Clinical Performance Guideline
Neonatal Resource Services
Chronic Care

**Purpose:** To provide direction in the management of the infant with unresolved medical needs that require ongoing skilled medical care.

**Target Client Population:** This guideline applies to both term and preterm infants in the NICU with chronic medical conditions.

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<th>Background</th>
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| Chronic care management is often required for NICU infants and graduates. Modern NICU care has led to an increased number of infants discharged to home with assistive care devices (e.g., tracheostomies and gastrostomy tubes) and chronic medical issues. Chronic care delivery models may include home nursing visits, case management and coordination of care between the primary care setting and the discharging facility. Partnership and shared decision making with the infant’s family are vital to the care of these complex infants. Successful discharge of infants with complex medical requirements and/or technology dependency requires multidisciplinary communication and coordination among the medical subspecialties, home healthcare agencies, respiratory therapists, durable medical equipment (DME) companies, pharmacies, social services and the family. Discharge of these infants is often delayed due to the lack of hospital-to-home transitional care. Prolonged hospitalization of infants with complex medical needs negatively impacts their development and disrupts the relationship with their parent. (Sobotka, 2017)

The specific needs of each infant requiring chronic care management vary greatly but there generally needs to be a guaranteed level of population management including common care goals. Unfortunately, there is a lack of consensus and evidence-based primary care management guidelines pertinent to the preterm infant. (Kuo, 2017) Acknowledge the need for psychosocial support of parents. (Purdy, 2015) |

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<th>Treatment Criteria</th>
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<td>Clinical evidence in the medical literature supports the following:</td>
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<td>- Gavage feedings may be utilized in the home environment when an infant is unable to consume enough nutrition by breast or bottle. (AAP, 2011)</td>
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<td>- A feeding gastrostomy tube may be utilized for long-term nutritional support when there is lack of progress in oral feeding skills. (AAP, 2011)</td>
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<td>- Home oxygen therapy may be utilized for infants who continue to require supplemental oxygen. (AAP, 2011)</td>
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<td>- A tracheostomy may be required if a congenital anomaly is affecting the upper airway or ventilator weaning has failed. (AAP, 2011)</td>
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<td>- Home nursing services may be required for infants receiving home ventilation. (AAP, 2011)</td>
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<td>- Cardiorespiratory monitoring should be provided for all infants receiving home ventilation therapy. (AAP, 2011)</td>
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<td>- Caregiver competency in all aspects of infant care, including skill in DME usage, should be demonstrated. (AAP, 2011)</td>
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<td>- Discharge planning of the infant requiring chronic care should begin early in</td>
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the hospital stay. A pre-discharge checklist should be utilized when possible. (AAP, 2011) Protocols and checklists are beneficial for safe discharge.

- A standardized discharge process for infants who require chronic ventilation may decrease their length of hospital stay. This would include interdisciplinary collaboration, formal caregiver training, discharge education materials for family and outpatient providers, and arrangements for home skilled nursing and respiratory services. (Baker, 2016)

- Infants who are discharged with unresolved medical issues should receive comanagement that includes a neonatologist or equivalent subspecialty from the discharging hospital. (AAP, 2011)

- Chronic care management in the primary care setting (medical home) may include care protocols, patient registries, workflow process mapping and shared decision making with families and discussion with tertiary care providers. (Kuo, 2017)

- Outpatient medical home clinics can provide the multiple specialty care needs that infants with complex and chronic medical conditions require. (Kuo, 2013; Mosquera, 2014)

The following specific tasks should be performed in a timely manner and should not cause a delay of discharge in the absence of a specific skilled nursing requirement:

- Complex care needs, goals for discharge, and plans for post discharge needs are identified.

- Facility identifies in network (INN), DME and home health (HH) providers or reports issues finding an INN provider for DME or HH. DME supplies are ordered and caregivers receive training with home equipment. Home nursing visits have been ordered for post discharge support.

- Any special home assessments for equipment use of equipment should be completed in advance to allow time for any upgrades to be completed before the infant is ready for discharge.

- Making advanced arrangements and prior authorizations for medications, DME and nursing visits when applicable.

- Medication prescriptions were completed, filled by the family, and administration teaching completed.

- Follow up appointments with primary provider as well as subspecialists are planned.

- Plans to transfer to a skilled nursing facility (SNF), acute inpatient rehabilitation (AIR), or long term care (LTC) should be identified early and preauthorization should be completed.

The following should be considered for the transition to care at home:

- NRS Family Advocacy CCM team referral submitted
- Outreach to the Special Needs Initiative team if needed

**Clinical Evidence**

- A 2018 clinical report from Mattson et al (AAP, 2018) outlined internal and external psychosocial factors that affect the health of children and youth with special health care needs (CYSHCN). There are an increasing number of children with medical complexity that may possibly be related to improved life-saving technology and neonatal care. Per the 2016 National Survey of Children’s Health (NSCH), approximately 42.4% of CYSHCN were reported as having a developmental, emotional or behavioral issue. Chronic illnesses are
correlated with these issues and lead to increased health care utilization. A medical home can monitor for psychosocial factors and coordinate the necessary services and support for these CYSHCN and their families.

- The American Academy of Pediatrics published a policy statement on the hospital discharge of a high-risk infant (reaffirmed March 2011). This document addresses four categories of infants determined to be high-risk: preterm infant, infant at risk due to family issues, infant with special health care needs or technology dependent and infant whose early death is anticipated. Ideally, all physiological functions should be mature prior to discharge. However, with mutual agreement between the family and medical team, if all medical support can be safely and effectively provided in the home setting discharge may be appropriate before all physiological maturity is reached. Discharge planning should be initiated early in an infant’s hospital stay in order for home transition to be successful without extending the hospital stay.

- Sobotka et al (2017) discussed the discharge delays for children who are dependent on medical technology. Throughout the prolonged discharge process these children may not need inpatient hospital care but they remain in the hospital because there is no other location for transition-to-home care. There needs to be a standardized discharge process for children with complex needs so the hospital stay is not prolonged unnecessarily. Children who are hospitalized for extended periods of time may experience developmental delays and are at high risk for disability. The authors discussed transitional and respite centers as a means to provide the support and education parents need in order for them to assume the long-term health care needs of the child at home.

- Zuo et al (2017) outlined a health care system redesign for preterm infants who are discharged from the NICU. Modern NICU care has resulted in a greater number of infants discharged from the hospital with medical devices. There needs to be optimal management of these infants following discharge which may necessitate changes in processes and organization within the primary care practice. Because there are no consensus-based care guidelines for preterm infants within primary care, care protocols and decision support tools could be created within a primary care practice based on current clinical evidence. A common set of patient care goals needs to be maintained within a standard level of population health management.

- A chart review performed by Khalil et al (2017) included 335 infants discharged on home enteral tube feedings. There were 84 infants fed via NG tube and 238 who were receiving feedings by G-tube. Tube feeding-related complications that required an ER visit occurred significantly more often in the infants who had G-tubes (33.6%) compared to those who had NG tubes (9.5%). There were two G-tube complications that resulted in the infants’ death. At six months following hospital discharge, only 19.3% of infants in the G-tube cohort were receiving full oral feedings compared to 71.4% of infants in the NG tube group. The authors indicate that home NG tube feedings do not appear to pose any higher risk for an infant than G-tube feedings and if a family has the necessary support and resources, NG tube feedings may provide infants with the opportunity to develop their oral feeding skills without undergoing invasive G-tube insertion.

- A retrospective cohort study by Jadcherla et al (2017) analyzed the outcomes of 194 convalescing preterm infants who were born at <37 weeks’ gestation. These infants had been referred to the neonatal feeding program for assessment and management of feeding difficulties. The feeding management
program provided an individualized diagnostic methodology and feeding strategy for each infant. Forty percent (77) of these infants had been discharged with a G-tube and 60% (117) were discharged on PO feedings. The G-tube cohort was found to have lower composite marks in communication, motor and cognitive sub-categories and greater percentages of neurodevelopmental delays at 18-24 months. The data also demonstrated that for each week of higher PMA at the time the initial G-tube was placed there appeared to be an increased risk of cognitive delay. The prevalence of respiratory morbidity at time of discharge and the length of hospital stay was also found to be significantly elevated in the infants with G-tubes. The authors indicated well-timed introduction of oromotor therapies and individualized feeding strategies may result in improved neurodevelopmental outcomes and enhanced feeding skills.

- Baker et al (2016) evaluated the utilization of a standardized discharge process for children receiving chronic ventilation. Chronically ventilated children are medically complex with substantial morbidity and mortality. The practice patterns of facilities caring for these children vary and their length of hospital stay is many times months or years. The goal was to reduce both length of stay and costs in these patients without negatively affecting their safety. The development of formal discharge materials, team-based care coordination, caregiver education, home nursing and durable medical equipment arrangements and interdisciplinary decision-making with the family was essential to the discharge process. The authors concluded that standardization of the discharge process for chronically ventilated children with a tracheostomy tube did reduce length of stay and hospital costs with compromising the safety of the patients.

- A study by Kuo et al (2015) studied health care utilization and costs based on the complexity of the medical care the pediatric patients received. The authors determined that children who required the most complex care had approximately 8.7 times more inpatient visits, 2.4 times more ER visits and 7.3 times more outpatient visits when compared to children who did not have any special health care needs. The primary care setting of health care was found to lack the integration of mental health services. Community-based services need to be integrated into the care of these children with medical complexity.

- A randomized clinical trial by Mosquera et al (2014) evaluated the efficacy of enhanced medical homes for high-risk children with chronic illnesses. Comprehensive care from primary care clinicians and clinic specialists was compared to usual care and found to not only reduce serious illnesses in this cohort but also reduce costs related to hospitalizations and ER visits. The comprehensive care was not found to significantly reduce mortality in this patient population, however.

- A prospective cohort study by Kuo et al (2013) evaluated the perceptions of parents regarding the health care delivery to their medically complex children. This cohort was receiving their treatment from the Medical Home Clinic for Special Needs Children at Arkansas Children’s Hospital. After 12 months of medical home treatment the patients’ families reported extreme satisfaction with the care that had been provided. However, the authors noted that care coordination and communication could be improved by the medical home in order to meet the families’ needs.

- A cohort study by Jadcherla et al (2012) included 100 NICU infants referred for the assessment and development of an evidence-based feeding strategy in an effort to avoid gastrostomy placement. The cohort group was then compared to 50 historical control patients by chart reviews that were evaluated for long
The infants in the cohort were evaluated as clinically indicated, then multidisciplinary individualized recommendations were made based on the clinical evidence and observations, and an individualized feeding management strategy was formulated. The infants in the cohort group (vs historical controls) were more immature and smaller in size (P<0.05). However, they still attained a higher feeding success rate at the time of discharge and again one year (P<0.001). Confounding comorbidity factors associated with feeding failure at discharge included BPD, neuropathology, combined neuropathology and BPD, and all three of these morbidities collectively. The greater part of the infants with gastrostomy tubes was able to regain considerable oromotor skills. The authors concluded that feeding attainment at discharge was attributed to a pathophysiology-based method prior to 43 weeks’ PMA.

### Bibliography


### Revision History

The following are approved changes incorporated into the revision numbers indicated below.

<table>
<thead>
<tr>
<th>Revision</th>
<th>Date</th>
<th>Description of Change</th>
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<tr>
<td>V1</td>
<td>01/16/2018</td>
<td>New guideline developed. Approved 07/10/2018. (CE)</td>
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<tr>
<td>V1.1</td>
<td>05/04/2019</td>
<td>Annual review by AJ. No substantive changes were made to the clinical content. Additional statement regarding the benefits of protocols and checklists for safe discharge was provided. (CE)</td>
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