

A Parent's Guide: Strengthening Your Parenting Partnership During Pediatric Illness

(Adapted from the video interviews @ courageousparentsnetwork.org/video-library/caring-for-the-family/marriage/)



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Child illness impacts a marriage in many ways and often forces couples to discover new means of coping and communicating with each other. This hand-out offers expert guidance and honest insights on how to adapt and grow as partners while caring for a child with serious illness.

You are not alone.

At Diagnosis: Learning to Move Together Through the Acute Crisis.

The early days following the diagnosis of your child's disease are a time of adjustment that can bring up many new feelings inside yourself and with your partner. Parents often feel a wide range of emotions that include guilt, fear, sadness and anger. Each parent may experience different feelings at different times and these feelings may not always be the same as what their partner is feeling.

This may be the first time that you and your partner are facing such extreme stress and difficult decision-making together. It takes time to process all the emotions and to discover each other's coping and communication styles. It is helpful to keep in mind that you are both sad and grieving and learning to navigate this new and unexpected world. And it is helpful to know that you and your partner are not expected to react in the same way. Your thoughts and emotions may often be different, but you can learn to understand each other and appreciate each other's needs.



Tips & Myths

"Most parents of seriously ill children end up divorced."

Having your child diagnosed with a potentially life threatening illness is one of the most stressful experiences a couple will face. However, despite what you may have heard, many marriages survive and even grow closer through their unique shared experience. Recent studies show that parents of seriously ill children are no more likely to end up divorced when compared to their peers.

Working Together and the Division of Labor

When a child is seriously ill, it becomes more necessary for the people in the couple to divide up the work. This division of labor can rarely be avoided. The intensity of your child's care will grow and this can increase the stress, anxiety and resentment between the parents. It is important to recognize—and even say aloud to each other—that neither parent can do it all. We simply cannot be in two places at the same time.

It is also important to recognize that each of you is contributing to taking care of the entire family. One parent may be working outside the home, or even taking a second job to support the additional costs and lost wages. This work is very important to the family, but leaving the child and home each day can often make that parent feel disconnected from the family. The parent may feel unsure of their ability to care for their child when they are together.

Meanwhile, a parent who is spending all of their time focused on their sick child's therapies, doctor's appointments, medication schedules, and hospital stay may begin to feel disconnected from their marriage and relationships outside the house.

Both situations can lead to resentment and insecurity within the couple, which causes more stress on the partnership. Accepting and talking about the division of labor can help a great deal. Parents help each other when they openly recognize what their partner is contributing and when they acknowledge that "We are in this together!"

Tips & Myths

Create written care instruction sheets and checklists that are available to both parents, as well as additional caregivers in the home. This can help build confidence in care and provide a greater sense of working together towards clear and common goals for your family.



Meeting in the Middle of Differing Views

The two parents may have very different ways they want to approach things, which can cause more stress and strain. For example, one parent may want information, while the other parent may not want information. One parent may want to think about the worst-case scenario, while the other may prefer to think only in an extremely hopeful way.

Parents need to acknowledge the typical gender stereotypes about emotions: that the woman acts more emotional and the man acts less emotional. This doesn't mean that the emotions aren't there in the man, and it doesn't mean that the woman isn't able to contain her emotions. Of course, these stereotypes aren't always true. We should wait and see what is happening in reality.

What matters is that emotions come up for everyone and they can arise differently in each parent at different times. One parent may cry when s/he is sad and the other doesn't, but that doesn't mean the parent isn't also feeling very sad.

It is very helpful to name the emotions and feelings—I am feeling sad, angry, depressed, anxious, worried, confused, irritated, frustrated. And it is helpful to recognize as much as possible what is causing the feelings in that moment: I am feeling frustrated with the medical team because

Staying Connected

It is never easy to find time but scheduling Time To Connect in both of your calendars now is important to maintaining a strong and lasting relationship for any couple. Try to actually take the time to just sit and be together, even if it is at the hospital or at home for just an hour with a cup of coffee or some food. You can almost always find a little time: nap time or when things are quiet and you can set work down and connect as a couple. When you sit together, do your very best not to talk about all the stresses.

And if you cannot be together that day, it's important to at least communicate by phone to let each other know what is going on and how you each are feeling.

There may be feelings that are harder to share with each other when it's just the two of you alone together. You may be afraid of hurting your partner or saying something they don't want to hear ... but that you really want to say. This is when a third person who isn't related to either one of you, such as a counselor, chaplain or therapist, can be helpful. This third, professional person creates space and time for the two parents to speak and listen and look carefully at a difficult issue together.



Tips & Myths

Utilizing Technology such as Skype and Facetime can help parents stay involved in real time discussion at home and at the hospital when it is otherwise impossible to be together. These technologies can be utilized in everything from decision-making meetings to participating in bed time routines.

Co-Parenting

Even when parents are divorced, it is important to try the things mentioned earlier in this guide to maintain a healthy co-parenting relationship. If possible, both parents should still hear new information at the same time and work together on decision-making. Both parents should have access to all of the medical providers and be included in the decision making if possible. This is certainly difficult, but every little effort helps.

When it is a difficult divorce, or one parent is really not involved, there needs to be a conversation early after diagnosis to make sure that everybody has the same medical information. A conversation that is organized and guided by a third person, such as a social worker, can be arranged so that both parents are clear on the goals of care for their child. There also needs to be a conversation about whether things are going to change now that the child is sick. For example, if there are other children, does one of the parents in the divorced couple need to do more with those other children?