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INTERNATIONAL
STEP by STEP
ASSOCIATION

SUPPORTING FAMILIES FOR **NURTURING CARE**

21

THE CARE OF SMALL AND/OR SICK NEWBORNS

PART 2 SUPPORTING FAMILIES TO CARE FOR SMALL OR SICK BABIES AT HOME

DRAFT

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CONTENTS

KEY MESSAGES - why is this topic important for you?

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.
- Therefore, families with small and/or sick infants should be prioritized for the progressive and individualised, needs-based home visiting services. They should receive all the support they need as early as possible to help their babies thrive.
- Empathy, good listening, problems solving skills, a good understanding of the challenges these babies and their caregivers are facing, and services available in the community are the most effective tools in supporting these families. For infants at very high risk (very premature or with very serious medical conditions), services may not be easily available in the community and this will require efforts in helping families identify the most appropriate service and get access to them.
- In addition, many babies discharged from NICUs with less severe health challenges (e.g. shorter NICU stays, longer gestational age, fewer apparent health issues) may be missed for additional support that could help them catch up more with their peers and thrive.
- Home visitors need always to keep the infant in mind, and the wellbeing of the parents and their ability to cope with this situation, will be one of the primary concerns.
- During the visits, the families will be looking for answers to their questions and concerns and guidance in what they can do. With their trusted home visitor, they may feel more open to discuss their questions, worries, and doubts than when visiting a busy clinic. Supporting them in finding evidence-based answers and practical and feasible approaches will be very important to the short and long-term outcomes for the baby and family.
- The key role of the home visitors is to provide families with advice and guidance in dealing with routine daily baby care and ways to support and stimulate the development of their baby.

LEARNING OUTCOMES

Part 2 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 after discharge from NICU or Pediatric ward.
- Advise families with practical approaches in the routine care of their baby, including common health concerns, health danger signs, and infant feeding and development.
- Provide guidance to caregiver for improving their wellbeing and strengthen the bond with their infant to enhance child's wellbeing and development.
- Support families in making better use of their networks, services and other resources and help families to access them.

SELF-ASSESMENT

1. What are some of the feeding challenges parents of small and/or sick babies may experience at home. (Mark all that apply)

a. Babies may not enjoy eating because it has not been associated with a pleasurable experience.
b. When mothers did not have free access to their babies or help in pumping breastmilk, their breastmilk may have dried up.
c. Babies may be excessively fussy or excessively sleepy.
d. Coordinating sucking, swallowing and breathing over a period of time is hard work for some premature babies.
e. Once babies are released from NICUs, their feeding behaviours are usually well established.

2. After discharge home, a baby born pre-term or with medical conditions should: (Mark all that apply)

a. Be protected from smoke or contaminated environment.
b. Can be taken out shopping and to crowded places, because they are now stable.
c. Be protected from individuals with respiratory and other infections.
d. Be in close contact primarily with family members and others that have completed their immunization schedule.
e. Should be held by the mother in the car because these babies are too small for car seats.

3. What areas should you address to help caregivers address their own wellbeing? (Mark all that apply):
   a. Exercise, relaxation, and adequate sleep particularly for the mother.
   b. Mental health and wellbeing.
   c. Participation in their church or mosque if they belong to a faith group.
   d. The caregiver network of relatives and friends.
   e. Good nutrition.
   f. Their awareness and access to relevant services.

4. Premature babies should be immunized later than term babies, because their immune systems are not ready to handle vaccines. (True/False)

5. What are some important messages to give to caregivers of small and/or sick babies? (Mark all that apply)
   a. Make sure the baby is fed every two hours, day and night.
   b. Have the baby sleep on the back on a firm surface and without soft bedding and plush toys.
   c. Bathe the baby every day to make sure s/he is clean.
   d. If the baby has cold feet and seems to be cold, remove any wet clothing, put on a hat, and put the baby skin-to-skin to warm if possible, and monitor his/her temperature.
   e. Watch for the cues and signs that your baby makes showing s/he wants to interact or play with you. By being responsive to these signs, you help your baby develop and catch up.

Answers

1. All answers are correct, except for e. Infant feeding at home is one of the most common challenges after the baby has been released from the NICU. More severe problems, if not addressed, can lead to re-hospitalisation. In addition, the baby's feeding experience may affect his relationship with food and maintaining a healthy weight across the lifespan.

2. Correct answers are a., c., and d. Taking these babies to crowded places can expose them to dust, smoke and infectious diseases. Car seats should also be used for these babies for their own safety, but caregivers need to make sure that the baby is well-positioned and breathing is not affected.

3. All of these areas can contribute to caregiver wellbeing.
4. False. Premature infants have a functioning immune system that can handle the vaccines. However, they are highly vulnerable to vaccine-preventable diseases. It is even recommended to ensure that all those in contact with these infants are up-to-date on their vaccines in order not to transmit such diseases.
5. The correct answers are b., d. and e. Babies should be feed as much as possible on demand every 2-3 hours and at least one feeding at night. Babies also do not need to be bathed daily, though it is important to keep the nappy area clean to reduce the likelihood of rashes.

GLOSSARY AND DEFINITIONS[1]

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[2].

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.

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[1] Adapted from: WHO (2019). 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.everypreemie.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

[2] 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.

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 ski 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

As discussed in Part 1 of this module, according to WHO, the Lancet, and the European Foundation for the Care of Newborn Infants[3, 4, 5, 6]. In 2014, 14.8 million babies were born prematurely (before 37 weeks of gestation) across the world and 5-6% of these babies were born before 28 weeks of gestation. The rates of preterm births varied widely across regions and countries, ranging from 5-18% globally. In Europe, the rates ranged from 6.3-13.3 % of live births. As a result of being born prematurely, infants are at-risk of long-term neurodevelopmental impairments, stunting and non-communicable conditions.

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. However, it should be noted that they are a highly diverse group with respect to the cause and severity of their conditions. During the first days and weeks after birth, many of these infants are separated from their mother, 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 these neonates are managed by specialists in the neonatal care unit, and sometimes by rehabilitation specialists and pediatricians upon discharge. However, 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 after being discharged.

Part 1 of the module provided you with some general information how you can support the family when the baby is placed in NICU. Part 2 discusses the support you can provide to the family for taking care for the sick or pre-term babies once at home.

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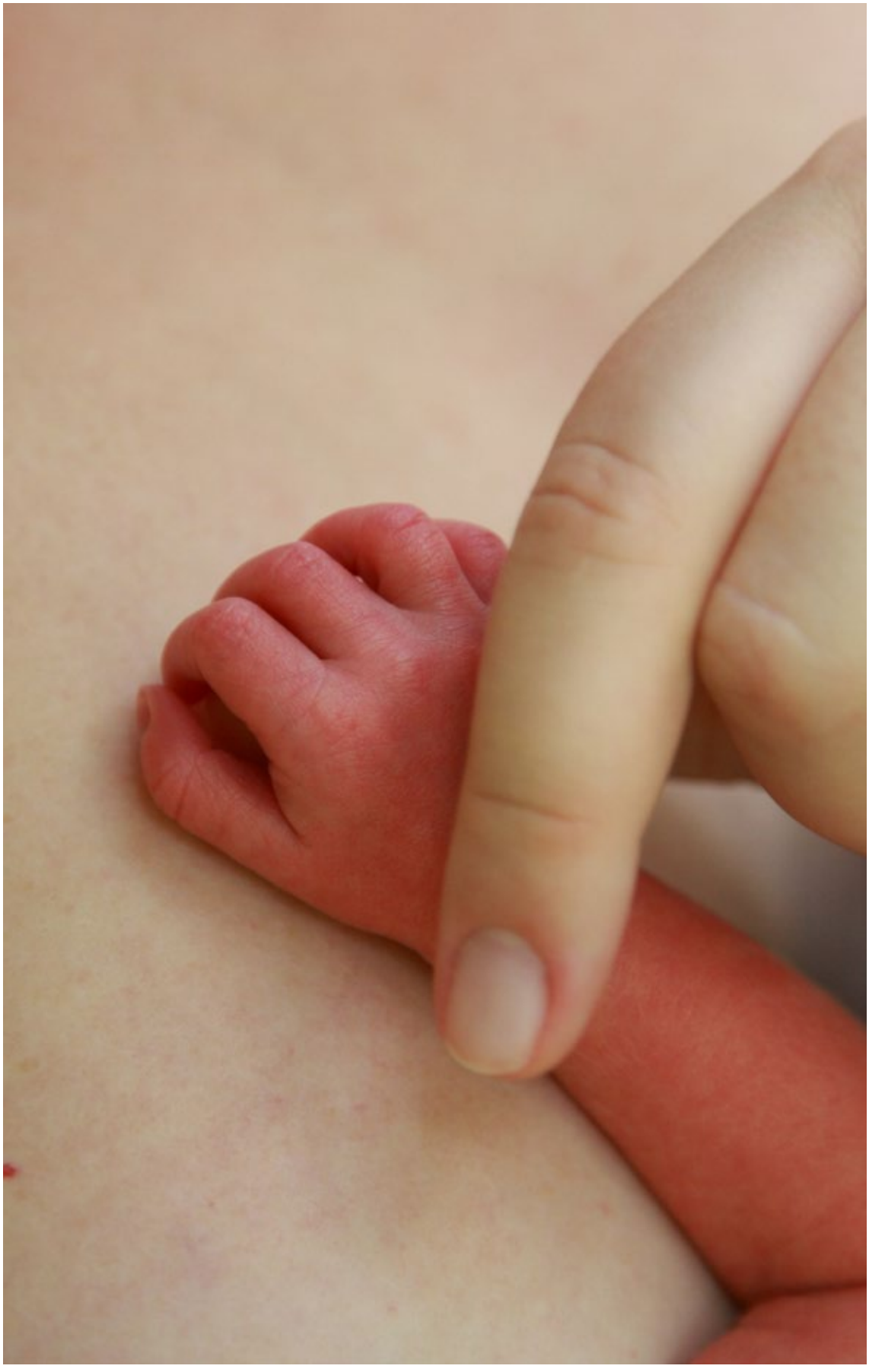
[3] The Lancet (2019). A new framework for managing extremely preterm births. 394, 1592. Chawanpaiboon S, Vogel JP, Moller A-B et al. (2018). Global, regional, and national estimates of levels of preterm birth in 2014: a systematic review and modelling analysis. Lancet Glob Health. (published online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

[4] 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

[5] The European Foundation for the Care of Newborn Infants, Definition and Epidemiology, 2019

[6] Lawn JE, Blencowe, H. et al (2014). Every newborn: progress, priorities, and potential beyond survival. The Lancet, 384, 189-205.



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II SUPPORTING THE INFANT AND FAMILY AT HOME

Reflection and discussion

The baby is finally home and settling in. You are making the first home visit to the mother, baby, and the family. Reflect on what some of the priorities for you to cover during this visit will be. Make a list, and afterwards, use the sections below to adjust your priorities and add items you may not have considered.

1. SUPPORTING CAREGIVER ADJUSTMENT AND WELLBEING

Having a newborn in neonatal intensive care disrupts the natural processes whereby parents of a healthy term baby can grow into their parenting role, gain caregiving competencies over time, and strengthen their relationship with the child (parental bonding and child attachment).[7] Mothers of premature infants are more likely than mothers of term babies to suffer from post-partum depression or anxiety, even into the second year after the delivery and longer, and fathers are also affected. One recent report from the U.S. stated that almost half of the parents experienced depression, anxiety, and stress when their baby was leaving the NICU[8]. There are also cases where caregivers may be coping in the structured NICU setting but seem to "fall apart" once they are on their own at home with their baby.

The Module "Parental Wellbeing" explains in details how parental mood (e.g. depression, anxiety) can affect the developing brain architecture of any young child. When an infant is already fragile due to prematurity, the combination of illness at birth, exposure to stressful experiences in the NICU, and depressed and anxious caregivers can magnify the long-term detrimental impact on the child's social-emotional wellbeing and development.

Caregiver responses vary greatly from individual to individual and family to family. While the baby has survived and is considered stable enough to go home, the challenges caregivers may experience can intensify. Mothers and fathers may still be grieving; struggle with emotional, financial and time demands, exhaustion, the diverse needs of other members of the family; and experience feelings of insecurity, uncertainty, and lack of competence and agency. Also, the baby's cues for attention and care may be weaker, less consistent, and less responsive to the maternal interaction. This can decrease parents' feelings of efficacy and make parenting more challenging and less rewarding.

This is why it is important for you to understand the mother and father's psycho-emotional status when you visit. You will need to determine if you can support caregivers on your own or if colleagues with more specialized training need to be involved. From reviewing Module the **"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 the 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).

Figure 1 shows key areas that contribute to the caregiver's wellbeing[9]. Keep in mind that caregivers can draw strengths from any of these areas but may benefit from your help to figure out how to access resources or

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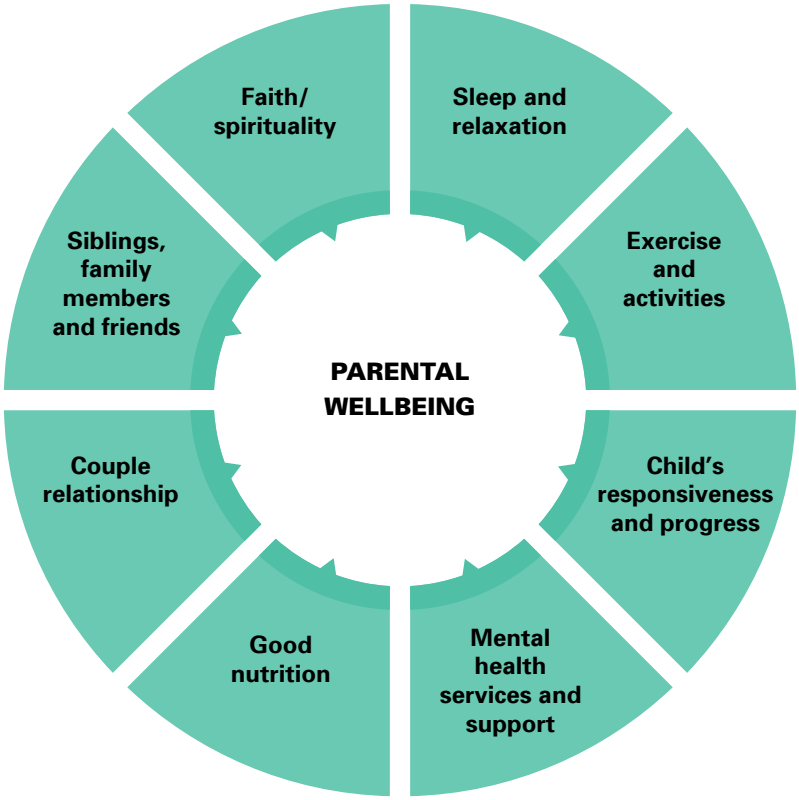
[7] Boykova, M (2016) Transition from hospital to home in parents of preterm infants. The Journal of Perinatal & Neonatal Nursing. 30 (4).

[8] Lamia Soghier M.D.; Katherine I. Kritikos, M.P.H.; Cara L. Carty, Ph.D.; Lisa K. Tuchman, M.D., M.P.H.; Randi Streisand, Ph.D.; and Karen R. Fratantoni, M.D., M.P.H.Children's National Health System. 45 percent of parents experience depression, anxiety and stress when newborns leave NICU. https://www.eurekalert.org/pub_releases/2017-09/cnhs-4po091417.php

[9] Some factors like family income, parent education, employment, etc. are also important determinants, but are not included because you will not be able to affect them.

find time to engage. Sometimes, parents may feel conflicted about being away from their baby to attend to themselves and ensure their own wellbeing. You can discuss with mothers and families how to adjust expectations of how family activities should be managed and how to engage their networks to gain support during these demanding days and months.

Figure 1. Key areas that can be leveraged to strengthen caregiver wellbeing



Good nutrition. A balanced diet is very important, particularly if the mother is breastfeeding. Advise the mother to have smaller, but more frequent meals and plenty of liquids, emphasizing locally available and affordable nutritious foods. You can also explore whether the family's network, relatives and friends, can provide support, e.g. helping with meal preparation.

Relationships. Be attuned to how having a small and/or sick newborn affects a couple's relationship. One effective way to increase the father's support is to engage him with his baby, to discuss his important role for the wellbeing of the mother and the baby, and to explore concrete activities he can take on to reduce stress on the family unit. Sometimes caregivers are worried that their baby is too small and fragile, making them apprehensive to handle the baby. But skin-to-skin contact and involvement in routine caregiving and play can make parents feel more comfortable and forge a stronger bond with their baby.

Siblings, family members and friends. Look at the role of additional secondary caregivers, such as grandparents, older siblings, and close friends and see how they can work together for the benefit of the new baby.

Faith and spirituality. Caregivers may receive practical and spiritual support from their church, mosque, or religious community, helping them to build hope and trust in the future.

Sleep and relaxation. Encourage the mother to take a nap when the baby is sleeping, listen to music, or engage in other restful activities. Maybe another caregiver or friend can take care of the baby for a while. Encourage the family to value sleep by creating family bedtime routines and schedules.

Exercise and fun activities. You may have seen in **Module "Healthy weight, physical activity, sleep, and sedentary time"** that the amount of time dedicated to exercise, particularly among fathers, reduces significantly after the birth of their baby. We can expect the impact of a baby born small and or/sick to be more considerable. Yet, we also know from research that being physically active and exercising can improve mood and reduce depression and anxiety.

Explore with the parents how they can be more physically active. You can even present this as a medical/health intervention to enhance parental wellbeing. It can include taking the baby for a walk in a baby carrier, meeting up with other caregivers, or finding a way to exercise at home (e.g. watching a YouTube video with suggested exercises), while somebody else cares for the baby. Also, showing caregivers how to use breathing and relaxation exercises and engaging in enjoyable, fun activities with their family can release the hormones (endorphins) that trigger feelings of happiness and positivity.

Child's responsiveness and progress. As discussed above, the signs and cues of premature babies can be weak and difficult to interpret. You can sensitize caregivers to these signs and help them to respond in a consistent, responsive and nurturing way. When caregivers start to see how the baby develops in response to their actions, in can enhance their feelings of efficacy and confidence in their parenting role.

Mental health services/support. If you decide that the needs of the mother or father for mental health support goes beyond your skills or ability, you will want to discuss this with the parent and make a referral for them to talk with a mental health professional. It is important that you keep the baby in mind when you help families make this decision. Information Card 3 provides information about the WHO Program "Thinking Healthy" aiming to aimed to reduce perinatal depression in low socioeconomic settings that can be integrated in the practice of home visitors.

2. SUPPORTING BONDING AND ATTACHMENT

Reflection and discussion

Read the case below. What are your questions and concerns in this case? What would you have done? What actions would you take?

Aigul was discharged from the NICU 2 weeks ago after her premature birth at 32 weeks. Home visitor Elena is making her second home visit with the family. While talking with, Nina, Aigul's mother, she notices that the baby is clean and sleeping in her cradle. When she begins to whimper, Nina picks her up and puts her to the breast. Aigul suckles for a few minutes on one breast and falls asleep again. Nina then proceeds to put a clean nappy on the baby. Elena weighs Aigul and notices that she has gained only a few grams since her first home visit. Nina then carefully places Aigul into her bed and tells her home visitor that Aigul is a quiet baby and sleeps well. When Elena asks her how she knows when Aiguls is hungry, Nina tells her that Aigul usually whimpers. When Elena asks Nina how Aigul has changed since her last visit, Nina is not quite sure what to say.

During your home visits, it is critical for the baby's development and wellbeing that you support the parents in bonding with their child. Attuned, predictable, and responsive caregiving helps babies to regulate their behaviour and supports sleep, wellbeing, and development, and enhances the caregiver's feelings of efficacy in their parenting role.

To support caregiver bonding, make sure you have set aside sufficient time during your home visit to observe how the caregiver(s) talks about, interacts with, cares for, and plays with the baby. Unless your observations are telling you that the caregivers are coping well and have sufficient support, these families should receive additional visits as part of the progressive home visiting component. Keep the following steps in mind during each visit:

Step 1. Observe the interactions of the primary caregiver with the baby. Observe how the caregiver responds to the baby's movements and cues. Are they aware of and responsive to the baby's signs and cues? Do they seem to be handling the baby comfortably and with affection? Whenever you see baby cues or signs the caregiver seems to have missed, point them out:

- *See, how he just gazed at you? He must really like how you are cooing and talking to him.*
- *Look how she just opened her mouth widely for you. She is telling you that she is ready to be fed your breastmilk.*
- *See how she is turning her head away from you? She is telling you that she enjoyed playing with you, but now she needs a break.*
- *When he is fussy, he is telling you that he is not comfortable with himself. See what happened when you put him skin-to-skin? He calmed down and feels cosy and protected by you.*

Use every opportunity to observe how the baby is handled by other caregivers, particularly the father and grandparents, and provide positive feedback and coaching.

Step 2. Ask the caregiver how they get the baby to respond to them (e.g. get the baby to turn to the caregiver, smile, gaze, interact playfully, calm down)? As the caregiver shows you what they do, you can make some additional suggestions of how to maintain a "serve-return dialogue[10]" with the baby. Identify positive actions or points to praise the caregiver and explain how important these activities are in supporting the baby's wellbeing and development.

Step 3. Discuss the baby's development with the caregiver, help them identify opportunities during the daily routines to interact with the baby in a way that is responsive, affectionate, and supports the baby's development. Propose some activities and actions to try out and mention that you will discuss them with the caregiver during the next visit.

The following are examples of signs that the caregiver is bonding with the baby:

- The caregiver handles the baby carefully, responsively, and affectionately.
- The baby looks well cared for (and clean).
- The caregiver finds positive things to mention to you about the baby, even when the baby is often challenging.
- The caregiver makes eye contact, gazes at the baby, smiles, talks, and communicates with the baby.
- The caregiver shares some of the progress the baby has made with you since the last visit.
- The caregiver gently coaches the baby, (i.e., when the baby makes a sound, moves, the caregiver tries to get the baby to do it again and tries to maintain the" serve-and-return" interaction).

Signs of stress and red flags you might notice:

- The caregiver does not make any positive comments about the baby.
- The caregiver has unrealistic expectations (how long or how much the baby should sleep or feed for).
- The baby is handled abruptly or roughly.
- The caregiver is not responsive to the baby's calls for attention or hunger.
- The baby looks neglected, has an unusually wet and dirty diaper.

[10] Serve and return" is a phrase coined by researchers to describe back-and-forth interactions between adults and children, using the analogy of tennis (or any net sport). The baby or the caregiver "serves" by offering up a sound, glance, word, or gesture, and the other "returns" it. For example, the baby smiles and the mother smiles back. These interactions are particularly important for the development of the child's brain.

The following topics will be discussed below, and you will find additional materials and links in the Information Cards in the Annex with practical suggestions and tips:

- reading the infant's communications or signs
- skin-to-skin contact
- infant massage
- responsive feeding
- interactions and play that stimulate child's development.

HELPING PARENTS READ INFANT SIGNS

As mentioned in Part 1 of this module, when born healthy and at-term, infants generally have the capacity to, "organize their neuro-behaviours," that is their breathing, movement and muscle tone, gastro-intestinal system, and their self-soothing or self-regulation ability. Healthy infants tend to go through clear transitions between different stages of sleep and alertness and their responsiveness to sounds and visual stimuli.[11]

Babies born pre-term are more likely to display weak and often less organized neuro-behaviours. For example, preterm babies may spend more time in active sleep, moving, squirming, and twitching. These behaviours tend to be more difficult for parents to interpret, which, in turn, makes it harder for parents to meet the needs of their baby. As a result, parents may feel less confident in their parenting skills.

However, as highlighted in Part 1 premature babies quickly become overstimulated or overwhelmed, and caregivers must read the cues and signs during these times and respond appropriately. Your role as a home visitor is to help and guide parents to understand the signs of their babies and establish responsive interaction.

Table 2. Using baby cues and body language to understand the baby's needs[12]

Infant state	Cues or signs
Tired	• Staring into the distance • Jerky movements • Yawning • Fussing • Sucking finger • Losing interest in people or toys
Hungry	• Getting restless • Moves lips • Makes sucking noises • Turns towards the breast
Ready to play	• Eyes wide and bright • Eye contact with caregiver • Smiles • Smooth movements • Hands reach out to caregiver
Needs a break	• Turns head away from caregiver • Squirms or kicks

[11] McManus (2015). Integration of the Newborn Behavioral Observations (NBO) System into Care Settings for High-Risk Newborns. Zero to Three.

[12] https://raisingchildren.net.au/newborns/connecting-communicating/communicating/baby-cues#about-baby-cues-and-body-language-nav-title

Caregivers of small and/or sick babies experience depression and anxiety symptoms that remain high, even as their child enters their school years[13]. Depression and anxiety can make the caregiver less attuned, and thus less responsive, to the baby's communications and needs. However, research shows that interventions that help caregivers become more attuned to the baby and engaged in shared activities can serve to counteract depression and low mood in the caregiver. The WHO training package for community health workers, "Thinking Healthy" provides concrete suggestions on helping mothers to improve their moods and engage with their infants (see Information Card 3 for a summary and link to the training materials).

PROMOTING SKIN-TO-SKIN CONTACT

As already discussed in Part 1 of the module skin-to-skin contact (also called kangaroo care) with the baby is an evidence-based and well-established intervention for small and stable babies in NICUs, which also brings benefits after the discharge. It was concluded in the USAID et al. implementation guide that "keeping the baby skin-to-skin is beneficial for adequate growth and survival of the baby after discharge. As such, this practice should not be stopped prematurely."[14] There are benefits to term and pre-term babies with respect to improved infant health and wellbeing, as well as parental mental health and bonding with the baby. Skin-to-skin contact allows fathers and other family members to experience the special closeness with the infant. The box below summarizes the benefits of skin-to-skin contact.

Skin-to-skin contact with your baby

Benefits of the skin-to-skin contact after the birth:

- Enhanced bonding which leads to contented infants who are less likely to cry.
- Easier to establish and maintain breastfeeding. Infants who spend time with the mother in skin-to-skin contact just after birth are more likely to breastfeed and to do so for longer. The mother is more able to know when the infant is ready to feed.
- Maintaining the newborn's body temperature and preventing chilling.
- Maintaining and stabilizing the newborn infant's heart rate, respiratory rate, and blood pressure and helps to prevent a drop in blood sugar.
- Prevention of allergic responses by allowing the infant's skin to be colonized with bacteria native to their mother.

Delivering skin-to-skin contact:

- Skin-to-skin contact should ideally last for at least an hour after delivery and should be repeated as often as possible during the baby's first few weeks of life.
- Unless the infant is unwell, skin-to-skin contact should be practiced often, as it reduces stress and promotes bonding between the caregiver(s) and their baby.
- The mother and the baby should be left to manage this natural process without being helped or rushed, unless support is requested, or the baby needs additional care.
- Some new mothers may be affected by medication or may be tired, so it is very important that they are supported with sensitivity.
- Touch and scent enable caregivers to feel closer to their baby. This promotes bonding and enables a sense of parental wellbeing.

[13] McManus (2015). Integration of the Newborn Behavioral Observations (NBO) System into Care Settings for High-Risk Newborns. Zero to Three.

[14] Kangaroo Mother Care: Implementation Guide. USAID and Save the Children. Kangaroo Care (USAID, Save) https://www.mchip.net/sites/default/files/mchipfiles/MCHIP%20KMC%20Guide.pdf

- Babies who learn to latch on to the breast easily are more effective feeders. This means that they are more satisfied and there is less damage to the nipple, so breastfeeding will continue for longer.
- If initial skin-to-skin contact isn't possible for whatever reason, do not despair. Skin-to-skin contact can be established effectively later, and this will confer great emotional and physical benefits to you and your baby[15].

The American Academy of Paediatrics also recommends "**baby-wearing**"[16], that is carrying the baby around in a front pouch, as the caregiver is engaged in daily tasks or walking, as soon as babies have the muscle strength to keep their heads up and their airways open in this position. Popular in many cultures, it can reduce crying and fussiness, enhance development, and support bonding with the baby.

INFANT MASSAGE

Infant massage is practiced in many countries and has become popular in higher income countries over the past years especially. For infants born at term, massage has been found to reduce bilirubin levels, irritability, sleep disturbances, and parental stress. Infant massage before bedtime also improved the quality of sleep for both the infant and mother. Regular massages reduced hypertonicity and muscle tone, respectively[17], in children with cerebral palsy and Down syndrome. Infant massage has also been used in the NICU with stable babies and can be used by the caregiver when the baby comes home.

IMPORTANT

It is important to point out that **small and/or sick babies can become easily overstimulated by touch**. Therefore, caregivers need to observe the baby's cues in response to touching and massage. Foremost, the massage should be pleasant and relaxing to the baby. If the baby becomes restless or starts squirming, it may be better to just hold them skin-to-skin.

Information Card 4 provides brief instructions on infant massage and the link to a video clip.

3. INFANT FEEDING AND BREASTFEEDING

Reflection and discussion

What are some common feeding issues (including breastfeeding) you have observed with infants born healthy and at-term during the first 1-2 months after discharge from the maternity? Make a quick list. What about children born preterm and/or with medical conditions? What differences have you noted, if any?

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[15] Adapted from Institute of Health Visiting (8.3.2016). Skin to skin contact with your baby. https://ihv.org.uk/wp-content/uploads/2016/03/PT_Skin-to-Skin_AW-V2.pdf

[16] https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/Baby-Wearing.aspx

[17] Field, T. (2019). Pediatric Massage Therapy Research: A narrative review. Children, 6, 78.

For small and sick newborns, "feeding is the most essential skill for both parents and newborns to learn before discharge. It is observed that if the parents have learned to feed in an individualized manner, they will have developed the other caregiving skills they need for the newborn to thrive".[18]

However, feeding is mentioned as one of the most frequent challenges with small and/or babies and can become a "battleground" when the baby comes home. For small and/or sick babies, feeding is hard work, requiring them to coordinate sucking, swallowing, and breathing for the extended time required to get a good feed. Babies may still be premature at discharge, with continuing medical issues, while they are learning to coordinate the complex mechanics of breastfeeding or drinking from a bottle. Some babies may not be able to provide their caregiver with clear signs that they are hungry, full, or too tired to feed or associate the mouth with negative experiences, because they had painful interventions (i.e. intubations) at the NICU. Sometimes, infants who had been feeding adequately in the NICU, develop feeding problems at home because the feeding context is now vastly different to what they were used to. These issues can lead to "forced" feeding, as parents become concerned about the lack of weight gain, while babies are learning that feeding is not a pleasurable activity, contributing to life-long issues with food, including overweight[19].

This section of the module and the accompanying Information Cards 2 and 5 will focus on some of the most common challenges home visitors encounter when visiting these families:

- How to help mothers to re/start/ and sustain breastfeeding successfully at home.
- Promote baby-led feeding and feeding on demand.
- Explain how mothers can tell that they are producing enough breastmilk.
- Common feeding problems and tips to address them.

Much of the information and tips provided here are relevant to support the feeding of all infants. Additional information can be found also in **Module "Responsive Feeding"** as well as in links and references in the Annex.

RE/STARTING BREASTFEEDING[20]

Make sure that mothers know that it may take several days to make the milk flow and days to weeks to produce an adequate supply of milk and that patience and persistence are essential.

Tips for mothers to start/restart breastfeeding:

- Show mothers how to hand express or use a breast pump (refer to the two videos below).
- Express for 10-15 minutes on each breast, swapping sides every few minutes.
- Express about 8 times in a 24-hour period, with at least once during the middle of the night when the levels of milk-producing hormones are highest.
- If the baby still has difficulty breastfeeding, have him/her nuzzle/suckle at the breast before feeding to stimulate the breast.
- If the baby is sucking and feeding, the mother can express between, and especially after each feeding to increase her milk supply.
- Encourage mothers to give other feeds by cups so that the baby uses the sucking reflex at the breast and not at the bottle.

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[18] USAID, 2019 - Nurturing Care for Small and Sick Newborns: Evidence Review and Country Case Studies, p. 53.

[19] Cardoso Andrade, A, Tavares Machado, MM, Kenner, C & Lindsay, AC. (2015). Prematurity, Overweight and Obesity: A Problem That Merits Increased Recognition by Healthcare Practitioners and Researchers. ScienceDirect, Volume 15, Issue 4, December 2015, Pages 174-176.

[20] Association of Breastfeeding Mothers: Relactation. https://abm.me.uk/breastfeeding-information/relactation/

Video clip

Find below two practical video clips that you can use to teach mothers to hand express their breastmilk:

Jane Morton. (2006). Hand expression of breastmilk. Hand Expressing Milk | Newborn Nursery | Stanford Medicine

Jane Morton. 2006. Maximizing milk production with hands-on-pumping. Maximizing Milk Production | Newborn Nursery | Stanford Medicine

Getting the baby to breastfeed:

- Have the baby skin-to-skin as much as possible, semi-inclined, with the baby's head close to the nipple.
- Put the baby to the breast as often as possible. Sucking will stimulate the production of milk.
- Soften the breast, hand express to start the milk flowing, put some milk on the nipple or trickle it into the baby's mouth to give the baby a taste and motivate sucking.
- Bring the baby to the breast, not the breast to the baby to facilitate a good latching on position. Wait till baby opens mouth wide with tongue down to latch on deeply to the nipple (take a big mouth full of the nipple).
- Don't wait until the baby is desperately hungry and crying. When the baby is upset, s/he may not be able to focus on coordinating sucking, swallowing and breathing.
- If feeding by cup or bottle, try to feed as closely as possible to the breast. Using cup feeding instead of bottle feeding has been associated with greater success in re-establishing breastfeeding.

Make sure mothers know to use the "hindmilk" that comes at the end of emptying the breast, because it is the creamiest and richest part of the breastmilk and high in fat content. It comes after about 10-15 minutes of sucking at the breast, helps the baby to feel full and satisfied, and is essential for the baby's growth:

- Have mothers use hand compression to empty each breast after a feed and make sure to use the hindmilk in the next feeding, if the baby did not completely empty both breasts.
- When using a pump, continue to pump after the breast seems to have emptied. Pumping regularly and frequently until the breasts have really been emptied, increases the fat content and amount of breastmilk produced.
- If feeding breastmilk by bottle, the milk should be body temperature and the mother should shake the bottle to make sure the fat does not stick to the bottle wall.

BABY-LED/ FEEDING ON DEMAND

For the most part, feeding should be "baby-led", that is by "baby demand". This means caregivers need to observe their infant carefully, even though signs of hunger and satiety can be much weaker in a small or sick baby. Advise the caregiver to look and see if the baby is stirring after sleeping, maybe licking their lips. More obvious cues include moving restlessly, rooting (moving the head toward the breast), sucking on a finger or fist, and not calming when held and cuddled.

If during the first few weeks at home, the baby is frequently refusing a feed after three hours of sleep, it is better to try and wake the baby gently. Also, it is very important to not let the baby skip the night feeds which have the milk richest in fat. Skipping the night feeding/s will also reduce the quantity of milk the mother produces.

Feeding length should be between 15-30 minutes, not rushed, but carefully paced because the baby is working hard to coordinate all components of their feeding behaviours. While babies born at-term may just stop sucking, relax their face, and fall asleep when they are full, satiety may not be so obvious for small babies.

IMPORTANT

For all babies, but especially for those with reflux (spitting up their feeds), recommend to the caregiver to change diapers **in the middle** of a feed and to burp the baby gently.

The video below, developed for low- and middle-income countries, where small babies are dependent on community care, explains the technique of cup feeding clearly and with all the necessary detail you need to teach caregivers to use a cup for feeding.

Video clip

Global Health Media. (13.01.2017). Cup Feeding Your Small Baby. As a new mother, you may find your small, preterm baby is able to swallow but not yet able to feed well enough from your breast. Try feeding her by cup. This video shows you how to use a small cup to feed your baby safely. https://www.youtube.com/watch?v=-6AU6y6qatc

For bottle feeding, it is recommended to watch the flow of liquid and keep the bottle horizontal and not vertical, feed with pauses to give the baby time to swallow. It is also important to watch for the baby's cues for feeling full. Overfeeding and overriding the infant's natural cues of satiety can increase reflux and contribute to weight problems later.

KNOWING THAT THE BABY IS DRINKING ENOUGH MILK

It is difficult for caregivers to know how much milk is sufficient for the baby, particularly when the mother is breastfeeding. Explain to mothers that a baby's stomach around term (9 months) is small and can only take about 30 ml of milk. It may help to show breastfeeding mothers the actual quantity and assure them that if they feed 7-8 times per day PLUS at least once during the night, their breasts will produce more milk as the infant's stomach grows and the strength and length of his/her sucking increases. Some tips for monitoring the milk intake are given below:

Signs the child has had enough breastmilk:

- 6-8 wet nappies in 24 hours;
- several loose bowel movements per day;
- the breasts feel full before feeding and empty after feeding;
- the baby is feeding 8 or more times in 24 hours, with at least one feed during the night;
- 140-210 grams of weight gain per week and positive growth on the baby's growth chart.

If you and/or the mother has doubts, the mother can keep a record of the number of feeds, length, amount (for bottle-feeding), number of wet and dirty diapers. If there is a sudden drop in the number of wet diapers over a day or two, the baby may be getting ill and should be assessed by their doctor.

The videos below provide you with detail about how to support mothers in establishing and increasing their milk supply.

Video clip

Global Health Media. (30.01.2017). Making Enough Milk: shows how to establish and maintain a good supply of milk for the small baby's growing needs and why expressing early and often is important. Making Enough Milk - Video - Global Health Media Project

Global Health Media. (20.05.2015). Not enough milk. Shows how health workers can help mothers increase their breastmilk supply. https://www.youtube.com/watch?v=e6DRf5TqqRU

To support the production of breastmilk:

- Tell the mother to drink liquids throughout the day, at least one glass of water with each feed.
- Advise her to take a warm shower or use a warm cloth to soften her milk ducts before putting the baby to the breast.
- Have the mother express some milk from the breast to have the baby get a taste when latching on.
- Have the baby latch on with their mouth wide open and tongue down to take a big part of the underside of the nipple.
- Show the mother different feeding positions to see if the baby and mother have a preference.
- Show the mother how to use hand compression during breastfeeding. This moves the rich hindmilk from the periphery toward the baby.

Pumping breastmilk:

- Pump after the baby has breastfeed or suckled at the nipple.
- Pump after a warm shower or use a warm cloth to open the milk ducts.
- Massage the breast while pumping, or in between pumping, massaging areas that feel hard and full to release the milk.
- Combine pumping with hand expression.

When bottle feeding:

- Have mothers use the same nipple as in the NICU during the first weeks after discharge. Narrow slow flow nipples are better during the first months because the milk is flowing more slowly, giving the baby an opportunity to coordinate sucking, swallowing, and breathing without choking.
- If more than one person is feeding the baby, the baby should be fed in the same way each time so the baby can learn to expect consistency during feedings.
- Unless they have other difficulties (e.g. reflux, cleft palate), it is easiest for babies to feed in a side-lying position on a pillow. The head and body should be aligned, and the head should be slightly higher that the lower body[21]. This position is also called the cross-cradle position (look at Information Card 2 for supportive positions to hold the baby in).
- Do not move the nipple or jiggle the bottle while the baby is feeding— the baby needs to be able to concentrate. Also, do not try to wake up the baby by moving the nipple in the mouth. Gently move the baby to the nipple instead.

[21] Lasby & Sharrow (2019). Preemie Care.

COMMON FEEDING CHALLENGES AND HOW TO ADDRESS THEM

With some exceptions (i.e., when an infant has a cleft lip or palate, cerebral palsy, medical problem), small and/or sick babies have similar feeding problems as term babies, and the approaches and tips provided here can be useful for any parent. Feeding challenges may be more prevalent or drastic in small and/or sick babies, and they may have more difficulty in adjusting to different feeding environments or taking the lead during feedings. Below are some tips you can share with caregivers to confront feeding challenges:

General tips:

- Experiment with the setting: lighting (dim vs. bright) and level of noise (quiet vs. noisy, music, ongoing activities).
- Unless the baby is very sleepy, feed based on hunger cues.
- Limit feeding time to no more than 30 minutes and feed baby every 2-3 hours.
- Feeding should be baby-led as much as possible, with baby feeding on demand and pacing the feeding (how much and at what rate).
- Soften the breast while breastfeeding to move the hindmilk from the periphery to the nipple.
- Provide at least one feed during the night.
- If bottle feeding, use same nipple as NICU in the beginning, give baby control over the flow.
- Start feeding when the baby is calm and alert. When a baby is stressed (crying, arched back, agitated breathing, pinched and scrunched up face), soothe the baby before trying to start to feed the baby.

Responses to specific feeding problems are addressed in the table below.

Table 3. Addressing Feeding Difficulties[22]

Common feeding difficulties	Approaches and tips
Babies born before 37 weeks of gestation	
• Difficulty latching to the nipple of the breast or gagging when taking the bottle • Difficulty sucking (i.e., weak suck); coordinating sucking, swallowing, and breathing; and difficulty swallowing (coughing, choking or gasping) • Frequent vomiting and spitting up • Falling asleep during feedings • Easily overwhelmed by changes in the environment • Sensitive around mouth or face due to past medical procedures • Fussy and irritable • Poor weight gain and growth	• Provide more frequent and shorter paced feedings, provide baby with time to rest and breathe, wake baby for feeding at night • Use same bottle nipple as in NICU • Hold baby in almost upright position, but hold bottle in neutral/horizontal position, not pointing down, to allow for baby-controlled flow • Do not force the baby to eat; feed in a quiet place with limited stimulation, stroke and stimulate lips to encourage sucking, calm baby before every feed
Sleepy, hard to wake baby (Down syndrome, heart conditions, born prematurely, exposed to substances…), and babies falling asleep during feeding with weak hunger cues	
• Weight loss and poor appetite • May not eat much at one time (reduced intake) • Difficulty coordinating sucking, swallowing, and breathing • Chokes easily • Tires quickly and hard to wake or keep awake • Easily overwhelmed and falls asleep while feeding • Irritable and fussy • Poor growth and slow weight gain	• Turn on the light, make noise, wake up the baby gently; if swaddled, uncover baby; touch, stroke, and talk to the baby • Walk around, putting the baby in an upright position • Change the diaper • Make sure the baby is awake; do not offer the breast or bottle to wake the baby • Feed more frequently, every 2-3 hours, but not exceeding 30 minutes per feed • Feed baby in semi-upright position • See if bright or dim lighting works better • If bottle feeding, ensure that nipple is soft, but that milk flow is not too fast for the baby to handle
Fussy baby, while feeding or not feeding, medical issues, cardiac problems, exposed to substances, with vision or hearing problems, neurodevelopmental delays	
• Babies are fussy overall, while feeding and while not feeding, and are difficult to soothe • Restless and may refuse feed • Poor appetite, growth, and weight gain	• Feed regularly, every 2-3 hours, before the baby gets upset • Don't force breastfeeding or the bottle while the baby is upset (crying, arching back, wrinkled face…), but try to soothe the baby first • Provide skin-to-skin and carry in pouch, using gentle rhythmic and soothing movements • Keep arms free from swaddling, so baby can self-soothe • Try feed in dim light and quiet setting

[22] Adapted from Holt International (2019). Holt International's Feeding and Positioning Manual: Guidelines for working with babies and children.

Baby who frequently spits up, i.e. with gastroesophageal reflux (GER) – food vomited up from the stomach	
• Uncontrollable vomiting and spitting up, after each meal and even between feedings • Fussiness and irritability during feeding, but refusing breast or bottle even when hungry	• Offer smaller feeds more frequently • Pace meals • With bottles, use a slow flow nipple • Feed baby in upright position or 30-45 degree angle, not lying down • Keep baby upright for 15-45 minutes after feeding • Use pacifiers before and after feeding to help baby control reflux and reduce spit-ups • Do not diaper or move the baby a lot after a feeding
Baby with cleft lip or palate	
• Swallows too much air during feed • Can't close lips around the nipple, difficulty latching on to breast • Liquids run out of the mouth • Choking, coughing, vomiting, spiting up • Frequent ear infections, ear drainage and poor weight gain	• Feed baby more frequently, at a slow rate, so liquid does not run out of the mouth or nose • Pace meals to reduce choking • For bottles, use a wider, slow flow nipple or a specialty bottle, and point the nipple down and away from the cleft • Feed in an upright, sitting position to keep milk from flowing back into the nose • Burp the baby gently more often because s/he takes in more air • Keep baby upright for 15-45 minutes after feeding
Baby exposed to alcohol or other substances	
• May have difficulty coordinating sucking, swallowing, and breathing • Fussy and irritable • Frequent vomiting and spitting up • Poor weight gain	• Frequent and regular feeds, ensuring night feeding • Feed baby in upright or semi-upright position • Feed in calm environment • Help baby to self-soothe and use of pacifier

4. INFANT HEALTH

Sick and/or small newborns, particularly those born with VLBW, have a significantly higher chance of being re-hospitalized during their first year after discharge than babies born at term and healthy[23]. In addition, parents of these babies may also be more concerned about their infant catching a cold or other infectious disease. Respiratory infections are the most common cause of rehospitalization, but babies may also be readmitted for feeding difficulties and gastroesophageal reflux. Re-admissions can also be related to be baby's medical condition (hearing, vision, heart condition, cerebral palsy, or neurodevelopmental problems).

With the following interventions, you can help families reduce the risk of rehospitalization:

- Teaching parents about danger signs.
- Attention to hygiene and the infant's environment.
- Protecting the infant against vaccine-preventable illnesses.
- Routine care.
- Paying attention to the baby's temperature.
- Promoting safe sleep practices.

[23] Healthy Children. AAP (21.11.2015). Common reasons for rehospitalization. https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/Common-Reasons-for-Rehospitalization.aspx

DANGER SIGNS

The following conditions should lead parents to seek care immediately:[24]

- Convulsions.
- A change in breathing, i.e. chest in-drawing, nasal flaring, noisy breathing and/or rapid breathing of more than 60 breaths per minute.
- A cough lasting more than 5 days and wheezing.
- A body temperature of > 37.5 degrees Celsius, especially if the temperature rises suddenly.
- A low body temperature of < 35.5 degrees Celsius.
- Blue lips, blue, pale, mottled, or patchy skin colour.
- A rash anywhere on the body (aside from a diaper rash that can be treated at home).
- The baby stops feeding; vomits all feeds; has frequent very liquid stool; has a significant decrease in the number of wet nappies, or urine that is dark in colour.
- The baby is jaundiced.

Video clip

Danger signs in the small baby: This video shows examples of small babies with each of 7 serious danger signs. https://bit.ly/2n7kuaS. While the examples are of babies that are very small, and such small babies may not have been discharged yet in your community, the explanation of danger signs is clear and easy to understand.

HYGIENE AND SMOKE-FREE ENVIRONMENT

All family members should help protect the baby by using **thorough handwashing techniques** with warm water and soap and reducing the spread of germs via coughing and sneezing. Anybody touching the baby must wash the hands thoroughly with soap. Caregivers can state that this is per doctor's orders.

IMPORTANT

Tips for parents.

Wash your hands:

> Any time you pick up the baby
> Before and after changing diapers
> Before and after food preparation
> Before feeding the baby
> After using the bathroom
> After touching your eyes, nose, or mouth
> When coming in from outside the home (after shopping, working, using public transport…)

[24] AAP. Common reasons for rehospitalization. www.healthychildren.org
Bliss. Common infectious illnesses. https://www.bliss.org.uk/parents/about-your-baby/common-infectious-illnesses

During the first months, the family should take active measures to reduce the baby's exposure to germs, i.e. avoid crowded public places with the baby. Friends and other visitors, including preschool or school children, that may have been exposed to respiratory conditions and other communicable diseases should be asked to visit when the baby is older, and their immune system is more developed. This may be difficult in some settings where family members have eagerly awaited the baby's arrival in the home; you may have to support caregivers in saying "no" to family and friends in such situations. Maybe you could propose for the family to place a sign on the door:

> "Our baby is still in recovery, and our home visitor/doctor has asked that we have no visitors until (date). We are happy to hear from you via text, WhatsApp, FaceBook, e-mail, or video chat."

Some infants have respiratory conditions when born and during the first weeks of their lives. Even after discharge, their lungs and general respiratory system remain fragile. As a result, these infants are more **susceptible to direct smoke**, in addition to the smoke that clings to a smoker's body and clothes, than infants born healthy. Help families understand that clean air is one of the greatest gifts for these infants and will help them to contract fewer respiratory illnesses.

Video clip

The video, Global Health Media video clip *"Protecting small babies from infection"* has good segments on handwashing and maintaining a clean environment but may benefit from adjustment to local context. https://globalhealthmedia.org/portfolio-items/protecting-small-babies-from-infection/?portfolioID=5623

VACCINE-PREVENTABLE ILLNESSES

IMPORTANT

Timely vaccination is extremely important for this group of children. While infants have a functioning immune system, even when born prematurely, they are more vulnerable to the dangers of vaccine-preventable diseases, like pertussis. **It is recommended to vaccinate babies born pre-term based on their chronological age, not their adjusted age.** Very pre-term babies may receive their first vaccinations in the hospital where they can be monitored for apnoea (temporary stopping of breathing). This is the only commonly reported complication with vaccinations for this group of babies[25].

In addition, it is **important that all family members and close contacts (e.g. visitors) be up-to-date on their vaccinations to reduce risks of exposure**[26]. Monitoring the vaccination schedule of these infants, their parents, siblings, and family members living together in the same home, is therefore an important part of your work to reduce risk.

In addition, babies born preterm or sick at birth **can also be protected against the common Respiratory Syncytial Virus** (RSV). This virus first presents as a common cold but can progress into pneumonia or bronchiolitis requiring hospitalization can be very serious threats to these infants.

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25 https://www.efcni.org/health-topics/going-home/immunisation-and-vaccination/
26 EFCNI (201?). Follow-up & continuing care.

ROUTINE CARE OF THE BABY

A valuable practice before discharge is to have the caregiver(s) in the room with their baby several days before discharge and have them take on, with 24-hour support from NICU staff, the full responsibility of caring for their baby. If this has not happened, the caregiver(s) may need your help to gain confidence in the routine care of their baby.

There are certain questions that parents ask about the routine care of these babies. Here are some tips to share with the caregivers[27]:

Washing and bathing the baby. How often and how to wash and bathe the baby, as well as how to take care of the baby's skin are common concerns of caregivers. The skin of premature babies is particularly sensitive and may need more care when the baby comes home. Giving the baby a bath once or twice a week with mild baby soap is sufficient during the early weeks. During cold periods of the year, a sponge bath can also be given uncovering one part of the baby at a time for cleaning so the baby does not become cold. Scented soaps, soaps with lots of chemicals, or antibacterial soaps are not recommended for the baby's sensitive skin.

The **baby's face and hands** can be washed daily and gently with a washcloth and warm water. One side of the face can be washed first and dried and then the other. Attention should be paid to the folds under the chin and between the fingers and palm.

The **baby's diaper area** should be kept as dry and clean as possible, with a change of nappy before or in the middle of each feeding. A dirty nappy should be changed as soon as it is noticed. The baby's bottom should be cleaned with a soft washcloth and lukewarm water. Mild baby soap or baby wipes can be used, but the baby's skin should be cleaned gently. If the baby develops a rash that does not go away after applying diaper rash cream, the baby should be taken to the doctor as they may have a yeast infection.

The **baby's umbilical cord** should be kept clean and dry, and the nappy should be folded down, so it does not cover the umbilical cord. If the cord area gets wet or dirty, clean it with mild soap, water and gently tap it dry.

The baby's **fingernails** are sharp, and baby might scratch themselves. Fingernails should be trimmed regularly to prevent this.

Baby clothes and bedding are best washed with mild and chemical-free laundry detergents.

Taking out the baby. Babies continue to build up their resistance after discharge, so it is best not to take them out into crowded or enclosed places (shopping centers, restaurants) during the first few months. It is also important to keep the baby away from smoky and polluted areas. Because most heat is lost through the head, the baby should wear a hat when taken out and be covered well when it is cold.

The discharge meeting and papers should provide you with information on any additional care these babies require.

INFANT SLEEP

Infant sleep patterns are highly individual. All babies go through periods of active or light sleep where they might twitch, make noises, change facial expressions, breathe irregularly, and flutter their eyelids. During deep sleep babies might have slow, regular, and peaceful breathing, and the baby might be difficult to rouse. Deep sleep is particularly important for the baby's health and growth. During one sleep period, a

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[27] Verywellfamily. Top NICU Discharge questions about bathing the baby. https://www.verywellfamily.com/top-nicu-discharge-questions-about-bathing-your-baby-2748713;
Taking care and protecting a premature Baby's skin. https://www.verywellfamily.com/protect-premature-baby-s-skin-4135015
How do I give my premature baby a bath. https://www.verywellfamily.com/how-do-i-give-my-premature-baby-a-bath-2748579

baby will move between active and deep sleep, and such cycles are shorter in pre-term infants who spend more time in active sleep.

When infants come home from the NICU, they may have difficulty sleeping at night in a dark and quiet environment but might not be bothered by noise and lights during the day. Infants' responses to quiet vs. noisy and light vs. dark environments depend on the individual. You can find some tips to share with families on promoting good sleep using Information Card 6.

For a review on the evidence and more detailed recommendations on **safe infant sleep practices** in general, please refer to **Module "Healthy weight, physical activity, sleep and sedentary time".**

IMPORTANT

The following best practices are critical for infants born small or with health conditions, as this group is at increased risk for Sudden Infant Death Syndrome (SIDS):

- Babies should be placed on their backs for naps and at night, on a firm surface, without soft bedding and plush toys, and in a smoke-free environment.
- Babies should not share beds with adults; and
- Breastfeeding protects babies against Sudden Infant Death Syndrome (SIDS).

KEEPING THE BABY WARM

The normal body temperature of a baby is 36.5 – 37.5 degrees. If the baby seems to have difficulty in regulating their temperature or feels cold, you can recommend the following to the caregiver(s):

- Ensure that the room of the baby is warm.
- Keep the baby and the baby's crib away from windows and drafts, and away from outer walls of the house.
- The baby should have 1-2 more layers of clothing or covers than the adults.
- Cover the baby's head with a hat, especially when the baby is taken outside. Put socks on the baby's feet.
- Check the baby's skin (for example child's feet, hands). If they look blue or white and feel cold to the touch, and if the baby's temperature is below 36.5 degrees, have the mother or other caregiver
  - Remove any wet diapers or wet clothing
  - Place the baby skin-to-skin (see Information Card 4 from Part 1 of the Module for more detail)
  - Cover the caregiver and baby with warm blankets
  - Call the baby's doctor.
- Breastfeed regularly to give the baby calories and energy and keep the baby from getting dehydrated.
- Use sponge baths for the baby instead of full baths, uncovering only the body parts that are to be cleaned.

If the baby looks flushed, red, or sweaty and has a temperature above 38 degrees, the caregiver should remove a layer of clothing and call the doctor. Also advise the mother to breastfeed to keep the baby well hydrated.

FOLLOW-UP CARE OF HEALTH ISSUES

Information Card 7 provides you with the Recommendations for Follow-up and Continuing Care of the European Foundation for the Care of Newborn Infants. Specifically, the hearing, vision, motor, and cognitive development of very premature infants should be monitored regularly. While the follow-up is generally the responsibility of the baby's paediatrician or specialist you should be aware of the types of follow-up appointments such children will have during their early years, and support the parents in accessing them.

5. SUPPORTING AND MONITORING CHILD DEVELOPMENT

IMPORTANT

Loving, stable, stimulating, and safe home and school environments, where the child can form close relationships, support his development. These kinds of environments can also help to make some development problems less severe and help children with early delays catch up by later childhood or the teenage years[28].

Most babies born prematurely, between 34-36 weeks, have typical development, particularly when considering their adjusted age during the early years.

Use the information from the **Module "The art of parenting - Love, talk, play, read"** to help your caregivers enrich their child's opportunities for learning with responsive and playful "serve and return interactions."

However, the more premature babies were at birth and the more medical complications they experienced in the NICU, the more likely they will encounter general difficulties and/or impairments in specific developmental functions[29]. These include:

- **Physical growth** – tend to be shorter and lighter, more likely to have dental problems.
- **Sensory development** – hearing and vision impairments are more frequent, and babies may be more sensitive to noise or have lower pain threshold.
- **Motor difficulties** – (gross and fine motor) including motor coordination and motor planning.
- **Cognitive development** – possibility of learning impairments or difficulties.
- **Social-emotional development** – may be less likely to interact with others, more likely to get overwhelmed and irritable.
- **Mental disorders** – more often affected by attention deficit hyperactivity disorder, autism spectrum disorders, and anxiety and depression.

The difficulties surrounding their birth can also affect the way their caregivers interact with them. Parents may be concerned about overstimulating their baby and become overprotective, thus reducing normal developmental challenges. At the other end of the spectrum, they may be worried that their children develop too slowly, start compensating and overstimulating the baby, not taking in the cues that the baby has had enough. The lack of progress can make parents more disillusioned or frustrated with the baby and question their abilities as caregivers. Please also refer to **Module "Children who develop differently"** for more information about parenting and the role of the family.

When monitoring the development of these children during their first year of life, (please also refer to the **Module "Monitoring and Screening"**), you will need to take into account the child's gestational age at

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[28] Raising Children Australia (13.8.2019). https://raisingchildren.net.au/newborns/premature-babies/development/premature-development-concerns

[29] Raising Children Australia. Premature baby development concerns. https://raisingchildren.net.au/newborns/premature-babies/development/premature-development-concerns

birth and use their corrected or adjusted age[30, 31] to understand whether they are relatively on-track with respect to their developmental milestones. For example, a six-month-old baby, born three months early, may just begin to sit independently, typical for a three-month old baby born at-term.

When you or the caregiver are concerned that the child is a bit slow for their chronological age, particularly during the first two years, adjusting expectations for the corrected age may indicate that the child is on track developmentally. Just as you will pay special attention to the baby's weight gain during these early months, it is essential that you monitor the child's developmental progress. If you and/or the caregivers have concerns about the baby's development, discuss the need for a developmental assessment and help them access relevant services. For assessments and early interventions, it will be important to share the information about the extent of prematurity and adjusted age with other health providers, caregivers, or early educators.

As broad guide, Information Card 8 provides you with the "Preemie Milestones" of the American Academy of Pediatrics[32].

© UNICEF/UN0205408/Pancic

[30] www.raising children.net.au Corrected age : How old is your premature baby ?
[31] Preemie Milestones https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/Preemie-Milestones.aspx
[32] AAP. Preemie Milestones. https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/Preemie-Milestones.aspx

ANNEX

1. INFORMATION CARDS

INFORMATION CARD 1: BENEFITS OF BREASTFEEDING

Benefits to baby	Benefits to mother
• Decreased mortality • 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, • Preterm birth is similar to the mother's amniotic fluid and contains growth factors and immune cells the baby needs to fight infections • Improved development of the immune system • Cognitive development • Later life: diabetes, heart disease, Crohn's disease, ulcerative colitis • Opportunity for skin-to-skin contact and bonding	• Reduction in post-partum bleeding • Helps control glucose levels after birth • Lower risk of breast, ovarian cancer, and type 2 diabetes

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. Small Wonders: CH4/2 - Establishing a good milk supply. 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. Research shows that through skin-to-skin contact, 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.Expressing breastmilk: ii. Establishing a good milk supply (Small Wonders series) - YouTube
- Best Beginnings. Graphic of the baby attaching on the breast. Small Wonders: CH7/3 - Illustration of baby attaching at the breast - YouTube
- Best Beginnings. Overcoming challenges. https://www.bestbeginnings.org.uk/watch-from-bump-to-breastfeeding-online

INFORMATION CARD 3: "THINKING HEALTHY"

Perinatal depression is a public health priority associated with high prevalence and poor child development. In High Income Countries (HIC), the value of total lifetime costs of perinatal depression has been estimated to be over US$ 100,000 per woman with the condition, with the majority of the costs related to adverse impacts on children. In Low Income Countries (LIC) where perinatal depression affects 1 in 5 women, and unlike HIC, is independently associated with infant undernutrition, the relative impact is likely to be greater.

The Thinking Healthy Programme (THP) aimed to reduce perinatal depression in low socioeconomic settings and to improve health outcomes in their children through the adaptation and integration of Cognitive Behavior Therapy (CBT) into the routine work of community health workers.

The Thinking Healthy Programme (THP) is a manualized intervention that can be incorporated into the routine work of community health workers. It incorporates cognitive and behavioral techniques such as active listening, collaboration with the family and non-threatening inquiry into the family's health beliefs; this is achieved through challenging beliefs and if necessary offering substitutes for some of these through alternative information.

Starting from pregnancy till one year postnatal, participants received 16 sessions of the evidence based "talking therapy". The sessions combined the therapy with activities to improve maternal well-being, mother-infant interaction and maternal social support. It also uses inter-session practice activities. It is designed to be integrated into existing maternal and child health education home visits.

From https://www.mhinnovation.net/innovations/thinking-healthy-programme?qt-content_innovation=0#qt-content_innovation

WHO 2015. Thinking Healthy – A manual for psychosocial management of perinatal depression. https://www.mhinnovation.net/sites/default/files/downloads/innovation/tools/WHO_MSD_MER_15.1_eng.pdf

INFORMATION CARD 4: INFANT MASSAGE

(adapted from Raising Children Australia and the International Association of Infant Massage[33])

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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[33] International Association of Baby Massage. https://www.iaim.net/benefits/

Video clip

Infant Massage Techniques | Isis Parenting. 27.12.2011.
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

© UNICEF/UN0510034/Sokhin

raisingchildren.net.au
the australian parenting website

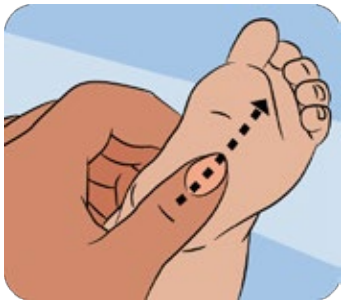
Baby massage

PARENTING IN PICTURES

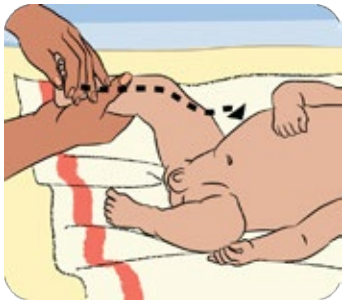
Suitable for 0-18 months

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.

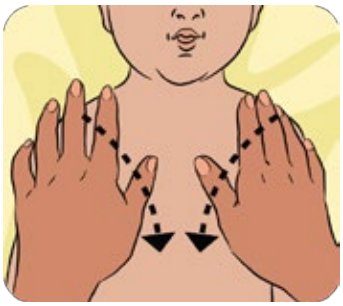


Smooth a few drops of baby massage oil or sorbolene cream into your warm hands and massage the soles of baby's feet. Use firm, gentle, slow strokes from heel to toe. Always keep one hand on baby. If you see signs of allergic reaction to the oil, wipe it off and see your GP.

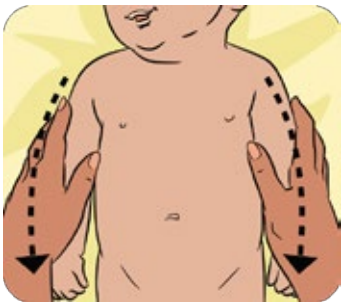


Do long smooth strokes up baby's leg. Massage from ankle up to thigh and over hip. Massage both legs at once or one at a time. Avoid the genital area. Hold baby's leg under the knee and gently press it towards the tummy to help release wind.

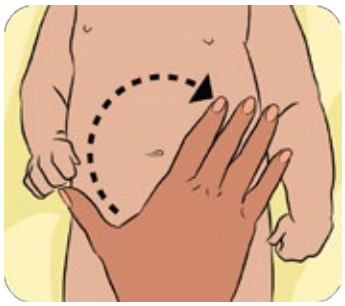
Upper body massaging for babies



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

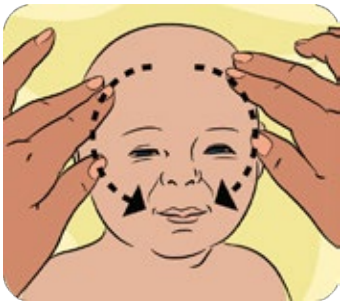


Massage baby's arms by stroking from shoulders down towards wrists. Try not to get oil on baby's hands. If you do, wipe her fingers clean before she sucks them.

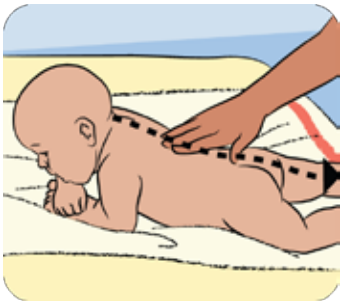


If baby's tummy feels soft, massage it with circular, clockwise strokes. If she gets unsettled, go on to the next step. Avoid the belly button area if baby's cord hasn't healed. Don't put pressure on the area between baby's nipples and tummy.

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.

INFORMATION CARD 5: ADDRESSING COMMON FEEDING PROBLEMS[34]

Common feeding difficulties	Approaches and tips
Babies born before 37 weeks of gestation	
• Difficulty latching to the nipple of the breast or gagging when taking the bottle • Difficulty sucking (i.e., weak suck); coordinating sucking, swallowing, and breathing; and difficulty swallowing (coughing, choking or gasping) • Frequent vomiting and spitting up • Falling asleep during feedings • Easily overwhelmed by changes in the environment • Sensitive around mouth or face due to past medical procedures • Fussy and irritable • Poor weight gain and growth	• Provide more frequent and shorter paced feedings, provide baby with time to rest and breathe, wake baby for feeding at night • Use same bottle nipple as in NICU • Hold baby in almost upright position, but hold bottle in neutral/horizontal position, not pointing down, to allow for baby-controlled flow • Do not force the baby to eat; feed in a quiet place with limited stimulation, stroke and stimulate lips to encourage sucking, calm baby before every feed
Sleepy, hard to wake baby (Down syndrome, heart conditions, born prematurely, exposed to substances…), and babies falling asleep during feeding with weak hunger cues	
• Weight loss and poor appetite • May not eat much at one time (reduced intake) • Difficulty coordinating sucking, swallowing, and breathing • Chokes easily • Tires quickly and hard to wake or keep awake • Easily overwhelmed and falls asleep while feeding • Irritable and fussy • Poor growth and slow weight gain	• Turn on the light, make noise, wake up the baby gently; if swaddled, uncover baby; touch, stroke, and talk to the baby • Walk around, putting the baby in an upright position • Change the diaper • Make sure the baby is awake; do not offer the breast or bottle to wake the baby • Feed more frequently, every 2-3 hours, but not exceeding 30 minutes per feed • Feed baby in semi-upright position • See if bright or dim lighting works better • If bottle feeding, ensure that nipple is soft, but that milk flow is not too fast for the baby to handle

[34] Adapted from Holt International (2019). Holt International's Feeding and Positioning Manual: Guidelines for working with babies and children.

Fussy baby, while feeding or not feeding, medical issues, cardiac problems, exposed to substances, with vision or hearing problems, neurodevelopmental delays	
• Babies are fussy overall, while feeding and while not feeding, and are difficult to soothe • Restless and may refuse feed • Poor appetite, growth, and weight gain	• Feed regularly, every 2-3 hours, before the baby gets upset • Don't force breastfeeding or the bottle while the baby is upset (crying, arching back, wrinkled face…), but try to soothe the baby first • Provide skin-to-skin and carry in pouch, using gentle rhythmic and soothing movements • Keep arms free from swaddling, so baby can self-soothe • Try feed in dim light and quiet setting
Baby who frequently spits up, i.e. with gastroesophageal reflux (GER) – food vomited up from the stomach	
• Uncontrollable vomiting and spitting up, after each meal and even between feedings • Fussiness and irritability during feeding, but refusing breast or bottle even when hungry	• Offer smaller feeds more frequently • Pace meals • With bottles, use a slow flow nipple • Feed baby in upright position or 30-45 degree angle, not lying down • Keep baby upright for 15-45 minutes after feeding • Use pacifiers before and after feeding to help baby control reflux and reduce spit-ups • Do not diaper or move the baby a lot after a feeding
Baby with cleft lip or palate	
• Swallows too much air during feed • Can't close lips around the nipple, difficulty latching on to breast • Liquids run out of the mouth • Choking, coughing, vomiting, spiting up • Frequent ear infections, ear drainage and poor weight gain	• Feed baby more frequently, at a slow rate, so liquid does not run out of the mouth or nose • Pace meals to reduce choking • For bottles, use a wider, slow flow nipple or a specialty bottle, and point the nipple down and away from the cleft • Feed in an upright, sitting position to keep milk from flowing back into the nose • Burp the baby gently more often because s/he takes in more air • Keep baby upright for 15-45 minutes after feeding
Baby exposed to alcohol or other substances	
• May have difficulty coordinating sucking, swallowing, and breathing • Fussy and irritable • Frequent vomiting and spitting up • Poor weight gain	• Frequent and regular feeds, ensuring night feeding • Feed baby in upright or semi-upright position • Feed in calm environment • Help baby to self-soothe and use of pacifier

Breastfeeding a Baby with Down Syndrome

Benefits. The same benefits as for newborns. Additionally, breastfeeding

- Protects the baby against respiratory and viral infections that babies with Down syndrome are more prone of acquiring
- Sucking strengthens the baby's facial muscles (lips, tongue), important for speech development
- Strengthens the bond of mother and child

Challenges.

- Low muscle tone (low muscle tone and strength in tongue, lips, and head support) – Help mother with a comfortable and proper position, so the baby can use his/her energy for feeding and get the most milk for his/her efforts.
- Moderate milk flow (if milk too fast position baby with throat and neck higher than the nipple, if milk too slow, start milk flow before putting the baby on the breast);
- Many children with Down syndrome are very sleepy in the early weeks. Counteract sleepiness by changing environmental conditions (light, temperature…)
- Protruding tongue. Ensure baby opens mouth wide and keeps tongue down
- Adequate weight gain. Monitor weigh gain and ensure baby nurses effectively and gets the calorie-rich brain milk

For Families with a child with Down Syndrome - A guide for new parents – frequently asked questions

https://www.downsyndrome.org.au/documents/resources/new_parents/DSA_AGuideForNewParents%28FAQ%29_Resource.pdf

Good positions for feeding and holding the baby

The video clips below show you how to teach mothers about different breastfeeding positions and mothers, fathers and other caregivers about common positions of holding the baby.

Intermountain Healthcare (July 17, 2017). 13 breastfeeding positions.
https://www.youtube.com/watch?v=YqzqR1aOtAg

Texas Department of State Health Services (Dec 19, 2016). Breastfeeding positions.
https://www.youtube.com/watch?v=XZfGzJBBwME

Raising children Australia. How to breastfeed: breastfeeding positions
https://raisingchildren.net.au/nvideos/breastfeeding-positions

Adaptable Dad. (8.8.2017). How to hold a newborn baby.
https://www.youtube.com/watch?v=7yL9pnDP6jY

INFORMATION CARD 6: SUPPORTING RESTFUL SLEEP FOR YOUR BABY – TIPS FOR PARENTS

Good sleep is essential for the growth and development of babies born small or with health conditions:

- Make sure that the baby is not hungry, wet, too cold or too warm, and has been burped after feeding.
- Diaper the baby before or in the middle of the feed, not after the feed.
- Always have baby sleep in the same place on his/her back and using safe sleep practices
- Some babies like to be swaddled while others may like a baby sack where legs can move freely
- Before putting the baby down to sleep, take baby to a quiet place, cuddle the baby skin-to-skin or rock the baby gently while standing or walking
- Some babies like white noise or music
- Before night time, give the baby a bath and/or massage the baby
- Wait until baby is in the light sleep cycle, if s/he has to be woken up to feed

INFORMATION CARD 7: RECOMMENDATIONS FOR FOLLOW-UP AND CONTINUING CARE[35]

It must be emphasized that many preterm infants and infants born at-risk are doing well, and that the babies and their families can expect significant improvement with early identification, early intervention and coordinated support.

To ensure that babies get the critical services they need, the ECFCI recommend an integrated schedule of follow-up services, involving also other disciplines, that ensures that infants and families neither fall through the gaps in care nor receive duplicative or uncoordinated services. The schedule is based on the principle that parents are the primary caregivers and equal partners in the multidisciplinary team around the child. The recommendations and schedule targets:

- Infants born before 32 weeks' gestation or
- Infants born after 32 gestation that have or had one or more significant risk factors such as:
  - a brain lesion on neuroimaging likely to be associated with developmental problems or disorders
  - grade 2 or 3 hypoxic ischaemic encephalopathy in the neonatal period
  - neonatal bacterial or viral meningitis/encephalitis
  - severe fetal growth restriction
  - known severe social or family problems with issues related to the safety for the child.

Area	Rationale	Recommended follow-up
Visual Function	At increased risk for visual dysfunctions, have negative outcome on academic skills of reading, writing, mathematics.	Standardized visual assessment at age 3.5-4 years, and visual processing at age 5-6 years
Cognitive impairment – can co-occur with motor and behaviour difficulties	General intelligence, executive function and achievement is related to length of gestation. Risk is greatest in extremely preterm births and infants affected by perinatal asphyxia.	Standardized test at two years and at transition to school. Moderate to severe cognitive impairments become apparent by the second year of life and tend to remain stable. Mild cognitive impairment can improve with early intervention or deteriorate, and thus needs to be monitored.
Communication, speech and language – often associated with delays in other developmental domains	Very preterm births and infants born with risk factors (brain injury, IUG restriction and social risks factors – maternal education, lack of responsive parenting) may have less advanced gestural and vocal language skills affecting learning, academic achievement and social interactions. Communication and speech may also be affected by weaknesses in other domains and by early feeding problems.	Standardized assessment at two to three years and at transition to school
Healthy lifestyle	Very preterm infants are at greater risk of inactivity and being less fit and have a greater risk of high blood pressure, obesity, stroke, type II diabetes, lung and bone health.	Monitoring from childhood to adulthood and promotion of healthy lifestyles and vigilance.

[35] Adapted from European Foundation for the Care of Newborn Infants, Home – EFCNI

Hearing screening	Very pre-term and infants with risk factors are at greater risk of congenital or early hearing impairments. Early identification and intervention are key during the sensitive period of auditory development in the brain with impact on language, speech delays and social emotional development.	Standardized hearing screening within one month of birth and interventions starting within the first 6 months.
Mental health	Very preterm, small for gestational age, or infants with risk factors are at increased risk for mental health problems, particularly emotional and attention problems (ADHD, anxiety disorders, and autism spectrum disorders). Early identification and intervention can also support parenting and the parent-child relationship.	Behavior, emotional and attention problems assessed at 2 years of age and transition to school.
Parental mental health	Parents of very preterm infants and infants with risk factors are at risk of depression and posttraumatic stress syndrome which affects child development and wellbeing mediated by the quality of the parent-child relationship. Interventions that focus on sensitive parenting and improved parent-child interaction can improve parental wellbeing and child development.	Targeted screening of parents six months after child has been discharged, at around two years, and during regular follow-up visits of the child
Motor and neurological follow-up assessment	Very pre-term and infants with risk factors. Early intervention can have a positive impact on motor development, and in the case of cerebral palsy reduce contractures and deformities.	Standardized neurological assessment of neurological status and motor development during the first two years and during transition to school.
Respiratory outcome	Infants are at greater risk of respiratory conditions, particularly constructive airways disease, and are the most common cause for rehospitalization.	Monitoring, reduction of exposure to passive smoke and environmental pollution.
Peer and sibling relationships	Very pre-term and infants with risk factors are particularly vulnerable to difficulties in peer and sibling relationships. Positive friendships and sibling relationships can serve as protective factors in daily life.	Comprehensive, developmentally appropriate screening for socio-emotional development and peer relationships as part of the standard follow-up program
Post discharge responsive parenting programs	Because infants are more likely to have multiple mild developmental problems they may be less responsive to their parents, while also experiencing difficulties with feeding, sleeping, self-soothing and self-regulation difficulties. Parents may be suffering from stress and depression. Responsive parenting interventions focusing on the parent-child relationship have been shown to improve mental health and child development and wellbeing	After discharge
Reproductive counselling	To evaluate and reduce the risk of another preterm or high-risk birth	Depending on the causes, some medical interventions can be offered.

INFORMATION CARD 8: PREEMIE MILESTONES IN DEVELOPMENT[36]

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	• Moves hands and legs actively • Keeps hands open most of the time • Lifts head and chest when lying on tummy • Controls head a little, but may still need support • Holds objects in hands	• Brings hands together, or to mouth • Lifts head and pushes on arms when on tummy • Reaches for objects • Turns or makes crawling movement when on tummy	• Puts weight on feet when held standing up • Sits by himself • Bangs and shakes objects • Transfers objects from one hand to another • Holds 2 objects at a time, one in each hand • Rolls over from tummy to back
Language	• Responds to sounds (for example, turns when hears voices and rattles) • Makes cooing noises like "aaaah" and "ooooh" • Cries when needs something	• Turns head to follow familiar voices • Laughs and squeals • Combines sounds more often (for example, "aaah-oooh", "gaaa-gooo")	• Responds to her name, turns and looks • Babbles, making sounds like "da", "ga", "ba", "ka"
Activities	• Fixes eyes on a person or object (a mobile, for example) and follows its movement • Has different cries for different needs	• Grasps more and reaches for objects • Brings objects to mouth • Increases activity when sees a toy	• Pays attention to what toys can do (make music and light up, for example) • Looks towards object that drops out of sight
Social/ emotional	• Makes eye contact and smiles; • Recognizes and enjoys interactions with mother or primary caregiver.	• Is increasingly interactive and comfortable with parents and caregivers • Shows interest in mirrors, smiles and is playful • Is able to comfort himself	• Is becoming more aware of surroundings • Notices if parents are present (or not) • Reacts differently to strangers • Expresses excitement, happiness and unhappiness

[36] From https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/Preemie-Milestones.aspx

INFORMATION CARD 9: 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 she 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[46].

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

[46] National Association of Neonatal Nurses (2018). Baby steps to home.

INFORMATION CARD 10: HELPING FAMILIES DEAL WITH HEART CONDITIONS[38]

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 Unites 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.*

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[38] Adapted from American Academy of Pediatrics. https://www.healthychildren.org/English/health-issues/conditions/heart/Pages/Challenges-Faced-by-Parents-of-Children-with-Congenital-Heart-Disease.aspx

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 Execellent 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). Preemie 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