

**Neonatal and Pediatric Developmental Guidelines in the Care of the  
Neonate/Child/Adolescent Cardiovascular Patient**  
What the Direct Care Nurse Needs to Know

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**Introduction of the Problem:**

Congenital heart disease (CHD) is the most common birth defect and is responsible for significant childhood morbidity and mortality. With increased understanding of the pathophysiology of CHD and technological advances in early diagnosis, cardio-pulmonary bypass, surgical procedures, and post-operative care more babies are surviving to adulthood. However, with this improved survival rate, as many as half of these children have impaired neurodevelopmental outcomes (Donofrio, 2010; Snookes et al., 2010). Although current practice incorporates the assessment and management of cerebral oxygen delivery and central nervous system function before, during and after surgical interventions, development delays persist. To improve long-term outcomes for these children, standard practice should include neurodevelopmental evaluation, identification of risk factors, and implementation of developmental interventions provided by an integrated, multidisciplinary team (NACHRI, 2014).

Specialized services for identified infants and children may be needed into adulthood (Marino et al., 2012).

### **Critical Thinking Points:**

- Children with structural heart defects (whether surgically repaired or not) are at higher risk of neurodevelopmental problems.
- Risk factors for developmental delay are present before and after surgery for congenital heart disease.
- Developmental and maturity problems are identified from infancy through adulthood.
- Risk factors are both biological and environmental.
- Biological risk factors include syndromes or genetic/developmental disorders, circulatory abnormalities, and required medical and surgical therapies.
- Environmental factors modify the biological factors at home, school and work.
- Early identification of developmental disorders/delays provides children with the best chance of reaching their maximum potential.
- Appropriate designation of the best provider to oversee the management of developmental disabilities will facilitate optimal and efficient care.
- Communication between providers at all stages of interventions is essential to optimal management of developmental outcomes.
- Early identification and intervention to prevent further delay decreases long-term sequelae.

### **Diagnostic Evaluation of the Problem**

#### **Key Points:** (Marino 2012)

- Infants and children with CHD are at increased risk of developmental disorders/disabilities/delays
- Continual, periodic developmental surveillance, screening, evaluation and reevaluation may enhance identification of significant deficits.
- Evaluation of the child with structural heart disease involves comparing the child's development with key developmental milestones.
- Early identification and referral will allow appropriate therapeutic interventions and education to enhance academic behavioral, psychosocial, and adaptive functioning
- A coordinated care model is essential to address developmental long-term care needs
- Developmental interventions include periodic, long-term outpatient evaluation and screening.

#### Prevalence of developmental delay in the CHD patient (Marino 2012)

- Increases with complexity of disease
- Associated with several genetic syndromes

- Categories of CHD patients at increased risk for developmental delays
  - Premature birth
  - Birth before 39 weeks gestation in neonates with critical CHD
  - Developmental delay recognized in infancy
  - Suspected genetic abnormality or syndrome
  - History of mechanical cardiac support (ECMO, VAD)
  - Heart transplantation
  - Cardiopulmonary resuscitation at any point
  - Prolonged hospitalization (Post-operative length of stay > 2 weeks)
  - Perioperative seizures related to CHD surgery
  - Significant abnormalities on neuroimaging or microcephaly

#### Periodic, sequential developmental evaluation

- American Academy of Pediatrics recommends children be screened for general development using standardized, validated tools at 9, 18, and 24 or 30 months and for autism at 18 and 24 months OR whenever a parent or provider has a concern.
- Risk stratification for developmental delay aids in planning interventions
- Periodic surveillance of developmental milestones
  - Administer screening tool at interval visits between 2 months and 5 years
  - Available screening tools on CDC.gov/actearly web site: <http://www.cdc.gov/ncbddd/actearly/index.html>
    - Tools available for all recommended age groups – 2, 4, 6, 9 months, 1 year, 18 months, 2, 3, 4, 5 years
    - Tools available in English and Spanish
    - Useful in outpatient setting
    - Could also be used in inpatient setting to identify patients for referral
    - Site is also appropriate for parental use
- Standardized, validated developmental screening tools available in *Pediatrics* Volume 118, Number 1, July 2006 410-413
- Neurodevelopmental Evaluations structured with a focus on the deficit:
  - Speech and language testing
  - Occupational, physical therapy, neuropsychological evaluations
- Abnormal or delayed assessments should prompt discussions to “act early” to address
  - Social/emotional development
  - Language/communication development
  - Cognitive (learning, thinking, problem solving) development
  - Movement/physical development
- Referrals
  - Identify consistent provider to track and manage developmental care

- For children < 5 years and not yet in kindergarten refer to Early Intervention
- For children  $\geq$  5 years refer to school programs or to appropriate provider(s) for formal developmental and medical evaluation
- Additional screening strategies:
  - School aged child
    - Ask the question: “ How is school going?”
    - Refer for formal evaluation
      - Answers that indicate concerns about trouble in school (or at home) either cognitively or socially
      - Answers that may indicate a learning disability
        - Difficulties with grades,
        - Teacher concern,
        - “Hating” school,
        - Difficulty completing assignments in a reasonable time
        - School refusal/multiple absences
      - Answers that may indicate attention deficits
        - Does not listen
        - Misses details or makes careless mistakes
        - Is easily distracted
        - Has difficulty organizing tasks or activities
        - Gives up easily on difficult tasks
        - Is restless or fidgety
        - Is constantly interrupting.
      - Answers that may indicate social or emotional problems
        - Parental concerns for anxiety or sadness
        - Lack of the child’s ability to make and keep friends.
  - Older child or young adult
    - Ask questions about school and/or work
      - Question issues related to work and success with adult developmental expectations
        - Work stability
        - Difficulties with obtaining driver’s license
        - Psychiatric disturbances
      - Evaluate presence of genetic syndromes or developmental delays
        - May require economic supports from Social Security Insurance (SSI) or Social Security Disability Determinations

- Evaluate ongoing family (issues with guardianship) or community supports. Families with teens who are significantly developmentally impaired should be referred for determination of the need for guardianship prior to age 18. After 18 years, the age of majority, the courts become involved with considerable cost in both psychological and financial areas.
- Treatment for the school age child and teen ager:
  - Tailor to specific deficits.
    - School Supports include an Individual Education Plan (IEP)
      - Formulated to address many issues
      - Support includes physical therapy, speech therapy, occupational therapy, adaptive gym programs, nutritional plans, extended day programs, extended year (12 month) programs, nursing supports, tutor supports, teacher aid support, organizational supports and other supportive services.
  - Link families to genetic specialty support groups
    - Genetic Disorders can have a significant impact upon the neurodevelopmental progress of a child.
    - Support and suggestions from Parent Groups and Support Groups specific to the genetic defect help the family make crucial decisions about future directions in their child's care. Associated Complications:
  - Special Considerations for reimbursement for nurse practitioner services:
    - Charges for Neurodevelopmental Screening Assessments can be part of the billing for Outpatient Cardiac Evaluations.
    - The diagnosis code given for any congenital heart defect can be linked with the need for an assessment (CPT CODE 96110- Developmental Screen, with a Reimbursement Recommended Rate of \$25 per screening at each visit substantiated by clinical documentation of the assessment and findings)

### **Pre-hospital preparation of patient/parents/caregivers**

#### **Key Points:**

- Well-established principles and practices for pre-operative preparation of children for surgery apply when we are preparing children with congenital heart disease (CHD) for surgery.

- There are additional pre-operative considerations for the many children with complex CHD who had heart surgery within the first year of their life and require subsequent surgeries during childhood and adolescence.
- Special Considerations:
  - Past medical trauma can make an already difficult surgical experience even more fear and stress producing for the child and parents.
  - Developmental delays and deficits (e.g., mental, psychomotor, language) can limit a child's coping repertoire.
  - Sensory challenges (e.g., fear of sticky things, strong dislike of hospital bracelet, sensitivity to noise) when not understood by health care professionals can lead to increased fears and sleep difficulties in the hospital environment.
  - Sensory processing issues if not recognized can lead to caregivers not taking the time needed to prepare frightened children for each and every invasive procedure that can also include oral medications in the post-operative period.
- D-E-F – After taking care of the basics of physical care (A-B-C: airway, breathing, circulation), promote the basics of psychosocial care (D-E-F: distress, emotional support, family).
  - **D** - Reduce **Distress** of the child by always asking about Fears and Worries
  - **E** – **Emotional** Support – Who and what does the child need?
  - **F** – **Family** – Assess and address family stressor and resources.

### **Empowering parents**

- Provide parents with resources that validate their concerns for their child's ability to cope with upcoming surgery and hospitalization and provide them with resources like:

[https://www.healthcaretoolbox.org/images/pdf/Hospital\\_Child\\_General.pdf](https://www.healthcaretoolbox.org/images/pdf/Hospital_Child_General.pdf)

[https://www.healthcaretoolbox.org/images/pdf/Hospital\\_Illness\\_Child.pdf](https://www.healthcaretoolbox.org/images/pdf/Hospital_Illness_Child.pdf)

### **Preparing children for procedural care**

- Acknowledge the pain the child has experienced in the past and will experience in the future through age appropriate play-orientated and/or story telling resources such as this one for school age children:  
[https://www.healthcaretoolbox.org/images/pdf/When\\_it\\_hurts\\_Jordan.pdf](https://www.healthcaretoolbox.org/images/pdf/When_it_hurts_Jordan.pdf)
- Assure children that they will not be alone and always have parents present with children during procedures.
- Acknowledge children's feelings before, during and after procedures and help children to organize their feelings.

### **Developing parents for collaborative care**

- Reinforce with parents that they play a key role in planning the care for their child during hospitalization. They know their child best and need to advocate for their child, especially for their emotional needs.
- Include parents in daily multidisciplinary rounds and ask them for their perspective of how their child is doing physically and emotionally.

## **Developmental Needs/Strategies to Manage Pain**

### **Introduction**

Developmental care is an individualized approach of care that promotes the maximal potential of development for premature or sick infants admitted in neonatal care units. This philosophy of care initiated in the mid-1980s and later adapted to general pediatric population, is based on the interpretation of infant's behavioral cues, specific intervention to maximize infant's adaptation to the extra-uterine environment as well as the early involvement of parents in the care of their infants. (Symington, 2006) This type of care promotes and maximizes the neurosensory integration essential to neurodevelopment, but also decreases, and even prevents in some cases, long-term neurodevelopmental complications. (Legende, 2011) Using developmental care strategies complemented with pharmacological interventions have shown to decrease physiologic and behavioral pain responses during routine nursing procedures and invasive treatments. (Wilson-Smith, 2011) Developmental differences do exist and they follow an orderly course that parallels other aspects of cognitive development. As children grow older, their descriptions of pain, reasons why pain hurts, and vocalizations about the value of pain change from simple, current, sensory information, to future-oriented, abstract reasoning.

### **Key Points:**

- A child's understanding of pain and illness develops over time
  - Begins with pre-logical conceptualizations
  - Progresses to concrete logical conceptualizations and formal –logical conceptualizations. (Finley, 2014)
- A child's understanding of illness also develops over time
  - Parallel to their understanding and communication of pain
- Pain vocabulary begins to develop at 12 – 30 months with words such as “ow”, “boo-boo”, or “hurt.” (Franck, 2010)
- The word “pain” gradually emerges at around 4 years old. (Franck, 2010)
- Between three to seven years old, understanding of pain and ability to self-report occurs. (Franck, 2010)
- Children with cognitive and neurological impairments are more likely to experience ongoing or recurrent pain
- Consider child's cognitive level instead of chronological age when selecting pain assessment tools
- Self-reported pain is considered the gold standard complemented by knowledge and understanding of the context of pain by the healthcare provider.

**Pain Assessment**

- Assessment of pain in children should involve one or in combination of the following approaches: (Association of pediatric anaesthetists, 2012)
  - Self-reports
  - Validated observational measures
  - Physiological indicators
  - Behavioral signs
  - Parent report.
- Acute and chronic pain have multiple dimensions (Eccleston, 2002)
  - Important to assess each of these domains
  - Sensory (e.g., intensity, word descriptors, duration, location, and frequency)
  - Affective/cognitive (pain unpleasantness)
  - Impact of pain in aspects of everyday life (physical, social, emotional, and role functioning).
  - Measurement of the intensity of pain or how much it hurts.
    - Most commonly used parameter in clinical and research practices

| <b>Strategies to the assessment of intensity of pain in children</b>  |                                |  |
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| <b>1. Physiological: heart rate, respiratory rate, blood pressure, SpO2</b>   |                                |  |
| <b>Tools</b>  | <b>Developmental Age</b>       | <b>Strategy</b>  |
| Physiologic bedside monitors  | All age group                  | <ul style="list-style-type: none"> <li>• Use with other composite measures as many physical measures are not specific to pain intensity.</li> <li>• Rationale:               <ul style="list-style-type: none"> <li>○ It is difficult to discriminate between the responses to pain and other forms of stress in the body, and vary according to extraneous factors.</li> <li>○ physiological indices habituate over short periods of time and not appropriate for the measurement of acute pain that may last over several days (e.g., postoperative) or chronic pain.</li> </ul> </li> </ul> |
| <b>2. Behavioral: observation of nonverbal clues about specific types of distress behaviors (e.g., vocalization, facial expression, and body movement) have been associated with pain and are very helpful in quantifying pain in children unable to provide self-report.</b> |                                |  |
| NIPS (Neonatal Infant Pain Scale)   | Gestational age 26 to 47 weeks | <ul style="list-style-type: none"> <li>• Facial expression, cry, breathing pattern, arms, legs, and state of arousal are observed for 1 minute intervals before, during, and after a procedure and a numeric score is assigned to each. A score &gt;3 indicates pain. (Hudson-Barr, 2002)</li> </ul>   |

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| <p>CRIES (Crying, Requires O<sub>2</sub>, Increased vital signs , Expression, Sleeplessness</p> | <p>Infant to &lt;1 year</p>                        | <ul style="list-style-type: none"> <li>• The tool is a ten point scale similar to the Apgar score. It is an acronym of five physiological and behavioral variables previously shown to be associated with neonatal pain.(Krechel, 1995)</li> <li>• Observer provides a score of 0-2 for each parameter based on changes from baseline.</li> </ul>  |
| <p>CHEOPS (Children’s Hospital Eastern Ontario Pain Scale)</p>                                  | <p>1 to 7 years</p>                                | <ul style="list-style-type: none"> <li>• Useful for postoperative pain Assessment is based on observations of 6 aspects of behavior: cry, facial expression, verbal expression, movement of torso, touching of wound and movement of legs. A score ranging from 0-2 or 1-3 is assigned to each activity and the total score ranges from 4-13.</li> <li>• May not be reliable outside post anesthesia care setting and may be cumbersome to use.</li> <li>• Recommended for pain associated with medical procedures and other brief painful events. (von Baeyer, 2007)</li> </ul> |
| <p>FLACC (Face, legs, Activity, Cry, Consolability)</p>   | <p>2 months to 7 years or cognitively impaired</p> | <ul style="list-style-type: none"> <li>• Provides a simple consistent method of pain assessment in nonverbal or preverbal children. Observer assigns 0-10 scoring for each behavioral parameter.</li> <li>• Can be used across populations of patients and settings, and the scores are comparable to those of the commonly used 0-to-10 number rating scale (Voepel-Lewis, 2010)</li> </ul>   |
| <p>FPS-R (Faces Pain Scale-Revised)</p>   | <p>4 to 12 years</p>                               | <ul style="list-style-type: none"> <li>• Assessment of pain using a series of six horizontal gender-neutral faces that depict a neutral facial expression of “no pain” at the left to “most pain possible” expression at the right. Intensity is rated using 0 to 5 or the 0-10 metric scales.</li> <li>• Has been recommended on the basis of utility and psychometric features (Tomlinson, 2010)</li> </ul>  |
| <p>TPPPS (Toddler-Preschool Postoperative Pain Scale)</p>                                       | <p>1 to 5 years</p>                                | <ul style="list-style-type: none"> <li>• Consists of 7 items among 3 behavior categories -- Vocal Pain Expression, Facial Pain Expression and Bodily Pain Expression (Hartrick, 2002)</li> <li>• Items are scored as a 1 if the pain behavior is present during a 5 minute observation period or as a 0 if not present.</li> </ul>   |

Note: Behavioral assessment tools may not be very appropriate for assessing recurrent and chronic pain as these children are vulnerable to habituation. Behavioral signs of chronic pain tend to dissipate as time passes, so it is difficult to observe reliably on these behavioral signs in cases of chronic pain.

**3. Self-report measures - Pain is a subjective experience. Self-report measures, therefore, most accurately reflect pain. Since limited verbal skills in children place them at a disadvantage in terms of communicating their pain, several pain assessment tools have been developed that facilitate self-report of pain in children.**

|                                      |               |  |
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| Wong-Baker Faces Scale               | > 3 years     | <ul style="list-style-type: none"> <li>• 6 cartoon faces showing increasing degrees of distress. Face 0 signifies “no hurt” and face 5 the “worst hurt you can imagine.”</li> <li>• The child chooses the face that best describes pain at the time of assessment. (<a href="http://www.wongbakerfaces.org">www.wongbakerfaces.org</a>)</li> </ul>   |
| Pieces of Hurt Tool(Poker chip tool) | 3 to- 5 years | <ul style="list-style-type: none"> <li>• This tool uses 4 red poker chips to quantify pain. (Some versions have a white chip to represent no pain). The red chips represent pieces of hurt. One chip is a little bit of hurt while all four chips are the most hurt the child can have. The child is told to select the number of chips that indicate how much pain he/she is experiencing.</li> </ul>   |
| Oucher                               | 3 to 12 years | <ul style="list-style-type: none"> <li>• This scale consists of 2 vertical scales, a numerical scale from 0-100 and a photographic scale that consists of 6 pictures of the face of a child with expressions demonstrating increasing discomfort.</li> <li>• Children use the Oucher scale by selecting the number or photograph that most closely represents their pain intensity.</li> <li>• Assess cognitive ability of the child by asking to identify six geometric figures in ascending order of size. (<a href="http://www.oucher.org">www.oucher.org</a>)</li> </ul> |
| VAS (Visual Analogue Scale:          | 3 to 18 years | <ul style="list-style-type: none"> <li>• Uses a 10 cm line with one end marked as no pain and the opposite end marked as the worst pain. The child is asked to make a mark on that line that is then measured in cm from the no pain end.</li> </ul>   |
| Word Graphic rating Scale            |               | <ul style="list-style-type: none"> <li>• The numeric scale utilizes a horizontal line with the end points identified as ‘no pain’ and ‘worst pain’. The divisions along the line are marked in numbers from 0 to 10.</li> </ul>  |
| Numeric Scale                        |               | <ul style="list-style-type: none"> <li>• The use of any numeric scale requires that the child must understand the concept of order, proportionality, and number which are skills achieved usually at 7 years old.</li> </ul>   |
| Pain descriptors                     |               | <ul style="list-style-type: none"> <li>• A multidimensional tool that includes a body outline, a word graphic rating scale and a pain descriptor list of 43 words. (Besenski, 2007)</li> <li>• Children are asked to mark the location of their pain on the body outline, rate the intensity by drawing a line on the Word Graphic Rating Scale and describe the pain by circling appropriate words that describe their pain.</li> <li>• Provides more comprehensive pain assessment but cumbersome to use.</li> </ul>   |

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| Other Self-Report Measures  |                      | <ul style="list-style-type: none"> <li>• Color association with colors which describes the extent of pain with red and black to be the colors most frequently associated with pain and yellow, blue, green and orange to be least frequently associated with pain.</li> <li>• Pain interviews, questionnaires and pain diaries</li> </ul>   |
| <p>Note:</p> <ul style="list-style-type: none"> <li>• Self-report measures are dependent on the child's social, cognitive and communicative competence such as his/her ability to match items, to place items in a correct series, and to listen to the instructions of the person administering the measure while looking at materials. (vonBaeyer, 2009)</li> <li>• Child reports are also influenced by their context (whom is asking the question, setting). Therefore, it is possible that children may respond in a biased fashion (e.g., minimize their pain for fear of getting needle).</li> <li>• Children may be subject to recall bias when they are used to ask to recall their pain over prolong periods (weeks to months). (Savdra, 1993)</li> </ul> |                      |   |
| <p>4. <b>Pain assessment with cognitive impairment. The majority of work in pain assessment for the cognitively impaired consists of observation of the frequency of occurrence of core sets of pain behaviors over varied observation periods.</b></p>   |                      |   |
| <p>NCCPC-PV (Non-Communicating Children's Pain Checklist – Postoperative Version)</p> <p>PPP (Pediatric Pain Profile)</p> <p>The University of Wisconsin Pain Scale for Preverbal and Nonverbal Children</p> <p>FLACC</p>   | <p>3 to a8 years</p> | <ul style="list-style-type: none"> <li>• Consist of 27 behaviors across 6 categories including vocal, facial, social, body and limbs, activity, and physiologic signs. Each of these behaviors is scored on a 0-3 point scale based on the frequency of observation of that behavior over a 10-minute observation period. The scores of all items are summed to provide a total pain score.</li> <li>• While this checklist provides a comprehensive pain assessment method for children with CI undergoing surgery, it may be cumbersome for frequent pain assessment in the clinical setting (Breau, 2009)</li> <li>• A set of 20 pain behaviors including facial expressions, body movement, tone, social reactions, mood and consolability are scored on a 4-point ordinal scale (0-3) based on frequency of</li> <li>• Occurrence over 5-minute observation periods.</li> <li>• This scale is comprised of 5 behavior categories (Vocal/cry, facial, behavioral, body movement/posture, sleep) with 4 descriptors for each. The overall rating using this tool is not a sum of scores of individual behaviors but a score assigned on a 0-5 scale based on the clinicians' judgment relative to assessment of individual categories.</li> <li>• The tool has reasonable inter-rater reliability and validity in children with varying degrees of cognitive impairment. (Voepel-Lewis, 2002)</li> </ul> |

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| INRS (Individualized Numeric Rating Scale) |  | <ul style="list-style-type: none"> <li>• Measures of agreement were found to be acceptable in the Face, Cry and Consolability categories but inconsistent in the Legs and Activity categories.</li> <li>• Incorporate parents' knowledge of their cognitively impaired child's pain expression.</li> <li>• Parents are asked to score severity of pain behaviors (based on previous painful experiences) on a 0-10 scale using the categories of the FLACC tool.(Solodiuk, 2003)</li> </ul> |
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### Special Considerations

- Fostering care through a developmentally supportive environment based upon continuous assessment, evaluation and feedback enhance the accuracy of pain assessment in children.
- Behavioral measures of pain should be used in conjunction with self-report whenever feasible and with careful consideration of the context of distress behaviors.

### Providing Developmental Care in the Cardiac Intensive Care Unit

#### Key Points:

- Prevent any increase in neurodevelopmental delay in patients with known risk factors due to Complex Congenital Heart Disease, combined with exposure to long term sedation, immobility and hemodynamic instability
- Provide developmental care in the Cardiac Intensive Care environment with the overall goal to reduce the risk of poor neurodevelopmental outcomes.
- Promote neurodevelopment and decrease morbidity by including nursing interventions
- Obtain Neurodevelopmental Consult at any point in a CICU admission if neurodevelopmental concerns arise to create a more individualized care plan

#### Neonate

- Thermoregulation considerations:
  - Neonates do not have the ability to auto regulate their body temperature.
    - Unable to shiver
    - Larger head/body surface area compared to adults
    - Utilize metabolically active adipose tissue “Brown Fat” to generate heat when cold.
      - Provide thermoregulation with radiant warmer device
        - When critically ill, patient should be placed in “Servo Mode” for improved thermoregulation



- Weekly height and Head Circumference
    - Daily weights (re-assess if hemodynamically unstable)
    - Nutrition consult for recommendations
  - Proper positioning is key to prevention of complications related to immobility from an intensive care unit stay
    - Proper positioning =Fetal Position:
      - Legs and arms flexed Elbows and knee's tucked midline
      - Spine straight and slightly curved
      - Chin tucked slightly to chest (may have modify with critical airway)
      - Avoid the "Frog position"
      - Arms and legs flayed outward
      - Causes muscle imbalance and
    - There are developmental care products available; however, simple blanket rolls can be utilized to support positioning.
    - When immobile postoperatively, turn every two hours and utilize pressure prevention devices, such as a z-flo mattress, to prevent pressure areas.
- Feeding
  - Some evidence exists that initiation of early feeding is positively correlated with decreased oral aversion and improved PO feeding postoperatively.
    - If physiologically stable, introduce PO bottle feedings and/ or breast feeding prior to surgical intervention. Assess for disorganized or weak suck /swallow.
    - Avoid negative oral stimulation during pre and post-operative course (i.e. oral suctioning, oral manipulation) as much a feasibly possible.
    - If patient unable to PO feed due to intubation or patient condition, promote positive oral stimulation while providing enteral tube feedings.
      - Offer pacifier during bolus feedings. Consider dipping pacifier in breast milk and or sucrose solution to improve positive correlation.
      - Consider placing baby in mothers arms near breast during enteral feedings to promote positive association with mother
      - Encourage parents to provide positive facial and oral stimulation during feedings. Gentile touching and kissing if tolerated.
    - Consider feeding team consult if concerns regarding disorganized suck/swallow, aspiration or oral aversion

## **Infancy – (1month to 1 year)**

- Cognitive- During this time period there is rapid brain growth and development of neuronal pathways.
  - Utilize visual and auditory games and items to promote problem solving
    - Introduce mobiles and tactile stimulation items that are appropriate for Cardiac Intensive Care Unit setting at age 1-2 months. Objects should be easily cleanable or specific to patient.
    - Encourage patient to fix and follow object, begin to reach and grab object and bring objects to mouth.
    - Educate caregivers on developmental milestones and encourage to be involved with the games.
- Social Development
  - Trust vs Mistrust (Erik Erikson). During infancy until 18 months of age is a critical time for an infant to begin to trust his/her environment and develop strong relationships.
    - Once physiologically stable, promote the idea of a daily schedule that included play time, nap /sleep time and “cares” time in which procedures, medications, etc. are provided.
      - Important to provide cues to quiet/ nap time (i.e.: decreased lighting, decreased stimulation, plan testing procedures around these times (if possible due to condition).
    - As a provider, use visual and auditory method of engagement when providing care.
    - Offer opportunities for social interaction:
      - If physiological condition warrants (with no infection control precautions):
        - With close observation, utilize stroller or play yard
        - Utilize high chair for feeding or play time
        - Recognize that stranger anxiety can begin to develop at approximately 9 -12 months of age
    - Promote positive caregiver interaction and encourage their involvement with planning daily schedule. Always, prepare families that the schedule may have to be altered based on the patient’s physiological status
- Language Development
  - During the first year of life the infant will begin to identify and form sounds. He/ she may begin speaking first words by 1 year.
    - Talk to patient while providing cares. Use facial expressions and gestures to encourage engagement and mimicking.
    - Encourage parents to read stories and talk with patient when able. Exposure to language is the importance not the content.

- When critically ill, continue to utilize recorded stories and/or lullabies to stimulation exposure to language.
      - Consider music therapy if available in your institution.
  - Musculoskeletal Development: Cephalo-caudal development or gross and fine motor skills continues as rapid rate during first year of life
    - Assess for adequate nutritional status for appropriate muscle development
      - Daily calorie count
      - Weekly height and Head Circumference
      - Daily weights (re-assess if hemodynamically unstable)
      - Nutrition Consult for recommendations
    - Provide passive ROM exercises when receiving deep sedation and / or paralysis (if able to be tolerated hemodynamically)
      - Consider Physical Therapy consult if prolonged anticipated sedation or length of ICU stay
      - Consider Occupational Therapy consult if suspected contractures or fine motor development concerns
    - When physiologically able:
      - Provide opportunities for “tummy time” to promote core muscle development and prevent Plagiocephaly.
      - Avoid boundaries to help facilitate movement
      - Utilize specialized devices to assist with sitting up and /or walking
        - Consult physical therapy, occupational therapy and/or neurodevelopmental program
      - Provide opportunities for fine motor development
        - Utilize art therapy
          - Promote drawing, finger painting when between 12-18 months
            - Consult child life
- Feeding and Self Care
  - If patient has been home, assess current feeding patterns and devices that are being utilized for feeding regimen
  - Avoid negative oral stimulation during pre and post-operative course as much as feasibly possible particularly if oral feeding has not been established.
    - Assess for other concerns if feeding aversion suspected
      - “teething”
      - Reflux
      - pain
  - If 6 months old or greater:
    - Consider use of sippy cup to promote oral feedings
    - Consider introduction of pureed solid foods if physiologically able to tolerate

- If patient unable to PO feed due to intubation or patient condition, promote positive oral stimulation while providing enteral tube feedings.
  - If patient likes pacifier, offer pacifier during bolus feedings. Assess for weak, disorganized suck which could indicate potential for oral feeding issues. Encourage parents to provide positive facial and oral stimulation during feedings. Gentle touching and kissing if tolerated.
  - Consider feeding team consult if concerns regarding disorganized suck/swallow, aspiration or oral aversion

### **Toddler through Preschool Years**

- Cognitive/ Language Development- Rapid Brain Growth continues from 12 months to Age 3 years old. Children during this time are working on discovering their world through identifying shapes, sorting categories, and the start of make believe play.
  - Children from age 12-24 months are considered in the Sensorimotor period. Toddlers during this stage rely on their parents or consistent caregiver to interpret their world.
  - From 24 months to 6 years, children enter the preoperational period of development. Thinking becomes more concrete and children explore and learn about their world through experiential play
    - Speak directly to child and explain care in very concrete terms
      - Avoid language such as “ I am going to take your blood pressure”
    - Utilize play therapy to help (consider Child Life Consult)
      - Explain procedures
      - This age group express their feelings regarding the ICU stay.
    - Distraction techniques can be very useful during painful procedures or long periods of NPO status.
      - Television and Video games can be helpful, but should be used on a limited bases.
      - Encourage reading, educational games, music therapy
  - Continue to utilize a schedule to map out sleep/ wake times, play time and cares. Include child likes and dislikes, encourage family involvement and (when age appropriate) the child in the creation of the list.
- Language skills are developing rapidly. Children within this age group will begin to follow simple instructions, begin to speak in sentences, learn their name and are starting to identify letters and numbers by age 3. Children should be telling stories, speaking clearly, understanding basic rules of grammar by age 5-6 years.
  - Children with developmental or speech delays may use sign language to express themselves.

- Ask parent or guardian to demonstrate key sign language words to help staff communicate more effectively with child
- Psycho -Social Development
  - (Autonomy vs shame) From 12-24 months, a child is struggling with separation from parent.
    - A support object such as a blanket or stuffed animal can be helpful in coping with an ICU stay (this may persist past 24 months).
  - From two –three years, fear of bodily injury develops. Children during toddler and pre-school period will be very concerned with “ouchies” and “boo boo’s”.
    - Dressings and Band-Aids are helpful in this age group.
      - Utilize a toy to help them practice helping the “boo boo” if they are able.
  - During pre-school time period (beginning of Initiative versus Guilt), the child is learning to be more independent but separation from parent or guardian is very frightening during times of stress.
  - Parents should be utilized as support to their child during frightening or difficult procedures (assess if a parent is able to tolerate being present first).
    - *Parents should not be used to restrain but to comfort and distract the patient during times of stress.*
    - Anticipatory guidance is needed to help the family understand the typical reactions of the child to the ICU environment and interventions they can do to help their child adjust to the experience.
    - Regression of previous learned skills is common during a CICU stay. Expect that children that may have been previously toilet trained or walking may revert back to more infantile behavior.

### **School Age Child**

- Cognitive- Children from age 7-11 years are entering into the Concrete Operational Period of development. During this stage, the child is able to understand cause and effect, can generalize experience and apply those concepts to multiple events.
  - Children at this age can understand the concept of their illness, yet continue to have a fear of disability and injury. They are attempting to master their environment and seek control.
    - Assess for Developmental Delay. Despite chronological age, the child may not be cognitively ready to process certain aspects of their care.
      - Utilize family or guardian to provide background information regarding developmental delay or prior learning style.

- Offer the child choices regarding flexible points in their care. If appropriate, include the school age child as part of the team
  - Prepare the child prior to procedures in concrete, clear terms.
    - Developmentally on target school age child can tolerate receiving advance information regarding upcoming interventions.
  - Answer the child's questions truthfully with concrete, factual information.
    - Assess child's response with open listening. Ask about what they heard. Do not elaborate with abstract concepts.
    - Use visual and tactile examples to help explain concepts.
      - Drawings, dolls with medical devices
    - Utilize the parent or guardian to help assess understanding of plan of care and ability to comprehend information.
- Psycho-Social Development (Industry vs Inferiority)
  - Despite the school age child's continued need for parental /guardian involvement and support, Peers gain more status during this time.
  - Children are learning empathy and the relationship of their interactions with others.
  - Utilize parents to coach child through difficult experiences encountered within the ICU environment
    - Ask child if they want parent or guardian present during a procedure.
  - Understand the value of peers. Concern may begin to surface regarding their illness and the perceived differences between their peers.
  - Provide opportunities for school age children to connect with peer groups when possible.
    - Possible use of social media and care pages to stay connected when in ICU environment
      - Anticipatory guidance should be provided to both parents and child regarding securing private health information when using social media.

### **Toddler through School Age Child**

- Musculoskeletal Development
  - Assess for adequate nutritional status for appropriate muscle development
    - Daily calorie count
    - Daily weights (re-assess if hemodynamically unstable)
    - Nutrition Consult for recommendations
  - Provide passive ROM exercises when receiving deep sedation and / or paralysis (if able to be tolerated hemodynamically)

- Consider Physical Therapy consult if prolonged anticipated sedation or length of ICU stay
  - Consider Occupational Therapy consult if suspected contractures or fine motor development concerns
- When physiologically able:
  - Initiate mobility as soon as possible
  - If delays are anticipated, utilize specialized devices to assist with sitting up and /or walking
    - Consult physical therapy, occupational therapy and/or neurodevelopmental program
  - Provide opportunities for fine motor development
    - Encourage the Toddler to School Age child involvement in activities of daily living when appropriate
      - Toddlers begin to learn to dress themselves in simple clothing, feed themselves and are in the midst of toilet training.
      - Preschoolers are able to use utensils, Brush teeth independently, get dressed and tie shoes
      - School Age children are beginning to master more complex fine motor control and abilities.
    - Promote play that incorporates fine motor abilities
      - Dolls that help tie, button, zip
      - Legos, manipulative toys that require fine motor coordination in older children
    - Utilize music and art therapy
      - Consult child life

### **Teenager/adolescent (13 to 18 years)**

- Additional resource on risky behaviors: Discharge information for Teens – See Appendix A for handout used by Children’s Hospital of Los Angeles
- A transitional stage of physical and psychological development between childhood and adult roles
  - Creates challenges for the health care provider
  - Few hospitals have specific units for teens
    - Limited contact with peers
    - Limited contact with other teens with cardiovascular disorders
  - Support modification in hospital environment for typical teenage behavior
    - Night-owl hours: Go to bed late, Wake up late.
    - Allow for personalized hospital room
    - Adjust testing and medication schedules
    - See last in scheduled daily rounds
    - Encourage peer interactions
      - Allow peer visitors, extend visiting hours

- Provide internet connections – Facebook, twitter
  - Provide links to websites for ACHD:
    - <http://www.achaheart.org/>
- Physical cognitive changes
  - Puberty and reproductive-related changes
  - Growth spurts
  - Confront issues with morality and sexuality
  - Address high risk behaviors:
    - Assess body image and self-concept
    - Sex education
    - Smoking and drug abuse
- Cognitive development
  - Increased knowledge
    - Clear and easily understandable explanation of diagnosis, treatment plan and expected outcomes.
    - Ensure teen’s understanding of education/communication with providers/caregivers/parents
      - Beginning to develop abstract thinking
      - Level of understanding may not be fully developed
  - Ability to reason
  - Communication strategies:
    - Active listening techniques
    - Use open-ended questions
    - Focus on identifying risk factors
    - Provide confidentiality
    - Build a supportive network to foster compliance with medications, treatments, diet, activity
      - Focus on understanding of health-related issues
      - Develop responsibility and an awareness of consequences of non-compliance
- Psychosocial development – Erickson’s identity vs. role confusion
  - Increasing struggles to confront issues with morality, sexuality, and future occupation
  - Developmental approaches:
    - Provide privacy
    - Respect modesty
    - Conduct interviews separately from parents
    - Ask permission to involve other health-care providers in interviews, treatments, and care
    - With teen develop and plan for parental education and involvement

- Keys to success:
  - Promote normalcy as much as possible in the hospital setting
  - Promote independence and self-care
  - Respect and maintain privacy
  - Provide emotional support
- Engage parental support:
  - Limit setting with understanding from the teenager
  - Provide freedom and choices when possible
  - Encourage decision making with an understanding of consequences

**Developmental Support of Transitions (Intensive Care to Acute Care, Hospital to Home):  
Key Points:**

- Patients/families/caregivers encounter many transitions as the patient grows and develops from the time of the cardiovascular diagnosis and moves throughout the healthcare continuum.
- The two transitions that have great impact on long-term outcomes are the transition between the intensive care and acute care units and the transition to home. (Chaboyer 2005, Blom 20120)
- The time of transition may be one of extreme anxiety impacting the patient and family long after discharge.
- A successful, smooth transition depends upon a clear, well-developed, tangible plan.
- The cardiovascular nurse plays the lead role in the development and implementation of this plan.

**Transitional activities:** (Refer to Neonatal and Pediatric Guidelines: Interstage Document)

- Communication (Green 2011, Chaboyer 2005)
  - Readiness assessment
  - Participation of all parties (patient/family/caregiver) in plan
    - Nurse liaison to assist in transfer
    - Patient/family tour of unit prior to admission to that unit
      - Neonatal Intensive Care Unit before birth
      - Pediatric/Cardiac Intensive Care Unit prior to surgery
      - Intermediate/Acute care unit prior to transfer
    - Equipment, medication, care needs, resources prior to discharge
    - Avoid any rushed transfer process
- Transition patients during daytime, weekday hours
  - Increase confidence of patient/family in competence of receiving unit or home to provide care
  - Increase ability to obtain meds and supplies on transition unit or home
  - Increase availability to access of prior caregivers for questions, concerns
  - Decrease anxiety of patients/family/caregivers to provide care

- Decrease concern over knowledge of staff on transition unit, numbers of staff available for care
- Preparation of receiving area for patient
  - Summary of defect, medical, surgical history
  - Personalized poster – ‘All About Me’
    - Name
    - Family
    - Likes (activities, colors, foods), dislikes
  - Whiteboard in room
    - Names of care team (RN, LIP, RT, PT/OT, Child Life)
    - Patient Goals
    - Questions for care team
- Preparation of patient/family/caregiver for transition (between units or to home)
  - Assess caregiver knowledge/needs/resources
  - Provide education on outcomes, expected care/developmental needs, medications
  - Encourage participation in care
    - Start in ICU
    - Include all caregivers
    - Allow questions
    - Observe caregiver providing care
- Partnering with team members to enhance developmental needs – Melanie
  - Child life: for daily scheduled and to promote normalcy in the hospital setting
  - OT/PT: to promote ADLs especially if there are limitations and contraindications due to current state
  - Referrals to outpatient providers BEFORE hospital discharge
    - Easier access to developmental programs from inpatient status
    - Improve continuity of care between inpatient therapies and outpatient providers
    - Early intervention programs for infants,
    - Community programs for children/adolescents

### **Transitions for long-term patients**

- Patients awaiting heart transplant - Ventricular Assist Device (VAD)
- May be any age
- Support developmental milestones as appropriate (ie. school time, play time, OT/PT sessions, Child Life Specialist collaboration)
- Provide daily schedule from waking up to bedtime and maintaining consistency
- Include family and patient (if adolescent and older) in daily rounds with multidisciplinary team regarding plan of care on a daily basis (ex. Daily rounds, specified update time)

## **Psychosocial Consequences of Developmental Delay**

### **Key Points:**

- Risk for maladaptive psychiatric disorders has been documented in children and adolescents following sudden or prolonged intensive care admissions.
- Most common disorders described in the literature are anxiety, depression and Post-Traumatic Stress Disorder (PTSD)
- Potential exists for the development of other psychiatric illnesses described in the Diagnostic and Statistical Manual of Mental Disorders (DSMV)
  - Ongoing observation for any behaviors that may be indicative of maladaptive behaviors

### **Intensive Care Psychosis**

- The incidence of delirium in the Pediatric CICU is not negligible, but at times may be difficult to recognize.
- ICU Psychosis may be considered a significant complication to ICU admission
- Requires a treatment/management plan
  - Signs of possible delirium in children include:
    - Confusion
    - Agitation
    - Anxiety
    - Moaning
    - Discomfort
    - Behavioral disturbances with no acceptable medical explanation
    - Failure of standard sedative treatment
    - A subset may present with hypoactive symptoms (inhibition/psychomotor retardation)
  - Consider a Neurology or Psychiatric Consult
  - Management
    - Medications
      - Haldol (urgent management)
      - Atypical antipsychotics (Risperidone, Seroquel)
    - Therapeutic interventions
    - Reorientation to environment
      - Parental presence –comfort measures throughout day and night
      - Provide familiar music, favorite toys, familiar smells, pictures of home and pets
      - Support from friends, school
      - Provide daily schedule with cycled lighting to reorient to diurnal rhythm

### **Anxiety, Depression and or PTSD in pre-school – school age children**

- Symptoms of these disorders will become more apparent in pre-school to school age child as manifested by:
  - Severe separation anxiety
  - Withdrawal from activities
  - Behavioral outbursts, severe tantrums
  - Somatic symptoms that appear separate and unexplainable from current hospitalization

- Nightmares (this can be normal during this age period)
- Changes in sleep and eating patterns that appear separate and unexplainable from current hospitalization
- Reliving the event, frequent disturbing memories, fear or fascination with death (PTSD).
- If a psychiatric disorder is suspected, obtain a psychiatric consult with a professional trained in child psychopharmacology and/ or child psychology.
  - Therapy and/or medication management may be indicated
- Anticipatory Guidance with parent or guardian regarding signs of these disorders in children should be discussed prior to discharge from CICU.

## **References:**

### **General concepts:**

Centers for Disease Control and Prevention: CDC 24/7: Saving Lives. Protecting People. web site: [www.cdc.gov/actearly](http://www.cdc.gov/actearly) <http://www.cdc.gov/ncbddd/actearly/index.html>

Donofrio, M.T., Massaro, A.N. (2010). Impact of congenital heart disease on brain development and neurodevelopmental outcome. *International Journal of Pediatrics*, 94-106. Retrieved from doi: 10.1155/2010/359390.

Marino, B.S., Lipkin, P.H., Newburger, J.W., Peacock, G., Gerdes, M., Gaynor, J.W., Mussatto, K.A., Uzark, K., Goldberg, C.S., Johnson, W.H .Jr., Li, J., Smith, S.E., Bellinger, D.C., Mahle, W.T. (2012). American Heart Association Congenital Heart Defects Committee, Council on Cardiovascular Disease in the Young, Council on Cardiovascular Nursing and Stroke Council: Neurodevelopmental outcomes in children with congenital heart disease: Evaluation and management: A scientific statement from the American Heart Association. *Circulation*, 126(9) 1143-1172.

Snookes, S.H., Gunn, J.K., Eldridge, B.J., et al. (2010). A systematic review of motor and cognitive outcomes after early surgery for congenital heart disease. *Pediatrics*, 125(4), 818-827.

### **Pain:**

Association of Pediatric Anaesthetists of Great Britain and Ireland. (2012). Good practice in postoperative and procedural pain management (2<sup>nd</sup> ed.). *Pediatric Anesth (Suppl)* 22, 11-79.

Eccleston, C., Morley, S, Williams A, et al. (2002). Systematic review of randomized controlled trials of psychological therapy for chronic pain in children and adolescents, with a subset meta-analysis of pain relief. *Pain*, 99, 157–65.

Finley, G.A., Chorney, J.M. (2014). Not small adults: the emerging role of pediatric pain services. *Can J Anesth*, 61, 180-187.

Franck, L., Noble, G., Liossi, C. (2010). From tears to words: the development of language to express pain in young children with everyday minor illness and injuries. *Child care health Dev*, 36, 524-553.

Hartrick, C.T., Kovan, J.P. (2002). Pain assessment following general anesthesia using the Toddler Preschooler Postoperative Pain Scale: a comparative study. *Journal of Clinical Anesthesia*, 4(6), 411-5.

Hudson-Barr, H., Capper-Michael, B., Lambert, S., Palermo, T.M., Morberto, K. (2002). Validation of the Pain Assessment in Neonates (PAIN) scale with the Neonatal Infant Pain Scale (NIPS). *Neonatal Network*, 21 (6), 15-22..

Krechel, S.W., Bildner, J. (1995). CRIES: A new neonatal postoperative pain measurement score. Initial testing of validity and reliability. *Paediatric Anaesthesia*, 5, 53-61.

Legende, V., Burtner, P.A., Martinez, K.L., Crowe, T.K. (2011) The evolving practice of developmental care in the neonatal unit: Systematic review. *Physical & Occupational Therapy Pediatrics*, 31, 315-338.

Symington, A., Pinelli, J. (2006). Developmental care for promoting development and preventing morbidity in preterm infants. *NICHD Cochrane Neonatal*. Retrieved from [www.nichd.nih.gov/cochrane/](http://www.nichd.nih.gov/cochrane/).

Tomlinson, D., von Baeyer, C.L., Stinson, J.N., Sung, L. (2010). A Systematic Review of Faces Scales for the Self-report of Pain Intensity in children. *Pediatrics*, 126, 1168-1198.

von Baeyer, C. L., Spagrud, L. J. (2007) Systematic review of observational (behavioral) measures of pain for children and adolescents aged 3 to 18 years. *Pain*, 127, 140-150.

Voepel-Lewis, T., Zanutti, J., Dammeyer, J.A., Merkel, S. (2010) Reliability and validity of the face, legs, activity, cry, consolability behavioral tool in assessing acute pain in critically ill patients. *American Journal of Critical Care*, 19, 55-65.

Wilson-Smith, E. (2011). Procedural pain management in neonates, infants and children. *Reviews in Pain*, 5, 1-10.

Wong Baker: <http://www.wongbakerfaces.org/>

### **Providing Developmental Care:**

Brosig, C., Mussatto, K., et al. (2007). Neurodevelopmental Outcome in Preschool Survivors of Complex Congenital Heart Disease: Implications for Clinical Practice. *Journal of Pediatric Health Care*, 21(1), 3-12.

Colville, G., Kerry, S., Pierce, C. (2008). Children's Factual and Delusional Memories of Intensive Care. *American journal of Respiratory and Critical Care Medicine*, 177. 976-982.

Gaynor, J. W., Gerdes, M., et al. (2010). Is Cardiac Diagnosis a Predictor of Neurodevelopmental Outcome after Cardiac Surgery in Infancy? *The Journal of Thoracic and Cardiovascular Surgery*, 140(6), 1230-1237.

Gaynor, J. W., Wernowsky, G., et al. (2007). Patient Characteristics are Important Determinants of Neurodevelopmental Outcome at One Year of Age after Neonatal and Infant Cardiac Surgery. *Journal of Thoracic and Cardiovascular Surgery*, 133(5), 1344-1353.

Kiekkas, P., Theodorakopoulou, G., et al. (2010). Psychological Distress and Delusional Memories after Critical Care: A literature review. *International Nursing Review*, 57, 288-296.

Leroy, S., Elixson, M., et al. (2003). Recommendations for Preparing Children and Adolescents for Invasive Cardiac Procedures: A Statement from the American Heart Association Pediatric Nursing Subcommittee of the Council on Cardiovascular Nursing in Collaboration With the Council on Cardiovascular Diseases of the Young. *Circulation*, 108, 2550-2564.

McQuille, P., Goff, D., Licht, D. (2010) Effects of Congenital Heart Disease on Brain Development. *Progress in Pediatric Cardiology*, 29(2), 79-85.

Rees, G., Glendhill, J., Garralda, M. E., Nadal, S. (2004) Psychiatric outcome following Paediatric Intensive Care Unit (PICU) Admission: A Cohort Study. *Intensive Care Medicine*, 30, 1607-1614.

Rennick, J., Rashotte, J. Psychological Outcomes in Children Following Pediatric Intensive Care Unit Hospitalization: A systematic Review of the Research. *Journal of Child Health Care*, 13(2), 128-149.

Schieveld, J., Leroy, P., et al. (2007) Pediatric Delirium in Critical Illness: Phenomenology, Clinical Correlates and Treatment Response in 40 Cases in the Pediatric Intensive Care Unit. *Intensive Care Medicine*, 33(6), 1033-1040.

### **Transition:**

Blom, H., Gustavsson, C., Sundler, A.J. (2013). Participation and support in intensive care as experienced by close relatives of patients – A phenomenological study. *Intensive and Critical Care Nursing*, 29, 1-8.

Chaboyer, W., James, H., Kendall, M. (2005). Transitional care after the intensive care unit: Current trends and future directions. *Crit Care Nurse*, 25, 16-28.

Green, A., Edmonds, L. (2004). Bridging the gap between the intensive care unit and general wards – the ICU Liaison Nurse. *Intensive and Critical Care Nursing*, 20: 133-143.

Ivarsson, B., Ekmeahag, B., Sjoberg, T. (2014) Waiting for a heart or lung transplant: Relatives' experience of information and support. *Intensive and Critical Care Nursing*, 30, 188-195.

Ludin, S.M., Arbon, P., Parker, S. (2013). Patients' transition in the intensive care units: Concept analysis. *Intensive and Critical Care Nursing*, 29, 187-192.

McCairn, A.J., Jones, C. (2014). Does time of transfer from critical care to the general wards affect anxiety? A pragmatic prospective cohort study. *Intensive and Critical Care Nursing*, 30: 219-225.

Selekman, J., Jakubik, L. (2008). Pediatric nursing certification review. Society of Pediatric Nurses: Pensacola, Fl.



## Living Life with My Cardiac Conditions: A Guide for Teens



### Contraception and Family Planning

#### *Will I pass on my cardiac problems to my children?*

- It depends. **Women** usually pass on defects and conditions **more than men**, and certain defects and conditions are **more inheritable** than others. Ask your cardiologist about your specific diagnosis. **Genetic counseling** might be a good choice when you start your family.

#### *Is it safe to get pregnant with my heart condition?*

- Again, it depends on your diagnosis. Some, like Marfan Syndrome or Eisenmenger Syndrome, have **very serious risks** for pregnancy. Others only have mild risk. For this reason, it's best to **plan** any pregnancy you have. **Talk to your cardiologist** before you conceive, or as soon as you know you are pregnant in the case of unplanned pregnancy.

#### *What kind of contraception can I use with my heart condition?*

- Barrier methods, like **condoms**, are safe for your heart but only effective when used correctly. The **morning after pill**, **progestin only pills**, **IUDs**, and **sterilization** carry only minor to moderate risk, but may be less effective or consistent. **Combined oral contraceptives** are effective, but are **contraindicated** (which means they cannot be used) for women with certain cardiac diagnoses. Ask your cardiologist what method or combination of methods is safe for you.

### Tattoos and Piercings

#### *Can I get tattoos or piercings with my heart condition?*

- There have been some cases of individuals with heart conditions contracting **endocarditis** after getting tattoos or piercings. If you want a tattoo or piercing, talk it over with your cardiologist. They might want you to take antibiotics beforehand to decrease your risk for infections like endocarditis. If you get a tattoo or piercing, make sure you stay **hygienic** and **clean the area** as you are instructed. Only get a tattoo or piercing from a **professional** who uses **sterile equipment**.

### Drugs and Alcohol

#### *Can I use drugs or alcohol with my heart condition?*

- As someone with a preexisting heart condition, using drugs and alcohol will never be the healthiest choice for you. However, there are some that are more dangerous than others. **Adderall** can cause **sudden death** in people with certain heart conditions, so only take this drug if you have a prescription which has been approved by your cardiologist. **Amphetamines**, such as meth, molly, uppers, ecstasy, ect., have been shown to be associated with **myocardial infarction (heart attacks)** in youth with preexisting heart problems.