

STAYING CONNECTED AS A COUPLE

a parent's guide to healthy living with cystic fibrosis

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COUPLES AND SPECIAL HEALTHCARE NEEDS

What You Need to Know

By Laura E. Marshak, PhD

Author's Note: The word "marriage" can be used interchangeably with couples relationships of all kinds. The relationship challenges are similar whether couples are legally married or not.

There is a general belief that having a child with special healthcare needs puts such a strain on marriages and relationships that it places them at great risk. Definitive statistics on the divorce rate of couples with children with special healthcare needs are not available but there is general consensus that it is somewhat higher than in families without a child (or children) with special healthcare needs. The impact of a child's special healthcare needs on marriage cannot be described by a simple formula but some points are clear:

- A child's special healthcare needs does have a large impact, but it is not known in advance whether it will have a positive, negative, or mixed effect.
- *Overall*, you can think of it as *magnifying* what occurs in a family and marriage without special healthcare needs. Closeness may be stronger, divisions greater, anger increased, sadness deeper, parenting decisions weightier, and happy times may be more thrilling.
- There is no doubt that marriage and relationships are more complicated.
- Just as we learn to adapt our child-rearing skills to meet the unique needs of our children, we generally need to do the same with our marriages. Both in child-rearing and marriage, having children with special healthcare needs requires that we develop even better skills than others may need to have.

INDIVIDUAL CHALLENGES AND COUPLES' CHALLENGES

The impact on a marriage of having a child with special healthcare needs is affected by each parent's own adjustment, the flexibility of their marriage, and their access to outside supports. Often a marriage can improve a great deal through successfully handling individual and couples' tasks, along with gaining additional resources.

Individual tasks are emotional challenges that need to be managed on a personal basis. While your partner may help you with these tasks, he or she cannot do them for you. Common individual tasks include:

- Managing grief
- Maintaining perspective
- Protecting a corner of life for yourself
- Finding sources of strength
- Coping with uncertainty and fears of future
- Managing guilt, fear and shame
- Finding healthy support outside of the marriage
- Finding meaning in the special healthcare needs experience

Common couples' tasks include:

- Build or rebuild a bond even though a child's special healthcare needs to be "all encompassing"
- Accepting differences in emotional reactions to special healthcare needs
- Adjusting to roles that meet family needs in a way that feels necessary, fair and does not breed hard feelings
- Maintaining a romantic connection and the ability to see each other as more than "parenting partners"
- Developing a creative vision for the future
- Being a team

In addition, some of the building blocks of a strong marriage can be put in place by dealing with problems and finding external supports and resources. The most determined, best-adjusted individuals cannot make a marriage work with a child (or children) with special healthcare needs if there is not a foundation of external support. It is only for a limited time that a couple can function on little sleep, have no time whatsoever without their children, and actively battle to obtain proper medical care and other needed services.



External supports include:

- Allowing others to help to give you time away from parenting
- Good medical, educational, and rehabilitative services
- Forming relationships with others for support, enjoyment, and emotional closeness

Improvements to your marriage may be made by using just a few of these building blocks of change. For example, positive changes can be seen when one partner learns to better handle his or her grief, reestablishing marital roles together, and finding new or additional sources of support from outside the marriage.

TAKING CARE OF YOUR MARRIAGE AND YOUR BUSY LIFE

The idea of taking care of your marriage while you're incredibly busy with children may initially feel like a big task. You may be used to putting your needs, as well as those of your marriage, on hold. This works for a short time. Over time, this becomes a problem. All people and all marriages need some care and it's not easy. Here are some of the common challenges couples face along with ideas for solutions.

Time

When a couple has a child or children with special healthcare needs, it is not realistic to expect that there will be as much time and attention to give to each other as there may be in other homes. This does not mean that the quality of a marriage has to suffer. Within this framework I think about the old motto, "Work smarter, not harder." Being *mindful* can help us work *smarter* without having to spend great amounts of energy. Being mindful is different than worrying. It means not letting the rest of life keep you from taking care of your marriage. *Being mindful* involves making small, consistent, deliberate changes in our attitudes and behavior within the marriage.

If you spent a focused twenty minutes a day on your marriage, the impact would be large and this would still be less than 2 percent of your day.

Are you already thinking, "*I really don't even have this much time for my marriage?*" Simply put: Marriages need some attention and that the time may need to come from other activities. This brings us to the art of prioritizing, an important part of adjustment to living with special healthcare needs. People can't "do it all" and when special healthcare needs enters the picture, there is a greater need to carefully pick and choose (as much as possible) where you put your time and energy.

Stress and Child-rearing Demands

Having children with special healthcare needs puts a marriage at risk of having more stress. It is easy to use stress as a reason not to pay attention to one's marriage because it feels as if there is no energy left. People sometimes say they will deal with their marriage *when things get easier*. The problem is that stress generally does not end. Even more importantly, it is in stressful times that a marriage can be particularly important. It is easier to handle things in general if one's marriage is strong.

Making small marital changes takes less energy than imagined and decreases daily stress.

Many parents find it hard to identify the times when it is all right to set aside a child's needs to tend to their personal and married life. This is difficult in many marriages but even more so when a child has a disability or illness.

On a daily basis, children's needs often do need to be taken care of first, yet a steady practice of putting a child over a spouse causes problems. It is also not best for a child.

MANAGING PERSPECTIVE

Living well with circumstances beyond our control often requires us not to get *stuck* in self-pity.

Mourning versus Self-Pity

It is important not to confuse mourning with self-pity. Mourning is the natural grieving process, which includes feelings of deep sadness. Self-pity is feeling sorry for oneself. It is not unusual for a parent to be wrapped up in both when learning of a child's special healthcare needs. This period of grieving helps some cope and move forward and can last as much as a year or two.

There is a time for self-pity and a time to contain it.

Self-pity is natural, but there is a time to control feeling sorry for oneself. The following is an example of one woman who understood the need to draw the line on self-pity in order to start moving forward:

"In the beginning, when I just found out about my son, there was a period of self-pity. Why us? Why me? How can this be? And I would go out and run and bawl my eyes out and cry in self-pity. I knew there had to be a turning point. I said to myself, 'I have to do something to get out of this. I can't get stuck here because these problems are not going away. If I get stuck here feeling sorry for us, we're not going to grow.' We have to accept it and say, 'What do we need to do to make it better?'"

The issue regarding self-pity is the amount of time spent with these feelings. I agree with the advice provided by one parent: "Pity parties are fine now and then but keep them brief." This is important because self-pity weakens you over time; compassion for yourself doesn't. Other parents caution that it leads to acting out on others:

"People could take a look at any of us having the children we have and feel like we've really been violated. Why us?! If you get stuck there, it affects your reaction to everything and everyone."

Feelings of self-pity need to serve as cues to do something better for yourself, not dwell in those feelings.

Practice Self-Compassion, Not Self-Pity

Self-compassion is a great substitute to self-pity. It is harder to parent children with special healthcare needs, and self-compassion can make it easier. Rather than feel entitled to feeling bad, feel entitled to treat yourself with compassion. Ways to practice self-compassion include:

- Giving yourself a break by accepting your limits, practicing self-forgiveness, and treating yourself kindly.
- Releasing yourself without guilt from activities you would have undertaken under easier circumstances and which often involve doing for others. This might include volunteering at school and being the host for holiday meals.
- Not feeling guilty if you just can't stretch yourself enough to meet everyone else's needs.
- Being less harsh with yourself when stress causes you to act in a way that is personally disappointing.



Change Your Frame

How do people find their way out of self-pity? You must find a way to step back and view a larger picture of your own making. When we are in a state of self-pity, we focus on the part of our life that is upsetting—this is the picture we see. It is as if it has a frame around it. One important way to genuinely feel better about your life is to *change your frame of reference*. Using a photography example, it is like switching from a zoom lens to a wide angle lens.

This new view can be accomplished in a few ways. One way to switch your focus is to use a structured way to make yourself look at what is good in your life.

In general, it is better not to compare.

Adjustment to special healthcare needs involves learning not to compare your child or situation to others'. You must find value and enjoyment in what you have, even if it differs greatly from the norm. This is also an important piece of learning to avoid self-pity. Many parents we interviewed spontaneously offered their thoughts on the importance of not comparing.

- “There is no *normal*. There is no such thing. Don’t watch too much TV or look at the soccer moms and feel that you have to live up to what they are. Don’t worry if you are different from those other women.”
- “Don’t compare your child’s achievements with others. It will drive you crazy!”

Part of not comparing requires not comparing to how you “assumed” your family would be. It can also be painful to compare your child to others who have the same diagnosis.

If you must compare, be thoughtful about how you compare.

Parents find some careful comparisons to be helpful. Examples follow.

- “There is always a silver lining: My daughter has all her problems, but she is not out getting pregnant and she’s not out smoking dope. My son’s not out wrecking my car. The problems are different, not the popular problems.”
- “This may sound odd but it works for me. Sometimes I think about all the children in the world together, not just those in my small part of the world. I think about what I have read in the newspapers. This includes the parents and children who died a few years ago (in the Philippines, I think) in an avalanche of garbage where they lived picking through the trash to get a means of subsistence. Believe me, this cures self-pity and pity for my child fast!”

A common strategy is to compare your situation to someone who has it worse. It works, at least for a little while. Sometimes a little while is all we need to regain a bit of strength to keep coping.

CONCLUDING THOUGHT

I wish to remind you of something that should be obvious but isn’t always: Being a good parent does not always equate to being a good husband or wife. One father commented:

“The roles and responsibilities of being a father and a husband often get intertwined, mostly for the bad. Overcompensating in one role usually means you’re neglecting the other role. For a long time I didn’t get it when my wife criticized me as a spouse. After all, I was doing more for our son than almost any father I knew. Eventually, I understood that I was doing a great job meeting my son’s needs but not hers. One does not make up for the other.”

This excerpt is from the book “Married with Special-Needs Children: A Couples’ Guide to Keeping Connected” by Laura E. Marshak, PhD and Fran P. Prezant, M.Ed., CCC-SLP. Thank you, Laura and Fran, for giving us permission to edit and reprint. www.DisabilityAndFamilyBalance.com.

CF AND RELATIONSHIPS: TOP DOS AND DON'TS

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

Having a child with CF affects many aspects of family life. There are more chances for conflict. Intense family situations and emotions frequently lead to mistakes. Basic communication skills and ground rules are helpful. Here are a few tips to help you resolve problems and, at the very least, help keep them from getting bigger.

Tool 1: Are We Going to Vent or Problem Solve?

Sometimes a person just wants to let off steam. This is okay every now and then but it could be a sign of anger problems if it happens regularly. Chronic anger can be very destructive to spouses and children. Problem solving can occur when both you and your partner:

- Are not angry
- Are willing to look at the situation in a non-emotional and thoughtful manner
- Know you both have the time to solve the problem
- Can look thoughtfully at each other's point of view

Tool 2: Don't Generalize

Generalizing is saying things like: "You *always*..." or "You *never*..." This triggers responses such as "I do *not* always...!" and can cause a bigger fight.

Tool 3: Stick to the Topic

Don't bring up other issues when trying to resolve a conflict. Stick to one issue, resolve it, and then work on the next.

Tool 4: Stop Name Calling

Need we explain further? Name calling is disrespectful and an invitation to fight.

Tool 5: Discussion by Appointment

Timing can be everything! Couples will sometimes try to solve a problem at the wrong time such as when one person is tired, hungry, stressed, or in a hurry. By setting an appointment to discuss an issue, you can avoid times that aren't good and more likely have a productive talk.

Tool 6: Don't Question Motivation

When your partner does something to upset you, never assume he or she is motivated by the desire to upset you. In our love relationships, we do things that upset another person. However, spouses, unless disturbed, seldom do things to *purposefully* upset the other. Assume your partner wants the best for you.

Tool 7: Use "I Messages"

An "I Message" clarifies our own position. They are statements about where we stand. They are never demands as to how another person ought to think, act, or respond. "I Messages" have three parts:

1. "I feel _____
2. when someone does or says _____
3. because then I feel (become, think, experience) _____."

Tool 8: Focus on Your Partner’s Actual Words

Don’t get caught up in body language, tone of voice, and facial gestures. Although we cannot always control our body language when we are upset, we can be responsible for the words we use. Stay focused on the actual words. And of course, be aware of how your body language, tone of voice and facial gestures may be perceived by your partner.

Tool 9: Turn Accusations and Statements into Questions

Accusations, demands, and statements are more effectively expressed as questions. For example: “Now don’t be late” can be better said: “Do you think I can count on you being on time?”

Tool 10: Your Way Isn’t the *Only* Way

Many relationships end up on the rocks because the partners don’t understand their differences in handling emotions. Don’t assume your way of handling a problem is the “right” way.

Travis and Suzanne’s baby girl was born with a disease that took her life quickly. Suzanne was very emotional and reached out to others for support. Travis was unemotional and dug into his job. Suzanne began to feel that Travis didn’t care about her. Travis felt depressed every time he was around his wife. Their marriage eventually crumbled and they divorced.

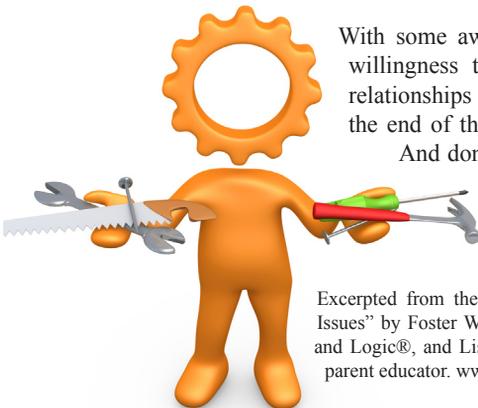
What went wrong? Each felt that the way they were handling the situation was the “right way” and did not understand their differences. It might take a counselor to help you work out these issues.

Tool 11: Recognize Your Emotional Temperature

When we start to feel frustrated, our emotional temperature starts to rise. At some point, we can get so “hot” that we lose control and say and do things we’ll regret later. When we start to feel angry, STOP. Take a time out and make an appointment to discuss the issue at a later time *after* you’ve had a chance to cool down and think about things a bit.

Tool 12: Practice the Art of Apology and Forgiveness

We all blow it at times and say or do the wrong things. Admitting our mistakes and apologizing can go a long ways. Accepting apologies and offering forgiveness is the other half of the equation. Make it a practice to end conflict with apologies, forgiveness, and hugs.



With some awareness of basic communication tools and a willingness to try them out, you’ll soon find that your relationships and family life will be calmer and happier. At the end of the day, it’s our relationships that really matter. And don’t forget, our kids are always watching us and learning by our example.

Excerpted from the award-winning book “Parenting Children with Health Issues” by Foster W. Cline, M.D, child psychiatrist and co-founder of Love and Logic®, and Lisa C. Greene, mom of two kids with cystic fibrosis and parent educator. www.ParentingChildrenWithHealthIssues.com.

ADVICE FROM OTHER COUPLES

Insight and Encouragement From Parents Who Have Been There

Other couples that have children with cystic fibrosis can help you through their experiences. They are always willing to share encouragement and advice to help you maintain a healthy marriage - even with the challenges that can come while caring for a child with CF. It's not always easy, but it can be done. Here are some experiences, tools and encouraging words straight from the mouths of other couples who have been there:

Make time for yourselves and one another - My husband and I go out on a date at least once a month. Additionally, we each get one 'free' day to enjoy, independently, and do whatever we want. At the beginning of the month we take a look at the calendar, pick our free days, and pick the date for our night out and ask ahead for one of our parents or friends to watch the kids. - *Sandra, mom of 2 year old with cystic fibrosis*

Get in quality time daily - Once the kids go to bed, so do we. This is our time to catch up and spend time alone. We haven't always done this, but it's what we do now, and it's incredible. I think making time for just the two of us is so important. This goes for anyone that has kids not just because we have a kid with cystic fibrosis. - *Mike, dad of 4 year old with cystic fibrosis*

Put your spouse first - One of the things my mother told me when I was young was that no matter what, my father would always come first before anything. We had the security of knowing that our family was strong. I have done the same with my two daughters - both with CF. They have been raised knowing that their dad and I would always be there for them, together. The key is to really appreciate each other when you are together and enjoy every moment." - *Terri, mom of 22 and 24 year old with cystic fibrosis*

Keep connected while apart - To stay in contact while in the hospital - provided you have a laptop with a webcam with you and your spouse has a computer with a webcam at home - video chatting is awesome! It is a way for me, as a wife and mother with one in the hospital and one at home, to see the child I'm not with and chat with my husband. Actually seeing each other versus just hearing their voices on the phone really helps. - *Sara, mom of 3 year old with cystic fibrosis*

Remember you're not alone - I like to remind myself that we're not much different from any other couple with any child. Everyone has things they are dealing with - CF is ours and that is way better than so many other things. - *Michelle, mom of 2 year old with cystic fibrosis*

Focus on the blessings you have - One of my favorite quotes is "Remember this - very little is needed to make a life happy" (Marcus Aurelius). Isn't it something how we humans seem to have an insatiable capacity to always want more? This holds true in the context of marriage and family, too. Rather than focusing on what we don't have, focus on enjoying the blessings we do have. - *Carl, dad of 12 and 10 year olds 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.

www.DisabilityAndFamilyBalance.com - Provides information and tips for building and strengthening couple relationships in the presence of special needs.

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