

Keeping Your Marriage Together When Your Child Fights for Life

Diamonds or Dust:

By Deborah Raiees-Dana

When your child is diagnosed with a life-threatening illness, the world seems as if it has been knocked off its axis and everything is spinning wildly out of control. There are new medical terms to learn, and new procedures and routines to master. You want to provide your child with every opportunity for survival without making any mistakes. Life as you know it is put on hold and you rely on adrenalin to get you through the initial crisis. Perhaps the hardest thing to deal with is the overwhelming unfairness of the situation. "This shouldn't happen to kids-especially my kid!" But it has.

As the reality of the situation sets in, your focus will need to change from the immediate to the long term. You will need to carefully evaluate your lifestyle and be willing to adjust it to your new reality. The circumstances that clamor loudest for your attention may not always be the most important ones to concentrate your limited resources on.

The Best Thing for My Child?

You may feel that strengthening your marriage relationship is one of those things that will just have to wait, but the truth is that one of the best things you can do for your child is to love your spouse. This is especially true now, because when so many aspects of your child's life are unpredictable and shifting, he or she especially needs the stability of a loving family.

Children often blame themselves for the marital problems of their parents. This is evidenced by the number of children who consider their parents' divorce to be their fault. Additionally, children tend to experience guilt over the many changes that have

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taken place because of their illness. Feelings of guilt from both of these sources can place a heavy burden on a child that is already fighting for his or her life. On the other hand, if your marriage is strong you will be better equipped to be the best caretaker you can for your child.

How Will The Marriage Be Affected?

You may have heard that a marriage has a 90% chance of failing when a child is diagnosed with a potentially fatal disease, especially if the child dies. However, these "statistics" are not upheld by research.

What is true is that your marriage will change because you will change. You are facing some of the worst fears and stresses that a parent can imagine, and that will affect the way you view the world from now on. Couples with chronically or terminally ill children do experience increased marital distress. If the marriage has problems to begin with, it may not be able to tolerate the increased strain. Most marriages do survive, however, and many become stronger and more intimate, bound together by the shared journey.

Diamonds and Marriage

Diamonds are the traditional symbol that a man and a woman desire to commit their lives to each other. The strength, clarity, and beauty of a valuable diamond represent so much of what we hope our marriages will be when we say, "I do." This emblem of faithful love also holds lessons for us on making that love flourish during times of stress.

The Microsoft Encarta Encyclopedia Standard 2001 states that for a piece of carbon to become a diamond it must undergo intense pressure and heat (1993-2000). But, if a charcoal briquette is lit on fire, placed on asphalt and run over by a semi-truck, a diamond will not be produced. Diamond formation takes more than just heat and pressure. It takes time in a special environment-one that surrounds and supports the carbon. It is the surrounding environment that makes all the difference.

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As your child battles this disease, your marriage will be exposed to "intense heat and pressure." Your family, however, does not need to be destroyed and ground into dust. Find the support you need during this time. Do not try to carry the burden alone. Be patient with each other. For the sake of your child, do what it takes to turn your marriage into a "diamond."

PRESSURE

Being aware of some of the problems your marriage will face can help prevent your being caught off guard and increase your sense of control during this turbulent time. The outside pressures exerted on your marriage will be intense. You may even doubt your ability to handle the increased load. You may also find, however, that the pressures will bring out a strength within you that you didn't know you had. It may even produce "the strength of a diamond."

Finances

Finances are a major source of friction in many marriages. When a child is first diagnosed with a major medical problem, the community is often mobilized to take up collections for the family. As time goes on, however, the bills begin to pile up. Besides the medical bills, there are expenses for travel, meals on the run, lodging, phone calls, and purchases of items you forgot to bring to the hospital. When your child is sick you don't have the luxury of time to cut coupons and comparison-shop. All this adds up to potential fuel for arguments.

If you need help, the social worker at the hospital may be able to direct you to organizations that provide financial support to parents in your situation. If you are having trouble with creditors, Consumer Credit Counseling is an organization that can help act as a liaison and does not charge for its services. Most communities have a local branch, which can be found through the phone book.

Lack of Sleep/Exhaustion

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Hospitals are not places to catch up on needed sleep. Even when your child is discharged and you can go home to sleep in your own bed, you can still expect your sleep to be interrupted. Medications must be given on a rigid schedule, and often your child will need other care throughout the night as well. Furthermore, worry and stress can prevent a good night's sleep, even if the opportunity is available. Depleted physical reserves from lack of sleep take a toll on the patience of a person and marital misunderstandings may become common.

Isolation

Extended periods in the hospital, especially when it is a long distance from home, can lead to feelings of isolation. Some diseases may even involve periods of segregation for your child after he or she returns home. Friends and family may be uncomfortable with your situation and avoid you because they "don't know what to say." Due to the demands of caring for a chronically ill child, you probably won't have much energy left to keep up contact with friends either. The saying, "Absence makes the heart grow fonder," is not always true under these circumstances.

If your family is accustomed to being relatively self-reliant and isolated you will have an especially difficult time. You may prize your "independent spirit," but caring for a chronically ill child taxes all available resources, and if your support system has been limited, you will have a much harder time.

Communication Breakdown

The lifestyle that results from caring for your child will make communication with your spouse difficult. Hospitals are also not conducive to private, in-depth conversations. If you allow the circumstances to prevent you and your spouse from talking, the result is a build-up of emotional tension that may explode, not unlike a pressure cooker. If you are in the hospital and need to have a serious conversation, ask the hospital staff if they have a room for parents to use for such purposes.

In the book, *Chronic Kids Constant Hope, Help and Encouragement for Parents of*

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Children with Chronic Conditions (2000), Elizabeth Hoekstra and Mary Bradford recommend using today's technology, such as beepers, cell-phones, e-mail and fax machines, to help keep in touch while apart. They also suggest starting a family journal. Family members are encouraged to write whatever they are "thinking about, struggling with, or rejoicing about . . . There are no right or wrong entries, this is simply a non-threatening way to communicate . . . When each family member reads the various entries, it increases understanding of what others are feeling and helps develop tolerance of differences."

Other Commitments

Even though you may feel as if your world revolves around the care of your child, the reality is that many outside commitments still remain. If there are other children in the family, they need to be cared for as well. The extended family may have expectations that can prove to be a burden to families engrossed in the care of a seriously ill child. Trying to balance the demands of a job with the extra needs of your child is extremely difficult. Many parents also have commitments to community organizations including religious, civic, and social groups. All of these compete for the little time you have left, and you may easily forget to make time for your spouse too.

HEAT

Many of the problems that couples experience stem from the internal difficulties of coping. Emotions are often heated, although everyone handles feelings differently. There is considerable room for misunderstanding, which only adds to your problems. Being able to see things from the other's viewpoint and giving your spouse the freedom to work out emotions in the way most suited to his or her personality, can make a world of difference in how well you as a couple will get along. Surviving the heat of the situation can produce a diamond-like clarity of purpose in your life. Things that were previously considered important are put into perspective and you gain an appreciation for what really matters. Some common "heat producers" follow.

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Differences in Opinion

Parents don't always agree on what is best for their child. When the results of your decisions are so important, there is much opportunity for resentment and communication problems. The Leukemia & Lymphoma Society suggests that, "When differences occur, it is easier to resolve them if the parent whose opinion prevails avoids scoring a victory. Resolving differences should not be thought of as a 'win or lose' situation but as a means for effective adjustment."

Emotions

Common emotions that parents struggle with are fear, anxiety, guilt, anger, depression, jealousy, resentment, denial, and hopelessness. When these feelings combine and become difficult to handle, relationships suffer. In their book, *Living With Childhood Cancer, A Practical Guide to Help Families Cope* (2002), Leigh Woznick and Carol Goodheart offer the following suggestions for dealing with emotions:

1. "Acknowledge the emotion for what it is." In other words, if you are afraid, and embarrassed to be afraid, don't cover your fear and embarrassment with anger. Strive to be honest with yourself.
2. "Clarify the trigger for the emotion." Pay attention to what is prompting your reaction. Perhaps your temper is short because you haven't had enough sleep.
3. "Develop alternatives for handling the emotion." Go on the offensive and find ways to improve the situation. These might include "soothing (such as reassurance, a hug, or music); self-talk messages or teaching such messages to children; activation of quick coping strategies (such as counting to ten, deep breathing, or finding a distraction), setting limits (on behavior, time, resources, or tasks), removing yourself from the scene until you can regroup, and asking for help." Many people have found that prayer can be an effective way of releasing their emotional burdens as well.

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You also need to guard against the temptation to use withdrawal as a means of dealing with your situation. Separating yourself emotionally may seem like the only way you can cope, but it inflicts a great deal of pain on those around you and ultimately makes the situation worse. Your spouse ends up shouldering the emotional burden alone, and your child may misinterpret your behavior as a lack of love-adding rejection, fear, abandonment, and loneliness to his or her physical suffering.

Another common, negative response is to vent your emotions on your spouse. Anger, guilt, and frustration almost seem to demand a scapegoat. Unfortunately it is easier to put toothpaste back into a tube than it is to withdraw words that have been spoken in haste. It is important to find effective ways to deal with your emotions constructively instead of fighting against them, letting them control you, or ignoring them.

Lack of Support from Spouse

When we come to the end of our ropes it is natural to turn to those closest to us for support. Human beings are social creatures and the need for attachment increases during times of stress. This is just as true for adults as it is for children. Unfortunately, when both of you are hurting, each is less able to help the other. Usually this leads to varied negative responses, such as anger or withdrawal, which only complicate your problems. Finding a compassionate, unbiased, listening ear can help reduce your stress, and hopefully give you the perspective you need to better relate to your spouse.

Grief

Grief occurs when loss occurs. Although your child is still alive, you will need to grieve the loss of hopes and dreams and "life as it should be."

Greg Adams of the Good Mourning Program with Arkansas Children's Hospital, says that grief is the pain of loss, while mourning is what we do with the pain. He

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compares it to receiving a deep wound in your hand. Grief is the pain. You don't have a choice about that. You do, however, have a choice in what you do with the wound. You can ignore it. You can cover it up. You can clean it and get it stitched up.

Some ways of dealing with grief are more productive than others, but you should never assume that because a person is not acting the way you would expect, that he or she is not hurting. Grief is very personal and everyone deals with it differently. How one person deals with grief may seem totally inappropriate to another. One person may cry all the time, while the other just stays busy. One of the best and most loving things you can do for your spouse, and your marriage, is to give each other the freedom to work through the pain and deal with the situation as needed, without judging the behavior.

Gender Differences

Fathers and mothers, although they share the same child, do not share the same relationship with their child. Each family is unique and individual personalities vary, but mothers usually are the ones who nurture and care for the child, while fathers tend to take on a protective, guiding role. Society has also defined gender-appropriate behaviors for dealing with grief and stress. As a result, fathers and mothers often find themselves confused, hurt, and frustrated over the actions of their spouse, with misunderstandings adding to the already intense stress load.

Mothers

Mothers are generally the ones who take over the primary care of the sick child, in addition to remaining the general household manager. They often feel responsible for the emotional well-being of the family too. This may lead them to shield family members from upsetting information, a practice that more often than not will backfire. The overwhelming burden that mothers carry may cause feelings of guilt, frustration, worry, anger, and depression.

It is often difficult, however, for a mother to take time for herself to renew and

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replenish her strength without feeling guilty. Whether due to maternal instinct or social conditioning, when a child is threatened a mother's first response is to attend to her child. This is not always the best long-term course of action. If you have ever taken a trip on an airplane you are familiar with the speech that the flight attendants make when preparing for take-off. They will tell parents to put their own oxygen masks on first, and then help their children. In the same way, mothers need to make sure they take care of themselves or they will not be able to care for their children.

Many women struggle with resentment against their husbands, whom they feel are not involved enough in the day-to-day care of their child. Women also generally deal with their emotions in a more expressive manner and have a strong need to talk about what they are feeling or going through. It is not uncommon, however, for their husbands to withdraw emotionally at this time. The result can be a lonely, frustrated wife that feels abandoned by her spouse at a time when she needs him the most.

Fathers

Women are not the only ones frustrated at this time. Men struggle with feeling isolated and cut off from the care of their child as they balance the demands of a job, increased responsibilities at home, and the desire to be with their child.

Men are also conditioned by our culture to be strong and not "fall apart" under the weight of intense emotions. The typical response to stress is that of "fight or flight." Though some men will become aggressive and "fight," others feel powerless to fight an unseen enemy and unable to release the tension through emotional avenues. As such, many often cope by withdrawing. This "flight" may take the form of denial and an attempt to normalize the situation, emotional withdrawal, preoccupation with work or other children, and might even result in alcohol abuse or outright abandonment.

Many times the husband is struggling with watching his wife suffer also. He may avoid discussing emotional issues in an attempt to protect her. Unfortunately, this is

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not seen as a loving, protective action by his wife, who rather perceives his behavior to be cold and uncaring.

Sexual Relations

The topic of sexual relations can be a major source of conflict at this time. Each partner may respond to the situation in a totally different way. One may desire the comfort and closeness of an intimate relationship, and the physical release may relieve some of the stress. The other may wonder how anyone could think about sex at a time like this. Physical exhaustion also diminishes the sexual drive and circumstances may limit your private time. Emotions are raw and you may even find yourself bursting into tears while making love. Please be gentle with each other. Communication is of utmost importance. You should be honest with each other about your needs, and considerate about the other person's needs. You may find it necessary to take the time to just hold each other tenderly.

DIAMOND FORMATION

The surrounding environment is the key to what makes carbon become a diamond. If your marriage had trouble before your child's diagnosis, you should seriously consider obtaining help. You will need to be able to talk to someone who can help you keep your balance during this time. Even families that haven't had serious problems previous to diagnosis will find that they will need to make adjustments. Communication is crucial to getting through this time together, and just as you are taking the time to learn how to care for your child, you may need to learn some new coping skills.

Do not expect your partner to be your savior. You may have been able to draw strength from your spouse in the past, and he or she may still be your best support, but remember that your partner is suffering too. If there is an area in which your spouse is unable to be supportive, give him or her the freedom to limp. For instance, if you need to talk about the future and your spouse just can't think that far ahead; find a good friend, family member, or counselor who will listen. Don't force the issue,

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or instill guilt; instead, offer understanding.

Periodically, schedule some time away together, just the two of you. If you can manage a night or weekend away you will have an opportunity to recover physically and spend some extended time together talking about things that have been set aside due to the urgencies of life. If an overnight time is not feasible, plan for a lunch or dinner alone, take a walk together, or go for a drive. You can even let the kids stay up late watching movies while you lock your bedroom door. For your marriage to remain healthy, you will need to commit to remaining intimate, both emotionally and physically.

Your family will function best if you and your spouse can share in the decision-making processes, the healthcare of your sick child, and the maintenance of your household. Taking on new roles in the family can actually be a refreshing change for some. Don't be too proud to accept outside help for routine chores and assistance with your other children, either.

Support

Family, friends, and communities of faith are often excellent sources of support for families in crisis. Sometimes, though, it is necessary to widen your support team and incorporate those with relevant experience. Be aware of what is available. Asking for help early could be vital to your family's well being.

Hospital Staff

Take advantage of the trained professionals at your child's hospital. They are already involved with your family and have experience in situations similar to yours. In addition to medical staff, hospitals may employ pediatric social workers, child-life specialists, chaplains, and mental health workers.

Clergy

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Clergy members are usually trained in counseling, and if they are not, they are often able to refer you to an appropriate source of help. Many people find that God is an important source of strength for them, and though their faith may be tested through the ordeal, it often becomes stronger because of their experiences.

Mental Health Workers

In her book, *Childhood Leukemia: A Guide for Families, Friends & Caregivers*, Nancy Keene states that, "Seeking professional counseling is a sign of strength, not failure. In dealing with children with cancer, problems often become too complex for families to deal with on their own. Seeking advice sends children a message that the parents care about what is happening to them and want to help face it together." There are various kinds of mental health workers including psychiatrists, psychologists, psychotherapists, social workers, and pastoral counselors. The best thing to do is to begin asking for referrals and suggestions from those you trust. Those you ask should also be familiar with the situation and the local mental health care providers in your area.

Other Parents / Support Groups

Having a child with a life-threatening illness can be very isolating. It is often helpful to connect with other parents who understand what you are going through and with whom you can be yourself. You may meet other parents informally while at the hospital, or there may be support groups available for parents in your situation. Men can find it especially helpful to develop friendships with other fathers who are dealing with the same struggles since they often wrestle with feelings of isolation.

Camps

There are numerous summer camps available for children with various medical diagnoses. Many of these camps also welcome siblings into their programs. Camp is a great opportunity for your child to enjoy being a child, and it offers an excellent chance for husbands and wives to have some time alone together. Talk to the hospital social worker to find out about camps appropriate for your child.

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Choices

No one chooses a potentially fatal disease for his or her child. It descends on you uninvited and forces its presence on all the members of the family. You also can't control those around you, and you can't expect them to react in ways that you perceive as best. Although you may feel as if you are at the complete mercy of your circumstances, the truth is that you are still in control of how you respond to this new reality. If you find yourself at the end of your resources, you can take the initiative to find options for help beyond yourself.

As a couple, you can decide together to do what it takes and not allow the disease to steal your marriage. You have all the ingredients necessary for diamond formation. Diamonds, however, are expensive, while dust is cheap. You will need to be willing to pay the price to transform your relationship into a gem. There is help and hope for those who commit together to do what is best for their marriage, their child, and their family as a whole. You do not need to go through the process alone. And when you have overcome, your strength, clarity, and light can bring hope to others.

If Only One is Willing

You may be reading this alone and wishing your spouse would read this and take it to heart. You may be struggling with anger, frustration, loneliness and bitterness over feeling abandoned at such a crucial time. Unfortunately, you cannot control the actions of your spouse, as much as you may desire to do so. We are each responsible for our own behavior, and pain is a powerful motivator, often in negative ways. Though the situation is no excuse for destructive behavior, understanding the pain behind the behavior may help you to release the bitterness that can keep you in bondage.

Even though you cannot force another person's responses, you do have control over your own. You can get the support you will need to be able to care for yourself as you care for your child. You may even be surprised to discover diamonds along the way. An intimate bond between you and your child is priceless. The new friendships

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you may develop as you reach out to others will be treasured forever. You may even find jewels within yourself as you discover a growing self-confidence and inner-strength, a joy in the simple things in life, and a renewed purpose for living.

You are probably facing some of the greatest challenges you will face in your lifetime. Don't be too hard on yourself. Reach out to those who are willing to help, and when you have made it through, you will be able to help others discover the diamonds within their own lives.

Postscript

This paper is written to honor the memory of my ten-year-old daughter, Jasmin Laura Raiees-Dana, and my fourteen-year marriage. When Jasmin was diagnosed with cancer in February of 1997, my spouse and I were given quite a bit of material concerning how to best care for her and deal with the situation. We were given literature on possible physical problems, sibling relations, schooling problems, and parenting issues, to name a few topics. None of the information mentioned the problems we would face as a couple, or offered any recommendations.

In October of 1999, Jasmin died and my spouse filed for divorce. I don't know if having something in our hands would have saved our marriage or not, but it would have been nice to have been forewarned, and to have understood the differences that often exist in coping styles between men and women. Watching my daughter suffer as she struggled with watching our marriage fall apart was almost as bad as watching her suffer from the disease that eventually took her life. I felt painfully helpless in both situations.

Scientists are working with incredible dedication to try to find cures for the diseases that threaten our children. The medical community is also dedicated to doing whatever possible to help save our children. We owe it to our children to do whatever we can to save our marriages. I understand that it takes two to make a marriage work, and know from experience that not all marriages will survive. For those, however, that decide together to not allow the situation to destroy their

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marriage, there is hope and help. Do not give up or think it will have to wait. Give your child the stability he or she needs during this difficult time, and commit to each other to get the help you need to make it work. You can become "diamonds."

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