



Child Development for Chronically Ill Children: Ages 2-4

At this stage, your child typically develops a strong sense of self but remains unable to regulate his/her emotions. As a result, your child may often feel frustrated and react by throwing tantrums. At this developmental stage, your child requires a great deal of support from you and other caretakers.

Typically at this age, adherence is not the main issue. However, normal developmental behavioral problems/struggles are prominent, and if managed early, can help later with treatment adherence.

(Schaefer,C.& Geronimo,D., 2000)



Child Development for Chronically Ill Children: Ages 4-6

At this stage children enjoy taking on new responsibilities but continue to need a lot of guidance from a parent/caregiver. As your child starts to become more aware of himself/herself, as an individual he/she will begin to gain more independence. At this stage your child will likely ask about why he/she is "different" as it is developmentally normal for him/her to compare himself/herself with others. At this stage you might experience some "push back" and arguments regarding treatment adherence. A predictable routine offers stability and security for children at this stage of development. Children at this stage may be "bossy" or demand their own way, as well as being critical of others.

(Schaefer,C.& Geronimo,D., 2000)



Child Development for Chronically Ill Children: Ages 7-10

Children at this stage remain very dependent on caregivers for safety and security. As your child continues to develop a sense of self-worth, he/she most likely will become more confident. Peers can have more influence in his/her life and he/she will likely want to model peer behavior so they can "fit in" with others. At this stage your child might feel uncomfortable with the idea of being perceived as different, and will express feelings that life is unfair, especially in regards to his/her medical treatment requirements. Children at this stage are often highly critical of themselves and likely need lots of encouragement and positive reinforcement. During this stage, your child may become more explosive, dramatic or outgoing. They may insist on having their own way, but are also able to listen to reason. Rudeness may be common at some point during this stage, but luckily they are often able to recognize this behavior and apologize.

(Schaefer, C. & Geronimo, D., 2000)



Child Development for Chronically Ill Children: Ages 11-13

At this stage of development, your child is primarily focused on the present with limited thoughts about the future. Your child might experience struggles with self-identity as they try determine what kind of person they are and how they fit in the world. They might begin to feel awkward about themselves and their body and are extensively worried about the need to be "normal". Children at this stage often desire greater independence and are strongly influenced by peers. On the opposite spectrum of this behavior, they might also return to "childish behavior" as they make the transition into adolescence. This transition occurs most often when they feel stressed.

Children can be moody and test limits. When they desire a greater amount of privacy, parents often feel shunned. During this period, it is important that the child continue to feel supported, safe, and secure in their family. Adults continue to play a crucial role in the adolescent's life, especially in regards to risky behaviors and poor choices. At this stage your child is likely to adhere to medical treatments since they can understand the reasons for the treatments and the implications of non-adherence. However, expect that your child might feel ashamed of their disease and reluctant to share their diagnosis with most peers.

(Schaefer,C.& Geronimo,D., 2000)



Child Development for Chronically Ill Children: Ages 14-18

At this stage your teen has a greater capacity for setting goals and is also able to think about moral reasoning and future planning. Teens are often intensely self-absorbed and their self-image can fluctuate from positive to negative rather rapidly. Teens continue to worry about self-image and the idea of being seen as "normal" in order to fit in with peers. During this time your child may have a tendency to want to distance themselves from parents and other family members. Popularity among peers can become a central issue at this stage and teens will often take advice from a peer rather than a parent. It is common for many teens to become angry or depressed about their illness during this stage of development. While this can be expected as relatively normal, signs and symptoms can escalate. If this occurs, it is crucial to seek professional help immediately.

(Schaefer,C.& Geronimo,D., 2000)

Parenting Tips: Giving Choices

Tips from Love and Logic: Parenting Children with Health Issues by Foster W. Cline and Lisa C. Greene

Using choices is a great way to avoid power struggles while setting appropriate limits for your child. By using this method, your child still has to complete a task, but he/she can have input in how he/she would like to complete the task.

The process:

1. Give choices before your child starts to resist a task, not after.
2. For each choice, give two to three options that are acceptable to you.
3. If your child does not make a choice within one minute, you should make the decision. Make sure your child knows one minute is allowed to make this decision before you make the decision for him/her.
4. Never give a choice unless you are willing to allow your child to live with the consequences of his/her choice.

The Magic of Choices

Use phrases such as:

1. "Would you rather _____ or _____?"
Example: Would you rather have applesauce or yogurt with your vitamins?
2. "Would it be best for you to _____ or _____?"
Example: Would it be best for you to do your homework first or wait until after dinner?
3. "You can either _____ or _____?"
Example: You can either do your treatment now or complete your treatment in 15 minutes?
4. "Are you going to _____ or _____?"
Example: Are you going to do your nebulizer treatment this morning or after school?



Parenting Tips: Helping Children Deal With Their Feelings

How To Talk So Kids Will Listen And Listen So Kids Will Talk, by Adele Faber and Elaine Mazlish (1980), addresses the direct link between children's feelings and their behavior. This parenting style is based on the belief that when children feel good, they behave well.

As a parent, helping your child feel good about himself/herself directly improves his/her positive behavior. It is important to accept and respect your child's feelings, even when you disagree with him/her. Accepting a child's feelings can often be difficult for parents since parents tend to take their child's feelings personally. Have you ever heard yourself say, "Oh come on, you're just saying that because you are tired"? Sometimes it is important to just be the sounding board for your child. Listen to your child and accept his/her feelings and understand that those feelings often have nothing to do with you. Being able to accept your child's feelings will reduce conflict and the amount of time spent arguing with your child.

How To Help Your Child Deal With Their Feelings:

1. Listen quietly and attentively.
2. Acknowledge his/her feelings.
3. Give a name to the feelings discussed by your child.

Example: "Oh....Mmmm....I see...."

3. Give a name to the feelings discussed by your child.

Example: "That sounds frustrating!"

4. Give your child his/her wishes in fantasy.

Example: "I wish you could make your airway clearance treatments shorter too!"

5. All feelings can be accepted, but not all behaviors.

Example: "I see how angry you are about having to do your treatments, and I know you still have to do them, but let's take some time to talk more about your feelings."

(Faber& Mazlish,1980)



Token Reward System

When trying to manage or change behavior, praise is often not enough to motivate your child to do chores, follow rules or follow directions (Christophersen, E. & Mortweet, S., 1997). It is often necessary to set up a program to help motivate him/her and reduce the struggle between adult and child. One intervention program displaying great success is the Token Reward System. This system is recommended when your child has the ability to complete a task but refuses (i.e. when your child refuses to complete treatments related to a chronic illness). This system can also help eliminate undesirable behaviors such as whining or swearing. When used properly, the Token Reward System can also encourage your child to practice a new skill and help manage a range of behavioral problems.

How It Works

Two Basic Principles:

1. A desired behavior you are working to increase with your child should immediately be followed by a positive, rewarding consequence. Immediately rewarding the desired behavior helps to improve the frequency of the desired behavior.
2. An undesirable behavior you are working to decrease with your child should immediately be followed by an unrewarding or punishing consequence. Immediately providing an unrewarding or punishing consequence after the undesired behavior helps to decrease the frequency of the undesired behavior.

You can use poker chips, marbles, coins or pasta wheels (*remember to use different colors for multiple children*). For this to work, earning a token should feel like earning money, and losing a token should feel like losing money.

Earning Privileges:

Privileges can be anything that your child likes. Examples may include: computer time, extra television time, special foods, special time with parents, or anything deemed acceptable by you. Your child should be required to "spend" the tokens for whatever privilege is decided upon.

Privileges must be available, as often as possible, when your child has tokens. If your child cannot immediately obtain his/her privilege, then the tokens lose value to him/her, and the token become less effective to motivate behavior.



Specifics:

1. Use the token system with all the children in your house; however, the rules of earning tokens may vary depending on the developmental capability of each child (i.e. *a younger child may earn tokens for something an older child does not*).
2. Make a list of behaviors that you think are suitable for earning tokens.

Daily Routine/Tasks:

Making the bed

Picking up toys

Picking up clothes

Getting dressed on time

Doing homework

(Extra tokens can be earned for specific jobs such as yard work)

Social Behaviors:

Saying "please and "thank you"

Sharing with a sibling

Not talking back

How It Works:

Example: If your child brushes his/her teeth when asked, tokens are earned. If your child does not follow through on this request, tokens may be taken away or not given (*up to the discretion of the parent*). Tokens should be placed in a special box in your child's room or on a shelf.

When Giving A Token:

Remember to praise your child for what he/she did. Reward your child using tokens. Make sure to describe the behavior so your child knows exactly what behavior is being praised.

Example: "Here are two marbles for helping me with the laundry."

When Tokens Don't Work And Your Child Refuses To Do What Is Asked:

Use brief time-outs and do not interact with your child in any way until your child has calmed down (*Disclaimer: You will need to immediately intervene if your child is doing something dangerous, harming themselves or others*). Time-out is the temporary revoking of all privileges and social interaction.

When The System Is Less Likely To Work or Not As Effective:

- This program is not as effective for older adolescents, but can be modified to meet the needs of an older child.
- When parents inconsistently follow the program.
- When a child is away from home for long periods of time and is not influenced by parents (*often occurs with older adolescents*).
- When a child does not have the ability to complete the skills required by the parents, or when parents have unreasonable expectations, such as a spotless room.

(Christophersen, E. & Mortweet, S., 1997)

Reinforcement Strategy

If a behavior is followed by a positive reward, that behavior is strengthened and is more likely to occur in the future (Forehand, R., Long, N., 1996). Two well-known types of reinforcement are tangible and social reinforcements. Tangible reinforcements include toys, food, stickers, awards, etc. Social reinforcements include attention, verbal or written praise, smiles, laughter, hugs, etc. Social reinforcements have the greatest positive impact on changing behavior.

Punishment vs. Reinforcement

Punishment gives your child the message of what to avoid, but does not help guide your child toward positive behavior. When using punishment as a behavioral intervention, parents often increase the level of harshness of punishment over time. This often leads to behavioral problems and feelings of anger and resentment.

Rewards/Reinforcement

1. Use rewards immediately after the behavior you want to increase/encourage with your child.
2. Initially reward the behavior every time your child displays this behavior.
3. Reward only behaviors you want to increase/encourage with your child.

Just as good behavior should be rewarded, undesirable behavior displayed by your child should be ignored.

Tips On Ignoring:

1. Do not touch your child – No physical contact
2. Do not talk to your child – No verbal contact
3. Do not look at your child – No eye contact

(Disclaimer: You will need to immediately intervene if your child is doing something dangerous, harming himself/herself or others.)

Behaviors To Ignore:

1. Inappropriately demanding attention
2. Demanding you do something you do not want to do
3. Crying for attention
4. Tantrums
5. Screaming
6. Pouting
7. Showing-off
8. Arguing
9. Acting irritable

Additional Tips For Ignoring Undesirable Behavior:

- * Select an undesirable behavior that can be ignored, and remove all your attention from the behavior when it occurs.
- * Once you start ignoring the undesirable behavior, keep ignoring it.
- * Expect the undesired behavior to increase in frequency before it starts to decrease in frequency.
- * Reward and point out appropriate behavior.

(Forehand & Long, 1996)



Time-out Interventions

Rules For Using Time-Out Effectively:

1. If your child displays an undesirable behavior during time-out, ignore it.
2. Social interaction should be forbidden during time-out. Instruct other family members to observe this rule.
3. As soon as your child is quiet for two to three seconds, time-out is over for him/her.
4. After time-out is over, do not remind your child of the reason for his/her time-out and do not ask your child why he/she was placed in time-out.
5. If you are using time-out to help your child calm down, you cannot “nag” your child after each time-out.
6. It is critical that your child learns to associate calming down with time-out.
7. As your child learns to calm down during time-outs, gradually increase the amount of time between calming down and the end of time-out.

Remember: Time-outs can be used with children of all ages.

Things To Consider:

- If your child’s behavioral issues bother you, it’s worth improving. If your child does something that annoys you, it probably annoys other adults as well.
- Be realistic about behavior change, and try not to be discouraged if the behavior does not change overnight. Change happens more quickly if you are consistent. Remember to remain patient and calm when using time-outs, and refrain from nagging. Not all days will be successful, but with consistency, patience, and love, your child’s behavior should improve.

(Forehand & Long, 1996)





For More Information on Parenting Skills

Books:

1. *Parenting with Love and Logic*
Cline, F & Fay, J. (1990)
2. *Parenting Children with Health Issues*
Cline, F & Green, L (2007)
3. *How To Talk So Kids Will Listen & Listen So Kids Will Talk*
Faber, A & Mazlish, E., (1980)
4. *Parenting the Strong-Willed Child*
Forehand, R & Long, N., (1996)

Websites:

1. loveandlogic.com - Provides in depth information on the *Love and Logic* program as well as provides free parenting handouts.
2. fabermazlish.com - For more information from the authors of *How To Talk So Kids Will Listen And Listen So Kids Will Talk*. Provides an advice column, parenting tips and offers the opportunity to email questions to the authors.
3. happyheartfamilies.com - Co-author of *Parenting Children With Health Issues (a Love and Logic Model)*, Lisa Green offers resources, stories, parenting strategies, and parenting tips specific for CF parents.
4. pbs.org/parents/childdevelopment - Provides basic child development information, resources for parents and parenting advice. Offers basic health and nutritional information.