NICU BABIES IN THE COMMUNITY:
A CONTINUUM OF CARE

Created by:
Parents of NICU graduates and the
Wisconsin Association for Perinatal Care
Southeast Region Work Group
Of parents and professionals

In conjunction with the Infant and Family Committee of the
Wisconsin Association for Perinatal Care

This document is possible because of the expert skills of Barbara Wienholtz,
Administrative Assistant at the Wisconsin Association for Perinatal Care. We are
grateful for her knowledge of design and layout, and for her patience and perseverance to
see this project to completion.

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Maternal & Child Health Bureau of the Health Resources and Services Administration,
U.S. Department of Health and Human Services.
INTRODUCTION

Purpose: NICU Babies in the Community: A Continuum of Care is a compilation of work by parents, public health nurses, neonatal intensive care unit (NICU) staff, Birth to 3 personnel, nutritionists and therapists. The intent of the document is to provide information that will better join the discharge process that takes place in the NICU with the health care system in the community. The ultimate goal is to have infants and families supported during this transition and throughout the first year of the infant’s life.

Intended Outcomes: The evolving health care system in the United States features an orientation to outcomes management. For this reason, we have identified five outcomes as central to the document. They are to promote:

1. Optimal growth for adjusted gestational age
2. Optimal development for adjusted gestational age
3. Parent-infant relationships
4. Family cohesion and parent satisfaction
5. Wellness

Intended Audience: The document is written as a guide for professionals. Baby Steps, a companion document, will be given to parents to empower them to advocate for the needs of their babies.

How to Use: Use this as a working document as you encounter infants in your health care role. The ability of the family to meet the five outcomes directly relates to the parent/family’s ability to manage their role as coordinator. During each encounter, do an assessment of the family in addition to an assessment of the infant. The format of the document is geared to simplify the assessment process:

• First, select an age that most closely matches the adjusted age of the infant you are seeing.
• Review the assessment and suggested interventions.
• Based on discussion with the family, use the resources indicated to further assist the family.

The outcomes remain the same for each age, but the intervention and education change. At the end of every encounter, be sure there is a plan in place for follow-through with the infant and family, whether with you or some other health care provider.

Background Information: This document grew out of the efforts of a group of concerned people who met at several regional and statewide meetings supported by the Wisconsin Association for Perinatal Care. During these meetings, families shared their experiences after discharge from an NICU and told us about the complex, disjointed system they faced. These families asked for assistance to help hospitals and communities shape a simpler, family friendly service. Many of the professionals in the audience also voiced concern about babies being discharged at an earlier gestational age (e.g. 34-35 weeks), with few health care providers in the community having experience to deal with the unique needs of premature infants.
What You Can Do: Please join us in this effort to provide connected, family oriented, outcome-based care to these special infants and their families.

How to Order Additional Copies: Share this document with others in your organization. You can download additional copies from the WAPC website at www.perinatalweb.org. If you have questions or feedback after reviewing the document, please contact Ann E. Conway by phone at WAPC (608)267-6060 or by email at aeconway@wisc.edu
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## Care in the NICU/Weeks Prior to Discharge

**Outcomes:**
1. To promote optimal growth for adjusted gestational age.
2. To promote optimal development for adjusted age.
3. To promote parent-infant relationship.
4. To promote family cohesion and parent satisfaction.
5. To promote wellness.

**Core Principles:**
1. Children and families are treated with respect and dignity.
2. Families are given complete information in family friendly language.
3. Families are encouraged to participate in decision making and care planning.

### Assessment

- In-house multidisciplinary assessments will continue. Assessments to include:
  1. Physical assessments for weight, length and head circumference
  2. Barriers to visitation and what has been done to facilitate: transportation, unit flexibility, any psychological or relationship issues experienced by the parents
  3. Parental caregiving
     - Holding
     - Bathing
     - Feeding
     - Complex care
  4. Parental comfort:
     - Being with baby
     - Grief issues (congenital anomalies, twin death)
     - Goals and concerns of the parents
     - Cultural and religious considerations of family
     - Emotional preparation for discharge

### Intervention/Education

- A full range of family-centered, multidisciplinary care will be provided to the infant and family to address the conditions that warranted the NICU admission. Guidelines will include the following:
  1. Principles of family-centered care are incorporated into the hospital policies and procedures as well as staff attitudes.
     - Developmentally supportive care in the NICU must be a standard of care.
     - Facilitate hands-on care for all parents
     - Visitation needs to be encouraged and facilitated. Be creative in discussions and contacts with families; avoid judgment when parents/families visit less frequently than expected
     - The central role of the parent needs to be acknowledged
     - Staff need to facilitate, support and guide the parental nurturing time with the baby
     - Provide parental support in identifying infant cues and in responding to their infant

### Resources

**Hospital:**
- Lactation Consultant/Dietitian
- Physical/Occupational/Speech Therapists
- Social Services
- Developmental Specialist
- Certified Nurse Practitioner
- Social Services
- Primary Care Provider
- Discharge Planner
- Bereavement Counselors
- Infant Massage
- Parent-to-Parent support

**Referrals:**
- Primary Care Provider/Neonatologist
- Specialists/Specialty Clinics
- Physical/Occupational/Speech therapists
- Public health department
- Home care agencies
- Birth to 3 agency
- Social Service Department
- Parish Nurse
- Dietitian
- Developmental Specialists
- Lactation Specialist
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<th>Assessment</th>
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| regulation and interest in the world (*App. B) Assess:  
• If parent is adapting his/her parenting and interactions to the developing and growing abilities of the baby  
• The appropriateness of parental expectations  
• Parental awareness of, and sensitivity to, infant cues & infant distress  
• The tone of the interaction—pleasure? struggle?  
• Infant’s enjoyment of touch and response to sounds  
6. Pre-discharge home visit to assess home, home safety, and family preparedness  
7. Parent’s understanding of role in care coordination. Knowledge of infant’s medical status and plan of care for specific problems after discharge  
8. Parental coping with an infant with special needs:  
• Depression  
• Family relationships and communication  
• Style of coping  
• Family support  
• Availability of medical care in the community  
• Financial and insurance concerns  
• Needs for referrals and special supports  
• Need for parent-to-parent support | 2. Families are encouraged to participate in decision-making and care plans in collaboration with the staff  
3. Families are given complete information regarding their infant in family-friendly language  
4. Hospital staff will look for opportunities to build on family strengths in order to enhance their abilities and foster independence  
• Facilitate parental caregiving as soon as possible: holding, feeding, diaper changes, bathing, kangaroo care  
• Begin to transition parents to their role post-discharge—overnight stays, 24 hour care  
• Assist parents to conserve energy needed post-discharge—encourage them to sleep before discharge, remain at home and rest in preparation for discharge  
• Bring in alternate caregivers prior to discharge, involve siblings  
5. Families will be treated with respect and dignity, recognizing unique family traditions, cultural heritage, and family values  
6. Hospital staff will educate and empower families so that they can effectively advocate for their infant  
• Update family on any changes in one-on-one meetings and group meetings  
• Give access to information on premature infants |  
• Follow-Through Clinics  
• HMO Case Manager  
• WIC  
• Family Support Groups  
• Mental Health Resources  
• Family Service Agencies  
• AODA Programs  
• Wisconsin First Step  
• Parent Education Programs  
• Family Resource Centers  
• Local Child Welfare Agency  
• Support Groups for Parents with Disabilities  
• Follow-up Care for Vision/Hearing  
• RSV Prophylaxis  
• Parent-to-Parent Support  
• EMS System  

**Published resources:**  
• American Academy of Pediatrics guidelines  
• *First Feelings* by Stanley Greenspan and Nancy Thorndike Greenspan, 1985, Viking Press  
• Karen Pridham, RN, Ph.D., Feeding and Caregiving Support Projects, UW-Madison School of Nursing, 608-238-7536  
• Growth charts (www.cdc.gov/growthcharts.com)  
• Internet [http://www.medsch.wisc.edu/childrenshosp/parents_of_preemies](http://www.medsch.wisc.edu/childrenshosp/parents_of_preemies)  
• Hawaii Early Learning Profile (HELP)  
• Books on premature babies
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<tbody>
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<td>• Identify who primary care provider will be</td>
<td>• Identify which health care professional is the primary resource for parents</td>
<td>Appendices:</td>
</tr>
<tr>
<td>• Identify which health care professional is the primary resource for parents</td>
<td>• Identify which resources parents need and who they should call for questions</td>
<td>A. A Bill of Rights</td>
</tr>
<tr>
<td>• Plot and graph weight, length, and head circumference and share with family (See App. C)</td>
<td>• Instruct family on individualized feeding techniques and nutritional intake required for their infant (See App. D)</td>
<td>B. Emotional Milestones</td>
</tr>
<tr>
<td>• Help families prepare for what to expect: developmental issues, behavior of preterm infant, supports of extended family, impact of discharge on family</td>
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<td>C. Growth charts</td>
</tr>
<tr>
<td>• Discuss coping strategies related to concerns about spoiling, crying</td>
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<td>D. Guide to feeding/definitions</td>
</tr>
<tr>
<td>• Teach families about car seats, never shake a baby, back to sleep/tummy to play, developmental milestones, importance of developmental screening (See App. E &amp; F)</td>
<td>• Teach families about car seats, never shake a baby, back to sleep/tummy to play, developmental milestones, importance of developmental screening (See App. E &amp; F)</td>
<td>E. Ages and Stages information</td>
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<tr>
<td>• Involve family in development of discharge plan</td>
<td>• Involve family in development of discharge plan</td>
<td>F. Denver Developmental Screening information</td>
</tr>
<tr>
<td>• Age appropriate play activities</td>
<td>• Age appropriate play activities</td>
<td>G. Birth to 3</td>
</tr>
<tr>
<td>• Need to count from baby’s due date, not actual birthdate, for developmental skills. Adjust for prematurity for 2 years (see App. D)</td>
<td>• Need to count from baby’s due date, not actual birthdate, for developmental skills. Adjust for prematurity for 2 years (see App. D)</td>
<td>H. Public health nursing</td>
</tr>
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<td>• Infant needs regarding handling, positioning, communication, motor development, brain growth and sleep</td>
<td>• Infant needs regarding handling, positioning, communication, motor development, brain growth and sleep</td>
<td>I. Follow-through programs</td>
</tr>
<tr>
<td><em>Throughout the document “App.” is used to abbreviate Appendix.</em></td>
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<td>J. Acute illness guidelines</td>
</tr>
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<td></td>
<td></td>
<td>K. Statewide Perinatal Centers</td>
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</table>
### Assessment

7. All families will be offered appropriate follow-through services and the opportunity to meet with related contact persons prior to discharge
   - Care conference before discharge should include: Birth to 3 (App. G), Prenatal Care Coordinator (PNCC), Public Health Nurse (App. H), Home health nurse, Follow Through Program (App. I) and other service providers.
   - Care conference should be audio taped for parents to refer back to and should focus on where the baby is NOW, as well as the discharge needs and plans
   - The current status of immunizations, hearing, vision and other screenings and what follow-up is necessary.

8. Parent-to-parent networking should be established as soon as possible after admission into NICU. Parent support should be specifically related to the diagnosis of the infant and the family’s needs

9. The NICU discharge plan is shared with all agencies and care providers who have roles specified in the plan

### Intervention/Education

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2. To promote optimal development for adjusted age.
3. To promote parent-infant relationship.
4. To promote family cohesion and parent satisfaction.
5. To promote wellness.

Core Principles: 1. Children and families are treated with respect and dignity.
2. Families are given complete information in family-friendly language.
3. Families are encouraged to participate in decision-making and care planning.

**Age 3 Months**

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<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>1. Weight gain, length, and head circumference (always weigh infant naked to assure accurate and consistent plotting)</td>
<td>1. Growth</td>
<td>Hospital:</td>
</tr>
<tr>
<td>2. Screen for feeding problems:</td>
<td>• Plot measurements on only one growth chart to plot progress and discuss with family (App. C)</td>
<td>• Lactation Consultant/Dietitian</td>
</tr>
<tr>
<td>• Respiratory compromise</td>
<td>• Discuss concerns with breastfeeding/review proper formula preparation</td>
<td>• Physical/Occupational/Speech Therapists</td>
</tr>
<tr>
<td>• Cough during feedings</td>
<td>• Anticipatory guidance for feeding changes and appropriate caloric intake</td>
<td>• Social Services</td>
</tr>
<tr>
<td>• Spitting/vomiting</td>
<td>• Refer, if needed, for growth faltering</td>
<td>• Developmental Specialist</td>
</tr>
<tr>
<td>• Fatigue</td>
<td>• Discussion regarding genetic potential</td>
<td>• Certified Nurse Practitioner</td>
</tr>
<tr>
<td>• Feeding aversion</td>
<td>2. Development</td>
<td>• Social Services</td>
</tr>
<tr>
<td>• Concerns related to breastfeeding</td>
<td>• Reinforce to the family the importance of counting from the baby’s due date and not birthday when looking at development</td>
<td>• Primary Care Provider</td>
</tr>
<tr>
<td>3. Monitor nutritional intake for infants who are at their genetic potential (App. D): Expectations: Weight gain should be 25-30 grams/day. If catch-up growth is necessary, or if chronic lung condition exists, weight gain should be 30-45 grams/day.</td>
<td>• Offer age appropriate, as well as anticipatory play activities</td>
<td>• Discharge Planner</td>
</tr>
<tr>
<td>4. Developmental milestones for corrected gestational age using a standardized tool (App. E&amp;F)</td>
<td>• Screen for failure to meet developmental milestones using Ages and Stages (App. E)/Denver Developmental Screening (App. F)/refer to Birth to 3 (App. G) when appropriate</td>
<td>• Bereavement Counselors</td>
</tr>
<tr>
<td>5. Infant’s emotional milestone: Self-regulation/Falling in Love (App. B)</td>
<td>3. Infant/Parent relationship</td>
<td>• Infant Massage</td>
</tr>
<tr>
<td>Assess:</td>
<td>Review with the parent:</td>
<td>• Parent-to-Parent support</td>
</tr>
<tr>
<td>• If parent is adapting his/her parenting and interactive style to the developing growing abilities of the baby</td>
<td>• The importance of consistency in care</td>
<td></td>
</tr>
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</table>

Referrals:
- Primary Care Provider/Neonatologist
- Specialists/Specialty Clinics
- Physical/Occupational/Speech therapists
- Public health department
- Home care agencies
- Birth to 3 agency
- Social Service Department
- Parish Nurse
- Dietitian
- Developmental Specialists
- Lactation Specialist
- Follow-Through Clinics
## Assessment
- The appropriateness of parental expectations
- Parental awareness of sensitivity to infant cues, identification of and appropriate response to the infant’s distress
- The tone of the interaction—pleasure? struggle?
- Infant responsiveness and evidence of growing attachment to parent
- If infant enjoys touch, brightens to sounds, enjoys movement up and down
- If infant gazes at parent with great interest

## Intervention/Education
### Caregivers/Childcare
- The infant’s growing attachment and the need to develop trust/“fall in love” with the parent/caregiver
- Potential stranger awareness in the near future with growing anxiety as the infant grows older
- The effects of separation

### 4. Family cohesion and parent satisfaction
- Address grief issues of the parent potentially caused by separation from the infant in child care, especially when the infant “falls in love” with the child care provider
- Support parents coordinator role in decision-making and collaboration with the primary care provider
- Look for opportunities to build on family strengths in order to enhance abilities and foster independence
- Demonstrate advocacy and empower the parent/caregiver to advocate independently and effectively
- Continue to provide services that are sensitive to the family’s traditions, cultures and values

### 5. Wellness
- Review and revise the care plan as needed/Indicate items completed
- Confirm future appointments/referrals
- Provide education about diagnoses, referrals, and medications and their administration

## Resources
- HMO Case Manager
- WIC
- Family Support Groups
- Mental Health Resources
- Family Service Agencies
- AODA Programs
- Wisconsin First Step
- Parent Education Programs
- Family Resource Centers
- Local Child Welfare Agency
- Support groups for Parents with Disabilities
- Follow-up Care for Vision/Hearing
- RSV Prophylaxis
- Parent-to-Parent Support
- EMS System

### Published resources:
- American Academy of Pediatrics guidelines
- *First Feelings* by Stanley Greenspan and Nancy Thorndike Greenspan, 1985, Viking Press
- Karen Pridham, RN, Ph.D., Feeding and Caregiving Support Projects, UW-Madison School of Nursing, 608-238-7536
- Growth charts
  - (www.cdc.gov/growthcharts.com)
- Internet: Parents of Premies
- Hawaii Early Learning Profile (HELP)
- Books on premature infants
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| 9. Parental coping with a child with special needs  
  - Goals and concerns  
  - Depression  
  - Family relationships and communication  
  - Style of coping  
  - Support system/respite |  
  - Help parents make referrals and complete appointments  
  - If family is moving to a new geographic area, provide appropriate referrals  
  - Contact # for local Public Health Department (App. H) | Appendices:  
A. Bill of Rights  
B. Emotional Milestone  
C. Growth charts  
D. Guide to feeding/definitions  
E. Ages and Stages information  
F. Denver Developmental Screening information  
G. Birth to 3  
H. Public health nursing  
I. Follow-through programs  
J. Acute illness guidelines  
K. Statewide Perinatal Centers |
| 10. Parent’s ability to demonstrate confidence in caregiving capabilities  
  - Feeding  
  - Play activities  
  - Sleep patterns |
**Outcomes:**
1. To promote optimal growth for adjusted gestational age.
2. To promote optimal development for adjusted age.
3. To promote parent-infant relationship.
4. To promote family cohesion and parent satisfaction.
5. To promote wellness.

**Core Principles:**
1. Children and families are treated with respect and dignity.
2. Families are given complete information in family-friendly language.
3. Families are encouraged to participate in decision-making and care planning.

## Age 6 Months

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| 1. Weight gain, length, and head circumference (always weigh infant naked to assure accurate and consistent plotting) | 1. Growth  
- Plot measurements on only one growth chart to plot progress and discuss with family (App. C)  
- Discuss concerns with breastfeeding/review proper formula preparation  
- Anticipatory guidance for feeding changes and appropriate caloric intake  
- Refer, if needed, for growth faltering  
- Discussion regarding genetic potential  
2. Development  
- Reinforce to the family the importance of counting from the baby’s due date and not birthday when looking at development  
- Offer age appropriate, as well as anticipatory play activities  
- Screen for failure to meet developmental milestones using Ages and Stages (App. E)/Denver Developmental Screening (App. F)/refer to Birth to 3 (App. G) when appropriate  
- Teach anticipatory play activities: encourage hand-to-hand and hand-to-foot playing, play alone and with parent, | Hospital:  
- Lactation Consultant/Dietitian  
- Physical/Occupational/Speech Therapists  
- Social Services  
- Developmental Specialist  
- Certified Nurse Practitioner  
- Social Services  
- Primary Care Provider  
- Discharge Planner  
- Bereavement Counselors  
- Infant Massage  
- Parent-to-Parent support  |
| 2. Screen for feeding problems:  
- Respiratory compromise  
- Cough during feedings  
- Spitting/vomiting  
- Fatigue  
- Feeding aversion  
- Concerns related to breastfeeding | | Referrals:  
- Primary Care Provider/Neonatologist  
- Specialists/Specialty Clinics  
- Physical/Occupational/Speech therapists  
- Public health department  
- Home care agencies  
- Birth to 3 Agency  
- Social Service Department  
- Parish Nurse  
- Dietitian  
- Developmental Specialists  
- Lactation Specialist |
| 3. Monitor nutritional intake for infants who are at their genetic potential (App. D): Expectations: Weight gain should be 25-30 grams/day. If catch-up growth is necessary or if chronic lung condition exists, weight gain should be 30-45 grams/day. | | |
| 4. Developmental milestones for corrected gestational age using a standardized tool (App. E&F) | | |
| 5. Infant’s emotional milestone: Falling in love/Developing intentional communication (App. B) Assess:  
- If parent is adapting his/her parenting and interactive style to the developing growing abilities of the baby | | |
### Care in the NICU/Weeks Prior to Discharge

#### Assessment

- The appropriateness of parental expectations
- Parental awareness of sensitivity to infant cues, identification of and appropriate response to the infant’s distress
- The tone of the interaction—pleasure? struggle?
- If parent and infant are connecting to one another
- If infant vocalizes back as you vocalize
- If infant gazes with great interest
- If infant smiles in response to vocalizations

#### Intervention/Education

3. Infant/Parent relationship
   - Provide feedback to parents regarding interactions with a focus on competencies and strengths
   - Teach emotional milestones of reaching out to the world and how the parent understands this concept
   - Eye-to-eye contact
   - Watch for communication cues
   - Talk with baby about what you are doing
   - Provide opportunities to sit
   - Teach importance of play
   - Importance of appropriate discipline
   - Appropriate limits for safety
   - Teach that play is baby’s work

4. Family cohesion and parent satisfaction
   - Address grief issues of the parent, potentially caused by separation from the infant in child care, especially when the infant “falls in love” with the child care provider
   - Support parent’s coordinator role in decision-making and collaboration with the primary care provider
   - Look for opportunities to build on family strengths in order to enhance abilities and foster independence
   - Demonstrate advocacy and empower the parent/caregiver to advocate

#### Resources

- Follow-Through Clinics
- HMO Case Manager
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</tr>
<tr>
<td>6. Safety/Lead issues</td>
<td>3. Infant/Parent relationship</td>
<td>- Parent Education Programs</td>
</tr>
<tr>
<td>7. Parents comfort in care coordination</td>
<td>- Provide feedback to parents regarding interactions with a focus on competencies and strengths</td>
<td>- Family Resource Centers</td>
</tr>
<tr>
<td>- Confidence in their knowledge of the infant’s medical status and the current plan of care for specific problems</td>
<td>- Teach emotional milestones of reaching out to the world and how the parent understands this concept</td>
<td>- Local Child Welfare Agency</td>
</tr>
<tr>
<td>- Current insurance status, transportation issues, and the availability/accessibility of medical/specialist care</td>
<td>- Eye-to-eye contact</td>
<td>- Support Groups for Parents with Disabilities</td>
</tr>
<tr>
<td>- Maintenance/prevention including immunizations and ongoing medical/dental care</td>
<td>- Watch for communication cues</td>
<td>- Follow-up Care for Vision/Hearing</td>
</tr>
<tr>
<td>8. Effectiveness/adherence to specific medical plan</td>
<td>- Talk with baby about what you are doing</td>
<td>- RSV Prophylaxis</td>
</tr>
<tr>
<td>- Prescriptions</td>
<td>- Provide opportunities to sit</td>
<td>- Parent-to-parent Support</td>
</tr>
<tr>
<td>- Specialists</td>
<td>- Teach importance of play</td>
<td>- EMS System</td>
</tr>
<tr>
<td>- Birth to 3</td>
<td>- Importance of appropriate discipline</td>
<td></td>
</tr>
<tr>
<td>- NICU follow-through clinic</td>
<td>- Appropriate limits for safety</td>
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<tr>
<td></td>
<td>- Teach that play is baby’s work</td>
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</tr>
<tr>
<td></td>
<td>4. Family cohesion and parent satisfaction</td>
<td></td>
</tr>
</tbody>
</table>
### Assessment

9. Parental coping with a child with special needs
   - Goals and concerns
   - Depression
   - Family relationships and communication
   - Style of coping
   - Support system/respite

10. Parent’s ability to demonstrate confidence in caregiving capabilities:
    - Progression of feeding
    - Progression of play activities
    - Sleep patterns and need for nighttime feedings

### Intervention/Education

- Continue to provide services that are sensitive to the family’s traditions, cultures and values
- Parents report successful networking to meet their family’s needs at home and in the community

### Resources

- **Appendices:**
  A. Bill of Rights
  B. Emotional Milestones
  C. Growth charts
  D. Guide to feeding/definitions
  E. Ages and Stages information
  F. Denver Developmental Screening information
  G. Birth to 3
  H. Public health nursing
  I. Follow-through programs
  J. Acute illness guidelines
  K. Statewide Perinatal centers
Outcomes: 1. To promote optimal growth for adjusted gestational age.
2. To promote optimal development for adjusted age.
3. To promote optimal development for adjusted age.
4. To promote parent-infant relationship.
5. To promote family cohesion and parent satisfaction.
6. To promote wellness.

Core Principles: 1. Children and families are treated with respect and dignity.
2. Families are given complete information in family-friendly language.
3. Families are encouraged to participate in decision-making and care planning.

Age 9 Months

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Intervention/Education</th>
<th>Resources</th>
</tr>
</thead>
</table>
| 1. Weight gain, length, and head circumference (always weigh infant naked to assure accurate and consistent plotting) | 1. Growth
- Plot measurements on only one growth chart to plot progress and discuss with family (App. C)
- Discuss concerns with breastfeeding/review proper formula preparation
- Anticipatory guidance for feeding changes and appropriate caloric intake
- Refer, if needed, for growth faltering
- Discussion regarding genetic potential | Hospital:
- Lactation Consultant/Dietitian
- Physical/Occupational/Speech Therapists
- Social Services
- Developmental Specialist
- Certified Nurse Practitioner
- Social Services
- Primary Care Provider
- Discharge Planner
- Bereavement Counselors
- Infant Massage
- Parent-to-Parent support |
| 2. Screen for feeding problems—diminished intake, more frequent feedings, vomiting and/or diarrhea, proper formula mixture, increased reflux, adequate amount of prescribed formula and medications available to family and concerns related to breastfeeding | 2. Development
- Reinforce to the family the importance of counting from the baby’s due date and not birthday when looking at development
- Offer age appropriate, as well as anticipatory play activities
- Screen for failure to meet developmental milestones using Ages and Stages (App. E)/Denver Developmental Screening (App. F)/refer to Birth to 3 (App. G) when appropriate |
| 3. Monitor weight gain. Expectations: For infants at their genetic potential (App. D) weight gain should be 15 grams/day if at genetic potential. If catch up growth is necessary, or if chronic lung condition exists, weight gain should be 30-45 grams/day. | |
| 4. Developmental milestones for corrected gestational age using a standardized tool (App. E&F) | |
| 5. Infant’s emotional milestone: Developing intentional communication. (App. B) Assess:
- If the parent is adapting his/her parenting and interactive style to the | |

Referrals:
- Primary Care Provider/Neonatologist
- Specialists/Specialty Clinics
- Physical/Occupational/Speech therapists
- Public health department
- Home care agencies
- Birth to 3 Agency
- Social Service Department
- Parish Nurse
- Dietitian
- Developmental Specialists
<table>
<thead>
<tr>
<th>Assessment</th>
<th>Intervention/Education</th>
<th>Resources</th>
</tr>
</thead>
</table>
| growing abilities of the baby | 3. Infant/Parent relationship | • Lactation Specialist  
| • The appropriateness of parental expectations | • Parents should demonstrate confidence in their caregiving activities and have the necessary training, resources, and support systems to meet their needs. | • Follow-Through Clinics  
| • Parental awareness of and sensitivity to infant cues, identification of and appropriate response to the infant’s distress | Key points to discuss: | • HMO Case Manager  
| • The tone of the interaction—pleasure? struggle? mutual? responsiveness? control? play/toys/body play? vocalization? laugh/squeals? | • Anticipate the child’s more complex behavior patterns—“peek a boo”, rolling a ball back and forth, pointing to desired objects | • WIC  
| • If the parent and the infant are closing “circles of communication” Does the baby expectantly look for the parent to respond? | • Anticipate baby’s growing assertiveness and testing of boundaries | • Family Support Groups  
| • The baby’s beginning assertion of independence and the parent’s comfort with this | • To anticipate a possible sense of loss/grief over the loss of baby’s emotional and physical closeness as baby develops | • Mental Health Resources  
| • Parents thought/plans on discipline | | • Family Service Agencies  
| • Whether the baby returns to the parent as a source of security | | • AODA Programs  
| 6. Safety/Lead issues | | • Wisconsin First Step  
| 7. Parents comfort in care coordination | | • Parent Education Programs  
| • Confidence in their knowledge of the infant’s medical status and the current plan of care for specific problems | | • Family Resource Centers  
| • Current insurance status, transportation issues, and the availability/accessibility of medical/specialist care | | • Local Child Welfare Agency  
| • Maintenance/Prevention including immunizations and ongoing | • To anticipate a possible sense of loss/grief over the loss of baby’s emotional and physical closeness as baby develops | • Support groups for Parents with Disabilities  
| Published resources: | | • Follow-up Care for Vision/Hearing  
| • American Academy of Pediatrics guidelines  
| • *First Feelings* by Stanley Greenspan and Nancy Thorndike Greenspan, 1985, Viking Press  
| • Karen Pridham, RN, Ph.D., Feeding and Caregiving Support Projects, UW-Madison School of Nursing, 608-238-7536  
| • Growth charts (www.cdc.gov/growthcharts.com)  
| • Internet [http://www.medsch.wisc.edu/childrenshosp/parents_of_preemies](http://www.medsch.wisc.edu/childrenshosp/parents_of_preemies)  
| • Hawaii Early Learning Profile (HELP)
## Care in the NICU/Weeks Prior to Discharge

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Intervention/Education</th>
<th>Resources</th>
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</thead>
<tbody>
<tr>
<td>medical/dental care</td>
<td>her/his interaction with the baby and the baby’s responses. Focus on competencies and strengths</td>
<td>- Books on premature babies</td>
</tr>
<tr>
<td>8. Effectiveness/Adherence to specific medical plan</td>
<td>• Provide role modeling behavior for parent by nurturing her/him relating to the infant</td>
<td></td>
</tr>
<tr>
<td>• Prescriptions</td>
<td>• Parents are able to report successful networking to meet their family’s needs at home and in the community</td>
<td></td>
</tr>
<tr>
<td>• Specialists</td>
<td>• Look for opportunities and empower the parent/caregiver to advocate independently and effectively</td>
<td></td>
</tr>
<tr>
<td>• Birth to 3</td>
<td>• Support parents role in decision making and collaboration with the primary care provider</td>
<td></td>
</tr>
<tr>
<td>• NICU follow-through clinic</td>
<td>• Demonstrate advocacy and empower the parent/caregiver to advocate independently and effectively</td>
<td></td>
</tr>
<tr>
<td>9. Parental coping with a child with special needs</td>
<td>• Continue to provide services that are sensitive to the family’s traditions, cultures and values.</td>
<td></td>
</tr>
<tr>
<td>• Goals and concerns</td>
<td>5. Wellness</td>
<td></td>
</tr>
<tr>
<td>• Depression</td>
<td>• Review and revise the care plan as needed/Indicate items completed</td>
<td></td>
</tr>
<tr>
<td>• Family relationships and communication</td>
<td>• Confirm future appointments/referrals</td>
<td></td>
</tr>
<tr>
<td>• Style of coping</td>
<td>• Provide education about diagnoses, referrals, and medications and their administration</td>
<td></td>
</tr>
<tr>
<td>• Support system/respite</td>
<td>• Help parents make referrals and complete appointments</td>
<td></td>
</tr>
<tr>
<td>10. Parent’s ability to demonstrate confidence in caregiving capabilities:</td>
<td>• If family is moving to a new</td>
<td></td>
</tr>
<tr>
<td>• Progression of feeding</td>
<td></td>
<td></td>
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<tr>
<td>• Progression of play activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Sleep patterns and need for nighttime feedings</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Appendices:
A. Bill of Rights
B. Emotional Milestones
C. Growth charts
D. Guide to feeding/definitions
E. Ages and Stages information
F. Denver Developmental Screening information
G. Birth to 3
H. Public health nursing
I. Follow-through programs
J. Acute illness guidelines
K. Statewide Perinatal Centers
**Assessment** | **Intervention/Education** | **Resources**
--- | --- | ---
| | geographic area, provide appropriate referrals | 
• Contact with local Public Health Department (App. H) |
Outcomes: 1. To promote optimal growth for adjusted gestational age.
   2. To promote optimal development for adjusted age.
   3. To promote parent-infant relationship.
   4. To promote family cohesion and parent satisfaction.
   5. To promote wellness.

Core Principles: 1. Children and families are treated with respect and dignity.
   2. Families are given complete information in family-friendly language.
   3. Families are encouraged to participate in decision-making and care planning.

### Age 12 Months

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Intervention/Education</th>
<th>Resources</th>
</tr>
</thead>
</table>
| 1. Weight gain, length, and head circumference (always weigh infant naked to assure accurate and consistent plotting) | 1. Growth  
   - Plot measurements on only one growth chart to plot progress and discuss with family (App. C)  
   - Discuss concerns with breastfeeding/review proper formula preparation  
   - Anticipatory guidance for feeding changes and appropriate caloric intake  
   - Refer, if needed, for growth faltering  
   - Discussion regarding genetic potential  
   - Educate families on how to advance feedings and safety issues related to feedings | Hospital:  
   - Lactation Consultant/Dietitian  
   - Physical/Occupational/Speech Therapists  
   - Social Services  
   - Developmental Specialist  
   - Certified Nurse Practitioner  
   - Social Services  
   - Primary Care Provider  
   - Discharge Planner  
   - Bereavement Counselors  
   - Infant Massage  
   - Parent-to-Parent support |
| 2. Screen for diminished intake, more frequent feedings, vomiting/diarrhea, proper formula mixture, reflux, adequate formula and medications available, and concerns about breastfeeding | 2. Development  
   - Reinforce to the family the importance of counting from the baby’s due date and not birthday when looking at development  
   - Offer age appropriate, as well as anticipatory play activities  
   - Screen for failure to meet developmental milestones using Ages and Stages (App. E)/Denver Developmental Screening (App. F)/refer to Birth to 3 (App. G) when necessary | Referrals:  
   - Primary Care Provider/Neonatologist  
   - Specialists/Specialty Clinics  
   - Physical/Occupational/Speech therapists  
   - Public health department  
   - Home care agencies  
   - Birth to 3 Agency  
   - Social Service Department  
   - Parish Nurse  
   - Dietitian  
   - Developmental Specialists  
   - Lactation Specialist |
| 3. Monitor nutritional intake for infants who are at their genetic potential (App. D) | | |
| 4. Developmental milestones for corrected gestational age using a standardized tool (App. E&F) | | |
| 5. Focus on infant’s emotional milestone: Emergence of an organized sense of self. (App. B) | | |
|   - Assess:  
     - If parenting style is adapting to growing abilities of infant  
     - Appropriateness of parental expectations  
     - Communication parent/infant | | |
### Care in the NICU/Weeks Prior to Discharge

**Assessment**

- Symbolic play (Limitation of parent-play with phone, broom etc.)
- Emotional tone of interactions
- Closes circle of mutual enjoyment (smiles and laughs)
- If infant plays in a focused manner
- Use of complex behavior to establish closeness
- Recovery from anger in a few minutes

**Intervention/Education**

- F)/refer to Birth to 3 (App. G) when appropriate
- Support/Encourage family to have formal developmental evaluations completed
- For those children who demonstrate developmental delay, referral for intervention and guidance for family to assess needed services

**Resources**

- Follow-Through Clinics
- HMO Case Manager
- WIC
- Family Support Groups
- Mental Health Resources
- Family Service Agencies
- AODA Programs
- Wisconsin First Step
- Parent Education Programs
- Family Resource Centers
- Local Child Welfare Agency
- Support Groups for Parents with Disabilities
- Follow-up Care for Vision/Hearing
- RSV prophylaxis
- Parent-to-Parent Support
- EMS System

**Published resources:**

- American Academy of Pediatrics guidelines
- *First Feelings* by Stanley Greenspan and Nancy Thorndike Greenspan, 1985, Viking Press
- Karen Pridham, RN, Ph.D., Feeding and Caregiving Support Projects, UW-Madison School of Nursing, 608-238-7536
- Growth charts (www.cdc.gov/growthcharts.com)
- Hawaii Early Learning Profile (HELP)
- Books on premature babies

<table>
<thead>
<tr>
<th>Infant/Parent relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipatory guidance regarding</td>
</tr>
<tr>
<td>Child’s growing use of words and social gestures such as pointing, use of “No,” giving hugs, working to explore and being assertive</td>
</tr>
<tr>
<td>Evolving play behaviors such as pretend play, spatial play, play alone, parallel play, not yet able to share well</td>
</tr>
<tr>
<td>Potential safety hazards in the home</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family cohesion and parent satisfaction</th>
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<tbody>
<tr>
<td>Provide feedback to parents regarding her/his interaction with the baby and the baby’s responses. Focus on competencies and strengths</td>
</tr>
<tr>
<td>Provide role model behavior for parent by nurturing her/him in relation to the infant</td>
</tr>
<tr>
<td>Parents report successful networking to meet their family’s needs at home and in the community</td>
</tr>
<tr>
<td>Support parents role in decision making and collaboration with the primary care provider</td>
</tr>
</tbody>
</table>

### 6. Safety/Lead Issues

7. Parent’s comfort in care coordination

- Confidence in their knowledge of the infant’s medical status and the current plan of care for specific problems
- Current insurance status, transportation issues, and the availability/accessibility of medical/specialist care
- Maintenance/Prevention including immunizations and ongoing medical/dental care

### 8. Effectiveness/Adherence to specific medical plan

- Prescriptions
- Specialists
- Birth to 3
- NICU follow-through clinic

### 9. Parental coping with a child with special needs

- Goals and concerns
- Depression
- Family relationships and communication
### Care in the NICU/Weeks Prior to Discharge

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Intervention/Education</th>
<th>Resources</th>
</tr>
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<tbody>
<tr>
<td>• Style of coping</td>
<td>• Demonstrate advocacy and empower the parent/caregiver to advocate independently and effectively</td>
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</tr>
<tr>
<td>10. Parent’s ability to demonstrate confidence in caregiving capabilities</td>
<td>• Review and revise the care plan as needed/Indicate items completed</td>
<td>Appendices:</td>
</tr>
<tr>
<td>• Progression of feeding</td>
<td>• Confirm future appointments/referrals</td>
<td>A.  Bill of Rights</td>
</tr>
<tr>
<td>• Progression of play activities</td>
<td>• Provide education about diagnoses, referrals, and medications and their administration</td>
<td>B.  Emotional Milestones</td>
</tr>
<tr>
<td>• Sleep patterns</td>
<td>• Help parents make referrals and complete appointments</td>
<td>C.  Growth charts</td>
</tr>
<tr>
<td>5. Wellness</td>
<td>• If family is moving to a new geographic area, provide appropriate referrals</td>
<td>D.  Guide to feeding/definitions</td>
</tr>
<tr>
<td></td>
<td>• Contact with local Public Health Department (App. H)</td>
<td>E.  Ages and Stages information</td>
</tr>
</tbody>
</table>
<pre><code>                                       |                                                                                        | F.  Denver Developmental Screening information |
                                       |                                                                                        | G.  Birth to 3                                 |
                                       |                                                                                        | H.  Public health nursing                      |
                                       |                                                                                        | I.  Follow-through programs                    |
                                       |                                                                                        | J.  Acute illness guidelines                   |
                                       |                                                                                        | K.  Statewide Perinatal Centers                |
                                       |                                                                                        |                                                |
</code></pre>
Appendix A: After Discharge Bill of Rights

• Families are entitled to care by knowledgeable professionals who understand that taking a premature baby home from the hospital can be a difficult time for families.

• The plans for follow-through care should be in writing and should be shared with the family, as well as all the other community health professionals who will be providing care for the child after the hospital discharge.

• Families are entitled to have community health care professionals assess and teach them in their home, if that is what they desire, and assist them in how to obtain the necessary services their child may need.

• Families should have a clear understanding of whom they should contact if they hit roadblocks or need assistance.

• Families should be able to obtain funding, if they are eligible, to allow them access to the services that their child needs.

• Community health care professionals should be available, in adequate numbers, to meet the community’s need in providing medical, nursing and therapy services to the children who need them, in a timely fashion.

• All health care providers should be able to talk to each other and help the family obtain and/or maintain the services that their child needs.

Wisconsin Association for Perinatal Care Infant & Family Committee
11/03
Appendix B - Emotional Milestones

In their book *First Feelings*, (1985) Stanley Greenspan and Nancy Thorndick Greenspan suggest that parents chart their baby’s emotional milestones. Such milestones include learning to see the world as regulating, interesting and loving. Later a child will demonstrate his assertiveness, curiosity and autonomy. Thinking about earlier development may help parents appreciate their baby more fully and see exciting opportunities.

The Greenspans use four emotional milestones and provide behaviors that help parents determine if their baby is accomplishing them. The four milestones that occur in the first year of life are:

I. Self-regulation and interest in the world (birth to three months)
II. Falling in love (two to seven months)
III. Developing intentional communication (three to ten months)
IV. Emergence of organized sense of self (nine to eighteen months)

The following are behaviors taken from *First Feelings*, as they fit into each of the four milestones’.

I. Self-regulation and interest in the world (birth to three months)
   Increasingly (but only sometimes):
   a. Able to calm down
   b. Sleeps regularly
   c. Brightens to sights
   d. Brightens to sounds
   e. Enjoys touch
   f. Enjoys movement in space

II. Falling in love (two to seven months)
   When wooed, increasingly (but only sometimes)
   a. Looks at you with special joyful smile
   b. Gazes at you with great interest
   c. Joyfully smiles in response to your voice
   d. Joyfully smiles in response to your facial expressions
   e. Vocalizes reciprocally

III. Developing intentional communication (three to ten months)
   Increasingly (but only sometimes) responds to:
   a. Your gestures with return gestures
   b. Your vocalizations with vocalizations
   c. Your emotional expressions with an emotional response
   d. Pleasure or joy with pleasure
   e. Encouragement to explore with curiosity
Increasingly (but only sometimes) initiates:

f. Interactions

g. Joy and pleasure

h. Comforting

i. Exploration and assertiveness

IV. Emergence of organized sense of self (nine to eighteen months)

Increasingly (but only sometimes):

a. Initiates a complex behavior pattern such as going to a refrigerator and pointing to a desired food

b. Uses complex behavior to establish closeness

c. Plays in a focused, organized manner on own

d. Examines toys or other objects to see how they work

e. Responds to limits that you set with your voice or gestures

f. Recovers from anger after a few minutes

g. Uses objects like a comb or telephone

h. Seems to know how to get you to react

If a child does not show a pattern of progressive accomplishments, despite practice and understanding, a professional consultation may be indicated.

Appendix C: Growth Charts

Growth parameters of NICU infants are carefully monitored. Growth charts provide a standardized norm with which to compare an individual infant’s weight, length, and head circumference to establish a baseline and identify special needs. There are a number of growth charts available using various reference populations. The reference population of the chosen growth chart should match the individual infant being evaluated as closely as possible in gender, ethnic, socioeconomic, and environmental variables.

The CDC released updated growth charts in May of 2000. These new charts use government data from the last three decades about formula- and breast-fed children from all racial and ethnic groups. Low birth weight infants (1500 – 2500 grams at birth) were also included in the CDC reference population. An alternate growth chart for use with very low birth weight (less than 1500 grams at birth) preterm male and female infants was developed from data obtained during the Infant Health and Development Program and is published by Ross Products Division, Abbot Laboratories. When these charts are used for premature infants, the growth parameters should be plotted according to the age adjusted for prematurity. In general, the adjusted age should be used until the child reaches 2 years or until the transition from the birth to 36 month charts to the charts for 2 – 20 year olds. When dealing with premature infants, it is important to note that once the infant reaches 40 weeks gestation, the caregiver must switch from using the growth chart developed for premature infants to the growth chart used for full-term infants.

To view and download growth charts, please click on the following link to the CDC website:

www.cdc.gov/growthcharts/.
Appendix D: Guide to Feeding

Feeding Definitions

1. **Adjusted Age.** An infant’s adjusted age is calculated using the expected due date as day one of life. Example: Expected due date (day/month/year) minus birthdate (day/month/year) = gestational age. Birthdate (day/month/year) minus gestational age (day/month/year) = adjusted age. For the purposes of this document, adjusted age will be used through the second year of life. (See “How to figure out your baby’s adjusted age for prematurity” on page 26.)

2. **Genetic Potential.** For infants born average for gestational age (AGA), their genetic potential is considered to be the exact growth percentile at which they were born. Infants may reset this potential at any time during the first two years. For infants born below the 10th percentile, the goal would be weight above the 10th percentile by age 2.

3. **Catch-up growth.** The purpose of catch-up growth is to recover at least the birth trajectory of infants born AGA or to reach the 10th percentile for those born below the 10th percentile. For a statement on catch-up growth, see pgs. 27-29 or www.perinatalweb.org, click on publications.

4. **Growth Faltering.** Dropping lower on the growth graph despite weight gain should be considered growth faltering and indicates a need for assessment. This may indicate an acute or chronic health problem. Both situations indicate a need for increased calories.

5. **Failure to Thrive.** Failure to thrive is defined as a deceleration of growth velocity in children, leading to the falling off of two major percentiles on a standard growth chart. Failure to thrive can be classified as **organic:** caused by a defect in the infant’s body system, or **inorganic:** caused by care-giving or psychosocial factors in the infant’s environment.

6. **Velocity.** Number of grams of weight, centimeters of length, or head circumference gained per day.

**Weight Gain:**

<table>
<thead>
<tr>
<th>Age</th>
<th>Norm</th>
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<tbody>
<tr>
<td>10 days-4 months</td>
<td>25-30 gms/day</td>
</tr>
<tr>
<td>4-8 months</td>
<td>20 gms/day</td>
</tr>
<tr>
<td>8-12 months</td>
<td>+15 gms/day</td>
</tr>
<tr>
<td>Over 12 months</td>
<td>5-10 gms/day</td>
</tr>
<tr>
<td>Catch-up</td>
<td>30-40 gms/day</td>
</tr>
</tbody>
</table>
Length Gain (up to 6 months)

<table>
<thead>
<tr>
<th>Age</th>
<th>Norm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full term</td>
<td>.66 cm/week</td>
</tr>
<tr>
<td>Preterm</td>
<td>.8-1.1 cm/week</td>
</tr>
</tbody>
</table>

Head Circumference--Norm is .5-1.1 cm/week.

Assessment of Growth Faltering/Weight Loss

1. Are there indications of impaired caregiver/infant attachment?
2. Are feedings fewer or shorter in duration?
3. Is breast milk supply adequate?
4. Is caregiver mixing formula correctly?
5. Is there an adequate supply of formula in the home?
6. Does infant have signs and symptoms of reflux?
7. Are there sucking or swallowing difficulties related to neurologic disease, congenital anomaly, or prematurity?
8. Is there adequate “latch on” during breastfeeding?
9. Does the infant have a malabsorption condition?
   - Cystic fibrosis
   - Celiac Sprue
   - Parasitic Infection
   - Milk Allergy
HOW TO FIGURE OUT YOUR BABY’S ADJUSTED AGE FOR PREMATURITY

The following sections are meant to provide guides for your baby’s development. It is important to remember that all babies are different and will develop at their own rate. Being sick or in the hospital, or having a condition such as chronic lung disease or gastroesophageal reflux can affect a baby’s growth and development. Remember to celebrate your baby’s progress.

If your baby was born early, you will need to use your baby’s adjusted (or corrected) age when looking at what to expect your baby to be doing. **Always use your baby’s due date to determine your baby’s adjusted age.**

Let’s say that your due date was June 3 and your baby was born on March 15. The difference between when your baby was due and when he was born is 80 days or approximately 11 weeks or 2 ½ months. Until your baby is at least 2 years old, you should take away that many days, weeks, or months from his actual age based on his birth date. This is called adjusting (or correcting) his age for prematurity.

```
April 1      May 1
March 15    Birthday
June 3      Due Date

80 days
Approximately 11 weeks
Approximately 2 ½ months
```

Here’s how you adjust his age. On September 15, he will be 6 months old according to his birth date. However, you know that he was 2 ½ months premature, so you take away 2 ½ months from 6 months, which leaves his age at 3 ½ months (his adjusted age). **You always use his adjusted age when you read about development and when you (or your baby’s doctor or nurse) fill out his growth chart.** Using his adjusted age helps to not expect too much of the baby and to respect that he was born early.

Now you can figure out your baby’s adjusted age:

- Date my baby was due: ________________________________.
- Date my baby was born: ________________________________.
- My baby was born ________ days or ________ weeks or ________ months early.

VIII-D-3
Catch-up Growth in Premature Infants
(Born Appropriate for Gestational Age = AGA)

A premature infant’s weight, length, and head circumference frequently fall below the 50th percentile when plotted on a growth grid, even when the infant’s age is adjusted for prematurity. The distance between where the infant’s growth actually falls and the 50th percentile is considered to be his or her growth potential, or the gap that needs to close in order to say that the infant is “caught up” with peers. Catch-up growth is based on growth velocity (the rate of change in growth over time), where the velocity excess during catch-up equals the deficit during growth faltering. Factors that influence catch-up growth include gestational age at birth, size for gestational age at birth, genetic potential, neurological injury, illness, and nutritional intake. Generally, catch up occurs first in head circumference, then length, then weight.

Community care providers are critical in supporting premature infants and their families in attaining healthy outcomes. These providers include primary physicians (family physicians and pediatricians), public health nurses, nurse practitioners, Birth to 3 providers, registered dietitians, and WIC nutritionists. Growth is a reflection of a young child’s well being. Compared to good growth, poor growth is more often associated with frequent illnesses and hospitalizations and lower bone density. Quality of care affects growth. Evidence-based care to support growth begins with adjusting a premature infant’s chronological age for prematurity. Quality care includes close monitoring of growth parameters to allow for early recognition of a downward trajectory, immediate efforts to encourage catch-up growth, (e.g., nutritional supplementation), and early detection and treatment of illness.

The purpose of this statement is
- To define parameters for adjusting an infant’s age for prematurity.
- To provide resources and intervention strategies for community care providers in their efforts to support optimal growth in premature infants.

Recommended Resource
For detailed information beyond the scope of this statement, we recommend that community care providers use the University of Washington’s website “Gaining and Growing: Assuring Nutritional Care of Premature Infants” as a primary source of good information on nutrition and growth of premature infants:
http://depts.washington.edu/growing

Adjusting age for prematurity
Adjusting age for prematurity helps health providers set realistic expectations for the infant’s growth and development. The provider can then communicate these expectations to parents and other individuals caring for the infant. For as long as the first two to three years, premature infants are likely to exhibit lower than average weight and length unless allowance is made for gestational age. Therefore, what is normal may not seem normal unless one adjusts for prematurity. For example, a baby born on March 30 and due on June 30 would be approximately 1 month old (or 4 weeks) on July 30. Here are some tips for adjusting a baby’s age for prematurity.

- Round off the adjusted age to the nearest week.
- Continue to adjust at least through 24 months (2 years).
- Even if a baby is caught up to the 50th percentile, careful monitoring is important since catch-up growth tends to wax and wane with illness, changes in nutrient intake, or other factors.
- Get accurate measurements.
  - Measuring length requires two people and a length board with a head and foot piece. One person holds the head in position. The second person straightens the
knees and brings the ankles to a right angle with the foot piece. Lengths done on exam tables using a tape measure are approximations at best, and often useless in accurately tracking growth.

- Weigh on a digital scale.

**Plotting anthropometric measurements**

It is important to plot a baby’s measurements in a timely fashion on a consistent growth chart. Incremental weight charts (measuring velocity) provide more graphic illustration than standard growth charts regarding the changes in weight over time, but these charts may not always be readily available or applicable to current age (such as if infant still has not reached term). Refer to the “Gaining and Growing” website for additional information on growth charts. You can download current growth charts available in English, Spanish, and French from www.cdc.gov/growthcharts (weight for age, length for age, head circumference for age, weight for length).

**Characteristics of growth faltering**

Growth faltering means that attained growth is inadequate or growth velocity is reduced, compared to expected growth velocity. One or more of the growth parameters may be below the 5th percentile on the growth chart, for example, with the infant’s age adjusted for prematurity. Alternatively, growth faltering describes the situation when one or more parameters drop two or more standard deviations (i.e., channels) on the growth chart (e.g., from the 50-75th percentiles to the 5-10th). Generally, growth faltering happens first in weight, then length, then head circumference. Poor head growth is a late, and more ominous, sign of nutritional deficits. **Intervening when an infant’s weight starts to falter may reverse the downward growth trajectory before it affects the infant’s brain and overall development.** Sometimes clinicians are deceived about growth by how a baby looks or the clinician might think, “Well, the parents are small.” Remember, to judge adequate growth, you need accurate anthropometric measurements.

**Providing optimum nutrition to premature infants**

Breast milk is the nutrient of choice for premature infants. Breast milk protects against infection, is easily digested and well tolerated, contains species-specific nutrients, enhances cognitive development and reduces cost of both health care and feeding itself. For specific nutritional requirements, refer to the “American Academy of Pediatrics Guidelines for Very Low Birthweight Infants” (available at www.aap.org or from “Gaining and Growing”).

- Infants who are breastfed, as well as those fed either breast milk or formula, may need additional calories and nutrients through supplementary feedings. (See, for example, Meier, 2003)
- Premature infants (even those who are 34-37 weeks) need closer monitoring than full-term infants.

**Summary**

The goal of monitoring the growth of premature infants is two-fold: to prevent or arrest growth faltering and to improve the odds of achieving partial or complete catch-up growth in a timely manner. For the newborn premature infant, care should focus on support of the infant’s return to his or her in utero growth trajectory prior to hospital discharge. For the premature infant who is already living in the community at large, family and health care energy should focus on provision of nutrients appropriate to support catch-up growth. While not every premature infant will achieve the 50th percentile, or even the 10th percentile weight, length, and/or head circumference for adjusted age, with few exceptions the goal should continue to be achievement of, or return to, the growth pattern the infant would have followed if he or she had been born at term.

*Authors:* Sherie Sondel, MEd, RD, CD, DHFS, Division of Public Health, Madison; Janine Bamberger, MS, RD, CD, Aurora Sinai Medical Center, Milwaukee; and Rana Limbo, PhD, RN, CS, WAPC staff

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Appendix E: Ages and Stages Order Information

by Diane Bricker, Jane Squires, Linda Mounts, LaWanda Potter, Robert Nickel and Jane Farrell

Order information:

www.pbrooks.com/store/books/bricker-asq
or email custserv@brookspublishing.com
Appendix F: How to order Denver Developmental Screening Materials

Prescreening Developmental Questionnaire (PDQ) and the Revised PDQ (R-PDQ):

Derived from the Denver Developmental Screening Test (DDST), the PDQ and R-PDQ are brief, valid developmental tests that are parent answered. Those who have suspected delays on the PDQ or R-PDQ may be screened using the Denver II.

Denver Developmental Screening Test (Denver II)

The Denver II is the new version of the DDST. It is used for screening the development of children from one month to six years of age. It takes 10-20 minutes and is administered by a professional or a trained paraprofessional.

To order Denver Developmental Materials contact:
Denver Developmental Materials, Inc.
P.O. Box 371075
Denver, CO 80237-5075
(303) 355-4729
1 (800) 419-4729
fax: (303) 355-5622
www.denverii.com/order.html
Appendix G: What to Expect From the Birth to 3 Program

The Birth to 3 Program is Wisconsin’s early intervention program for infants and toddlers with developmental delays and disabilities and their families. The federal Individuals with Disabilities Education Act (IDEA) provides the framework for the program, and the Department of Health and Family Services (DHFS) oversees the program in Wisconsin. The Birth to 3 Program is available in every county in Wisconsin. The program may be called by a different name locally, but all operate under the same provisions.

Birth to 3 services and supports for this family-centered program are primarily provided in the family’s home, or other “natural” environment for the family, such as child care locations or other community settings. In the natural family setting early intervention services can be embedded in everyday routines and activities.

Health care providers, including NICU staff, are part of an informed referral network for Birth to 3 and are required to refer a child to Birth to 3 for a screening or evaluation no more than two days after the child has been identified. The NICU staff may conduct a screening if it is suspected that the infant has a developmental delay, and a referral may be made for a Birth to 3 evaluation. An infant with a physician diagnosed physical or mental condition which has a high probability of resulting in developmental delay should be referred for an evaluation. For purposes of evaluation the baby’s age is adjusted for prematurity.

Ideally, the Birth to 3 service coordinator and the NICU staff interact before discharge for transition from the hospital to home. Services may begin prior to the child being released from the NICU and continue until the age of three if needed.

Making a referral, locating the correct county program, and obtaining further information can be accomplished by calling First Step at 1 800 642 7837. First Step is an information and referral service to assist Wisconsin families who have a child with special needs. When you know the correct county of residence, you may also obtain direct telephone contact information on the DHFS website by searching under any county name plus “Birth to 3.”

After referral, and with parental consent, eligibility for Birth to 3 services is determined by a local early intervention team. A Birth to 3 service coordinator will bring together an evaluation team or use an evaluation conducted in the NICU if the format meets Birth to 3 criteria. Common members of an evaluation team include: early childhood educators; occupational, physical and speech-language therapists; nurses; and social workers. Eligibility for this program is not affected by the family’s income; however, parents may need to contribute to the costs of services.

After eligibility is determined, the service coordinator, early intervention staff, and family members become a team to identify family strengths, priorities, concerns, and resources. Within 45 days of the referral, the team develops an Individualized Family Service Plan (IFSP) that identifies outcomes and steps to achieve the outcomes for the child and family.
In addition to special instruction, therapy, and social work, some other common services that may be included in the IFSP are assistive technology, family education and counseling, vision, nutrition, audiology, and related health care.

At the age of three, the service coordinator again prepares the child and family for transition to schools and other agencies if the team recognizes the need for continued intervention.

Visit the following DHFS web page for more information:
http://www.dhfs.wisconsin.gov/bdds/birthto3
The state Birth to 3 office can be contacted at (608) 266-8276.
Appendix H: Public Health Nursing Visits

The following basic level of individual and family services is offered to all families who have a newborn discharged from an NICU. The intensity and length of service is based upon the presenting needs of the family, available community resources, and the family’s internal strengths and resources. The public health nurse is responsible for assessing family’s needs, strengths, and resources; providing nursing care and management of the infant as appropriate; health teaching; and anticipatory guidance to parents and care coordination with other providers as needed.

The standard of care from the public health nurse is as follows:

1. All NICU units will contact the public health department prior to discharge of an infant, and the public health nurse will make contact for a visit within several days of discharge. The timing of the discharge referral and visit will depend on arrangements made between Local Public Health Departments (LPHD) and the NICU of the region.

2. All parents of an infant discharged from the NICU will be offered a home visit. Components of the home visit will include:
   - **Well child exam** including suggested contents of a health check exam
   - **Health and developmental history**
   - **Environmental assessment and teaching**
   - **Psychosocial assessment** including adjustment of the family and sources of support
   - **Health teaching and guidance** to include sleep, growth and development, nutrition, immunizations, comfort measures, etc.
   - **Care coordination** to assure service needs are being met through the assessment of service needs, making appropriate referrals, providing ongoing monitoring and follow-through as needed, e.g., referral to WIC, immunization, W-2, primary physician.
   - **Postpartum assessment and assessment of other family members**

3. All public health nurses will follow-through with the infant’s primary care provider after the first home visit either in writing or by telephone.

4. All public health nurses will complete a written visit report to the referring NICU within three weeks of referral if a written report is sent from the NICU.

5. Ongoing LPHD services are based on the plan of care developed with the family.
Appendix I: Follow-through Programs

Newborn intensive care has improved the survival of preterm infants and sick newborns. Associated with the increased rate of survival is an increase in the number of infants who are at higher risk for having some degree of central nervous system dysfunction which may manifest as cerebral palsy, mental retardation, autism, blindness, seizure disorders, auditory disturbances, or other brain dysfunction. It is crucial that the physical and developmental progress of such high-risk infants be routinely monitored. When abnormalities are suspected, full diagnostic and treatment services must be provided.

The neonatal follow-through program is meant to complement the ongoing care, treatment and guidance provided by the infant’s primary health care provider. The purpose of this program is to identify, at the earliest possible time, those infants and children who are experiencing some physical or developmental abnormality. The follow-through program is composed of a team of parents and professionals who are trained in the subtle nuances of developmental delay. This nurse-physician team are experienced in evaluating development and are present to serve as resources to integrate the child’s medical needs as they may impact on the child’s developmental outcome.

The goal of high-risk neonatal follow-through is to assist the family in helping the child reach his or her fullest developmental potential. Screening in the neonatal follow-through program takes place at regular intervals to evaluate skills that correspond with emerging brain development. Generally these occur at three to six months when motor skills and antigravity movement begins; at 18 to 24 months when cognition begins to be measurable; and at 30 to 35 months when early pre-academic skills emerge. Routine screening across this continuum also focuses on the child’s emotional development and attachment, as well as family support and coping. Recommendations based on evaluations are shared with the family and are communicated to the primary health care provider for potential referral to medical specialists and therapy services. Families are provided with resources to assist in meeting the child’s special needs.

For additional information regarding Neonatal Follow-Through Programs (also known as Developmental Assessment Programs) in Wisconsin and your area, please contact your local Neonatal Intensive Care Unit or Perinatal Center, or contact the Wisconsin Association for Perinatal Care.
Appendix J: Common Illness Guidelines

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For information, contact Karen Pridham, PhD, RN, Professor Emerita, University of Wisconsin-Madison School of Nursing, 600 Highland Ave., Madison, WI, 53792; 608-263-9886 or 1-800-241-4776; kpridham@facstaff.wisc.edu.
Dear Parent:

The common illness guidelines that are attached were prepared to support families of very low birthweight babies in giving safe care and communicating effectively with the baby's doctor when the baby is sick. The guidelines are written for babies who weighed 1500 grams or less at birth and are under 12 months of age, adjusted for prematurity. They are intended to help you to communicate with your baby's doctor about handling illnesses.

These guidelines contain general information and typical guidance based on that information. It is not possible to include in these guidelines all the background information that you might need to know about your baby's common illness care. The guidelines are not a substitute for professional medical advice and treatment recommendations for baby's illnesses.

You should consult your doctor, who is familiar with your baby and your baby's medical history, for specific advice and treatment recommendations. Please be sure to contact a doctor whenever you think consultation about your baby is needed. Please also be sure to follow the recommendations that the doctor makes for your baby.

Sincerely,

Karen Pridham
Karen Pridham, PhD, RN
Family Caregiving Project Director
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How to Use the Common Illness Guidelines

For each guideline, there are two sections.

Section 1 has information about:

1. What the common illness or problem is.

2. What tells you that your baby may have the illness or problem.

3. What to do to take care of your baby when you notice the signs of the illness.

4. When to call the doctor.

Section 2 includes:

1. A place to write what the doctor wants you to do when your baby has the illness or problem.

   When you take your baby to the clinic for the first time, talk with the doctor or the nurse about what you should do when your baby has the common illness sign or problem. Fill in the blanks with what the doctor or nurse tells you.

   Look at what you have written down when your baby has a sign of illness.

2. Questions the doctor or nurse may ask you when you call the clinic.

   Think about the answers to these questions before you call the doctor. Your answers will help the doctor or nurse get a better idea of what is happening.

3. Ask the public health nurse who works with you to look at what your doctor wants you to do. Talk over with the public health nurse how she/he might guide you concerning your baby’s care when sick.

Remember, when the guidelines give an infant’s age, the age is adjusted for prematurity. Three months, for example, means three months of age adjusted (or corrected) for the amount of time the baby was born early.
Who to Contact: Names and Telephone Numbers

Doctors:

*Baby’s Primary Care Doctor* .................................................................

How/best times to contact ..................................................................

*Specialist Doctors*  ..........................................................................

.................................................................................................

.................................................................................................

.................................................................................................

Nurses:

*Public Health Nurse* .................................................................

How/best times to contact ..................................................................

*Clinic Nurse* .............................................................................

How/best times to contact ..................................................................

*Special Care Nursery Nurse* ..........................................................

How/best times to contact ..................................................................

*Home Care Nurse* ........................................................................

How/best times to contact ..................................................................

*Project Nurse* .............................................................................

How/best times to contact ..................................................................

*Family Service Worker:* ..............................................................

How/best times to contact ..................................................................

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Therapists (Physical Therapist, Occupational Therapist, Speech Therapist):

Early Childhood Program (Birth to 3, Early Head Start):

Dietitian:

Pharmacy:

Vendors:
Apnea Monitor
Oxygen

Others:
COMMON ILLNESS GUIDELINES: BREATHING DIFFICULTY

DEFINITION: The breathing pattern indicates when your baby is having to work hard to breathe or has to struggle to breathe.

SIGNS: • Nasal “flaring” (the nostrils flare out and get wider when a breath is taken in).
• Pulling in of the skin between the ribs/above or below the rib cage.
• Noisy breathing, for example, a crowing or croupy noise during feeding.
• Wheezing.
• Coughing.
• Choking with feeding.
• Apnea (pauses of 10 or more seconds between breaths) or frequent pauses in breathing of more than a few seconds.
• If your baby is less than 6 months old, breathing rate (at rest or with feeding) is greater than 60 breaths per minute. If your baby is 6 months old or older, breathing rate greater than 40-50 breaths per minute is abnormal during feeding. Greater than 40-50 breaths at rest is not normal.
• Runny or stuffy nose, sleepiness, fussiness, unable to rest lying down, poor appetite, fever.

ADVICE FOR CAREGIVER:
• Remember that babies who are born very low birthweight will tend to get sicker quicker. Babies with chronic lung disease may have ongoing signs of respiratory problems. However, the doctor should be contacted when any signs of illness get worse.
• Keep your baby’s nose clear by cleaning the outer nose with tissue or using a bulb syringe.
• Use a bulb syringe to put saline drops in your baby’s nose to keep secretions thin. To make saline, mix 1/4-tsp. salt with 1 cup of warm water. Use exact measures of the salt and water. Keep this solution clean and in a clean container.
• Use a cool water humidifier in your baby’s room. Clean the humidifier according to instructions.
• Use of cough medicine or antihistamines is NOT recommended in infants because coughing is a protective reflex.
• Your baby should not be exposed to smoke in either home or car.
CALL DOCTOR IMMEDIATELY:

- If your baby’s color is pale gray, pale blue, or darker, especially around the lips and nail beds.

- If your baby looks tired, very drowsy, or floppy.

- If your baby has difficulty drinking or is unable to drink liquids.

- If your baby has trouble crying or speaking.

- If your baby has retractions. This means that, when breathing in, the baby’s skin pulls in between the ribs, under the rib cage, or in the neck area.

- If your baby’s breathing becomes noisier.

- If your baby’s cough becomes high-pitched or sounds like barking.

CALL DOCTOR:

- If secretions from the nose are yellow, green or blood-tinged.

- If your baby has continuous coughing with vomiting.

- If your baby has signs of a breathing problems with a fever (temperature of equal to or greater than 100.4°F rectally or 99°F (axillary) for greater than 1-2 days.

- If your baby has clear drainage from the nose, occasional cough, congested nose or low grade fever for greater than three days. A low grade fever is around 100.4°F rectally or 99°F axillary.

- If you believe that you need to talk with a doctor about your baby’s breathing difficulty.

CALL DOCTOR WITHIN ONE DAY:

- If your baby’s breathing is hard and fast. This means:
  - more than 60 breaths per minute if your baby is less than 6 months old.
  - more than 40-50 breaths per minute if your baby is 6 months old or older and your baby has not been breathing that fast.
BREATHING DIFFICULTY - GUIDELINES

My baby’s doctor recommends using a cool water humidifier. _____ Yes _____ No

My baby’s doctor recommends use of saline drops. _____ Yes _____ No

My baby’s doctor would like to be called if my baby:
  Has a fever greater than ______ for ______ hours/days.
  Is wheezing. ______
  Needs more than ______ nebulizer treatments in ____hours/day.
  Is coughing for longer than ______ hours/days.
  Has had a runny nose for longer than _____ days.

Questions the Doctor May Ask You

1. Is your baby coughing up mucous (describe color)?
2. How bad is the cough?
3. Does your baby's coughing result in vomiting?
4. Is the cough dry or moist sounding?
5. Does the coughing sound like an animal barking?
6. How long has your baby been coughing?
7. Is the cough worse at night?
8. Is the cough getting better or worse?
9. What medicine has your baby had to treat the cough?
10. Does your baby have a fever?
11. Does your baby have mucous coming from the nose? What color is it?
12. Has your baby’s feeding pattern changed? Is your baby feeding less at a feeding or feeding less often?
13. Is your baby more sleepy than usual?
14. Is your baby more fussy than usual?
15. If your baby already has chronic lung disease, what has changed? Are there any new signs of breathing difficulties?
COMMON ILLNESS GUIDELINES: CONSTIPATION

DEFINITION: Hard, painful, or difficult to pass stool/bowel movements. Infrequent stools (every 2 to 4 days or more).

SIGNS:
• Straining, crying, or cramping when passing a stool.
• Unable to pass stool after straining more than 5-10 minutes.
• Small babies may strain due to weak abdominal muscles.

ADVICE FOR CAREGIVER:
• A baby may not have a stool every day and still be in good health.
• Give a 20 minute sitz bath in warm water. A sitz bath means that you hold your baby so that the warm water covers the buttocks. This may help relax the anal sphincter (muscular opening to the bowel) so your baby can move the stool out.
• Mix your baby's formula exactly like the directions say.
• Prevent constipation if your baby’s stools tend to be hard.

If your baby is 4-6 months old or older
• add non-citrus juices such as pear, apple, peach, prune, or white grape (1-2 ounces) 2 times/day.
• add baby foods with high fiber content such as peas, beans, apricots, prunes, peaches, plums and pears.
• adjust the amount of juice or high fiber foods depending on the response of your baby’s stools. If the stool is too loose, give less juice or fibrous food.
• when you have found an amount of juice or fibrous foods that help to keep your baby’s stools soft, use once or twice daily for 1-2 months.

CALL DOCTOR:
• If there is bleeding from the anal area or blood in the stool more than one time or the first time for an infant under 1 month of age.
• If constipation becomes worse (there is a longer time between stools).
• If diet changes but does not relieve constipation or if the baby is on a non-constipating diet for longer than 1 week and the number of days between stools is still more than 2-3.
• If you believe that you need to talk with a doctor about your baby’s stools.

CALL DOCTOR WITHIN ONE DAY:
• If baby seems to have pain in the abdomen.
CONSTIPATION - GUIDELINES

My baby’s doctor would like to be called if my baby goes ___________ days without having a stool.

My baby’s doctor recommends the following non-constipating diet:
- corn syrup______   amount________________
- non-citrus juices______   type________________
- amount____________
- high-fiber baby foods______   type________________
- amount____________

My baby’s doctor recommends gentle rectal stimulation. ____ Yes ____ No       If yes, this stimulation should be with __________.

My baby’s doctor recommends a warm sitz bath. _____ Yes _____ No

Questions the Doctor May Ask You

1. How long has your baby had constipation?
2. How many days between two stools that your baby had without help from you?
3. What type of foods are you feeding your baby?
4. Is there any blood in your baby’s stool?
COMMON ILLNESS GUIDELINES: DEHYDRATION

**DEFINITION:** Dehydration means a serious loss of water and salt from the body. Dehydration is a very serious and even dangerous problem and is often the reason for babies being hospitalized. If it is not treated, dehydration gets worse.

Your baby may become dehydrated with poor appetite, vomiting, diarrhea, or fever. Vomiting and diarrhea are the most common causes of dehydration in babies. Babies may become dehydrated when the weather is hot and they do not have enough liquid to drink. Babies who take diuretics, such as Lasix, are at greater risk for dehydration. If your baby is receiving a diuretic medication, ask the doctor how best to prevent and treat dehydration in hot weather.

There are three stages of dehydration—mild, moderate, and severe. The goal is to prevent the baby from becoming moderately or severely dehydrated by taking care of signs of mild dehydration as soon as they are noted.

What the baby is like for each stage is described below. It will help you to recognize dehydration if you know about how often your baby usually wets his/her diaper when he or she is feeling well.

**SIGNS:**

*Mild Dehydration*
- Wets a few less diapers than he/she usually does
- Has a slightly dryer mouth
- May be more thirsty or hungry than usual

*Moderate Dehydration (in addition to the signs listed above)*
- Is fussy and irritable
- Is less playful and may lack interest in things
- Has a mouth that feels dry or sticky
- Has fewer tears when crying
- Has skin that feels looser than skin usually feels—the skin may not spring back when it is pinched together
- Wets fewer diapers
- Has a soft spot on the top of the head that is sunken instead of being flat
- Is quite thirsty
Severe dehydration (in addition to the signs listed above)

- Is very fussy or irritable
- Or is very sleepy or hard to wake up
- Has sunken eyes
- Does not have tears when crying
- Has cool hands and feet that may be blue and blotchy
- Has wrinkled or loose skin—the skin makes a tent that remains after the skin has been pinched together
- Does not wet a diaper for several hours
- Has a sunken soft spot on the top of the head
- Breathes rapidly and deeply

ADVICE FOR CAREGIVER:

Take steps to prevent dehydration.

If your baby has diarrhea, vomiting, or a fever, be sure to carefully follow the Guidelines for these illnesses. Following these Guidelines will help keep your baby from becoming dehydrated.

Remember that young babies who are born very low birth weight and babies who are receiving diuretic medication will get dehydrated quicker than other babies. However, any baby will get even mildly dehydrated faster than an adult. A baby cannot store water very well and turns it over faster than an adult. Babies depend on adults to take care of fluid needs and cannot satisfy thirst on their own.

Pay special attention to your baby when the weather is hot. A baby needs extra liquid in hot weather to make up for losses of water and salt through sweating. When it is hot outside, try to keep your baby cool. Prevent sweating. Use a fan to cool your baby’s room if you do not have air conditioning. Place the fan so that it does not blow directly on the baby. Keep your baby out of the sun and out of cars that cannot be kept cool. Never leave your baby in a parked car even for a short time. The temperature inside the car can quickly become higher than 100 degrees.

Dress your baby for comfort. A diaper may be all the baby needs to wear in hot weather. Baby’s clothes should be light weight and fit loosely. A baby does not need to be dressed more warmly than you would dress yourself. When outside, the baby should wear a light weight, loose fitting hat to keep the head cool.

Keep track of the amount of formula or the number of breast feedings your baby is taking. If your baby takes too little formula or breast milk, he/she could become dehydrated. Your baby, whether breast or bottle
fed, may need more frequent feedings in hot weather. Do not dilute formula unless the doctor tells you to dilute it. Breast milk or formula is better for your baby than water because it replaces salt that is lost through sweating. Water does not include salt and nutrients that the baby needs. Do not give liquids that are high in sugar (Jell-O, soda pop, fruit drinks, sports drinks), high in salt (canned or packaged meat broths), very low in salt (water or tea), or sugar-free or diet beverages.

Keep your home at a reasonable temperature. During the winter, a temperature of about 68 degrees is a reasonable temperature for a baby weighing more than 5 pounds.

**If your baby has signs of mild dehydration, immediately take care of any problems that may be causing dehydration—diarrhea, vomiting, fever, or being in a place that is too warm.**

**CALL DOCTOR IMMEDIATELY:**

If your baby has signs of mild dehydration that do not improve with the recommended measures. These measures include taking care of any problems that may be causing dehydration—diarrhea, vomiting, fever, or being in a place that is too warm.

If your baby has signs of moderate or severe dehydration that are listed above.

Call your baby’s doctor or public health nurse if you have questions about caring for your baby to prevent dehydration.
DEHYDRATION - GUIDELINES

My baby’s doctor would like to be called if my baby:

After my baby’s doctor has checked him or her for dehydration, the plan for what and how much my baby should drink and what my baby should have to eat is:

<table>
<thead>
<tr>
<th>Liquids</th>
<th>How much</th>
<th>When to start</th>
<th>When to stop</th>
<th>Remember:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Solid foods</th>
<th>How much</th>
<th>When to start</th>
<th>Remember:</th>
</tr>
</thead>
</table>

Questions the Doctor May Ask You

Besides questions about diarrhea, vomiting, and fever that are listed under the Guidelines for these problems, the doctor may ask you questions about dehydration:

1. How much breast milk or formula has your baby had in the last 24 hours?
2. What besides breast milk or formula, if anything, have you been giving your baby to drink? How much has your baby had? How much water has your baby had?
3. How long ago was your baby’s last wet diaper? How many wet diapers has your baby had in the last 6 hours?
4. Does your baby’s tongue feel dry or moist? Can you feel moisture (saliva) in your baby’s mouth or does it feel dry?
5. What does your baby’s skin feel like when you pinch it together?
6. How do your baby’s hands and feet feel?
7. What does your baby’s soft spot (fontanel) feel like? Is it flat or sunken?
8. Is your baby more sleepy than usual?
9. Is your baby more fussy than usual?
10. What is your baby’s breathing like? If your baby already has chronic lung disease, what has changed? Are there any new signs of breathing difficulties?

These guidelines were prepared with input from public health nurses of the City of Milwaukee Health Department, from Lorna Cisler-Cahill, MS, RN, Children’s Hospital of Wisconsin, Mary Krolikowski, MSN, RN, PNP, Doctoral student at University of Wisconsin-Milwaukee School of Nursing, and from John Meurer, MD, and Christine Walsh-Kelly, MD, Medical College of Wisconsin.
COMMON ILLNESS GUIDELINES: DIARRHEA

DEFINITION: Frequent, watery stools, the “runs”.

SIGNS: Abdominal pain; cramping; loose or liquid stools; bloody stools; explosive stools; unusual, foul smelling stools; vomiting; fever; poor feeding.

ADVICE FOR CAREGIVER: Good washing of your hands is the best way to prevent diarrhea or the spread of gastrointestinal infection. Wash baby’s buttocks after each stool to prevent diaper rash. You may use protective ointments such as A&D or zinc oxide.

**Bottle-fed Infants**
- If diarrhea is mild (less than 2 stools in 24 hours), your baby is not vomiting, and his/her mucous membranes are moist, continue giving formula/the usual diet.

- If diarrhea is more frequent or severe (more than two loose or watery stools in 6 to 8 hours), has mucous membranes that feel dry, is vomiting, and/or is under 2 months of age, contact the doctor immediately. The doctor may ask you to offer a commercially available electrolyte drink (like Pedialyte) in place of formula. Your baby should be offered this drink even though vomiting continues.

- Avoid gelatins (like Jell-O), sport drinks, or fruit drinks. Gelatins and these drinks do not have enough salt. They also have too much sugar, and may make the diarrhea worse. Avoid giving water, too.

- Return to full-strength formula in no longer than 24 hours. If the diarrhea is not severe and vomiting has stopped, let your baby eat the regular diet.

- A baby’s formula should be changed because of watery stools only with an order from the baby’s doctor.

**Breast-fed Infants**
- Continue breastfeeding at frequent intervals.

- Offer an electrolyte drink between breastfeedings for a maximum of 24 hours.
CALL DOCTOR IMMEDIATELY:
- If your baby has suddenly developed diarrhea and seems to have abdominal cramping and a fever.
- If your baby has very watery stools and there is blood in the stool, or your baby has a temperature of greater than 100.4°F rectally or 99°F axillary.
- If your baby is looking very pale, drowsy, or floppy.

CALL DOCTOR: WITHIN ONE DAY:
- If your baby is less than 1 month old and has 3 watery stools.
- If your baby is younger than 3 months, has 2 very watery stools, and has vomited 2 times, your baby may be getting dried out (dehydrated).
- If your baby is 2-3 months old or older, has had 6 watery stools, and has vomited 3 times in a day.
- If your baby has had diarrhea for 5 or more days.
- If you believe that you need to talk with a doctor about your baby’s stools.
DIARRHEA - GUIDELINES

My baby’s doctor would like to be called if my baby has _______ of stools in ________ hours.

Change diet only after talking with the doctor. ____ Yes ____ No

My baby’s doctor recommends I use 1/2 strength formula. ____ Yes ____ No. If yes, give ½ strength formula for _____ hours.

My baby’s doctor recommends I use an electrolyte drink if my baby has diarrhea. ____ Yes ____ No

The drink I should use is ________________________________.

Questions the Doctor May Ask You

1. What do the stools look like?
2. Are the stools watery or runny? Bloody? Green? Is there mucous in the stools?
3. How many runny stools has your baby had?
4. How often is the baby stooling?
5. Has the baby vomited? How often?
6. Does the baby have a fever? What is his/her temperature?
7. How many wet diapers has your baby had? How often is your baby urinating? What color is the urine? What does it smell like?
8. Has there been a change in your baby’s formula?
9. What are you feeding your baby other than formula?
10. What medicine is your baby taking?
11. What remedies are you using?
COMMON ILLNESS GUIDELINES: FEVER

**DEFINITION:** The baby’s body temperature is higher than normal.
Rectal temperature (thermometer in the rectum): equal to or greater than 100.4°F.
Axillary temperature (thermometer in the arm pit): equal to or greater than 99.0°F.
Tympanic (special probe in the ear canal): equal to or greater than 100.4°F.
If your baby’s axillary or tympanic temperature is as high as any of the above temperatures, recheck the temperature with a rectal thermometer.

**SIGNS:**
- Skin is flushed, baby feels warm, and the lips and inside of mouth look dry
- Baby may shiver as if chilled
- Baby may be crabby, restless, fussy, or listless
- Baby feeds poorly

**ADVICE FOR CAREGIVER:**
- What is needed depends on the age of the baby and how high the temperature is, and how your baby is looking and behaving.
- Remember a fever may help your baby in fighting infection.
- Make sure your baby is not over dressed or over heated.
- Recheck your baby’s temperature in 3–4 hours if it has been higher than normal.
- Take the steps the doctor advises for bringing your baby’s temperature down.
- If your baby is under 3 months of age, give medicine (acetaminophen or Tylenol) to reduce the fever only after talking with the doctor. Ask your doctor about how much medicine to give your baby to bring the fever down.
- NEVER GIVE A BABY ASPIRIN due to risk of Reye’s Syndrome.
- Ibuprofen (Motrin or Advil, for example) is not recommended for babies less than 2-3 months old
- Take these steps when your baby has a fever of any grade:
- Offer your baby cool liquid. Let your baby take as much as he/she wants. The goal is to keep your baby from getting dehydrated.

- Dress your baby in light clothing. Do not dress, cover, or bundle your baby too warmly.

- If your baby is older than 3 months, a sponge bath in lukewarm water for 15-20 minutes may increase comfort. A sponge bath will, however, not make a difference for the illness. Give your baby acetaminophen 45 minutes before the bath to reset the “temperature center” and avoid shivering. If your baby shivers, stop sponging or use warmer water. NEVER USE RUBBING ALCOHOL OR ICE.

- Do not:
  - Give an enema
  - Cover your baby in a wet sheet or blanket
  - Raise the room temperature or dress your baby so warmly you see sweat

**CALL DOCTOR IMMEDIATELY:** if your baby is less than 2 months old

- If your baby has convulsions (a seizure or a spell) or jerking movements that your baby is not controlling, no matter what the temperature is

- If your baby’s temperature gets higher along with symptoms such as:
  - Difficulty breathing or bad cough
  - Listlessness (much less active than normal)
  - Pain, vomiting, diarrhea, or poor feeding

- If your baby looks sick or is unusually drowsy and hard to arouse

- If your baby is irritable (can’t be soothed as usual), is much less active than usual, and is not smiling, playing, or interacting with people
CALL DOCTOR WITHIN ONE DAY:

- If your baby is 3 months old or younger and has a rectal temperature of 100.4° F or greater, no matter what his/her behavior
- If your baby is between 3 and 6 months, has a rectal temperature of 101° F or greater, and other signs of illness
- If your baby is 6 months or older, has a rectal temperature of 103° F or greater, and other signs of illness

CALL DOCTOR:

- If 1 hour after giving medicine to bring the temperature (fever) down, your baby still looks sick or becomes worse
- If your baby is 6 months old and has had a fever for 2-3 days
- If your baby has any of the following signs of illness (with or without a fever):
  - Sunken eyes
  - Discharge from an ear
  - Swollen neck glands
  - Difficulty swallowing
  - A rash
  - Pain with urinating
  - Pain in the belly (abdomen)
- If you believe that you need to talk with a doctor about your baby’s fever
- If your baby has sickle cell anemia or another immune deficiency disease (like HIV), follow the doctor’s instructions about calling when your baby has a fever
FEVER – GUIDELINES

Take your baby’s temperature by this route:
_____ in the rectum
_____ in the ear
_____ under the arm

Call your baby’s doctor if your baby’s temperature is ___________ or higher.

Give fever-reducing medicine—acetaminophen (Tylenol) or Ibuprofen (Advil, Motrin)—as soon as possible if your baby’s temperature is ___________ or higher. Give fever-reducing medicine if the temperature is ___________ and lasts for longer than 4-6 hours.

The correct dose of acetaminophen and Ibuprofen is based on your baby’s weight. There are two different kinds of acetaminophen (drops and syrup). Be careful to give the prescribed dose for the kind of acetaminophen you are using. Ask your baby’s doctor for the correct dose for your baby.

Questions the Doctor May Ask You

1. What is your baby’s temperature?
2. How did you take it?
3. When did the fever start?
4. What do you notice about how active your baby is?
5. What has been done about the fever?
6. What have you given your baby for the fever?
7. Did your baby’s temperature go down with fever-reducing medicine (like Tylenol)?
8. Did the fever go away and come back again?
9. What other symptoms does your baby have?
10. Has your baby been around other babies?
COMMON ILLNESS GUIDELINES: SPITTING UP/GASTRO-ESOPHAGEAL REFLUX

**DEFINITION:** Effortless spitting up of 1-2 mouthfuls of stomach contents. Small amounts of spit up often occur with burping. Large amounts can occur with overfeeding. Spitting up is usually seen after feedings.

**SIGNS:** Regular spit-ups during or after feeding; frequent wet burps; choking; refusal to eat; arching of the back during feeding; food comes up from stomach into mouth but is not spit out; baby appears to be moving food around in the mouth.

**ADVICE FOR CAREGIVER:**

- Cut back on use of pacifier. Sucking on a pacifier can fill the stomach with air.

- Check bottle nipple and enlarge holes if necessary. Liquid should drip out at a rate of 1 drop per second.

- Make sure baby does not get air into bottle.

- Avoid pressure on the abdomen. Avoid tight diapers. Do not hug or play vigorously with baby after eating.

- Keep in an upright position for 30-60 minutes after feeding. Limit time in infant seat or swing. The baby's position in an infant seat or swing increases contact of stomach acid with the lower part of the tube that takes food from the mouth to the stomach (esophagus).

- Do not stop the baby's rhythm of feeding to burp. Burping 2 to 3 times each feeding is probably enough.

- Raise the head of the bed/crib 30º by adding a block of wood under the crib mattress.

- Place baby on right side in crib. This position helps the stomach to empty.

- If baby is 1 month or older, add rice cereal to formula. Use 2 to 3 teaspoons of rice cereal for 4 ounces of formula.
CALL 911 IMMEDIATELY:

- Choking on milk or other food should be attended to quickly. Call 911 right away if it looks like your baby’s life is being threatened due to choking—not being able to get air, having a gray or blue color, or if your baby is just lying there limp, not responding to things. Call your baby’s doctor promptly if your baby chokes again and again.

CALL DOCTOR

- If spitting up causes choking or harsh coughing that lasts more than 2 hours

WITHIN ONE DAY:

- If baby has no weight gain or has any weight loss in 2 weeks or more
- If baby is constantly fussy or spits up more than usual
- If baby has a harder time staying asleep at night or wakes up often crying
- If you believe that you need to talk with a doctor about your baby’s spitting up
SPITTING UP - GUIDELINES

My baby’s doctor wants me to call if my baby spits up more than _____ times a day.

My baby’s doctor recommends my baby should be upright after feeding for ______ minutes/hours.

My baby’s doctor recommends my baby sleep with the head of the crib raised.  
_____ Yes _____ No

My baby’s doctor recommends formula thickened with rice cereal.  _____Yes _____No
If yes, give formula thickened with ____teaspoon rice cereal per _____ ounce of formula.

My baby’s doctor recommends that I stop thickening the formula when

Questions the Doctor May Ask You

1. How many times a day does your baby spit up?

2. Does the spitting up occur during feedings, right after feedings, or after your baby lays down?

3. How much formula is spit up?

4. What has your baby’s growth in weight been? How much weight has your baby gained or lost?

5. What are you doing to take care of your baby’s spitting up?

6. What medicine is the baby taking? When do you give the medicine? How many times in a day? Do you give it at the time the directions tell you to do? Or do you give it at different times?

7. Is your baby taking medicine for spitting up, like Zantac?
COMMON ILLNESS GUIDELINES: VOMITING

DEFINITION: Throwing up: stomach contents come out of the mouth with force

SIGNS: Throwing up, spitting up large amounts, cramping, dehydration, refusing to eat, diarrhea, or fever

ADVICE FOR CAREGIVER:

Bottle-fed Babies
- If baby has vomited 1 time, offer 1/2 strength formula for 24 hours maximum.
- If baby has vomited 2 times or more, offer an electrolyte drink in small amounts frequently.
- Give 1 tablespoon (15 cc) of the electrolyte drink every 10-15 minutes. Give ½ the amount you usually give twice as often. For example if your baby takes 4 ounces of formula every 4 hours, give 2 ounces of electrolyte drink over a 2-hour period.
- If there has been no vomiting for 4 hours, increase the amount of electrolyte drink.
- If there has been no vomiting for 8 hours, restart your baby on formula. If your baby is 4 months old or older, restart cereal or strained bananas. Return your baby to the usual diet in 24 to 48 hours.

Breast-fed Babies
- If your baby has vomited 2 times, nurse on one side every 1 to 2 hours.
- If your baby has vomited more than 2 times, nurse 4-5 minutes every 30 to 60 minutes.
- After 8 hours of no vomiting, your baby may return to your regular pattern of breastfeeding. In the meantime, express your breastmilk to keep up your supply.

CALL DOCTOR IMMEDIATELY:
- If your baby has had poor intake, a very dry mouth, or no urine for more than 6 to 8 hours
- If your baby is pale gray or pale blue
- If your baby is difficult to awaken or is awake and irritable
- If your baby has had a recent head or abdominal injury
- If your baby has been crying continuously for more than 1 to 2 hours
• If your baby has vomited 2 to 3 times or more on the electrolyte drink diet
• If your baby is less than 1 to 2 months old and has vomited 2 times or more
• If your baby is taking medication that can cause vomiting (like erythromycin or theophylline)
• If you believe that you need to talk with a doctor about your baby’s throwing up
VOMITING - GUIDELINES

My baby’s doctor recommends I call if my baby vomits _____ times in _______ hours.

Change diet only after talking with the doctor. ____ Yes ____ No

My baby’s doctor recommends I give my baby 1/2 strength formula. ____ Yes ____ No

My baby’s doctor recommends I give an electrolyte drink for a maximum of _______ hours if my baby has diarrhea. ____ Yes ____ No. The electrolyte drink I should use is ________________.

Questions the Doctor May Ask You

1. What does the vomit look like?
   --Is there blood in it?
   --Is it brown?
   --Is it green?
   --Is it undigested formula?

2. What medicines is your baby taking?

3. When did the vomiting start?

4. How many times has your baby vomited?

5. How much has your baby vomited?

6. Does your baby seem to be in pain?

7. Does your baby have a fever?

8. Does your baby have diarrhea?

9. Has there been any change in your baby’s diet? For example, has there been a change in formula? Has a new food been added?

10. How many wet diapers has your baby had today?

11. Do you see tears when your baby cries?
References


Acknowledgements

The review and critique of the Common Illness Guidelines by Michele Schroeder, PhD, RN, Assistant Professor Marquette University College of Nursing; Rana Limbo, PhD, RN, Clinical Nurse Specialist, Family Caregiving Project, University of Wisconsin-Madison School of Nursing; John Pascoe, MD, and Richard Rice, MD, are gratefully acknowledged. Both Dr. Pascoe and Dr. Rice are faculty members of the Department of Pediatrics of the University of Wisconsin-Madison Medical School.
Appendix K: Statewide Resources
Helping Hands for Little Feet

**Wisconsin First Step:** 1-800-642-7837 (STEP)
Call this agency first. You may not need to make any other calls.
This is an information and referral service to assist Wisconsin families with children with special needs ages birth to 21. It is available 24 hours a day.

**Birth to 3 Program:** Any family that has concerns about their child's development may contact the Birth to 3 Program directly. Screenings and evaluations are available at no charge to any family. Professional teams from the Birth to 3 Program will work with each family to evaluate your child's development. If your child is eligible for intervention, there may be a cost share for supportive services based on parent income. Every county in Wisconsin has a Birth to 3 Program. Call the First Step Hotline number included in this section to find your Birth to 3 Program.

For referral to local breastfeeding assistance, contact Mary Pesik, RD, CLE, CD, WIC MCH Breastfeeding Coordinator, Wisconsin Department of Health & Family Services, Madison, WI. Phone: 608-267-3694. Email: pesikmj@dhfs.state.wi.us

**Breastfeeding Resources:**

- [www.pediatrics.wisc.edu/patientcare/preemies/BrestfeedingPremature.pdf](http://www.pediatrics.wisc.edu/patientcare/preemies/BrestfeedingPremature.pdf)
  “Breastfeeding Your Premature Baby” is by Paula Meier, DNSc, RN, FAAN, internationally recognized expert in breastfeeding of premature babies.

- [www.parentingweb.com](http://www.parentingweb.com)
  This website supports breastfeeding in specific circumstances (e.g., prematures, mothers working outside the home, pumping and storing breastmilk).

  is a web site with many links and lots of info-including a list of lactation consultants in your area (click on L.C. Directory).

- La Leche League can be found in your phone book (1-800-LALECHE). They also have a web site at [www.lalecheleague.org](http://www.lalecheleague.org).

- [www.medela.com](http://www.medela.com)
  This website from Medela, a manufacturer of breastpumps and breastfeeding accessories, gears its advice at ensuring that breastfeeding is comfortable and easy. The site gives information ranging from the benefits of breastfeeding to both mother and child, to problems that may occur while breastfeeding, and even to how to deal with returning to work while breastfeeding. There is also a live online chat on breastfeeding with Kathleen Bruce, RN, IBCLC made available.
• www.parentsplace.com/readroom/bf.html: This website offers answers to questions about breastfeeding that may arise during pregnancy, and from birth through weaning the child. Also, special concerns regarding breastfeeding are addressed (e.g., nursing of a premature baby, adoptive moms and nursing, tandem nursing, etc.). In order to access breastfeeding information, simply click on “breastfeeding” under the Hot Topics menu.

• “Breastfeeding Your Premature or Special Care Baby” by Marsha Walker, RN, BS, IBCLC (4th Edition, 1998. 16 pages, 8 ½ x 11). This booklet deals with the problems mothers may encounter when breastfeeding premature babies. Information ranges from positioning, to skin-to-skin care, to alternative methods of feeding. Single copies are $5.50 apiece.


• “Welcome to the Rush Mothers Club.” Available from Special Care Nursery, Rush-Presbyterian-St. Luke’s Medical Center, 1653 West Congress Parkway, Chicago, IL 60612.

Community Coordinated Child Care, Inc. (4-C): 1-888-750-KIDS (5437) or 608-271-9181. www.4-c.org
This service is for parents looking for a child care provider and will help find resources in any community in the state. All care providers are licensed or certified. If you are moving out-of-state and need child care, 4-C can connect you with resources nationally.

CSHCN (Children with Special Health Care Needs Centers): http://www.dhfs.wisconsin.gov/DPH-BFCH/cshcn
The Regional Children with Special Health Care Needs Centers, staffed in part by parents of children with special health care needs, are located in five regions of the state:

The five regional CSHCN Centers are as follows:
• Northeastern Region: 1- 800-236-3030 ext. 8296 (for families)
  St. Vincent Hospital in Green Bay

• Northern Region: 1-888-266-0028
  Family Resource Connection, Department of Sacred Heart/St. Mary’s Hospital in Rhinelander

• Southeastern Region: 1-800-234-5437, Milwaukee area: 414-266-6333 (NEED)
  Children’s Hospital of Wisconsin in Milwaukee

• Southern Region: 1-800-532-3321 (for families)
  University of Wisconsin System at the Waisman Center in Madison

• Western Region: 1-800-400-3678 (For U)
  Chippewa County Department of Public Health in Chippewa Falls
**Home Health Agency:** Check the yellow pages in your local telephone directory for a phone number. Home health agencies provide specialized services in the home for children with special health care needs. Services may be covered by insurance.

**Keys to Caregiving:**
This is a series of parent booklets and videos: “Infant State” (baby’s sleep and wakefulness), “Infant Behavior” (ten behaviors parents find helpful in understanding their baby’s abilities), “Infant Cues” (the verbal and nonverbal language of the baby), “State Modulation” (techniques to awaken and soothe infants), and “The Feeding Interaction” (strategies for both breast and bottle feeding, information about parent infant interaction). These are available from NCAST Programs, University of Washington, Seattle. E-mail: ncast@u.washington.edu. You may also contact your local public health nurse for information about how to obtain these booklets.

**MCH (Maternal Child Health) Hotline: 1-800-722-2295**
The MCH Hotline is available 24 hours a day. Callers who do not speak English can access the Hotline through the AT&T Language Line. Information and referral are provided on services and programs (e.g., WIC, BadgerCare) and conditions (e.g., postpartum depression).

**MUMS: 1-877-336-5333 (toll free) [www.netnet.net/mums/](http://www.netnet.net/mums/) email: mums@netnet.net**
This is a national parent-to-parent network to help parents who have a child with any disorder or medical condition connect with other parents whose child has the same or a similar condition.

**Neonatal Follow-Through Clinic:** Contact your baby’s NICU.
This is a clinic that monitors the physical and developmental progress of infants. If difficulties are identified or suspected, further diagnostic and treatment service can be provided.

**Public Health Department:**
Public Health Nurses can provide health teaching and guidance, growth and development assessments, immunizations, and resource information. Services are usually free or at low cost.

**Websites:**
Parenting the First, Second & Third Years.
University of Wisconsin–Extension
[http://www.uwex.edu/ces/flp/parenting](http://www.uwex.edu/ces/flp/parenting)
(Informacion en Español)

Homepage for PREEMIE-L at:
[http://www.preemie-l.org](http://www.preemie-l.org)

[http://www.pediatrics.wisc.edu/patientcare/preemies](http://www.pediatrics.wisc.edu/patientcare/preemies)
(Informacion en Español)

[http://www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu) (a global community of disability-related resources)
(See also Breastfeeding Resources)
**WIC (Women, Infants and Children Program):**  Call 1-800-722-2295 or visit www.dhfs.state.wi.us/WIC to find your local WIC clinic.  
WIC is a supplemental nutrition program that provides food, formula, and nutritional counseling to pregnant and breastfeeding women, infants, and children under 5 years of age. Eligibility for the program is based on income, health, and nutritional needs.

Revised 12/01
Appendix L: Infant Mental Health

1. Risk

- NICU babies often experience long-lasting developmental and behavioral problems, many of which are not identified until school age, but can persist into adulthood. Often, these problems can only be identified at an early age by trained professionals. Many premature infants and toddlers are eligible for early intervention. Complications include:
  - Permanent neurosensory impairment
  - Cognitive and language delays
  - Motor deficits
  - Neurobehavioral and socioemotional problems
  - Learning disabilities
  - Visual-spatial skill deficits
  - Regulatory disorders
  - Anxiety
  - Problems with peer relationships
  - High risk for abuse and neglect

- Parents of NICU babies often have long-term negative effects as well including:
  - Recurring dreams or negative memories of their NICU experience
  - Overprotection of NICU babies

2. Effects of the NICU on the Infant

- Disruption of parent-infant relationship
- Loud, unpredictable sounds in NICU disturb baby’s physiologic and behavioral organization
- Inappropriately timed visual stimuli can harm the developing structure of the brain - the visual system develops late in gestation, so a preemie’s eyes may not be ready for the direct light of the NICU
- Mom isn’t nearby so baby can’t learn to recognize her smell and turn to her as a source of comfort and nourishment
- Lack of well-timed sensory stimuli which could affect later-developing sensory systems and behavior such as attachment
- Repeated painful interventions may have long-term adverse behavioral and physiological effects

3. What Healthcare Providers can do to Support Infants in the NICU

- Protect NICU babies from direct light especially during already stressful procedures by using cycled, dim lighting in the NICU. The benefits of this are twofold:
  - Provides a restful, calm environment for the infant
  - Provides rhythmic cycles that infant was used to in the womb
- Provide cloth with mom’s breast milk odor on it to support the continuity of sensory recognition
• Use supportive bedding that “nestles” the baby to prevent deformities from lying on the back for extended periods of time and to reduce behavioral disorganization and long-term disabilities
• Use analgesia for invasive procedures and surgeries
• Use non-pharmacological techniques to reduce discomfort during heel sticks, intubations, etc. such as swaddling, positioning, pacifier use and sucrose
• Skin-to-skin care provides the following benefits:
  o More organized sleep patterns
  o Better oxygenation
  o Adequate temperature regulation
  o Better attachment relations
  o Influences hormone level, increasing milk production and balancing stress hormones
• Careful introduction and timing of stimuli as to not overwhelm the infant is important, but make sure to provide stimuli above what the NICU itself provides such as:
  o Gentle touch
  o Massage
  o Music
• Provide family-centered, individualized care

4. Disruption Between the Parental-Infant Relationship can be Caused by:
• Prenatal and Postnatal Factors:
  o Long-term hospitalization
  o Other medical complications
  o Diagnosis of congenital anomaly
  o Preterm birth
• Parental Factors:
  o Depression, post-traumatic stress
  o Feeling of grief, anger, helplessness and guilt
  o Family violence
  o Language barriers and cultural differences can lead to feelings of isolation
• Infant Factors:
  o Disorganized or hard-to-read behavior
  o Less responsiveness
  o Difficulty calming and quieting
  o Being sleepy or unable to engage socially
• Hospital and NICU Factors:
  o Policy issues
  o Relations with professional caregivers
  o Access to resources

5. Ways Healthcare Providers can Support the Parental-Infant Relationship
• Use existing psycho-educational interventions
  o Enhance parents’ ability to read infant cues and respond appropriately
  o Validate parents as advocates
  o Provide forums for communication and emotional support
• Providing mental health services in the NICU
  o Access resources and negotiate conflicts between parents and staff
  o Provide therapy
  o Conduct infant behavioral exams
• Connecting families with parent-to-parent support groups
  o e.g. www.preemie-l.org is an online support group
• Training staff on how to promote the infant-parent relationship
• Modeling developmentally supportive caregivers on:
  o Pain management
  o Benefits of parent-infant relationship
  o Supporting infant’s ability to stay awake or asleep and transition between states
  o Pacing and timing interactions
  o Support parents in adjusting to environment
• Creating meaningful moments
  o First pictures, first breastfeeding, first smile, etc.
  o Providing meaning and structure to the end of an infant’s life when infant is dying
• Providing ongoing monitoring, assessment and support long after discharge
  o Access resources
  o Reduce emotional distress
  o Enhance relationships with partners or others
  o Alleviate fears about having subsequent children
  o Provide safe place to voice concerns about the baby
• Support of NICU staff
  o Note that NICU staff report higher levels of depression and psychosocial dysfunction when compared to control groups
• Ensure that decisions are made collaboratively between parents and caregivers
• Ensure parents understand the information that is given to them

References:

1. Browne, Joy (Nov. 2003) “New Perspectives on Premature Infant and their Parents” Zero to Three vol. 24(2) p. 4-12


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