

Advocating for your Child in the Hospital

Amy Smith, CCLS

Certified Child Life Specialist



Medical City **Children's** Hospital™

Objectives

- Identify hospital stressors and ways to minimize them
- Share strategies for effective communication with medical team
- Taking care of yourself

The Environment

Stressors:

- Medical Equipment
- Limited mobility and freedom
- Confined Space
- Unfamiliar surroundings
- Lack of choice
- Frequent Disruptions
- Lack of Control

Minimizing Stress:

- Provide age appropriate explanations and opportunities for medical play
- Bring favorite comfort items from home
- Encourage play
- Provide realistic choices when possible
- Advocate for care to be done together when possible

Multiple, Unfamiliar Caregivers

Stressors:

- Stranger Anxiety
- Multiple caregivers and/or seen by multiple medical professionals at once
- Separation Anxiety
- Inconsistency of care-giving techniques

Minimizing Stress:

- Limit caregivers and visitors when possible
- Is primary nursing an option?
- Encourage staff to introduce themselves to your child and get down at their eye level
- Provide staff w/ examples of helpful techniques with your child

Inconsistency of Routine

Stressors:

- Changes in habits from home
- Interrupted sleep
- Tests and procedures interrupt schedule
- Unpredictability

Advocating for Routine:

- Develop or modify a routine for hospital visits
- Signs posted “I’m asleep, if possible come back later”

Stress/Anxiety of Caregivers

Stressors:

- Balancing two lives- hospital and home
- Concerned for siblings
- Various emotions
- Family responsibilities

Managing stress:

- Accept help when offered
- Have one contact person for updates
- Delegate responsibilities when you can
- Take breaks, ask for a volunteer to stay with your child
- Have date night with your spouse or friends

Developmental Care Board Ideas

- All about me: (include family information, pictures, etc)
- Things I like:
- Ways I tell you that I like something:
- Things I don't like:
- Ways I tell you that I don't like something or that I'm uncomfortable, upset, or in pain:
- My daily routine:
- Things I'm working on right now that you can help me with:
- Ideas for things we can do together when I'm alert, awake, and ready for interaction:
- My special requests:
- Please help me grow by:

Effective communication with your child's medical team

- Empower and engage your child to participate in conversation with medical staff
- Create Signage:
Preferred name, likes/dislikes.. (as it relates to healthcare) I cope best when.., Please do not..., this really scares me...
- Patient Care Conference
- Write questions down, encourage your children to do the same
- Developmental Care Boards
- Develop a coping plan
- Investigate Family Advisory Board participation
- Support group opportunities

Easing Pain, Discomfort & Fear

For procedures:

- Honesty is the best policy
- Ela-max, numbing cream, cold spray, J-tips
- No more than 2 pokes please!
- Treatment Room- why is this important
- Positioning for Comfort
- Need for control, choices!
- Is your child being sedated for a procedure? Ask if labs or IV can be started while asleep

Advocating for your child when multiple procedures/surgeries are necessary

- Develop a coping plan and use it!
- Assess and reassess if pre-op meds are necessary
- Choices for control
- Medical Consent forms, risks of surgery, and questions for medical staff
- Parental support during induction
- Keep a notebook, what meds work well, which meds haven't worked effectively in the past
- Involve child in decisions about timing of surgery when possible