature and sick babies throughout the country.

<https://www.youtube.com/watch?v=cgnXDKcMRIQ>



## INFORMATION CARD 5: INFANT MASSAGE – TIPS FOR PARENTS<sup>45</sup>

Baby massage has the following benefits (International Association of Infant Massage):

For your baby

- Helping your baby to feel securely attached
- Helping your baby to feel more loved, valued and respected
- Reduced crying and emotional distress
- Increased levels of relaxation and longer sleep
- Development of body awareness and coordination
- Relief from wind, colic, constipation and teething discomfort
- For the parent
- Feeling closer to your baby
- Gaining a deeper understanding of your baby's behaviour, crying and body language
- Providing an enjoyable opportunity to spend one-to-one time with your baby
- Feeling the relaxing effects of giving your baby a massage
- Increased confidence in your ability to care for and nurture your baby
- Learning a life-long parenting skill.

Massage is good for premature babies. **Premature babies put on more weight when they're massaged**, which means they can leave hospital earlier. Massage might also help your premature baby's brain develop, promote his sleep, boost his immune system and circulation, help his tummy and bowels work better, and satisfy his need for touch and closeness. It can also help you to learn more about your premature baby's behaviours and responses. Some NICUs may have a physiotherapist who can teach you about massage. You'll need to speak to your baby's nurse or doctor before massaging your baby. Massage won't do as much good if your baby is stressed or not well enough.

### Tips for massaging your baby

- Keep your baby warm by using towels or an overhead heater. Make sure your hands are warm too.
- Move your hands slowly so your baby gets to know the difference between your massage and other kinds of touch.
- Use firm strokes or circles. Light touch can be ticklish and annoying. It's easier to use your whole hand for firm touch.
- Massage different parts of your baby's body in the same order every time – for example, head, arms, legs, back, bottom, chest and tummy.
- Watch your baby's reactions to your touch. If she's enjoying it, she might lie still, stretch slowly and hold her hands near her face or mouth. If your baby makes a face, arches her body and makes lots of jerky movements, it might mean she doesn't like this touch right now.
- If your baby isn't enjoying the massage, pause, keep your hands on him and rock him gently. Then try massaging again, pacing yourself in response to your baby's signals.
- Have fun. Baby massage can be relaxing and enjoyable for you too.

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<sup>45</sup> Adapted from Raising Children Australia International Association of Baby Massage. <https://www.iam.net/benefits/>



### Video clip

Videos demonstrating baby massage:

Infant Massage Techniques. Isis Parenting. (2011)  
<https://www.youtube.com/watch?v=mbCv6BBTV5c>

Baby 101: How To Massage Your Infant. February 1, 2016.  
<https://www.youtube.com/watch?v=rrASOAFRf-s>

Raising Children Australia – The Australian Parenting Website. How to do baby massage.  
<https://raisingchildren.net.au/newborns/videos/how-to-do-baby-massage>



## Baby massage



PARENTING  
IN PICTURES

Suitable for

0-18

months

### Getting started with baby massage



Massage can be soothing for babies. Make sure the room is warm, your baby is quiet, well-rested and alert, and you're relaxed. Try massage after a nap, when your baby is being changed or in the cot, or after a bath. You can do massage for 10-30 minutes.



Smooth a few drops of baby massage oil or sorbolene cream into your warm hands and massage the soles of baby's feet. Use firm, gentle, slow strokes from heel to toe. Always keep one hand on baby. If you see signs of [allergic reaction](#) to the oil, wipe it off and see your GP.

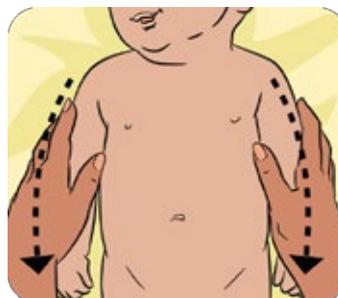


Do long smooth strokes up baby's leg. Massage from ankle up to thigh and over hip. Massage both legs at once or one at a time. Avoid the genital area. Hold baby's leg under the knee and gently press it towards the tummy to help release wind.

### Upper body massaging for babies



Start upper body massage with your hands on baby's shoulders. Make gentle strokes in towards the chest.



Massage baby's arms by stroking from shoulders down towards wrists. Try not to get oil on baby's hands. If you do, wipe her fingers clean before she sucks them.



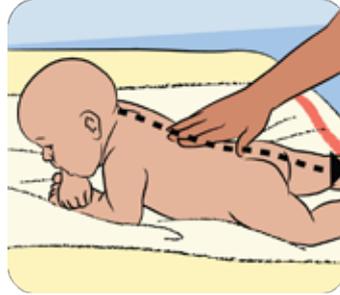
If baby's tummy feels soft, massage it with circular, clockwise strokes. If she gets unsettled, go on to the next step. Avoid the belly button area if baby's cord hasn't healed. Don't put pressure on the area between baby's nipples and tummy.

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**Face and back massage for babies**



Use your finger pads to massage baby's face. Stroke from the middle of baby's forehead, down the outside of his face and in towards his cheeks. Massage the scalp in small circles.



If baby is still relaxed when you've finished massaging the front of his body, you can turn him onto his tummy and use long, smooth strokes from head to toe.



Use a soothing touch. Stop the massage if your baby seems uncomfortable. Avoid massage if you're very tense, or if your baby is upset. Make sure your fingernails are short.

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## INFORMATION CARD 6: PREEMIE MILESTONES IN DEVELOPMENT

Adapted from:

<https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/Preemie-Milestones.aspx>

*Note: The information below shows how young children typically develop. It is important to use the child's adjusted age when tracking his development. So, if the baby is 21 weeks old, but was born 5 weeks early, his adjusted age is 16 weeks (or 4 months). This means one should refer to the milestones listed under "at 4 months (16 weeks)" to see what the child should be doing at this age.*

Weeks	8	12	16
Motor	<ul style="list-style-type: none"> <li>Moves hands and legs actively</li> <li>Keeps hands open most of the time</li> <li>Lifts head and chest when lying on tummy</li> <li>Controls head a little, but may still need support</li> <li>Holds objects in hands</li> </ul>	<ul style="list-style-type: none"> <li>Brings hands together, or to mouth</li> <li>Lifts head and pushes on arms when on tummy</li> <li>Reaches for objects</li> <li>Turns or makes crawling movement when on tummy</li> </ul>	<ul style="list-style-type: none"> <li>Puts weight on feet when held standing up</li> <li>Sits by himself</li> <li>Bangs and shakes objects</li> <li>Transfers objects from one hand to another</li> <li>Holds 2 objects at a time, one in each hand</li> <li>Rolls over from tummy to back</li> </ul>
Language	<ul style="list-style-type: none"> <li>Responds to sounds (for example, turns when hears voices and rattles)</li> <li>Makes cooing noises like "aaaah" and "oooh"</li> <li>Cries when needs something</li> </ul>	<ul style="list-style-type: none"> <li>Turns head to follow familiar voices</li> <li>Laughs and squeals</li> <li>Combines sounds more often (for example, "aaah-oooh", "gaaa-goo")</li> </ul>	<ul style="list-style-type: none"> <li>Responds to her name, turns and looks</li> <li>Babbles, making sounds like "da", "ga", "ba", "ka"</li> </ul>
Activities	<ul style="list-style-type: none"> <li>Fixes eyes on a person or object (a mobile, for example) and follows its movement</li> <li>Has different cries for different needs</li> </ul>	<ul style="list-style-type: none"> <li>Grasps more and reaches for objects</li> <li>Brings objects to mouth</li> <li>Increases activity when sees a toy</li> </ul>	<ul style="list-style-type: none"> <li>Pays attention to what toys can do (make music and light up, for example)</li> <li>Looks towards object that drops out of sight</li> </ul>
Social/emotional	<ul style="list-style-type: none"> <li>Makes eye contact and smiles;</li> <li>Recognizes and enjoys interactions with mother or primary caregiver.</li> </ul>	<ul style="list-style-type: none"> <li>Is increasingly interactive and comfortable with parents and caregivers</li> <li>Shows interest in mirrors, smiles and is playful</li> <li>Is able to comfort himself</li> </ul>	<ul style="list-style-type: none"> <li>Is becoming more aware of surroundings</li> <li>Notices if parents are present (or not)</li> <li>Reacts differently to strangers</li> <li>Expresses excitement, happiness and unhappiness</li> </ul>



## INFORMATION CARD 7: COMMON HEALTH CONDITIONS OF PRETERM AND SICK NEWBORNS

**Respiratory Distress Syndrome (RDS).** A breathing disorder related to the baby's immature lungs. The lungs of preterm babies often lack surfactant, a liquid substance that allows the lungs to remain expanded. Artificial surfactants can be used to treat these babies, along with breathing tubes and a ventilator to help them breathe better and maintain adequate oxygen levels in their blood. Sometimes, extremely preterm babies may need long term oxygen treatment and occasionally may go home on supportive oxygen therapy.

**Chronic Lung Disease/Bronchopulmonary Dysplasia (BPD).** A term used when babies require oxygen for several weeks or months. They tend to outgrow this condition, which varies in severity, as their lungs grow and mature.

**Apnea and Bradycardia.** A temporary pause (more than fifteen seconds) in breathing that is common in preterm infants. It is often associated with a decline in the heart rate, called bradycardia. A drop in oxygen saturation is called desaturation. Most infants outgrow the condition by the time they leave the hospital for home.

**Retinopathy of Prematurity (ROP).** An eye disease in which the retina is not fully developed. Most cases resolve without treatment, although serious cases may need treatment, including laser surgery in the most severe instances.

**Jaundice.** It happens when a chemical called bilirubin builds up in the baby's blood. As a result, the skin may develop a yellowish color. Treating it involves placing the undressed baby under special lights (while the eyes are covered to protect them).

**Anemia of prematurity.** A low red blood cell count

**Congenital heart defects.** Can affect the shape of the baby's heart and/or the way it works. Patent ductus arteriosus (PDA) is the most common heart problem in premature babies where blood circulates abnormally between two of the major arteries near the heart, due to the failure of a blood vessel (the ductus arteriosus) between these arteries to close properly. In some cases, medications are sufficient to close the passageway, and if not, surgery is needed<sup>46</sup>.

**Necrotizing Enterocolitis (NEC).** This potentially dangerous intestinal problem most commonly affects premature babies. The bowel may become damaged when its blood supply is decreased. Bacteria that are normally present in the bowel invade the damaged area, causing more damage. Babies with NEC develop feeding problems, abdominal swelling and other complications. If tests show that a baby has NEC, he will be fed intravenously while his bowel heals. Sometimes damaged sections of intestine must be surgically removed.

**Cerebral palsy.** Caused by damage to areas of the brain controlling movement and muscle tone, children may have difficulties with motor control, in speech production, and sometimes cognitive development. Premature infants and infants with severe jaundice are at greater risk. Early intervention helps the child and family to deal with the specific challenges.

**Pneumonia.** This lung infection is common in premature and other sick newborns, treated with antibiotics and oxygen.

**Sepsis.** Infection of the bloodstream. Tested for when the baby has symptoms such as temperature instability, high or low blood sugar levels, breathing problems or low blood pressure. Treated with antibiotics.

Adapted from AAP. Healthy children. <https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/Health-Issues-of-Premature-Babies.aspx>.

March of Dimes. (August 2014). Common conditions treated in the NICU.

<https://www.marchofdimes.org/complications/common-conditions-treated-in-the-nicu.aspx>

<sup>46</sup> National Association of Neonatal Nurses (2018). Baby steps to home.



## INFORMATION CARD 8: HELPING FAMILIES DEAL WITH HEART CONDITIONS

### About Congenital Heart Defects

**Congenital Heart Disease (CHD)** is the most common type of birth defect affecting 8 out of every 1,000 newborns.

Each year, about 35,000 babies in the United States are diagnosed with CHD. Nearly 25% of those are **critical congenital heart defects**—ones that require surgery or other interventions within the first year of life to survive. Parents of these children often sit by their child's side in the hospital hoping and praying their child survives.

As a result of dramatic advances in the medical and surgical management of CHD, 85% of infants with CHD are now expected to survive to adulthood, and CHD is regarded as a chronic disease rather than a terminal one. However, survival rates for children with critical congenital heart defects is lower; they often need specialized medical care throughout their lifetime.

### Understanding Unique Parenting Challenges

All parents are caregivers, but parents of children with CHD have extra challenges.

#### Learning “normal” and more specialized parenting skills:

Aside from the typical stresses and adjustments new parents face, in most cases, parents who have a baby with CHD are also struggling to care for a baby who may have spent months in the Neonatal Intensive Care Unit (NICU) and may have tubes or attachments to his or her tiny body.

When babies have open-heart surgeries, their ability to learn to eat can be compromised. Some babies have to be fed through a feeding tube. In addition to feeding issues, many children with CHD have trouble gaining weight and must go on special high-calorie diets.

#### Becoming an expert and advocate.

Knowledge is power. Parents often immerse themselves into learning as much as they possibly can about their child's diagnosis, medication, and treatment plan. It is important to avoid “internet overload” by sticking to reputable websites. *See the additional resources at the end of this article.*

#### Making changes to safeguard their child's health:

Infants and children with CHD have weaker immune systems than the average child. They can end up in the hospital for illnesses that others recover from on their own. Thus, many parents take extra precautions to try to keep their child healthy. This may mean having serious talks with friends and family about getting their annual flu shot and a Tdap shot to prevent whooping cough. *See the additional resources at the end of this article.*

## 2. KEY REFERENCES AND SOURCES OF INFORMATION

### Useful websites

The focus here is on materials that can be used by home visitors and with parents. Technical guidance documents can be found in the reference section.

1. American Academy of Pediatrics. <https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/default.aspx> A wealth of information about premature infants, their care in the NICU, as well as discharge and follow-on care.
2. Raising Children Australia. <https://raisingchildren.net.au/newborns/premature-babies> Excellent parenting advice, including video materials.
3. BLISS for babies born premature or sick. Parent information. <https://www.bliss.org.uk/parents/about-your-baby/common-infectious-illnesses/what-do-i-need-to-know>
4. Verywellfamilies – Preemies. <https://www.verywellfamily.com/preemies-4157380> . Extensive and easy to understand information about the NICU experience, discharge and home care.
5. Support NICU Parents. Developed by **50 thought leaders and stakeholders**— physicians (both neonatology and obstetrics), nurses, nurse practitioners, nurse midwives, developmental care specialists, psychologists, social workers, public health experts, parent support group leaders and parents—to **develop interdisciplinary guidelines for psychosocial support services for parents whose infants are hospitalized in neonatal intensive care units (NICUs)**. Has NICU staff and parent information. <http://support4nicuparents.org>
6. National Association of Neonatal Nurses (2018). Baby steps to Home. <https://babystepstohome.com/nicu-discharge-module.pdf> . Clearly written and easy to understand materials about care in the NICU experience.
7. Newborn Individualized Developmental Care and Assessment Program (NIDCAP). A neonatal intensive care approach that focuses on family-centered developmentally appropriate care to the small and/or sick newborn with many resources for caregivers and professionals. <https://nidcap.org/en/families/what-is-nidcap/>
8. Cerebral Palsy Alliance. <https://cerebralpalsy.org.au>
9. Australian Breastfeeding Association (March 2017). Breastfeeding babies with clefts of lip and/or palate. <https://www.breastfeeding.asn.au/bfinfo/cleftpalate>
10. Tommy’s. Has information about miscarriage, stillbirth and premature birth, and provides pregnancy health information to parents. <https://www.tommys.org/pregnancy-information/pregnancy-complications/premature-birth/your-babys-time-hospital/your-premature-baby-vision-and-hearing>
11. Lasby, K. & Sherrow, T. (2019). Premie Care – A guide to navigating the first year with your premature baby. Excellent textbook written by two neonatal nurses with useful information and a website that contains three presentations and additional information.

### Additional Videos

<https://www.youtube.com/watch?v=ieUJmCFnvvQ>

Best beginnings series. Born to soon - Part 1: parenting documentary

Born Too Soon follows the stories of pre-term babies and the experiences of their parents and their extended families. The birth of a child is one of life’s most joyous moments, but for those whose babies are born prematurely, the trauma of unexpected and early birth can be devastating – with months of uncertainty to follow. <https://www.youtube.com/watch?v=gxM-MAyY0Pw>