

# Ages and Stages: Living and Growing with Cystic Fibrosis

## The First Years: Illness in Infancy

- Bonding and attachment take place when an infant's needs are consistently met for love, food and comfort.
- Don't let an infant "cry it out." Hold your baby often especially if the baby might be in pain.
- The mother's emotional state is important. Get support if needed.
- If you can't distinguish between a want or a need, meet the need.
- Don't get into control battles over bodily functions which includes eating.
- Avoid expressing anger and frustration with your baby.

## Preschool Children

- Parental attitudes are contagious.
- Toddlers generally mirror parental emotions.
- Toddlers understand the world through pictures and gain mastery through physical touch, manipulation and play.
- Creativity and fun are especially effective.
- Choices are very effective during these years.
- Now is the time to teach children about limits and authority using effective skills.
- Avoid showing anger and frustration at misbehavior. Use empathy and consequences instead.
- Visit [www.TipsForCFParents.com](http://www.TipsForCFParents.com) for resources for handling eating/ food issues.

## Handling "I Can't"

- When a child can't do the task:
  - Are our expectations reasonable for a child of this age/ developmental level?
  - Have we provided appropriate training for the task?
- Steps to helping kids with self-care tasks:
  - Keep expectations high. "You can do it!"
  - Teach the specifics step-by-step:
    - Use visual cues along with verbal ones. Go slowly.
    - Have the child do the step right after you show them.

- Respond with encouragement after each step.
  - Repeat at least 5-7 times.
  - Be silly, creative and have fun together!
- Adjust expectations downward only when it is obvious the child is unable to do the task.
  - Don't show disappointment or frustration.
  - Show happy anticipation and re-direct: "Hey! I have a better idea. Let's try..."

## **Elementary School Years**

- Your child's brain is operating in concrete operations mode (black and white thinking) until hormones kick in.
- Parenting seems deceptively simple but don't be lulled into a sense of false security.
- *Now* is the time to teach children about the possible consequences of bad self-care.
- Love and Logic principles build character by assuming that children have the strength and ability to handle the absolute truth when it is given in a loving and caring manner.
- The transition to adult independence starts *here*, not when kids are teens.
- Wise parents use the same parenting style with their children now that also works in the teen and adult years.
- Use questions with curiosity to encourage "heart to heart talks".
- Help your child take ownership of the new way of working. "Was this more your idea?"
- Encourage children to give themselves a lecture.
- Help children improve by asking them to grade themselves.

### **Coping with CF at School**

- Be open with classmates and school personnel.
- Help your child learn how to respond to questions and comments from peers.
- Increase parental involvement appropriately but not automatically.
- Visit [www.TipsForCFParents.com](http://www.TipsForCFParents.com) for resources for CF at school.

## Preteens and Teenagers

- The preteen years are characterized by physical and emotional change. Hormones change the way the brain functions to “formal operations.” This means kids can understand metaphors.
- The presence of health issues modifies and impacts all areas of a teenager’s life.
- As teens start thinking about the future, the long-term reality of illness starts to sink in.
- Some preteens and teens may make self-destructive choices for many reasons.
- Nagging, lecturing and punishing often makes things worse.
- “I am not a disease!”
- Parents must rely on facts and options about healthcare rather than demands and orders.
- Curiosity and interest always trump worry, concern and upset. Talk less and listen more.
- Wise parents always show acceptance- which is different than approval.
- Teens will be secretive and hide some poor healthcare decisions from parents.
- Teens will make mistakes just like we do.
- Get help from peers, mentors, coaches, and other close adults to communicate important self-care information to your teen.

### Coping with Peers

- Allow the teen to decide what, when and how information is shared with peers.
- Teach teens the skills to respond to questions and comments from peers.
- Be sure the teen knows all of the facts about his/her medical condition.

## Transitions Into Young Adulthood

- A time of great parental pride *and* concern as children become fully responsible for self-care.
- Parents are no longer able to access medical information and must rely on the child.
- Unhealthy parental control issues may come to a head. An unhappy child can just leave home.
- Family dynamics change.
- There may be identity issues for those left behind especially for parents who “need to be needed.”
- Being a Consultant Parent is important in maintaining a close relationship as well as helping children become independently successful. **Start early!**