

Tips for Sustaining a Healthy Marriage in Families with Children with Special Needs

Raising children with developmental, emotional, behavioral or medical special needs inarguably impacts a marriage.

The manner in which it changes, however, is not determined by the nature or severity of the child's disorder nor even by the number of children with disabilities in a family; the impact is determined by the manner in which the couple handles intensive child-rearing demands and related stressors.

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Juggling the seemingly endless logistical and emotional issues associated with parenting children with special needs can cause couples to make their relationship much less of a priority. The couples that do well under these circumstances are those who find ways to stay connected to each other. One successful couple

describes their experience like this: “We work as a team, give each other breaks and realize that we are in this together; we share our joys and disappointments.”

Make the decision together that your marriage is worth protecting no matter how great your child's needs are. There are many ways a couple can strengthen their marriage under the kinds of extreme demands they encounter. This tip sheet highlights effective principles and strategies.

Commit to spend time together every day (or as often as you can)

Parents often resist this because they believe it will detract from the care of their child. This is a dangerous myth. Parents who become (and remain) 100% consumed in their child's care often unduly place their marriage at risk. The bottom line is time and energy spent on your marriage benefits the entire family. Pledge 2% of your day to each other; this is only 20 minutes. You will have to be creative to find that 20 minutes to connect, but couples who decide to protect their marriages will find it. Remember, it is that loss of connection that can destroy a marriage. It is absolutely appropriate to create boundaries with your children by explaining that this is you and your partner's time. Have your child work on an activity or watch a TV show while you have couple time. Don't spend your time together discussing the children's needs or other family business such as money or in-laws; this time is for you and your partner to focus on each other. Talk about issues that interest you. Make eye contact with each other, hug and hold hands; a little of this will go a long way.



Some children require so much care that it is virtually impossible to make it through the day without giving them 100% of your time; if this is your situation, respite care is a way to get time away together. Respite care is different from babysitting and comes in many different forms. Providers are usually formally trained to deal with children who require specialized supervision and are available to take your children for a couple of hours or even overnight. Unfortunately, respite care has been notoriously difficult to obtain. The good news is that policymakers at both the federal and state levels are beginning to understand the importance of respite care and are taking steps to make it more available and affordable. Make locating respite care and understanding the way in which your state's respite services are offered a priority and then utilize those services!

Realize that it may take a few years to resolve the upheaval that a diagnosis of a special need creates in a marriage; do not lose hope during this period

Several factors contribute to this rocky period for couples. Couples are struggling with strong emotional reactions, and they have not yet learned how to cope individually; in turn, this stresses the marital relationship. It is important to remember that couples can adjust to new circumstances and that family life can greatly improve. Note that any transition causes individual and relationship stress, whether it is framed positively or negatively. Expect these emotions and give your partner support when he or she is having a particularly hard time.

Be a team

Problem solving skills are essential to teamwork. Your skills can be tested daily, or even hourly, when you are parenting children with special needs. It is important to make it a priority to work on these skills together, even if you only have time to listen to a relationship education CD in the car. Relationship experts say that it is normal for some problems to never be solved; the key to maintaining connection is understanding one another.

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Part of teamwork requires accepting and embracing some differences between how you and your partner parent. Although consistency is important in child-rearing, it is better to accept differences rather than to repeatedly correct your partner. Partners who feel overly criticized pull back from active co-parenting. Being teammates means that neither parent should be considered the ultimate "expert" on the child's needs. Consider discussing concerns with one of your child's specialists to decide if a parenting issue is actually causing harm to your child before you comment. Many parents have reported that teamwork will help maintain a routine and give the opportunity to take breaks. Be able to ask for and accept help from your partner and be available to give your partner the help when he or she needs expresses the need.

There is value in the saying "take one day at a time". Thinking about the future can be overwhelming, so it helps to break things down into manageable pieces. Together, create a list and then prioritize. Life with children is unpredictable and can feel chaotic. If one of you gets just one thing done from your list a day, be proud of yourself! If it wasn't you who did it, offer a compliment to your partner. Neither of you should be afraid to say "no" to something that goes against your family's priorities.

In order to take care of your relationship, you each need to be able to take care of yourself. Think about the last time you were on an airplane; when the flight attendant gave instructions, she directed you to put the oxygen mask on yourself before putting it on your partner or even your child. This is because a person must be taken care of him or herself in order to assist others. The same concept can be applied to your marriage. Find some time to do whatever it is that you like to do. It is not selfish to do something for yourself. Caring for your own physical and mental well-being must be one of your priorities. The team is only as strong as each member. It is essential to support your partner in caring for his or her individual needs. Decide together what is appropriate in terms of frequency and time away.

Protect romance and sexual intimacy

A couple's romantic life often times becomes lost in the midst of parenting. This is particularly the case when children have special needs. Due to the obstacles to be overcome and the logistical problems to solve, parents are tired and stressed making a little "down" time or a good night's sleep more appealing than sexual intimacy. Keep in mind that the physiological effects of sexual intimacy on the brain are positive and helpful for managing stress! Over time, many parents report feeling like "parent-partners" rather than husband and wife. To address this, many couples find creative ways to protect this part of their relationship. Some couples actually schedule time for sex, but sex is not the only way to be intimate with each other. One woman, married for close to 25 years and who has a child with Down syndrome and one with autism, shared her approach with us: "My husband and I have a Friday night date night. Cooking is my passion, so I cook us a gourmet meal every Friday. Oftentimes, we each have a child on our lap, but we still sit together with lighted candles and a glass of wine."

Communicate with each other

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It is easy to feel bombarded by receiving "too much" information about your child at once, especially in the initial stages of diagnosis. If possible, both partners should be involved in meetings with professionals. If this isn't possible, it is important to find a way to share the information so you are both on the same page. If only one of you can

attend meetings, bring a relative or a patient's advocate. Tape record a meeting and/or request the information in writing to assure that both you and your partner receive the same information. Then set aside time, without distractions, to discuss the diagnosis, treatment options and how you feel.

When a child is diagnosed with special needs, couples sometimes find that the roles they established and agreed to in the beginning of the relationship no longer work well. One partner may feel that the overwhelming responsibility for the child has become his or hers or perhaps feels his or her career has been compromised. Regardless of what the issue is, it is easy for an imbalance in the relationship to occur. It is critical that as a couple, you are flexible enough to openly communicate with each other about your roles and make changes if you need to. It is likely that this process will take a while and expect it to be much trial and error.

Use resources

One of the things on your list of priorities will need to be to take time to research the organizations both in your community and nationwide that can help connect you to information, other parents and couples, and forms of assistance. Use the internet to search for parent groups in your area or national groups online. Interacting with other couples who are living in similar circumstances can be a great support to you and your spouse. Utilize any free resource available to you, such as a hospital social worker, the public library or your community's public health agency. Both professionals in the field and other parents dealing with similar issues can help connect you to social service groups, respite care, counseling services, etc. Splitting this research chore between you and your partner is a great way to facilitate teamwork. Get together for coffee or tea and discuss what you find. The key is to be prepared for the issues that arise; don't wait until your family is in crisis to start this process.

Take away message: Make your marriage a priority! Focus on staying connected and working as a team. Expect both your partner and yourself to experience intense emotions and expect to renegotiate some of your roles within your family. Arm yourselves with information before a crisis occurs, offer support, ask for help when you need it, and nurture yourself as an individual.

Some online resources to begin with are:

<http://specialchildren.about.com>

<http://www.pacer.org>

www.nichcy.org

www.fathersnetwork.org

www.npsis.org

www.npnd.org

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