



# *You Need Help; I Want to Help Why Doesn't It Feel Good?*

## The Barriers to Effective Support

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**C**hronic illness wears you out physically, mentally and emotionally. It takes its toll on caregivers, too. So how do you cope? The literature tells us patients and caregivers fare better when they are supported by friends and family, when they have a social support network.

Although most of us have family and friends out there who have the capacity to provide support, sometimes they just don't come through for us.

Usually, people want to help, but sometimes they just don't know what to do.

According to Benjamin Karney, a professor of social psychology at University of California Los Angeles, there is often a disconnect between your feeling supported and what people are doing to offer support. When you have been to your fifth doctor appointment in a week or when you have just realized that a new wonder drug has long-term side effects, it can be painful and confusing to call a friend who wants to chat about her bad day in the office. Even when people try to help, you may not feel supported because they may not be doing things that effectively support you, and this doesn't feel good to either of you.

**Support Influences Health**

There's a lot of evidence that support does influence physical health (e.g., blood pressure, cortisol levels, tumor growth) and psychological health (e.g., depression, anxiety,

self-efficacy). For example, partner support has been linked to depression vulnerability such that more support decreases vulnerability to depression and a lack of support increases vulnerability. There is also evidence of the importance of support for relationship satisfaction. For example, spouses reporting higher levels of partner support are more satisfied with their marriages than those reporting lower levels of support, and spouses often identify lack of partner support as a major reason for relationship dissatisfaction and dissolution.

What makes support effective? How do you accomplish the goal of making someone feel supported?

In considering effective support, an important distinction can be drawn between the *quantity* of support and the *quality* or *adequacy* of that support. Just as the amount of support influences physical and mental well-being, the effectiveness of support also contributes to individual well-being. Because not all support provided may be welcomed by the recipient, one person may believe he or she is providing a great deal of support whereas the other person perceives he or she is receiving little support.

Studies comparing the quantity of support with the quality of support across relationships have found both to be important contributors to one's physical health. For example, greater quantity of support, as measured by greater network size, is associated with higher levels of self-efficacy concerning pain and symptom management among women with fibromyalgia, whereas greater perceived quality of

support was associated with lower levels of depression, helplessness, and mood disturbance, higher levels of self-efficacy for function and symptom management, and greater overall psychological well-being. In another study, greater satisfaction with support was associated with lower cortisol responses and lower blood pressure.

For some people, less frequent support may actually be preferred. People have unique coping styles or dispositions. If an individual is not receiving the type of support that matches his or her preferred coping style (or is not receiving enough of that type of support), the result may be negative. For instance, the provision of undesired support may lead support recipients to view the support provider as insensitive or patronizing, especially if support is in the form of unwanted advice-giving. Support recipients may also experience feelings of guilt if they do not embrace the undesired support provided by another.

### What Can Go Wrong

Some people may at times feel pressured to offer support, but if they do not know how to do so effectively, the pressure can lead to bad feelings. Then the provider may blame the person he or she is attempting to help: "I tried to support you, but you did not accept my support. It is your fault you do not feel supported."

Also, it is threatening to others when bad things happen to good people. People want to feel safe, so if they observe someone suffering from hard times or illness, it is tempting to look for a reason that person has been targeted. Out of self-protection, they may rationalize that "if misfortune happens for a reason and I am a good person, it won't happen to me!"

Undoubtedly, self-protective impulses can compromise the ability of a provider to offer adequate support. Dr. Karney says that researchers have determined several ways in which support might break down (see Figure 1).

### The Just World Hypothesis

If observers are worried that they might experience the same problem as the person suffering, they might conclude that the other person has self-inflicted the suffering. We tend not to want to help people who "get what they deserve." In chronic illness, this may underlie the attitude that "you are overreacting" (see Zara's Story). In other words, someone in your support network who may see only snapshots and not the whole picture of your life might conclude that you are not really as sick as you think you are. Therefore, you don't really need help. This person may believe that if you stop overreacting, you will no longer have a problem and, consequently, not need support. In some cases, this may play into unexpected reactions and lack of responsiveness from physicians.

### Fundamental Attribution Error

There is a general bias toward overestimating the control people have over their own actions or behavior and toward underestimating external influences or circumstances. This becomes a problem, for example, if someone comes home to a partner in a bad mood. The tendency is to say, "Why are you being so grumpy? What is wrong with you?" It takes increased effort to look beyond the bad mood and ask "What happened today that put you in a bad mood?"

### Compassion Fatigue

Well-meaning people who want to help can become fatigued or tired of helping after offering long-term care. They may then become indifferent or look for ways to "let themselves off the hook." This fatigue can affect nurses, people who work with the chronically ill, and unpaid caregivers, such as family members. One mom told me that her loved ones couldn't keep up the effort to help her with her child; they simply became unavailable. "When they stop, they stop for good," she said. "Indifference is the worst thing." ➤

Figure 1. Issues that can compromise social support



### Support Mismatch

There may be a mismatch between the type of support offered and the type of support needed. This can make the person in need feel unsupported and the provider feel unsuccessful. Psychologists speak of several types of support that can be broadly separated into two categories: 1) instrumental support, defined by active help (like buying groceries or cleaning the house) and 2) emotional support, defined as validation and sympathy. If you just need someone to listen, or tell you that they love you and think well of you, but that person wants to help you by taking you out for dinner, you may feel unheard and they may feel unappreciated.

### Ineffective Request for Support

This is related to the support mismatch problem. Sometimes people do not know how to effectively ask for the kind of help that they need. For example, if you ask for support and are then critical of the support you receive, the person offering support may not want to try again. Once you express a specific need, it is not so helpful to instruct people how they should fulfill it. For instance, you might say, "I need you to take care of the dishes," or "I just need you to listen," and then let your caregiver determine how he or she can best do that for you. Although it may be hard to ask for help effectively when you are embarrassed by the request or when you do not want to feel beholden, people are usually happy to know specifically how they can help you.

### Different Types of Support

Another important issue concerns the different types of support that can be provided. Researchers and clinicians typically consider there to be four types of support:

1. Emotional support (e.g., providing reassurance, love and affection)
2. Informational support (e.g., providing information and advice)
3. Esteem support (e.g., validation or showing confidence in the partner's abilities)
4. Instrumental or tangible support (e.g., providing direct or indirect assistance in solving the problem).

Sometimes a fifth type of support is included:

5. Network support (e.g., encouraging the partner to make use of social resources, such as family and

friends). However, network support has more to do with the size and/or availability of one's support network rather than a particular type of support.



### The Art of Asking for Support

Being able to ask for and accept support is as much a skill as being able to provide support. Although most people focus on the effects of providing support, there is evidence that the ways in which a person asks for and accepts (or receives) that support also influence physical and psychological health. In one study, women's ability to provide support positively affected their own health status more than their ability to receive support, as indicated by fewer absences from work due to illness. However, among men, receiving more support predicted fewer absences than giving more support.

People typically don't think about asking for support and accepting support as skills. One possible reason for this oversight is that people usually conceptualize the support provider as having an active role whereas the person requesting or on the receiving end of the support is often perceived as being a passive recipient.

It is important to understand the role that denial plays in these issues. While denial in a situation such as Zara's can be toxic, in many cases it is a simple coping mechanism. If two parents are caring for a sick child, they may choose to divide responsibility so that one parent is primarily responsible for the child's health and the other parent is responsible for paying the bills. The parent paying the bills will have to be able to focus on the workplace and fulfill job responsibilities without being sleep-deprived or distracted by what



is happening at home. Mild denial, in that case, might even be functional. But it can still be hard on the parent bearing the brunt of the medical situation at home.

These factors will play into every relationship. Failure of social support occurs on a continuum. In a healthy relationship, the level of social support can vary throughout a relationship. In an unhealthy relationship, social support can fail dramatically. In these situations, the only way to get what you need is to get creative. But, in a healthy relationship, effective communication and nurturing might provide some of the answers.

### Real Life Answers

Caregivers are portrayed in the media as indefatigable providers—heroes who operate without needing anything for themselves. This is not reality. Trying to care completely for another person's needs, putting them first 100 percent of the time, can lead to compassion fatigue. It is critical that the caregiver be refreshed. This can be a very frustrating message when you are caring for someone with a chronic illness, because taking time off may not be an option. But, if you acknowledge this need, even though instrumental support may not be possible, emotional support may fill some of this gap. Successful support, even successful emotional support, is concrete, but not prescriptive. In other words, it helps if support providers make specific offers that don't sound like orders, such as "Would you like me to make some calls for you?" Or, if you are the one needing respite, it helps to make specific requests such as "Could you watch Sara so I can rest for an hour?" This kind of careful effort is difficult, especially when you have many demands on your time and emotions.

For example, when Kristin's son, Conner, began showing the signs of a significant immune deficiency, she and her husband felt isolated. But they shored each other up and turned to their community for help. Once they began to reach out, their friends, family and church came through with an incredible show of support (see Kristen's Story). Because of her experience, Kristin developed some specific suggestions for offering instrumental help and emotional support (see Kristin's Tips). Although designed with an immune deficient child in mind, these suggestions generalize well to any chronic illness.

Improving your ability to ask for support effectively can help prevent support mismatch. And, being aware of and preventing compassion fatigue by getting some respite (even if just an emotional break) is important. But it is also important to try to prevent fundamental attribution error. Simply

being aware of our tendency toward bias may be the best way to accomplish this. When your friend starts in about her bad day at the office, try to remember that her stress is impacting her ability to listen to you. Most people we rely on for support are already dealing with their own stressors, and their circumstances matter, too.

Zara's story shows that, for reasons beyond your control, there may be times when your closest loved ones simply are unable to offer support. In these situations, you may need to seek out other forms of respite. For Zara, solace came from her community activities, activism and her faith.

Easier said than done, finding respite requires a lot of self-awareness and good communication. It is usually too simple to say that there is no support out there. People generally care and want to give support, but they encounter the significant barriers discussed above. People's reactions are a function of what they encounter and what emotional history they bring to that encounter. One mom says, "You can move toward pain and address it in a constructive manner with those you trust. Or you can move away from it and tell people that you are 'fine' when you are not. Moving away from pain may lead to suffering in isolation."

Being aware of the factors that inhibit support, anticipating those factors we can control, and understanding those that we cannot control may help us feel less alone. Ultimately, sometimes the best method for determining how to provide or receive the most effective support is to ask: If you want support, ask for it; if you want to offer support, ask what would help.

### Zara's Story

Zara was a healthy woman when she married her boyfriend of 17 years. Although they had had their ups and downs, he had recently been diagnosed with multiple sclerosis, and she wanted to take care of him.

The reality has proven quite different.

Zara's husband has remained fairly healthy on his treatment, but after 18 months of marriage, Zara developed polymyositis, a condition so debilitating that at times she has trouble getting up from her chair. Zara takes a lot of medication to maintain her physical function, including steroids, which have caused her to gain weight. Rather than supporting her, however, her husband retreats into silence. "He will stop talking at the drop of a hat, maybe after I ... get upset with him for not doing something ➤

that he could easily have done, it is hard to say but it has been more and more since being diagnosed.”

It almost seems as if Zara’s husband equates silence with stoicism. He doesn’t talk about his own illness either. When Zara tried to share a small triumph with him (she found a way to put on her socks), he commented, “Oh quit feeling so sorry for yourself.” Zara dissolved into tears and then resolved to look elsewhere for support. Beyond stoicism, Zara’s husband seems to resent her illness. When Zara tried to ask him why, he angrily responded, “Bothered, bothered, I’m not bothered about it. I don’t understand this medication thing.” By this, he confessed he meant that he was upset by Zara’s weight gain—the only part of her illness that seems to register with him.

Today, Zara has accepted her situation. She has developed a significant online support community through a blog she maintains and also through The Myositis Association support group. She even logs onto multiple sclerosis support sites to gain insight into her husband’s illness.

## Kristin’s Story

Kristin first began to realize that there was a serious problem with her son, Conner, when he was 9 years old. Conner is a triplet who was born prematurely.<sup>1</sup> He and his siblings had always had some illnesses, but it began to seem that Conner was much sicker. Chris, Kristin’s husband, would tease Kristin when she panicked over Conner’s frequent colds. But when Conner had trouble breathing after one of his colds and was hospitalized, it was time to treat the problem seriously.

Chris began joining Conner and Kristin at doctor appointments. At first these were a frustrating experience, because doctors didn’t seem to take the situation seriously. They switched pediatricians to get Conner better care and referrals to specialists, but even the immunologist they saw was not sure how serious Conner’s problem was. Later, when Conner was diagnosed with NEMO (a serious primary immune deficiency), the doctors became more supportive, and Chris also completely understood and supported his medical care. Kristin and Chris were almost relieved to have a diagnosis, because they felt that they could start concrete action toward finding a cure.

Kristin stays home and spends more time caring for Conner than Chris, who works full time. As a result, she feels hyper-alert whenever Conner is sick. Chris is concerned

about Conner’s long-term health, but is not as upset by the roadblocks on the way. The important thing is that Kristin and Chris understand each other’s fears and coping mechanisms, and they successfully support each other. When Chris is too tired or overwhelmed to talk about Conner’s health, he takes the kids and sends Kristin off to have dinner with her friends. Chris is a very hands-on dad, and he plays and spends a lot of time with the kids when he is not working. As a result, Kristin gets some respite, and she feels appreciated. Kristin also makes sure that Chris has time away from the family to play softball with his friends and to unwind.

At first, Conner’s extended family was not very involved. They did not seem to want to talk about Conner’s health problems. They also seemed to blame some of Conner’s health problems on his parents, implying that he wouldn’t be sick so frequently if his parents took better care of him. Kristin and Chris felt very alone. Fortunately, they were able to talk to each other about it, but they did not know how to reach out for help until Kristin confided in her best friend, who began organizing a fundraiser when she learned that Conner would need a bone marrow transplant. Through raising funds, she raised awareness. Soon everyone who had been unable to talk about Conner’s illness knew how they could help. Friends and family contributed time and money, and were also able to be more emotionally involved. Kristin realized that they had wanted to help all along, but had not known how.

The family’s church was also a great source of support. The pastor helped with fundraising and organized significant renovations to the family home, which made it safer for Conner. Church members donated money to remove carpet and put in wood floors to ease Conner’s breathing problems. The church continues to raise money for Conner’s medical care and has been very active in supporting his upcoming transplant.

Even Conner’s school has pitched in. At first, Conner had trouble at school because the children, teacher, and staff did not understand his illness. But Chris’ sister asked the teachers to pass out fliers that explained Conner’s situation and how to support the family. Not only did the fliers help Conner and his parents, they also helped Conner’s brothers and sister, who attend the same school. Now that people understand what they are experiencing at home, the siblings are also receiving more support. ■

<sup>1</sup> For more about Conner, please see “Bone Marrow Transplant: The Search for a Cure” in the August-September 2007 issue of *IG Living*.

## Kristin's Tips for Supporting Families With Primary Immune Disorders

Living with a primary immune disorder may leave the family dealing with frequent hospitalizations and clinic visits, as well as serious financial difficulties. Some days may be overwhelming and can lead to feelings of loneliness and frustration for everyone.

Here are everyday ways you can help your friends or loved ones cope with managing their illness:

- Let the family know that you care about them and you want to help. Don't avoid them when you don't know what to do or say; this will make them feel as though you are indifferent to their situation. Make a point to check in with the family on a regular basis. Your support is invaluable in this life-long situation!
  - Don't wait for the family to call you for assistance; they may not know how to ask for help. When necessary, make specific offers, such as mowing the lawn, baby-sitting, bringing dinner, picking up groceries, providing transportation, etc.
  - Be available to listen and learn about the family's medical issues, but reserve comments that may suggest you question the diagnosis or minimize the seriousness of the illness.
  - Always be considerate of the family's need to avoid germs by washing hands frequently during visits and staying away from the family when you are ill.
  - Continue to invite the family to do fun things, and ask how you can make it work with their related health needs. They may not always be able to participate, but will appreciate the offer.
- Keep in mind that when the family says they are doing fine, they may be trying to hide their fears and frustrations. Continue to let them know that you are there for them.  
  
Here are ways you can give them help during hospitalizations:
    - When possible, go and sit with the patient or parent(s) in the hospital. Even routine hospitalizations can be lonely and overwhelming at times. Just listening and providing empathy is very helpful.
    - Help coordinate care for the siblings at home, if necessary. Don't forget that they may be scared and confused. Make sure they feel important too by being available for them to discuss their concerns, scheduling fun activities and sending cards or small gifts.
    - Offer gifts for those who are hospitalized. Children in the hospital might enjoy small treats like stickers, coloring books or puzzles. For teens, consider offering to arrange transportation for their friends to visit at the hospital.
    - For the patient or parent, consider bringing gift certificates for restaurants and video rental stores near the hospital, as well as magazines or favorite snacks. Due to risk of infection for the patient, avoid bringing or sending live flowers, plants or fruits without permission.

### For More Information

For respite care resources near you, visit the ARCH National Respite Network at [www.archrespite.org](http://www.archrespite.org).

To learn about primary immune deficiency disorders, visit [www.primaryimmune.org](http://www.primaryimmune.org) and [www.jmfworld.org](http://www.jmfworld.org).