Strengthening Your **Parenting Partnership**



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■ INTRODUCTION

Learning to adapt and grow

A child's serious illness impacts a parenting partnership in many ways, prompting the family to discover new means of coping and communicating. For those parents who are sharing parenting responsibility, here are expert guidance and honest insights on how to adapt and grow while caring for your child.

At Diagnosis: Moving, together, past acute crisis

Having your child diagnosed with a potentially life-limiting illness is one of the most stressful experiences you will face. Whether the diagnosis was expected or a long, drawn-out discovery, the early days are a time of adjustment that can bring up all sorts of new feelings within your relationship. Parents often experience a wide range of emotions that may include quilt, fear, sadness and anger. Each parent in the relationship may experience different feelings at different times, and those feelings may not always be aligned.

This may be the first time that you are facing such extreme stress and complex decisionmaking together. It can take time to process all of these emotions and to discover each other's coping and communication styles. It is helpful to keep in mind that you are both grieving and learning to navigate this new and unexpected world, and that no two people are expected to react in the same way. With time, you can learn to understand and appreciate each other's needs.

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Strengthening your parenting partnership

Can a family/partnership survive this?

It absolutely can. You may have heard that families fall apart, that marriages fail. However, many families survive and even grow closer through their unique shared experience. Know, too, that recent studies show that parents of seriously ill children are no more likely to end up divorced when compared to their peers.

Sharing (or dividing) tasks and roles

As the intensity of your child's needs progresses, so too can feelings of stress, anxiety and resentment within the parenting partnership. It is important to acknowledge early on that neither of you can do it all, nor be in several places at the same time. Each person's efforts are an important contribution to the family unit.

One of you may be working outside the home, or even take a second job to support new costs and lost wages. While obviously fulfilling an important need, working outside the home may lead to this parent feeling disconnected from the activities at home, and questioning their ability to properly care for the child. Meanwhile, the parent who is spending their time focused on their sick child's therapies, doctor's appointments, medication schedules, and hospital stay may begin to feel disconnected from relationships inside and outside the home. Both situations can lead to resentment, which can place an additional burden on the partnership.

Accepting and talking about the division of labor can help a great deal. You and your partner can better support each other when you are able to openly recognize what you each are contributing, and by acknowledging that you are in this together. Creating written care instruction sheets and checklists that are available to each of you, as well as to additional caregivers in the home, can help instill confidence in care and provide a greater sense of working together towards clear and common goals for your family.

Recognizing and resolving different ways of coping

In those instances when you and your partner have different views and/or different ways of approaching things, it can cause strain in the partnership. One of you may seek information; the other may not want information. One may want to think about the worst-case scenario; the other may prefer to think only in an extremely hopeful way. One may want to communicate widely, to family and friends; the other may crave privacy and resent what they experience as intrusion.

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Emotions arise and can arise differently in each of you—and differently at different times. It is important and helpful to name the emotions and feelings: being sad, being angry, feeling depressed, anxious, worried, confused, irritated, frustrated, frightened. These feelings might be directed at each other, or at the medical team, or simply at the situation.

The more that you can be aware of what in the moment is making you feel the way that you do, the better you will be able to cope and help your partner cope.

Staying connected

It is important to take time to just be together, doing your very best not to talk about all the stresses. Especially if your schedules are not in sync, making a point of finding this time is important to maintaining a strong and lasting relationship. If you cannot be together on any given day, at least communicate by phone or text or video, to let each other know what is going on and how you each are feeling. Technology can also help you and your partner stay involved in real-time discussion and events at home and at the hospital, when it is otherwise not possible to be together.

Some feelings may arise that are harder to share with each other, or that don't seem to have a reason that you can't really explain. There may be assumptions and expectations that are hard to express and hard to hear. Not knowing how to communicate your feelings may make you feel vulnerable—or perhaps you are afraid of upsetting your partner. This is when a third party, a neutral person such as a counselor or therapist, can be helpful. This person creates a space where there's time for everyone to speak and listen to each other, and time to look carefully at a challenging issue together.

When parents don't live together

Families exist in all kinds of constellations, and healthy, helpful co-parenting relationships are possible even if the parents don't live together. It is important to ensure that everyone has the same information about the child's condition. It's also critical that both of you are clear on goals of care, and that you consider whether (or how) things are going to change now that your child is ill. A mediated discussion can help everyone discuss the concerns.

Some questions to consider:

- Do you have a formal custodial relationship, and will that work now?
- What are your respective expectations about how and when to receive information?
- What will your protocol be for emergencies?
- How will you work together on decision-making?
- How will your respective extended families be involved?

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CONCLUSION

An opportunity to grow together

Parenting a very sick child can be all-consuming. It is important to recognize—even anticipate—how this responsibility will challenge you and your relationship. Staying committed to and nurturing the partnership, as much as you are able, may help you find even greater strength and courage to go forward.