



Parenting as an adult with CF

Adults with CF are able to meet many of life's many milestones. One of the choices you may have is whether or not to become parents. Becoming a parent can be a challenging and rewarding time in your life. It will be a balancing act, as it is with everyone. You have the added responsibility of caring for your CF, so you can be there through many years of parenting.

In this section we will explore the unique challenges of being a parent while having cystic fibrosis.

- **Learn about parenting with cystic fibrosis** to help you plan and think ahead
- **Work with your CF care team** to help you stay adherent to your therapies and be able to enjoy time with your child.
- **Manage your time** so you will be able to balance your self-care and your parenting role
- **Get help when you need it** so you will stay well and be effective in your role as a parent.
- **Discuss CF with your child** so you will feel comfortable having age appropriate discussions with your child.

Planning and thinking ahead:

For those with CF, becoming a parent may occur naturally, via MESA (microsurgical epididymal sperm aspiration), or require other reproductive assistance. You may choose to adopt or use a surrogate.

If you are male, you should already be aware that 95-97% of males with CF have congenital absence of their vas deferens (CAVD) and cannot father a child naturally. Only 2-3% of men with CF are able to father a child naturally. If you would like to have children who are genetically yours, you and your partner will need to go to a fertility specialist. You would need to undergo a sperm aspiration by a procedure called MESA or TESA (testicular sperm aspiration). Sperm is retrieved from the male; the mother of your child would then need to go through in-vitro fertilization.

CF does not necessarily affect a woman's reproductive health. (link to "Pregnancy and CF" article)

Perhaps you have decided to adopt. This is also a wonderful option and your CF care team may need to write a letter of support for you. This will depend on your adoption agency.

You will have other issues to consider and plan as you think of becoming a parent. It is important for you to think through some of the following questions and have a plan prior to becoming a parent.

- How will you fit in your required treatments and also care for a child?
- What will you do on the days you don't feel well?
- Who will help you?
- Who will get up during the night with the baby/toddler?
- What will you do when your child is sick?
- What is your plan should you need IV antibiotics and/or hospitalization?

You have had cystic fibrosis all your life, so you should be used to planning ahead and being flexible. The issue of parenting is really no different. With some forethought, you should be able to deal with family planning as well as child rearing.

~Making the decision to have a child is momentous. It is to decide forever to have your heart go walking around outside your body. ~Elizabeth Stone~

Working With Your CF Care Team

Your CF care team is an excellent source for help when you need support, advice, and tips. They can be a wonderful resource for you before, during and after your child is born. In order to enjoy your family life, it will be important for you to be adherent with your therapies. It is very common for parents to put their children before themselves. It is very easy to get busy with your child and forget to do treatments. This is a temptation you need to resist. It is of utmost importance to make your health a priority. Your CF care team can help you assess what support you will need in order to maintain your health and enjoy your family.

Perhaps finances become an issue with your growing family. Talk with your team social worker. He/She is there to help you take advantage of the various programs that might be available to you.

You, your child, significant other or other family members may need some help coping with the added stress of parenting and all it entails. This may change during your child's various developmental stages and your changing health status. Perhaps you think your spouse/partner or other family members are feeling an emotional impact of having to 'pick up the slack' of parenting. Your CF care team can help you. Don't be afraid to admit that parenting is causing you and others stress. As your child grows, he or she will need a realistic image of health and wellness. You will have various levels of wellness. Sometimes you will need to go to the center for well visits, and other times you may have an exacerbation. You may need to be hospitalized

for treatment. Your CF care team can help prepare you and your child for the separation that will be occurring while you are hospitalized. Your child will need reassurance you may only be gone for a short time, but someone will be there to care for them, maybe their other parent or a grandparent or other family member. Your child's response may be unpredictable. You need to be realistic about what is going on and give them enough age appropriate information so they can remain hopeful and not expect the worst.

~A healthy attitude is contagious but don't wait to catch it from others. Be a carrier.~ Tom Stoppard

Managing your time

Don't isolate yourself; CF is part of your life and part of your family life as well. Depending on your child's age, they can help you with this task. This is a way they can feel special and useful and will help alleviate fears. It could be as simple as getting your water for you to take your oral medication. Just make sure they understand they are not to take the medication, and keep it out of their reach. Perhaps exercise would be good for you; when your child is young, look into a Mommy & Me class. Put your young child into the stroller and take a walk. These are all ways you can get your child involved in your care when they are young, while keeping it a natural part of your everyday life.

Sometimes you might have to revise the expectations of your family life. You will have to deal with good and bad days. It is important to have a plan for those bad days, Alternate plans will need to be discussed and agreed upon by others involved in your child's care before they become issues.

You may want or think you can do it all. But you can't! It is important to know your limitations. Balance your abilities and limitations. When you are not feeling well, you may have to alter what you do. Perhaps you will not be able to go to the park, but you could spend time with your child on the couch, reading a book to them, or doing a puzzle with them. Remember that CF will not get in the way of love, hugs, teaching and spending time with your child. CF should not consume your family life. However, it should be a normal part of the household. CF is part of your life-it is not your life.

It is important to be honest with yourself and know your limitations. What treatments do you struggle with? What sabotages your treatments? For example, do you get too busy and forget or run out of time to do your treatments? You may need to develop a schedule for your treatments that helps you complete your treatments so you can then focus your attention and time on your parenting responsibilities. Push yourself during your 'better' times. Your CF care team can help you develop a schedule to manage your time so that you can complete your treatments and enjoy family time.

~Boundary setting is really a huge part of time management~ Jim Loehr

Get Help When You Need It:

It is important to realize that you do not (and should not) do everything yourself. Don't be afraid to ask for help from your child's other parent, your family, your friends, and your CF care team. For example, if you are hospitalized, or too sick to attend a school function, consider asking a grandparent, favorite aunt or friend to take your place. Maybe they can record the function for you so you can sit and watch with your child. This can still be a very special time for you to share in their life.

It is important not to feel that it is a sign of weakness to ask for help. This will show your child that it is ok to ask for help from others in your community. You can ask your child to help out at times. However, it is very important to make sure you let your child be a kid, and not your caretaker. Your child's teacher, guidance counselor and school nurse will be important allies to assess how your child is dealing with your illness. It is important to have good communication with the staff at school. Your positive attitude can also help your child realize that having a disability or illness does not affect a person's worth.

It is important for you to always make CF your first priority. Just as they tell you before a plane takes off, parents should put on their masks before tending to their children. It is the same with CF and parenting. In order to be the best parent you can be, it is important for you to remain healthy, so take care of yourself, before tending to your child. Caring for yourself first is not being selfish. Caring for yourself is a gift you are giving to your family so you can be as healthy as possible and able to enjoy family time, both in quality and quantity.

Some parents have found journaling to be very therapeutic,. You can write down things they said and did, special times you spent together and also how these events made you feel about them. They will treasure these books forever, and you will be able to look back over these memories and realize how much a part of your child's life you are.

~Each day of our lives we make deposits in the memory banks of our children. - Charles R. Swindoll ~

Discuss CF with your Child

It is important to discuss CF with your child. Through the different stages of their lives they will have different levels of understanding, and the information you give them will have to change as they grow and develop. Your child will have questions, and it is important to remember to only answer the question they are asking. Don't shield your children from what is happening to you. If it is appropriate for their age, include them in discussions. This will help them cope with what is happening and create a family bond; be honest about your health. If you don't know what to say, ask your CF care team to help you. Perhaps you can practice your discussion with someone from the team.

Preschool: Infants and toddlers like routine. They can be very sensitive to the emotional environment in your home. If you are hospitalized, it will affect their routine, and perhaps their sense of security. They will need plenty of reassurance by touching, hugging, loving and repeated verbal assurance.

TIP: If you are hospitalized, it will be important to have your spouse, a grandparent, or aunt help care for them so their routine is not disrupted too much. It is important to think ahead and have a plan ready should the need arise.

Preschoolers may feel they caused your illness. It is important to make sure they do not feel guilty for your health. They also need to realize they cannot catch this disease. It may help them explore their feelings by getting them a doctor's kit.

Ages 6-12: children in this age group will start to ask more questions and become more curious. They may start asking, "Why do you cough so much?" They will also start to realize that their friends' mommies don't cough as much as you do. This may cause a little bit of embarrassment when they are with their friends. This age group will become aware of their emotions, but not comfortable with them. It is important to make sure they talk about their feelings. They also may start to be aware of death and may ask questions about dying and heaven. They are at a stage where they can help you with simple tasks, like getting your water for your medication. This will help them feel special and useful. These tasks may also help reduce their fears of your illness. Provide them information in simple terms that they can understand. At this age, they should know how to dial 911 in case of an emergency.

Adolescents: This is a time of physical and emotional change. They will need a good support system. It is important for you to make sure they have permission to go out and enjoy themselves, and not always have to stay home and help you. They will expect you to be honest with them. It is common for teens to think abstractly. They may look into things for meaning.

TIP: If you have to stay in the hospital emergently, your child may feel it important for them to see you right away. You may want to make a deal with your child that the non-CF parent will come get them, wherever you are and bring them to the hospital to see you. Your teen may have the need to talk with someone throughout your health crisis. This might be you, their other parent, or other family members, if that is not possible, find someone your teen can open up and talk to.

Throughout your child's life, it will be important for you to assess if your child is having difficulty dealing with issues.

- Watch them to see if they start to withdraw or act out
- Evaluate any change in eating habits
- Do they complain of frequent stomach or headaches
- Have they regressed to former behaviors
- Do they isolate themselves
- Experience new or irrational fears or increased anger
- Change in school performance

You might have to deal with preparing your child for your death. This will be very difficult, but how you handle the issue will help them have the tools and confidence to cope with this sad part of life.

Tips:

- Create memorable times with your child-make the most of the time you have together
- Consider making a video or special photo album
- Consider writing letters to them that they will be able to open at special events during their life, in case you are not there with them.
- You may prefer a memory box filled with special items

In the book, *Now that I Have CF*, Karen Mackle gives her personal perspective of having a parent with CF. She says that it never made a difference to her. Her mother doing treatments, or IV's, was just something her mother did. She suggests that children be involved in their parent's care so CF will be viewed as part of the daily routine of the family.

Additional Resources:

<http://psychcentral.com/blog/archives/2010/09/27/10-challenges-for-parents-with-chronic-illness/>

http://claireberman.com/mag_chronic.html

www.cfinfo.org

<http://www.cysticfibrosis.ca/assets/files/pdf/WhenAParentHasCFE.pdf>