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## Parents' Grief Process After a CF Diagnosis

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When parents hear that their child has cystic fibrosis, they are shocked, scared, confused, angry, sad, and unsure if they can handle the situation. You may be experiencing similar feelings and may be worried that your feelings might overwhelm you at any time. These feelings are normal and to be expected. But how do you get through this time? How do you function while experiencing these feelings? Anticipating months of acute grief and preparing for your child's milestones can be helpful, but most important is to seek out the support you need now and in the future.

### The Grief Process

The grief process involves, but is not limited to, the following phases:

– **Acute grief:** Waves of emotion can overwhelm you frequently during the day while you process:

- Strong emotions of anger, sadness, and fear
- Shattered dreams
- Denial
- Adaptation

– **Chronic grief:** Many parents experience this form of grief during their child's developmental milestones, for instance when their child:

- Goes to kindergarten
- Goes camping with friends
- Graduates from high school

### Acute Grief

Therapists call the first part of the grief process acute grief. This phase can last months, during which parents might experience overwhelming sadness, anger, confusion, and fear. Some parents have described acute grief as a wave of feelings washing over them. And sometimes these feelings take them by surprise because they don't anticipate the trigger.

What can trigger feelings of grief? You may see a child playing or running and wonder if your child may be limited in her ability to run. Or you may see a roly-poly child in the grocery store and feel cheated because you work so hard to help your child gain weight.

### Shattered Dreams

These triggers are examples of shattered dreams. While you prepared for your child's birth, you probably dreamed about your child excelling at sports ("He will be a soccer world champion!"), or at a career ("She's going to be the chief executive officer of a big company." "He's going to be a doctor."). Or maybe you were thinking about things you wanted to teach your child ("I can't wait to show him how much fun it is to hike a mountain and ride a bike."). Most parents dream about all their child will

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be able to do.

A chronic illness diagnosis can shatter those dreams. Although cystic fibrosis may not necessarily limit your child from fulfilling any of the above-mentioned dreams, you have begun to worry. You are wondering if your child will be able to do any of these things, because you are unsure what cystic fibrosis will really mean for her.

One challenge as a parent of a child with a chronic illness is to ask your healthcare providers the questions that have you most concerned. Some questions you may have include:

- Will my child be able to play sports?
- Will my child be able to travel?
- Will my child be mentally capable of succeeding in school?
- What limitations can I expect my child to have in school, on the playground, or in daycare?
- Will my child have normal play dates or sleepovers, or will there be limitations?

Although you may worry about the answers, it is important for you to ask all the questions floating in your mind. Having the information you need will help you understand what parts, if any, of the dreams are really shattered.

### **Denial**

Another normal part of the acute phase of grief is denial.

- You can't believe that your child has this illness, and you feel unable to perform the medical treatments necessary for your child's health.
- Or, you are thinking that these treatments will be short term. Just a few months ago, you were concentrating on all your child would be able to do. Now you are asked to perform medical treatments many times a day.

**Needing time to process the meaning of the diagnosis.** Healthcare professionals seldom allow time for a parent to process what the diagnosis means. They move ahead and begin teaching you what you need to know. Almost immediately you may realize that you don't remember even half of what they tell you. Do not be afraid to go back and ask them to repeat the information over and over. You can absorb only so much medical information to begin with, especially when you are also trying to manage your feelings.

**Asking for help.** During this phase, you need to ask for help.

- **Discuss with your healthcare providers** what home services are available. Sometimes nurses or aides can visit your home a few times a day to perform treatments so that you get some needed relief.
- You also may want to **ask family and friends** to learn what tasks need to be done. Even if they can't help with the treatments, they may be able to help you with meals or chores so you can get as much relief as possible.
- Grieving is difficult work. It takes a toll on your body and energy. So it is vital that you **get enough sleep and eat three meals a day**. With a little help from friends and family, you can.

One thing to remember is that your spouse or partner may not be experiencing grief in the same way you are. He may be in denial and unable to help in any way. Or he may be very emotional and need to talk at length about his fears and anger. Although you are both grieving the loss of a healthy child,

you cannot be the only support available to each other. When someone is grieving, it is difficult enough to function, much less provide emotional support to another. This is not to say that you cannot comfort each other, or spot each other during treatments. It means simply that you must rely more on friends and family for emotional support.

**Adaptation.** After a few months, you will realize that you are experiencing fewer waves of grief. Some people may say that you have accepted your child's diagnosis. However, acceptance is difficult and may be impossible for most parents. Acceptance requires parents to stop fighting, or to stop feeling sad or angry about the illness.

Instead of accepting the diagnosis, most parents adapt to it. They perform the treatments, give the enzymes, coax their child to eat, but all the while, they may feel some pain about the illness. This is to be expected. However, the waves of grief do decrease, and you will move into the next phase, chronic grief.

### **Chronic Grief**

Although your grief will lessen, expect that there will be times when you experience more waves of grief. Some of these waves can be anticipated. Most parents have difficulty during the milestones of a child's life. For example, when your child goes to kindergarten,

- You may find yourself wishing you could just worry about your child getting on the bus or making friends. Instead, you worry about whether your child will become ill frequently during the school year.
- You worry that children may find out about your child's illness and may be afraid to become friends.

Generally, children adjust well in school and make friends easily. However, as a parent you worry more and may find yourself grieving again. It is important to realize that these are bumps in the road. Experiencing grief during these milestones is temporary and often short-lived. They are easier to experience if you can anticipate them. Remember that milestones will be difficult for you. Explain to your friends that there will be difficult times ahead and that you will need them during these times.

### **Asking for Help**

Some parents may find it difficult to reach out to others for support. Generally, when a child is born, parents tend to close off and focus on the immediate family, often forgetting that the outside world exists. This is normal, because parents need to focus on their child and learn how to read his messages and cries, as well as when it is necessary to feed, change, or put him to sleep.

However, shutting off the world after a child is diagnosed with a chronic illness can be detrimental to your family. As mentioned before, your spouse or partner may be experiencing grief in a different pattern and may be unable to provide the support you need. In addition, you need time to absorb all the information necessary to help your child. So, it is important to consciously seek outside help from your friends and family, your healthcare provider, and your community.

### **Friends and Family**

Getting outside support may mean asking friends and families for help. Many times, parents expect others to anticipate their needs. When those needs are not met, they assume their friends are unavailable to them. Your experience is unique. Most friends will not know how to help but are more than willing to do what you ask. So tell them what you need. For example, you may ask them to:

- Watch your child for a few hours on Wednesdays so you can rest
- Prepare a meal once a week
- Help with the laundry

Let them know that this is a difficult process, and for a few months you will need some help. As you move into the chronic grief phase, you may ask that they be available should something come up.

During those times, you may ask them to listen to your worries or to watch your child so you can write in a journal or go for a walk. Again, most friends are relieved when you tell them specifically what you need.

### **Your Healthcare Team**

Seeking outside support may also mean going to healthcare providers. Your healthcare team can answer questions, reassure you, and let you know that your experiences are normal. However, you may need more consistent support. Ask for a referral to a therapist who understands chronic illness, and if possible, cystic fibrosis. It can be helpful to talk to someone who has seen other parents experiencing the same process.

The therapist may suggest the use of antidepressant or anti-anxiety medications. If so, she will refer you to a psychiatrist or physician for a prescription. It is important to recognize that you are going through an extremely difficult phase in your life and you may need to be open to all the options available to help you get through it.

### **Community Support**

There also are support groups available. Ask your healthcare team about support groups in your area. Check local organizations that help parents deal with chronic conditions or cystic fibrosis. It is often helpful to meet other parents who understand your worries and fears.

### **Importance of Maintaining Relationships**

In addition to shutting out the world, parents of babies also may forget to focus on their close relationships (for example, relationships with their spouse, friends, relatives). When your child is diagnosed with a chronic illness, it is easy to focus all your energy on your child. Although it is important to provide care for your child with cystic fibrosis, you will also need to focus on your other relationships. Relationships and marriages that are neglected can suffer and sometimes even end as a result. As a parent under great amounts of stress, you will need to maintain your adult relationships. To accomplish this, try to do the following:

- When you prioritize your life, put your relationships at the top.
- Take time away from your child and focus on your marriage.
- Go out for an evening or away for a day.
- Teach a friend or family member to baby-sit your child, and ask him to be available twice a month.

A chronic illness is long lasting, and you need a respite. It is important to remember that unless you nurture your relationships, they may become weak and you may lose them.

A chronic illness diagnosis can feel devastating, especially when it is your child who is diagnosed. Expect rough times and times when you need support. Anticipating the process of months of acute grief and then difficult times during milestones can be helpful, but most important is to seek out the support you need now and in the future.

This article was written by **Teresa Kleinschmidt, MS**, a licensed family therapist in the Department of Pediatrics at the University of Minnesota. She holds a master's degree in child development and family science and has worked with children, adults, and families with grief issues for more than 10 years. This article was reviewed in 2007 by **James W. Wallace, MD**.

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