

RAISING SUCCESSFUL TEENS
a parent's guide to healthy living with cystic fibrosis

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TEENS AND CYSTIC FIBROSIS

The Quest for Healthy Independence

By Siri Vaeth-Dunn

As all who have survived the teen years know, they can be full of challenges. Many changes occur at the same time in all parts of life. Friends may pull teens away from parents and their control. Teens seek to “call the shots” more often. They struggle to know how to do that. While some choices made during this stage can be harmful to health, the health effects for teens with cystic fibrosis (CF) can be much worse.

It is normal for teens to feel that nothing can hurt them. It can be hard to see how current actions affect the future. When teens experiment, it can include new hair colors and dress styles, body piercings, tattoos, drugs, alcohol, and sex. Since the peer group takes on greater meaning, many teens seek to fit in and do not want to stand out as “different.” It is “normal” for teens to challenge authority. All teens face these issues but they have a greater impact on teens with CF.

Many teens with CF do treatments as prescribed. They say that doing so makes them feel better and helps them do what they want to do. When they skip treatments, they “pay” for it! Still, many studies and countless parents know the teen years to be a challenge when it comes to following the medical routine. In studies, teens give many reasons for skipping treatments. They want to fit in, want more time with friends, do not like being told what to do, and feel the treatments do not help.

CF is a progressive disease. It affects many organs and body systems. Teens have spent much of their lives in CF clinics where the care team has talked mainly to parents. As teens become young adults, they need information shared clearly with them as well. There are often health issues about which teens do not want to speak in front of their parents. They must have the chance to speak alone with the care team.

Teens are often shy about asking certain questions. The care team should share certain things without being asked. Many teen girls with CF suffer in silence with yeast infections caused by the antibiotics they take. The nurse or doctor should ask girls about this directly. This will give them a chance to put fears and shame to rest and get treatment. Also, many teens with CF - often girls - have stress incontinence due to increased pressure on the bladder from chronic coughing. There are exercises that can help, but they may be too shy to bring it up on their own.

For many teens with CF, puberty is delayed. This can affect self-esteem and make them feel different. Reproductive health may be hard for teens to talk about yet must be addressed. CF can affect birth control options for girls. Certain antibiotics may cause birth control pills not to work as well.

Many teen boys with CF, but not all, are sterile (unable to produce children). Over 95% of boys with CF have Congenital Bilateral Absence of the Vas Deferens (CBAVD). This means that the vas deferens tubes are blocked or absent. Sperm is made but cannot be carried out in the semen. Boys with CF should not assume they are sterile. Without testing, there is no way to know. Boys with CBAVD should know that they are still able to father their own children due to advances in medical science.

While scare tactics seldom work, teens need reminding that respiratory therapy is vital. Teens that spend more time on their own need to be able to share about increased breathing problems. The CF care team should make teens aware of problems like hemoptysis (coughing up blood), which affects over 60% of people with CF. Teens need to know what to do if this occurs. Nutrition is

key for teens with CF. Due to malabsorption, teens need extra calories, and often extra calcium. For teens with CF-related diabetes (CFRD), the care team must help them understand how blood sugar levels and lung function are related.

While healthy teens need over 9 hours of sleep each night, few teens achieve this. One recent study found that only 15% of teens slept over 8 hours per night on school nights. For teens with CF, their sleep needs are even higher for best health. Yet, they report sleep disruptions from chronic cough and medicine side effects. A lack of sleep can increase infections, make them unable to think straight, and cause mood swings. Teens with CF are more prone to worry and depression, which are worsened by lack of sleep.

Teens with CF report being depressed for many reasons:

- Feeling physically unwell
- The challenge of endless daily treatments
- Medicine side effects
- Being in the hospital and thus missing major life events (sports, parties, concerts, prom)
- Feeling different from peers

As one teen put it, “Living with CF is like having a clock ticking above my head. My friends don’t have to deal with that.” In addition to CF-specific issues, these teens also cope with the stressors that all teens face.

Among these stressors is peer pressure. Though teens with CF have many health issues, they are not immune to pressures to try cigarettes, drugs, alcohol, and sex. While studies find lower rates of “risky” actions in teens with CF, a study of teens at the five major CF Centers in North Carolina found that 1 out of 5 teens had tried cigarettes and nearly 30% had had sexual intercourse. A second study found that youth with chronic health issues were involved in sex at the same rates as their healthy peers.

Whether they are depressed, anxious, or seeking relief from CF issues, teens with CF may use alcohol or drugs to feel better. Depression can lead to self-harm like “cutting” and eating disorders. Depressed people are less likely to care for themselves and follow their medical routine. Parents and the CF care team must help teens find support and learn coping skills. These can include therapy, sports, art, religion, and CF-related or other social support networks.

The teen years often spark the move from pediatric to adult CF Center. This can be a tough move, as teens are often nervous about seeing a new care team. At the same time, many teens are thinking about goals beyond high school. The thought of applying to college, moving away from all that is known, and losing the daily health care support of parents can be fun and scary. Help teens take charge of their medical routine. Show them that they can manage on their own.

Teens with CF cope with huge stressors. Recognize the unique pressures they face. Help them access the resources and support they need. They will be better able to travel through their teen years. Celebrate their strengths! Support them in their quest to be on their own and healthy!

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RAISING TEENS WITH CYSTIC FIBROSIS

Making Good Life Choices

By Foster W. Cline, MD and Lisa C. Greene

There is a common myth that teens rebel and are hard to parent. The fact is teens and parents can be great friends. Love and respect grow when teens start thinking like adults. Of course, this does not make the nightly news! The press does not cover healthy, happy stories the way it covers problems. Many think it is the norm for teens to rebel and cause strife and pain. It does not have to be that way!

That said, the journey can be hard. In this article, we discuss how to respond to your teen during those rare (we hope) rough times. The way parents respond to their teens can have a big impact on how well things go both during the conflict and later.

The Main Reasons for Teen/Parent Conflict

1. Parents and teens may not spend enough time together having fun. Even though teens might not seem like they want to spend time with the family, experts stress finding activities the whole family can enjoy. Having fun outdoors is especially good for bonding. Try things like hiking, rafting, camping, biking, and other sports. When people spend time with each other, love and friendship grow.

2. Research shows that the teenage body is perfectly made for hard work and extreme sports. However, parents often view this as the path to certain death! Research also shows that teens are still learning cause and effect thinking so may not always have good judgment. Thus, what some say is a danger to teen bodies, teens often view as quite safe!

3. Teens search for their identity. They have new energy, sexual urges, and priorities. These may not match their parent's values, customs, and beliefs. At this stage, teens may question and reject family ideas, practices, and values.

4. Teens want more space and privacy. This can lead to secrets and sneaking, which causes tension. Teens may feel that what they are doing is just fine. But they may also feel that if their parents knew what they were up to, they would freak out, be disappointed, or not understand. Teens may hide things because they love their parents and do not want to hurt them or because they do not want to cause conflict or be punished.

Conflict can Increase with Health Issues

In any home, the four issues above can stress the way parents and teens relate. It can be even tougher when teens have a serious or chronic illness. These teens are more likely to make poor, harmful choices including skipping medications. Parents are even more apt to freak out, be disappointed, or not understand!

As a result, parents may "crack down" and set firmer limits. This pushes teens to rebel even more. They may rebel by making poor choices about their illness. Teens angry with parents who love them may think they can get back at their parents and upset them by not taking their medicines. This becomes a vicious cycle: Teens make poor health choices. Parents get concerned and try to control by setting stronger limits. Teens rebel still more.

We must note, at this point, that most ill teens adhere to medical routines like adults do. Adherence is often poor no matter what the age! Research shows that people adhere to only about 50% of their medical routines. What may look to some as a teen being a rebel may really be a teen being a human!

Health issues can cause teens to rebel and battle for control. How should parents respond to a teen's poor, harmful choices?

How Not to Respond to Your Teen's Poor Choices

When kids behave in a harmful way, parents may respond by getting...

- ...mad at...
- ...frustrated with...
- ...hurt because...
- ...worried about...
- ...fearful that...
- ...sad for...

It is normal for parents to feel these six things, but showing the first four will often make things worse! The last two may not help but may, at least, not increase the chance of rebellion.

Making Poor Choices Easy

Parents can unwittingly finance or promote their teens' poor choices. When over-protective parents do too much for their kids, the kids have harder time standing on their own. They may also become entitled and, in extreme cases, hostile- dependent.

Children who have reached the stage of hostile-dependency are very difficult to deal with. They feel helpless, cheated, and victimized by their circumstances. Always demanding more, they expect parents to be unendingly available, comforting and nurturing. They do not accept the responsibility for taking care of their own wants and needs because they expect (and demand) others to do this for them. Such children are said to "bite the hand that feeds them".

How To Respond to Your Teen's Poor Choices – What Often Works

When teens make poor choices, parents often seek professional help. Ask yourself, "How would a therapist respond?" Therapists will not show the first four emotions. Therapists will not say, "I feel so hurt when I have a client like you," "I am so mad at you," "A client like you frustrates me so much," or "I am so worried about you that I can't sleep at night."

Therapists may show sorrow, empathy, or concern for their clients, but will not be wringing their hands. Most often, therapists work to tone down the emotions. They listen, are curious, explore options, use problem-solving skills, wonder about the results of choices, and help clients respond in helpful (rather than unhelpful) ways.

Consultant Parents

Love and Logic® is a parenting program taught throughout the United States in schools and communities. It teaches parents how to be Consultants rather than Helicopters or Drill-Sergeants. Briefly, Consultant Parents...

- share ideas and give advice but let kids make decisions and affordable mistakes.
- set an example by taking good care of themselves.
- offer choices and options, not orders.
- set firm limits, not demands.
- use meaningful actions with empathy when things go wrong.

Consultant Parents send this message: “You are in charge of the quality of your life. You can do this. I believe in you!”

One of the main tools a Consultant Parent has is to be curious and show interest by asking loving questions. Questions imply choices and offer teens healthy options and control. To listen and ask questions improves almost all relationships. When relationships work well, life works well! If your teen is making poor choices, ask questions like...

- What are your choices here?
- What ideas/thoughts/feelings do you have about ...?
- How does this fit with your plans for your life?
- If you keep doing this, how worried are you about your future?
- What do you think is the best option?
- What is your plan for...?
- What can I do that will help you to...?
- How could you make the situation better?
- How can I help you with...?

When asking questions, do not put your child on the witness stand. The idea is to be gently curious and move your teen into thinking and problem solving.

Consequences

When teens continue to make poor choices even after problem-solving, parents may need to impose consequences. Consequences should:

- Be carried out calmly, in a matter-of-fact manner with empathy.
- Make sense and be related to the “crime.”
- Mimic what might happen in the real world as much as possible.
- Not be carried out with the intent to make the child feel bad or guilty.

When teens continue to make bad choices, counseling is advised. A counselor can help improve communication, focus on problem solving, enhance relationships, and end the cycle of teen rebellion. Counseling can stop concerned, loving parents from imposing punishments that do not work.

Parents as Models

Kids learn far more from the examples set than from the words and lectures parents give. Parents can be good role models by taking good care of themselves. Eating right, exercising, getting enough rest, and taking medications properly are all a part of setting a good example.

Caring for your own physical and mental health also means being sure you are not making it easy for your kids to make poor choices. There is such a thing as parents spending too much time, energy, and resources to “save” their kids from the results of their own poor choices. This is often seen with drug addiction. It can be applied to teens with CF making poor choices with no desire to change. When all else fails, parents must give this message:

- It is not healthy for me to watch you make choices that may kill you.
- I feel used when I see my money wasted.
- If you feel you must...(name the harmful behavior), you will have to do it elsewhere.

A Contract with Your Child

At some point, parents may have to require contracts and/or send their child to a safe place away from home. Good contracts include clear, and fair, expectations. Most starting by giving teens a choice:

If you expect to live here...

...you can expect these things from us...

...we can expect these things from you...

...you agree to these consequences if you break this contract...



In Summary

A child's poor choices are perhaps a parent's toughest problem.

Wise parents grow a relationship with their teen based on love and respect for each other. Both parents and teens give time and energy, respect privacy, show concern, and respect choices of friends and clothes.

Wise parents attempt to avoid direct confrontation about their teen's self-destructive behavior. Instead, they show interest, ask careful questions, and wonder about their future while not allowing their teen to control the parent's emotional environment.

Many parents find counseling helpful.

If questions, choices, and problem solving do not work, study the art of consequences and use it with your teen.

Using consequences may involve a clear, thoughtful behavior contract, which outlines the results of breaking the contract.

Parents must always model taking good care of themselves. They must not help their child make poor choices.

This is the outline of what a Consultant Parent looks like. These are the basics of a happy, healthy, loving, life-long relationship with your teen.

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ADVICE FROM ADULTS WITH CYSTIC FIBROSIS

Insight and Encouragement From Adults Who Have Lived It

The teenage years weren't easy for many of us. This time can be even more challenging for teens with CF and their parents. For that reason we asked adults with CF to look back on that period in their lives, reflect on how they were parented, combine that with what they know now, and give advice to parents of teens:

Get Them Involved

As a parent, reinforcing, encouraging, and supporting their teen with CF to be active is critical. Participation in activities for teens not only carries physical and social benefits for teens with CF, but also holds opportunity for experiences of personal achievement, confidence, trust, success, and most of all, fun. The interactions required in activities leads to connections and friendships, which ultimately could become part of the teen's support system. Peer support first requires disclosure of even having CF, and that can be an incredibly scary thing in adolescence that requires significant trust. Activities are the grounds for building that trust.

My advice to parents would be to do everything in your power to support, encourage and nurture the exploration of some type of activity for your teen with CF. The physical, psychological, social and emotional benefit of an active lifestyle may, in time, be the factor that helps them not only survive CF, but to even thrive with it. - *Brian, 36 year old patient with cystic fibrosis.*

Treat Them Normally

My parents never tried to raise a child/teen with an emphasis on CF. They just raised me like any other kid. I was encouraged to pursue my dreams to their fullest. I was held to high expectations in terms of they type of person I was. When I wasn't meeting those expectations, I was corrected. Overall, I was treated "normally."

That being said, they also didn't hesitate to say, "Hey, you're sick. Let's take care of that." When I was down and out they were very supportive and engaged without coddling me or being overly sympathetic. Maybe they felt that way, but they never showed it. - *Patrick, 29 year old patient with cystic fibrosis.*

Use Motivational Interviewing

The one thing I know about raising teens is that they hate to be told what to do. This, of course, is a big problem if you have a teen that needs extensive time-consuming medical interventions in order to stay healthy. You can talk till you are blue in the face about how something is important, mandatory, critical, or "insert adjective here." The bottom line is that unless they think it is important to them, it isn't.

There is a concept in change psychology called "motivational interviewing." I learned about this when I was becoming a coach, and I cannot express how much it is coming in handy as a mother of teens. The idea is that you need to find a way to make the teenager talk about why something is important to them, instead of telling them why. This is called "change talk." And then you do the hardest thing you can imagine...you shut up. You say, "Really? Tell me more about that." Research in change psychology tells us that the brain believes what it tells itself, not what another brain tells it.

So when my healthy son decides in his great, adolescent wisdom that math homework is optional and brings home a less than ideal mid-quarter grade, here is what this looks like:

What I want to say: Are you serious? Math is your best subject! How can you possibly be failing? Geometry is so simple...just do the stupid homework!

What I do say: Wow, you know you won't be able to do crew if you don't get a better grade in geometry. What would that be like? Tell me how crew has been good for you the last two years. How do you think you could bring your grade up even though you can't understand your teacher? How can I help?

And then I shut up and listen. As soon as he starts talking about his teacher's accent and all the reasons that he can't change his grade (the opposite of change talk), I ask him how he could work around this problem. I probe and probe until he comes up with solutions. - *Julie, 51 year old with cystic fibrosis.*

ADDITIONAL RESOURCES

Valuable Online Resources for Information and Encouragement

There are many useful and encouraging web sites that you can visit to get information about cystic fibrosis and living with CF. These are sites that we recommend you visit to find information, comfort and friendship. Be sure to check out any medical advice with your doctors *before* putting it into practice.

www.ParentingChildrenWithHealthIssues.com - Discover the skills to raise happy, healthier children with CF. Free video, audio, and other resources provide effective, practical tools to empower, motivate and communicate with children of all ages. Based on the popular Love and Logic® parenting program (www.loveandlogic.com).

www.CysticLife.org - A social network providing the CF community with peer-generated tips, information and encouragement with access to blogs, forums, reviews and user profiles, as well as the ability to directly communicate with other members.

www.TipsForCFParents.com - Provides tips and resources for parents of children with CF. Lisa C. Greene is the mom of two kids with CF, a parent coach and co- author with Foster Cline, MD of the award-winning *Parenting Children with Health Issues*.

www.cff.org - The Cystic Fibrosis Foundation (CFF) provides information about living with CF, treatments and research. The CFF assures the development of the means to cure and to control CF and improve patient's quality of life.

www.CFLiving.com - An educational site that offers information and support for those living with or caring for someone with cystic fibrosis. It is designed to help you work more closely with your Care Team, learn about treatment options, and provide interactive educational resources.

www.cfri.org - CFRI's mission is to fund research, provide educational and personal support, and spread awareness of cystic fibrosis.

www.CFvoice.com - An online community for those living with cystic fibrosis. A place for motivation, inspiration and connection to the CF community.

www.CysticFibrosis.com - An online community offering tools and resources for Cystic Fibrosis.

www.cystic-L.org - A free email service dedicated to the exchange of information and support specific to cystic fibrosis.

www.Esiason.org - The Boomer Esiason Foundation is a dynamic partnership of leaders in the medical and business communities joining with volunteers to heighten awareness, education and the quality of life for those affected by CF.

www.Facebook.com - This internationally known social network is used by many CF-related organizations and community members to share information and encouragement.

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