

Responding to Chronic/Terminal Illness & Injury Developmental Perspective

Age/ Developmental Issues	Perception of Illness	Impact of Illness/hospitalizations	suggestions
Infancy: Birth – 2 year • Establishment of trust • Need for parent bonding • Responsiveness and close physical proximity	Generalized perception of pain and discomfort	Stranger Anxiety (6 – 10 months)	 Allow parent to comfort infant Allow parents to assist in care of the infant as much as possible Explain procedures to parent so their anxiety is lessened so they can comfort the baby or help effectively
		• Mistrust	 Develop trust by alleviating distress For example, in giving a blood test to an infant – give the blood test, then cuddle and hold the infant, talk gently to the infant and/or have parent cuddle the infant Turn on musical toy to help soothe the infant

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Developmental Issues			
 Early Childhood: 2-6 Years Develop sense of mastery and independence Learn to cope with separation Need for careful preparation for frightening events and separation Possibility of regression 	Illness is not separate from treatment; both hurt and can be punishment for "bad" behavior. Magical thinking (hospital "gave" them diabetes when they were there – want to give it back). See parents as very powerful and able to stop illness/pain if they want to do so. Can see illness as their own fault because they were 'bad"	Separation Anxiety	 Allow parent to participate in the procedure. Give them suggestions on how to use coping mechanism in helping their child through the procedure. For example, show the parent how to pace a child's breathing through a party blower. A favorite toy or blanket is important for security.
		Likes to imitate adults	 Have parents participate in child's care shows the child that the parent approves of the hospital routine Explain to child and show
		Fear of Mutilation	pictures of body parts involved. Stress that no other part of his/her body will be involved. For example, "I will need to give you a blood test in your arm. The rest of you will be just like it is now."
		Preoccupied with blame and guilt	Explain repeatedly that no one is to blame for his/her diagnosis or hospitalization
		Constant questioning as a means of learning about the outside world	Explain procedures in age appropriate language. For example, "Doctors can learn a lot about a person's body and what is making him/her sick by testing the blood."
Latency Age: 6 – 8 Years	May still see self as causing illness or death; increasingly starts to see illness as caused either by outside agency (germs) or through failure to follow		Because of rule-bound beliefs, may tend to be more compliant with treatment regimen
Mastery of skills & tasks valued by teachers/society	health rules, either due to disobedience or imprudent behavior.		

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•	Increasingly aware of teacher and societal rules	Contagion theory is strong, i.e. illness is catching. May do victim blaming as way of making self immune.	Separation Anxiety	Although school age children are better able to cope with separation in general, the stress imposed by illness or hospitalization may increase their need for parental security and guidance.
			Want to understand why things are happening. They are able to reason.	Give simple explanation of anatomy and physiology and what is wrong and how it will be treated. Use of pictures, dolls, and other visual aids help them to understand.
			Perception of time	When the child needs a test, tell him/her ahead of time.
•	Preadolescent 9-12 years Peers become increasingly important Evaluation of self is in relationship to peers Growing need for precise explanation of events impacting them	Now understand bodily processes and functions as true cause of illness. Understand relationship of treatment to illness. Needs to have accurate explanation about illness and treatment as well as justification for choice of one treatment over another.	 Primary concern is interference of illness/treatment in social relationships and activities as well as being perceived as different. Lack of bodily control or "wholeness" may affect emerging sense of identity. May become demanding, rebellious and non-compliant with medical regimen as a way of reasserting control as well as "testing the hypothesis." 	Accurate information about illness and treatment can be useful tool in managing anxiety.
•	Adolescence: 13 – 18 years Needs to be an individual, separate from family	More aware of complexities of health/illness; more sophisticated about the interaction of internal and external factors in illness. Able to intelligently question and deal with all information about illness.	Loss of control and independence. High risk of non-compliance with treatment routine as way of asserting control or denying impact/severity of illness.	 Involve adolescent in decision making and planning for procedures. Explanation of procedures

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	Developmental Issues			
•	Wants to be like peers and avoids being different	Early adolescence marked by focus on discrete symptoms rather than overall impact of illness;		
•	Preoccupation with physical changes	later adolescence marked by emergence of fuller appreciation of hypothetical future consequences.	Alteration in body image	Provide privacy
•	Beginning to deal with stressors as an individual Does not want to rely on	Denial is primary defense against thoughts of illness and consequences.	Interference of treatment or hospitalization in school/social activities seen as threat to	Encourage visiting from peers
	family for support		"normal" life	

Sources: J. Temple Eisele, Child Life Program, University of Massachusetts Medical Center M. Bernadetter Reidy, 1999