

The following article is an excerpt from the booklet 'Cystic Fibrosis Parent Guide' published by the Cystic Fibrosis Association of New Zealand. It was first published in 1996 and was revised and reprinted in 2005.

Emotions and Reactions

By now you know some of the facts about CF, but how do you feel about it? It is important to know that many of your feelings have been shared by other parents and you are not alone. Here we have included some of what other parents of CF children have said when their children were diagnosed.

It is very likely you will be grieving. This may surprise you as you have not lost your child and the doctor will have told you that the outlook for children born with CF is now optimistic. But you have lost the healthy child you thought you had, and letting go of that 'ideal' is difficult and can only be done little by little. Grief is a complex group of feelings and everyone experiences these feeling differently. You may be confused and have a variety of different reactions, or your feelings may be very clear to you. Your reactions can be immediate or they could emerge slowly over a long period of time.

Finding out your child has a potentially life threatening condition can be a frightening experience, and it may take a while for the information to be taken in.

"I knew it was serious by the way they spoke. I didn't hear anything after 'Cystic Fibrosis', not one word sank in".

"When they told me, I couldn't even pronounce it".

You may find yourself feeling relieved at being able to put a name to your child's problem; this is not unusual and there is no need to feel any guilt over it. You are relieved because you now know what you are dealing with and you are learning how to live with it.

Sometimes life's events seem to be unexplainable and quite unfair and in frustration, many people look for someone or something to blame.

Parents may take out their feelings on a convenient scapegoat and may react quite unreasonably to something that person says or does.

"There was something awful about the way he told us. I know I'll hate that doctor forever. I'm glad we didn't have him looking after our son".

"My aunt said she thought it would be a good thing if she died young. I can't forgive that. My baby was sick but I wanted her to live."

Because CF will change your life in a number of ways, you may not want to accept the condition or medical opinions; you may even look for alternative ways of handling your child's condition. Just remember though, it is healthy for you to have an open mind, but it is also healthy for your child to have all the help they can to combat the effects of CF and clinics have a good track record in this area.

Treatment for CF can disrupt family life as schedules have to be rearranged. This can be a serious problem if there is more than one child with CF in the family, or if both parents work.

If this applies to you, don't struggle with the impossible; there are people you can talk to and resources you can use while you adapt to new routines. Whenever there is extra pressure on the family, there is help available.

Because you carry the gene for CF, you may feel responsible in some way for your child's condition. People who are grieving frequently feel guilt and need to express this; try talking about it to someone who will listen with respect and not argue.

"I felt so awful when I found out it was genetic. Of course I hadn't known, but no one would let me talk. They kept cutting me off and trying to reassure me".

Also try to work out your feelings about the situation and clarify them for yourself, so you can begin to deal with them.

"For a long time I said 'why me?', then one day I said 'why not me?'; what was going to stop things happening to me?"

Sometimes grief interferes with your ability to enjoy yourself, or your appetite or sleep patterns are affected; you may have prolonged bouts of sadness and lack of motivation. If this sounds like you, you are probably depressed. Usually depression will work itself out in its own time, but it can be very difficult for each individual. It can be a great help to talk to someone close to you or share your thoughts with someone who can empathise with you.

"I felt so guilty about not being able to feel good for so long...about two years...Then I heard someone else say it took her five years before she accepted it."

This is a time when extra strain could be placed on your relationship with your partner. Individuals, even if they are close, react differently to bad news and communication could become difficult. Try to be understanding with each other and don't expect the other person to know exactly what your feelings are. Accept the fact that you may need support; either talk to a close friend or even use a professional to take some of the strain off your relationship.

Try to avoid making big decisions at this point; you already have a lot to cope with and even if you move house or take a holiday, you will still be taking this challenge with you.

Some parents who investigate their family trees have found instances of infant deaths many years ago. The babies either died for no apparent reason or from pneumonia. It is quite possible that these children had CF and it does seem to help some parents if they can see a pattern, and not feel as if what has happened to them is a 'bolt out of the blue'.

Other family members may be concerned about their chances of having a child with CF, or they may be worried about symptoms their children have which resemble CF. Genetic counsellors and doctors with knowledge of CF are the best people with whom to discuss these concerns.

The reactions of close family members can be a problem. Grandparents, who are often very upset at the illness, may claim that the condition does not come from their side of the family.

“When our daughter was ten years old I talked about CF with Ian’s mum. I’d said it all before so many times, but as we sat having a cup of tea together, I think she heard me for the first time. She finally realised it was something from both of us.”

It is probably best to work out a strategy together to deal with attitudes that could cause friction, or when deciding whom and how much to tell. Some people are not inclined to disclose problems outside the family, or they may wish to protect their child from feeling ‘different’.

“When I told my best friend about Cystic Fibrosis after seven years, she was shocked that I had kept it from her, but I wanted our daughter to feel she was considered for herself and not for the condition.”

On the other hand, some parents feel they can contribute to helping those with the condition through publicity, fundraising and educating wherever possible on the problems of CF.

“I felt the problems of families were not known and that children could suffer from the ignorance of CF. I mean, at school, taking tablets is really hard for kids if no one knows anything about it (CF).”

“It’s really important people know about this, after all, it can happen to anyone can’t it?”

“The best thing I could think of to do was to raise money for research.”