



## LIFE TRANSITIONS AND CF: PREPARING FOR THE REAL WORLD®

With Lisa C. Greene, MA, CFLE

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## Three Stages of Transition

- Envisioning a Future
- The Age of Responsibility
- The Age of Transition
  - Adolescence (Ages 12-17)
  - Young Adulthood (Ages 18-23)

(Reiss, Gibson, & Walker, 2005)

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### Stage 1: Envisioning a Future

- Starts at the point of diagnosis
- Ask general questions about the future
- Don't worry about the details early on
- Where do you want your child to be in 20 years?
- Focus on hopes and dreams
- Set high expectations with a "can do" attitude
- As child grows, dream and plan for education, career, and independent living



(Reiss, Gibson, & Walker, 2005)

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### Stage 2: The Age of Responsibility

- Start laying the foundation for responsibility
- Teach child self-care tasks including medical care
- Help child develop own routines and systems
- The habits developed now will last a lifetime
- Gradually shift full responsibility for medical tasks with adult oversight and support
- Continue to envision the future and start laying the foundation for education and career planning

*Ideally occurs prior to adolescence*



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### Stage 3: The Age of Transition

#### Adolescence (Ages 12-17)

- Ideally, child is taking full responsibility and initiative for medical tasks with adult oversight and support.
- Educate at a higher level about CF medical knowledge and self-care tasks.
- Heavy focus on planning for continuing education, career, and independent living.
- Shifting of responsibility for communication with doctors, ordering medications, scheduling appointments, noticing symptoms and making treatment decisions with adult oversight and support. Teach advocacy skills.
- Legal documents, medical records, insurance coverage, and transfer process planning.

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### Stage 3: The Age of Transition

#### Young Adulthood (Ages 18-23)

- Transfer may occur at 18 or 21. Be prepared.
- Your young adult needs your support however do not hover or take over.
- Legal documents, medical records, insurance coverage, and transfer process planning.
- Remain present and available for support and problem solving.
- Develop a flexible way of communicating with your child so you can stay informed while not seen as interfering. (Kieckhefer & Trahms, 2000)

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## How to Stay COOL When You Feel HOT!

Why do we lose our cool? There are many reasons why people get upset and lose their cool. Here are some of the most common reasons:

1. Stress and feeling overwhelmed
2. Lack of good self-care
3. Family of origin patterns and responses
4. Personality traits, genetics, cultural influences
5. We feel threatened in some way
6. When our expectations aren't met
7. A reaction to some kind of obstacle
8. When something we are trying to communicate isn't received
9. We are worried, afraid, or hurt



Anger itself is not good or bad. It can keep us safe or tell us that something is wrong. However, the way we cope with anger is critical. It is not okay to spew it all over others. Having some simple tools to help us calm down will increase the odds that we will handle anger appropriately and get down to the business of solving a problem rather than escalating it.

### Tips and ideas for calming yourself down and staying cool:

- Pause. Take five deep breaths slowly.
- Pause. Count to 10.
- Pause. Take a drink of cold water.
- Say: "I am very upset right now. I need a moment to myself. I'll be back soon." Leave the room.
- Practice mindfulness or pray each day for 5-10 minutes.
- Say a calming phrase over and over: "This will soon pass." "This relationship matters." "It's only a phase." "I can get through this." "Stay cool."

### One or two new "cool" ideas I will use the next time I feel "hot":

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## HOW TO BE A GOOD LISTENER

Listening is "attaching meaning to sound through knowledge and experience." Hearing is just the physical reception of sound, it's passive and automatic but listening is active and intentional. Listening involves three functions: (1) Hearing, (2) Processing the message and (3) Reacting to the message through communication- words or body language.

**There are four components to effective listening:**

### **1. Being present**

A simple concept but hard to actually do. This is being in the moment with the person we are listening to, not thinking about the past, the future, what we want to say, or the fight we had with our spouse that morning. This also means focusing on the speaker, not ourselves. It is *other focused*.

### **2. Take in information without judgment**

Being judgmental is a major barrier to communication. When we are reactive or defensive, we can't listen. We need to set aside egos, biases and inner thoughts so we don't filter the message until we've had a chance to think about it.

### **3. Acknowledge the speaker in a way that invites communication to continue**

When we don't show a visible reaction, it's easy for the speaker to assume we aren't listening. Or they might think we don't understand or maybe that we don't like the message. Listeners can interpret our body language in a number of ways ranging from interested to bored. Body language in the form of gestures, nods, eye movements, and posture all provide clues to the speaker- for better or worse. So use *verbal* cues: wow, hmm, I see, aha, really?

### **4. Wait for the period at the end of the speaker's sentence before formulating a reply**

This is a hard one for most of us and I can admit it is for me. Notice that this is not only wait until the period to say something but wait until the period before you FORMULATE your reply. When we are working through what we are going to say, we aren't listening to the speaker's complete thoughts. Many misunderstandings and communication conflicts occur because the listener is too involved in preparing a response to really listen to what is being said.

**In summary:** Listening is a critical life skill. Being present, non-judgmental, expressive and waiting for the speaker to finish will improve your relationships, reduce misunderstandings and might even change a life.

By Lisa C. Greene, MA CFLE [www.HappyHeartFamilies.com](http://www.HappyHeartFamilies.com)

Reference: Shore, Leslie (2012). Listen to Succeed. CreateSpace Independent Publishing Platform.

# Problem Solving Models

When we think about problem solving, we want to engage in a process that helps both parties to participate fully. We also want to figure out how both parties can have a win, even if it means giving up a little something to meet halfway. The outcome is dependent on the process you use. Here are three problem solving models which provide guidelines for working through a problem methodically and collaboratively.

## Steps to Problem Solving

1. Identify the problem that needs to be solved
2. Empathy and reflective listening about both sides of the issue
3. Ask: How can we (or you) solve this problem?
4. Generate possible solutions
5. Identify the consequences / outcomes to possible solutions
6. Pick a solution and create agreements
7. Follow through and follow up



## WE CAN

- W: What is the situation?
- E: Evaluate the options
- C: Can anyone help?
- A: Agree
- N: Notice the difference

Reference: Drummond, Fleming, McDonald & Kysela, 2005



## Suggestion Circles

1. The person with a problem (the listener) states the problem in a clear, concise way.
2. One person makes a written list of the suggestions so the listener can give full attention.
3. People in suggestion circle to center their bodies and think carefully about their possible solutions.
4. Go around the circle and give one high-quality, concise response with "You could..." or "You might consider..." or "I would ...". No discussions, no comments, listener to simply say "thank you".
5. When the suggestions have been given, the listener is given the list, takes them home and decides what to use.

Reference: Jane Illsley Clarke, 1998, *Who, Me Lead a Group?*

## TOOLS AND TIPS FOR GAINING COOPERATION by Lisa C. Greene, MA CFLE

Whether children need to pick up their toys, brush their teeth, do homework, be home on time or take medication, gaining cooperation is a critical skill set. In their haste to get a job done quickly, adults can sound more like a drill sergeant than a parent: "Pick up your toys," "Brush your teeth," "Do your homework," and "Take your medicine." When kids don't comply, the result can be power struggles, nagging and reminding, threats, warnings, and frustration all around.

While it may take a little longer at first as you are learning, using strategies and skills to gain cooperation will save time in the long run as well as build positive relationships. Here are several ways to engage cooperation. Keep in mind that having age and developmentally appropriate expectations are an important part of gaining cooperation. Most of these tools are effective for kids of all ages. Experiment, rotate them around. If you try something and it doesn't work today, it might tomorrow. Kids change quickly. Parents change, too!

### EDUCATE, GIVE INFORMATION.

There is no particular order to these tools but if one of them should be tried first, it's this one. Often times, when kids understand *why* something needs to be done, they do it. Keep your explanations short and sweet: "Toys left outside get dirty and broken." "Shouting hurts my ears." "Throwing toys at your sister will hurt her." "Skipping your medicine will \_\_\_\_." "Taking your medicine late will \_\_\_\_."

### TEACH WITH PICTURES, ART, AND ACTIVITIES.

Children's brains work differently than adults. Kids learn best with pictures, art, play, and activities. So use drawings or pictures to show your child what you want him or her to do. Do a role play with toys or puppets. Draw faces to help your child learn about feelings.

### CHECK OUT YOUR CHILD'S UNDERSTANDING.

This one goes along with the first two. If you've already educated your child about an issue, then he or she should be able to give you a reasonable response. If your child genuinely doesn't know the right answer, then you now have a new opportunity to teach. And if your child is pushing your buttons, you'll probably know that, too. Here are some ways to check out your child's understanding: "What needs to happen before \_\_\_\_?" "What should you be doing right now in order to \_\_\_\_?" "What do you think will happen if \_\_\_\_?" "What are the steps for \_\_\_\_?" "What did the doctor say about \_\_\_\_?" "What did your teacher say about \_\_\_\_?" "When is bedtime?" If your child says, "I don't know" you can ask: "Would you like help remembering?"

### GIVE CHOICES.

Choices are very powerful. As discussed in an earlier section, it's important to share control as much as possible, within limits. Here are some examples: "It is time to take your medicine. Would you like to take it with apple juice or grape juice?" "Would you like to do your medical treatments before or after breakfast?" "It is time to clean up. Would you rather pick up the puzzle or pick up the crayons?" "Would you like your labs done Friday or Monday? You decide."

### ASK POWERFUL QUESTIONS.

Questions imply choices. Used correctly, questions can be a very effective way to help others dream, think, plan and take action. Therapists and coaches use powerful questions to invite clarity, action, and self-discovery. Parents can also learn to use powerful questions to guide and support children.

Examples of powerful questions: What do you think? What do mean by \_\_\_? What does it feel like? How do you feel about \_\_\_? What do you want? Can you tell me more? What have you tried? What caused \_\_\_? What are your options/ choices/ possibilities? How does this decision relate to \_\_\_ (better health, your life purpose, etc.)? How important is this? How will that work out for you? What resources/support/help do you need to get \_\_\_? What is stopping you? What is possible? What are you dreaming of? What do you hope for?

#### INVITE RESPONSIBILITY FOR TAKING ACTION.

More powerful questions: What is your plan for \_\_\_? How will you make \_\_\_ happen? Now what? What next? When will you be doing \_\_\_? What will you have to do to get \_\_\_ done? What was our agreement about \_\_\_?

#### AVOID ACCUSATIONS AND INTEROGATION.

Questions can be very effective as long as you don't act like an interrogator or a prosecutor. Be genuinely curious and interested. When you first notice that a child isn't doing something they should be doing or is doing something they shouldn't, avoid saying things like: "Did you \_\_\_?" "Why aren't you \_\_\_?" This invites defensiveness and arguing, especially if asked in a critical way. "Why weren't you home at 11:00?" can be re-phrased to "What was our agreement about curfew?" Or: "I noticed that you \_\_\_ (didn't take your medicine at 3:00)." Then try one of the other tools in this book.

#### POINT OUT WAYS TO BE HELPFUL.

"It would be helpful if you do your breathing treatments on time so we can get to the game before it starts." "It would be helpful if you could put the crayons in the box." "It would be helpful if you could get your medications ready to go." "It would be helpful if you could move over so your brother can sit there, too."

#### ASK FOR HELP.

"I need your help. Can you help me understand why you don't want to do \_\_\_ (your homework, take your medication, clean up your room, etc.)?"

#### STATE WHAT YOUR CHILD CAN DO

"Feel free to play inside as long as you talk quietly." "You may have a snack after you take your medicine." "You are welcome to go to your friend's house after your \_\_\_ (homework, chores, medication) is done."

#### REFRAME REQUESTS INTO THE POSITIVE.

Ask for the behavior you want instead of telling kids what you don't want. Kids do better when we use positives. So instead of saying "Don't yell" try "Please talk quietly." Or instead of "Don't run" try "Please walk." Or instead of "Don't forget to pack your medicine" try "Remember to pack your medicine."

#### DESCRIBE THE PROBLEM.

"I see toys all over the floor that have not been put away." "It's getting late and homework is not done yet." "We have to be at \_\_\_ by \_\_\_ but your medical treatments aren't done yet."



**Want more? There are many more tools for gaining cooperation in Lisa's new book: "No More No! How to Gain Your Child's Cooperation with Self-Care, Medication and Just About Everything Else" available at [amazon.com](http://amazon.com) and [pcwhi.com](http://pcwhi.com) under "resources". © 2015 by Lisa C. Greene. All Rights Reserved.**

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## What Should I Say?! How to Talk with Your Kids about Difficult Issues

by Lisa C. Greene, MA CFLE and Foster W. Cline, MD

I asked the doctors, "So how do I talk to my children about their illness? What do I tell them when they ask questions about how long they'll live?" And they said, "Treat it just like when kids ask questions about sex- answer them on a 'need-to-know basis'." "Okay," I thought, "I can do that." I figured that my kids are young so I'll have plenty of time to figure it out.

But then, as we were driving down the road one day, a question came out of the blue: "Mommy, how does the daddy seed get into the mommy's tummy to make the baby?" I stuttered and swerved and mumbled something about needing to pay attention to the road so I'd have to get back to them on that. I thought, "A need to know basis?! What does a four- and six-year-old need to know about that?" And that's when I realized I didn't know how to talk to them about sex any more than I knew how to tell them that the disease they were born with, cystic fibrosis, has a life expectancy of 37 years of age.

Parenting is tough enough at times for just about every parent. Parents sometimes need to talk with children, or answer their questions, about difficult issues like divorce, the death of a loved one or the loss of a parent's job and lifestyle change. But the situation can be even more difficult when a child has a serious health issue. What do you say to a child who struggles with life-threatening allergies, cancer, cystic fibrosis or diabetes? What do you do when parenting is truly a matter of life and death?

Parents must navigate a complex maze of medical information and cope with children who may be resistant, confused, or frightened. There are many difficult-to-answer questions that a child may ask: "Will my disease kill me?" or "Will it hurt when I go to the doctor?" or "What will happen if I don't take my medication?" Unprepared parents may find themselves at a complete loss. Here are some tips to help you become more prepared for these challenging moments.

**Teach your children early on about their medical condition and be honest about the consequences of non-adherence.** One of the most challenging things for parents is to have a difficult discussion about life-threatening content in a matter-of-fact manner.

The key is to show curiosity and interest while outlining the consequences (of non-adherence). Do your best not to show fear and angst about the issue. Generally speaking, if parents don't show fear and angst, then the child is less likely to become fearful. Children pick up on our cues and young children tend to mirror them almost exactly. If you are having trouble controlling your own emotions about these tough issues, grief counseling might be helpful.

Oftentimes, we just don't know how to handle these issues with our kids. So when you don't know what to say, do what therapists do: be curious and ask questions. Then your kids end up guiding you! If that method is good enough for therapists, it's good enough for parents. Some good questions to ask are:

- "What do you know about CF?"
- "How worried are you?"
- "How are you handling it?"
- "What can I do to make things easier?"
- "Is there anything more you need to know?"

Obviously, we would explain things differently to a three-year-old than to a seven-year-old or a twelve-year old. Concrete examples, word pictures and drawings are important communication tools for explaining things to young children. Condition-specific children's books that are geared to your child's age can be very helpful.

Ideally, children should be fully aware of the details of his or her illness by around the age of eight or nine. This might sound a little young to some of you, but when children go to school, we lose control of the information they will be getting. It is not uncommon for a child to come home from school upset saying, "Susie said I'm gonna die from CF. Is that true?" It's better that parents "break the news" about these types of issues than children hearing it from their peers who may be simply insensitive or downright mean.



Here are some *guidelines to follow when discussing difficult issues* with your children:

- Before you give answers, ask yourself whose needs are you addressing - yours or your child's?
- Consider whether you are giving more information than the child wants or needs to hear.
- Be open to your children talking with you about anything and everything.
- Show empathy and use reflective listening.
- When you are not sure how to give the answer, ask more questions; show genuine curiosity.
- Know that children may try to protect parents by hiding their fears.
- Show acceptance even when you can't show approval.
- Every answer dealing with life-and-death issues should leave room for hope.

**Set the example for healthy habits and a positive attitude. Kids learn from our modeling.** It's never too early to start teaching good health habits. Wise parents cheerfully model the behavior they want their child to learn: "Here's some cereal for you. Let's check if there are any peanuts in it. Nope! That's good. Peanuts can make you very, very sick. This is a no-peanut zone!" Remember, toddlers can understand what you say long before they can talk clearly. And when we model a positive, hopeful, can-do attitude even in the face of the challenges we face, then it's more likely our kids will grow up with the same attitude.

In summary, what we say depends on the age of the child, the ease of the parent in dealing in a matter-of-fact way with reality laced with hope, and upon the parent's religious beliefs.

Dr. Cline answered my questions about talking with my kids about their illness so well that I figured maybe he had some ideas about how to talk with them about sex, too. And here's what he said...

"When your kids ask how the daddy seed gets into mommy's tummy, try answering with something like this: 'It's a special thing that they need to help each other with because the seeds are really small so it's hard to get them inside.'"

Dr. Cline said that the key is to be really general and see how specific the kid is. Does he keep asking for clarification or will the above (or something like it) do the trick? As children get older, you can fill in the details as needed. Dr. Cline adds this thought: "And if we're *really* lucky, Mother Nature will help us along and we can say: 'Oh, look at those dogs! The seeds are being popped out of the boy dog and into the girl dog. Pretty slick the way that works...'"

Of course, that might start up a whole new round of tricky questions. Isn't parenting fun?

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From the book "**Parenting Children with Health Issues: Essential Tools, Tips and Tactics for Raising Kids with Chronic Illness, Medical Conditions and Special Healthcare Needs**" by Foster W. Cline, M.D and Lisa C. Greene.

Dr. Cline is a child psychiatrist, author, and co-founder of Love and Logic. Lisa is the mother of two children with cystic fibrosis and a parent coach. For free audio, articles and other resources, visit [www.ParentingChildrenWithHealthIssues.com](http://www.ParentingChildrenWithHealthIssues.com).

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## Consequences or Punishment

*Consequences* allow the adult to be an educator —  
*Punishment* allows the adult to be a law enforcement officer.

*Consequences* always relates to the misbehavior —  
*Punishment* rarely relates to the misbehavior.

*Consequences* give a child a choice of behavior and results —  
*Punishment* gives no choice to a child.

*Consequences* retain respect for the child —  
*Punishment* belittles the child.

*Consequences* allow the adult's voice to remain calm and friendly —  
*Punishment* encourages the adult's voice to be loud and angry.

*Consequences* are concerned with the present misbehavior —  
*Punishment* concerns itself with present and past misbehaviors.

*Consequences* show the adult as interested in the situation and its outcome —  
*Punishment* shows the adult interested in retaliation.

*Consequences* accept the child while rejecting the misbehavior —  
*Punishment* infers that the child is valueless.

*Consequences* are seen by the child as fair —  
*Punishment* is seen by the child as unfair.



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## Components of Effective Consequences

- ☆ They contain a value message. Your rules and expectations should be based on your core values such as respect, tolerance, kindness, honesty and responsibility.
- ☆ They place responsibility back on children.
- ☆ They are atonement and restitution based.
- ☆ They are delivered with empathy and concern on the part of the parent.
- ☆ They can extend over time and encourage the children to think about their behavior.
- ☆ They are action oriented and require effort on the part of the children.
- ☆ They focus on attachments vs. isolation.

## Value-Based Consequences

A value based consequence places responsibility on the child and contains a value message. This type of consequence requires more effort and action. These consequences are atonement and restitution based. They encourage the child to think about their behavior and can occur over time. They are delivered with empathy and concern and focus on attachments, not isolation.

- *“If you abuse it — you lose it!”*  
This includes privileges, material items and relationships.
- *“If you want the goodies — you have to pay the vendor.”*  
Relationships are reciprocal. Life is reciprocal.
- *“If you break it — you have to fix it.”*  
This can include trust, material items and relationships.
- *“If you mess it up — you clean it up.”*  
This takes action on the part of the perpetrator. If you mess up a relationship or hurt a person’s feelings you have to face the victim and “clean up the mess.” This obviously applies to other types of “messes” (i.e., classroom, cafeteria, etc.)
- *“If you take something, you have to give something back.”*  
The more the child has to give back...the more attached they become. This could include the teacher’s or janitor’s time.
- *“If you do something mean, then you have to do something nice.”*  
It must be done in a kind and gently way.



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