



# till sickness do us part



A chronic illness diagnosis can strain a marriage beyond its limits, but learning communication skills and seeking support can help couples survive and even thrive.

By Trudie Mitschang

**APPROXIMATELY 35.3 MILLION** Americans are limited in their daily functioning because of a chronic mental health or physical health condition, according to the American Association for Marriage and Family Therapy.<sup>1</sup> For the vast majority of these individuals, family members in general and spouses in particular are often the primary caregivers, and it's a role that can take a toll on even the strongest relationships. For married couples, navigating a "new normal" can be especially daunting, particularly when the illness becomes like a third-wheel personality, interrupting the couple's communication, hobbies, lifestyle and even bedroom activities.

Dr. Toni Bernhard, author of several books on chronic illness,

including *How to Live Well with Chronic Pain and Illness: A Mindful Guide*, says of all the areas in a marriage impacted by an illness diagnosis, communication breakdowns seem to be the most problematic. "We do a poor job in this culture of preparing people for the inevitability of health problems. Because of this, when one partner becomes ill, couples are caught off guard, and both of them are likely to start living in 'crisis mode,'" she explains. "Couples need to be rational and calm in order to effectively evaluate how chronic illness may affect their relationship, and in order to decide what steps both of them can take to make their lives as easy and as pleasant as possible, given their new limitations."

For many couples, the person who is ill becomes the center of attention, and while some spouses may step comfortably into the caregiver role, others struggle with the title and responsibility. In his book *Beyond Chaos: One Man's Journey Alongside His Chronically Ill Wife*, author Gregg Piburn describes how his wife's struggle with fibromyalgia and other health problems changed not only her life, but their life together as well. He describes his feelings of anger, frustration and guilt, and how the experience ultimately led him to reevaluate his expectations and priorities. In an interview about his journey, Piburn says he and his wife eventually allowed the diagnosis to draw them together, becoming allies against the illness they dubbed "the intruder."<sup>2</sup> "Like an intruder, chronic illness sneaks into your house unexpectedly and robs valuable items from everyone who lives there. I find value in personifying the illness because it creates an impetus to fight back," says Piburn. "We go to war against 'the intruder'; however, we fight wars on several fronts. My book focuses on how to fight chronic illness on the emotional and relational fronts."

## Understanding the Strain

Illness, whether temporary, chronic or terminal, demands time and attention from everyone impacted. A once-healthy couple used to juggling the daily demands of work, childrearing and social obligations may suddenly find themselves straining under the burden of endless medical appointments, mounting insurance bills and complex health regimens. For spouses who find themselves suddenly ill, the additional need for rest and even assistance in showering and dressing can provoke feelings of guilt and helplessness, while putting tremendous pressure on the healthy partner. This is where communication can begin to break down and resentments may begin to build; sadly, many marriages simply disintegrate under the pressure.

In the general population, the lifetime divorce rate has long been reported at 50 percent, and some studies suggest a chronic illness may bump that number up to as high as 75 percent (a figure that remains unsubstantiated). Still, there's no question that the impact of chronic illness can be detrimental to matrimonial harmony. And, for those marriages that do survive, it can be touch and go — a day-to-day decision to tough things out — with unique challenges for both the caregiver and patient. "Caregivers often make the mistake of trying to be 'super caregiver.' This can easily lead to caregiver burnout and depression," says Dr. Bernhard. "It's important for caregivers to recognize that it's OK for them to have days when they feel weary of their role. In my experience, the life of the caregiver is affected as

much by chronic illness as is the life of the partner who is struggling with health issues."

Dr. Bernhard adds that partners who are chronically ill tend to make the mistake of entertaining a "pity party" mentality, believing that their loved one doesn't care enough about them: "Those who are chronically ill often make the mistake of expecting too much from their caregiver/partner — of not realizing that their partner is as confused and shocked as they are over this unexpected change in their lives and their relationship."

## The Influence of Gender Roles

Studies show that men and women react differently to a diagnosis of chronic illness, and may exhibit different coping skills. One study,<sup>3</sup> which analyzed 20 years of data on 2,717 marriages from the Health and Retirement Study conducted by ISR since 1992, examined "the role of serious physical illness onset in subsequent marital dissolution via either divorce or widowhood." The study found an elevated risk of divorce at the wife's illness onset, but not the husband's. There is "evidence that when wives become sick, marriages are at an elevated risk of divorce," says Amelia Karraker, a researcher at the University of Michigan Institute for Social Research (ISR), and one of the study's authors, "whereas we don't see any relationship between divorce and husbands' illness."

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Elvira Aletta, PhD, a licensed clinical psychologist who was diagnosed with a rare kidney disease in her 20s, and later diagnosed with scleroderma, a chronic connective tissue disease, says the problem can come down to an inability to deal with displaced emotions. "Men, in particular, are programmed from birth to fix things. Our healthy spouses hate that in the face of chronic illness, they can't fix things," she explains. "Their frustration can come out as irritability, sniping, overcompensation, co-dependent, enabling-type behavior, throwing themselves into

work (an area where they can feel competent) and/or shutting down emotionally, appearing kind of flat. All of these can be masking depression.”

Another study published in the journal *Cancer* found that a married woman diagnosed with a serious disease is six times more likely to be divorced or separated than a man with a similar diagnosis.<sup>4</sup> Among study participants, the divorce rate was 21 percent for seriously ill women and 3 percent for seriously ill men. A control group divorced at a rate of 12 percent, suggesting that if disease makes husbands more likely to split, it makes wives more likely to stay. Scientists point to a few possible explanations for the disparity. For one, being a caregiver is not a traditional role for men, says Dr. Marc Chamberlain, director of neuro-oncology at the Seattle Cancer Care Alliance and one of the authors of the study. “The majority of husbands take excellent care of their partners, but men on the whole tend to be less comfortable doing so,” he says.

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### Seeking Help and Support

A diagnosis of chronic illness often comes with a confusing mix of emotions, including anger, grief and even shame. When an individual suffers from an invisible illness such as an immune deficiency disease, those feelings can be compounded. Dr. Aletta encourages couples who sense long-term illness is threatening the stability of the marriage to seek outside support and help sooner rather than later. Getting toxic feelings and fears out in the open by discussing them with a neutral third party can give both the patient and caregiver improved coping and communication skills. In her article, “10 Ways to Care for Your Marriage When You Have a Chronic Illness,” she advises:

1. Be honest with yourself. Only you in your heart can know how much you reasonably can and cannot do. When you know your limits, there is no need to be defensive.

2. Remember you are on the same team. Your marriage is a

cart being drawn by two horses: you and your spouse. Being a team, when you pull in the same direction with the same speed, your cart goes forward. If you run in opposite directions, the cart falls apart.

3. Keep the chronic illness outside of yourself. Keep it figuratively “out there.” That way the problem isn’t you; the illness is another problem to face and deal with, like the mortgage. That way, it’s easier for the two of you to face it together and problem solve shoulder to shoulder.

4. Let your partner take responsibility for his or her own emotional life; don’t try to shoulder the burden.

5. Remember, we cannot change them. We can only ask ourselves: “Am I being the best partner I can be?” Miraculously, by not responding defensively to their provocations, for example, not yelling back when we are yelled at, we role model real versus pseudo communication.

6. Be creative. I know a couple who uses a non-verbal signal for pain levels. You can also be creative about “lightening the load.” Are there other community, friend or family supports that can be utilized better? The two of you can also Internet search healthy, easy recipes for dinner.

7. Find a routine you both can count on. Stress thrives in chaos. Health — emotional as well as physical — loves regularity. The more you can plan your day and week, the easier for both of you. Take a few minutes at least once a week to go over what will be happening the week ahead.

8. There’s always therapy. I know I can be a broken record about this, but couples counseling is for more than just couples who are fighting and heading for divorce. A good couples’ counselor can help you loosen up your creative energy when you are too deep in bad habits. A lot of spouses will go to couples therapy “for you” and then get help for their own adjustment problems or depression.

9. Let him know, every day, in small but direct ways, when he is appreciated. The carrot, rather than the stick, is the most powerful tool for positive change.

10. The book *The Power of Two* by Susan Heitler is a favorite of mine. It is a practical resource that helps even the best marriages by teaching couples to pay attention to how they are communicating, talking and listening to each other.

### Pulling Together When a Child Is Sick

When chronic illness strikes a marriage partner, the road ahead can be a difficult one. But when illness impacts a couple’s child, a whole different level of stress bombards even the happiest unions. Jessica Johnson is the mother of three

boys with X-linked agammaglobulinemia (XLA), a rare immunodeficiency disease. A fourth son passed away from XLA, a tragedy that has taken a toll on her 16-year marriage. “Chronic illness, specifically XLA, has somewhat taken away our positive outlook for the future. It’s positive enough ‘given the circumstances,’ but there is definitely a shadow of doubt when it comes to how long our kids will maintain healthy and active lives,” she explains. “It has also had an effect on how many kids we had. I think if we hadn’t continued to have sons afflicted with XLA, we might have had one more child. We’ve also lost one child to XLA, and that loss has affected our family in so many ways. We have one less child in the house. We may feel like we’re busy, running four kids here and there, but we should be even busier.”

While some couples are able to unite in the face of tragedy, Jessica says her and her husband’s different coping styles have created a gulf between them: “It has definitely created a wedge. I’m a worrier and I tend to place my concerns for the kids above everything else, particularly my husband’s needs. I can’t live in the moment if they’re sick or if I’m preoccupied with thoughts of their illness. If it’s flu season, for example, I’m pretty mentally checked out, and that creates distance in my relationship with my husband.”

Taking care of a child, or in Jessica’s case, multiple children, with ongoing health problems can be one of the most difficult tasks a parent can face. Relationships within the family will be altered, and sometimes strained, as everybody adjusts to

the situation and perhaps takes on additional responsibilities. Sometimes other children get a lot less time and attention. In addition to worry and concern about the child’s health, there may also be financial worries. The cost of medical treatments and procedures can be expensive for families, and sometimes parents need to go back to part-time work, or not work, to care for their child, which can create additional financial strain.

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According to the Women’s and Children’s Health Network,<sup>5</sup> these types of pressures can lead to stress, exhaustion and tensions within family relationships. However, there are some things that adults can do to help support the family and prevent the situation from destroying the marriage. Some suggestions include joining a support group, asking for help from extended family members, giving yourselves “time out” from caregiving to just be a couple again, and considering professional help from counselors and therapists. “The initial diagnosis of chronic illness can be pretty shocking, and it may seem life-altering at first,” says Jessica, “but as you get used to incorporating the treatments and/or therapies into your daily and weekly routine, you can start returning to life the way it used to be, with a few adjustments.” ■

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