

## Chapter 8

### *In this chapter:*

- Focus on What Matters
- Resetting Goals
- Finding the Benefits
- Meaningful Moments
- Allowing Laughter

# *Caring for the Caregiver* *Maintaining* *Well-being*

As the caregiver, you already know how a loved one's serious illness can cause intense and prolonged psychological stress. **The signs of stress are well known: worry, anxiety, sadness and other negative emotions begin to color each day.**

You may have trouble with sleep, and during the day you may be tired, find it hard to concentrate, especially on tasks that seem irrelevant. Because of the effects of stress on the immune system, you may also experience more physical problems, including colds, flu, and other upper respiratory illnesses.



Surprisingly, even when things are going badly and stress is intense, people do have moments when they experience positive emotions such as joy, happiness, love, and compassion. And, in fact, except when the situation is truly dire, these upbeat moments occur surprisingly often over the course of a day or week<sup>1</sup>.

These positive moments are often fleeting, but they are very important because they help you sustain your well-being in the midst of stress. They can do this in several ways. They provide a “breather” from the distressing emotions that accompany stress. Many of these positive moments help motivate us and keep us going by reminding us of what matters. They can also help to reduce the harmful effects that can occur when the body is under stress for a long time.

*These positive moments sometimes just happen, but at other times, you can make them happen with specific coping strategies. These strategies don't make the stress of caregiving go away. But they can provide respite, renew purpose, and restore psychological resources that are often depleted by the stress of caregiving.*

These coping strategies do not require extensive training. You simply need to think about them to make them happen.

Here are five strategies to help maintain your own well-being in the midst of stress:

## 1 FOCUS ON WHAT MATTERS.

Focusing on what matters can strengthen your sense of purpose and meaning in your life. It can help direct the choices you make and can help sustain you when the going gets tough.

As a caregiver, you can get caught up in responding to day-to-day demands and easily lose sight of why these activities matter. As a result, your resources can become depleted and you can burn out.

A family caregiver who participated in an important research project on stress in caregiving helps us understand the importance of reflecting on what matters. This man's partner had advanced AIDS during the time before effective treatments were available. He described a night that was much like most other nights when his partner experienced severe night sweats. The caregiver had to change the bed linen, sponge his partner and help him into fresh pajamas. This caregiver reported that he usually had to do this about four times during a night; the previous night, however, it had been eight times. And what got him through this night after night? He focused on what mattered to him — the underlying love they had for one another and how these efforts were an expression of that love.

For some caregivers, what matters may have to do with love. For others it may have to do with a sense of what is right and moral, of what a “good” person does. It might have to do, for example, with valuing compassion and being able to reduce suffering.

The most important thing is to be aware of what matters to you. Remind yourself of it, especially when things are going badly.

Some people find it helpful to create a “matter-ing” list. *What would be on your list? Why do these things matter to you?* What are the deeply held beliefs and values, the deeply held fundamental truths, that guide you and that underlie your list?

# 2

## REALIGN YOUR PERSONAL GOALS ACCORDING TO WHAT MATTERS TO YOU.

One of the reasons a diagnosis of a serious illness is often a shattering experience is that it means that the big life goals we had previously held no longer fit our changed reality. These big life goals, even those that we were not entirely conscious of, rise to the surface as we realize they are no longer realistic or they no longer seem to be as important as they once were.

The awareness that life goals need to be changed can create intense stress. Putting important goals on hold, or even having to give them up, involves loss. It is not unusual for caregivers to feel sadness, anger and resentment about this loss.

But as a caregiver, you need to identify new goals in order to address the demands of your loved one's illness. Identifying realistic goals that matter now, in relation to your changed reality, can renew your sense of purpose, creating a heightened sense of energy that can motivate and direct you. It can help you marshal your resources to do what needs to be done.

### Here are three steps that can help with “resetting” goals:

- Think about the goals you had before your loved one became ill. They may have to do with goals you had for your family or at work. Some of these goals will no longer matter. Others will still matter, but are no longer realistic. Let go of goals, at least for now, that no longer matter or that are no longer realistic. This will reduce frustration, anger, and anxiety. At the same time, this may make you feel sad and possibly resentful and angry.
- Identify new goals that matter and that are realistic. Many of these will be related directly or indirectly to your role as a caregiver.

- Think about why these new goals matter. Which of your underlying values do they represent? Knowing why they matter will reinforce your sense of purpose and your awareness of meaning in your life.

Initially, it can help to focus on near-term goals over the next days or weeks. These can be very concrete goals, the kinds of things that you'd put on a To-Do list for the day. And, in fact, it is often helpful to make up a daily To-Do list that includes tasks that you are likely to get done that day or the next. Try to make these near-term goals as realistic as possible. If you set yourself up to be successful, you'll feel more capable and in control.

In caregiving, long-term goals are often shared between the caregiver and the person who is ill. If possible, talk together about your shared long-term goals, what it is that you each want for the other and for yourself. These conversations can clarify what matters to your loved one, which is likely to shape your new goals. These conversations can increase intimacy and intensify feelings of affection and love. They can also decrease anxiety for both of you.

# 3

## BENEFIT FINDING AND BENEFIT REMINDING.

Research on coping with stress shows that many people discover that they have benefited from their stressful experiences. Caregivers, for example, talk about how they've gained knowledge and skills that make them much more competent. Some caregivers talk about the increased intimacy that they experience with their loved one that comes from talking openly with one another or from appreciation the patient expresses for the caregiver's efforts. Other

caregivers feel they have gained wisdom or that they have experienced deepened spirituality or religiosity. Some report that the family has become closer.

Take time to reflect about ways in which you've grown, the skills and knowledge you've acquired, deepened spirituality or understandings of the world and your place in it, changes in relationships with your loved one, family members and friends, or other benefits that have come from your caregiving experience. Then remind yourself about these benefits when you are feeling down.

## 4 INFUSE ORDINARY EVENTS WITH MEANING.

In a sense, this strategy is something like the old adages, “take time to smell the roses” or “don't just do something, sit there.” Positive moments occur throughout the day. They can be something as ordinary as not getting stuck in traffic, having a salesperson greet you in a friendly manner, or seeing a beautiful sunset. When such a moment occurs, take advantage of it. Dwell on it, reflect on why it makes you feel good. If you have the opportunity, tell someone about it. These moments give you an emotional time-out from anxiety and worry. They can help reduce your stress and restore you.

You might want to reflect on a day's positive moments just before you go to sleep. This can help quiet distress and create an upbeat mood that can help you fall asleep.

## 5 ALLOW YOURSELF TO LAUGH.

Humor is one of the healthiest and most powerful methods to help provide perspective on life's difficult experiences, and it is frequently shared during periods of crisis.<sup>2</sup> To help find humor during a stressful time, think about what typically can make you laugh and bring it into your day. Don't feel guilty about your laughter — enjoy the moments of levity and know that they will help restore your energy and perspective.

There is a body of research showing that humor and laughter can be very therapeutic and assist in the psychological recovery from crisis.<sup>3</sup> Laughter and humor have been shown to provide relief and even facilitate survival. It may at first feel like a challenge to find humor during a hard time, but take comfort in knowing that if you can not laugh today, you may be able to tomorrow.

Bottom line: Positive moments and positive emotions are a part of the experience of stress. This may sound counterintuitive, but a lot of research supports this observation. Take advantage of these moments. They can help keep you focused on what matters, and sustain you when things are especially difficult. Know what creates positive moments for you, and use some of the strategies described above or others that work for you so that you can make the most of these often fleeting, but very important, moments.

<sup>1</sup> Folkman S. & Moskowitz, J. Stress, positive emotion, and coping. *Current Directions in Psychological Science*, 9,115-118, 2000.

<sup>2-3</sup> Sultanoff S. Levity defies gravity: using humor in crisis situations. *Therapeutic Humor*, 9 (3): 1-2, 1995.