



INSIDER INFORMATION FOR CAREGIVERS ONLY

A summary of material from
Search for Light : Ten Crucial Lessons for Caregivers

UNDERSTANDING THE BASIC CONCEPTS

Lesson One: Finding the Blessings

If you are caring for someone who is seriously ill or injured, you probably feel as if you are in a time of darkness. Your first lesson is to know that giving and receiving love in gestures of kindness and caring provide light in your darkness. Gifts of seemingly small pleasures like a bouquet of flowers, time together in talking and really listening, or a shared special meal are blessings. Through this kind of giving and receiving love, you both can find larger insights about yourselves and your relationship, and ultimately the transcendent meaning of life.

Lesson Two: The Emotional Impact

Your second lesson is to know that the emotional impact of the illness or injury of your loved one is as significant as the physical condition itself. That significance affects you, the caregiver, as well as your patient. Dr. Elisabeth Kubler-Ross, a psychiatrist, in her landmark study of dying patients, outlined a five-stage emotional process that they experienced. Denial, anger, bargaining, depression, and finally acceptance are now seen to occur in all “deaths” in our lives—divorce, job loss, even a move to a new home. Those same reactions are part of the emotional impact that the patient, and you, the caregiver will be experiencing.

Lesson Three: The Connection of Mind, Body and Spirit

In the overwhelmingly physical process of your patient’s medical journey, it is easy to forget the third lesson—that we are all whole creatures of intellect and soul, as well as body. One of your tasks as caregiver will be to help your loved one stay connected to mind and spirit while there is so much focus on the body. This is what is described as a holistic, integrative or complementary approach to the medical process. To accomplish this balance, you and your loved one need to be open to practices such as prayer, meditation, relaxation techniques like bio-feedback, therapies such as acupuncture and a daily dose of laughter.

PUTTING THE BASICS TO WORK

Lesson Four: The Diagnosis

The diagnosis of a serious illness or occurrence of a serious injury are shocking events, and both you and the patient will be in denial for a time. The fourth lesson is that both the patient and you, as caregiver, need to shift into an active mode in order to meet the new challenge. The goal is to help your loved one become a medical consumer who gathers information and makes choices based on that information, rather than a passive patient who simply follows whatever regimen is presented without questioning it. Second opinions are vital to being a medical consumer, as is gathering as much information from books, periodicals, the Internet, and through networks of patients with similar conditions.

Lesson Five: The Medical Team

The single most important lesson on your patient’s medical journey is to always have one more person, in addition to the patient at a medical appointment. There is too much information, much of it shocking, for one person to absorb by themselves. A second person can take notes, prompt questions, or ask his or her own. The medical team consists of all of the physicians, nurses, therapists, pharmacists and others who are treating your patient. Figure out who’s the team “captain” and make sure that medical person is apprised of all treatment and medication prescribed for your patient. Know who to call with a question or in time of a crisis, and when to expect a call-back.



Lesson Six: The Patient

There are a series of lessons within Lesson Six: 1) No one wants to be the patient. 2) Your patients are not their illness or injury. 3) You can't fix it, you can only support your loved ones. 4) Your loved ones are not in this condition just to make your life difficult. These are all hard to remember in the midst of the arduous process of caregiving. You can support your patient by asking questions about treatment and its side effects, by recognizing the emotional and spiritual impacts in both of you, and by encouraging healthy behaviors.

Lesson Seven: The Patient's Team

The seventh lesson is that patients need a team of their own, starting with you, the caregiver. It is unrealistic to expect one person to provide all the help required by a seriously ill person living at home. Hospitals and care institutions use a team approach, and so should you. Ask for help from family, neighbors, friends, or your faith community. Do you or your patient work for a large corporation that has a wellness program that could help? Ask the medical team for leads to low-cost or no-cost assistance. Don't try to go it alone. Your health could be endangered.

Lesson Eight: Being With the Patient

The lesson here is to set aside your list of all that needs doing in order to just be. Being with patients on their terms, at their speed, honoring their needs is a great gift. Don't impose your needs on theirs, be it at meal time, in watching television, or in emotional or spiritual realms. Ask for help in meeting their needs when you can't. For instance, if you are not a spiritual person, and they want to pray or talk about spiritual concerns, find someone who can do that with them.

Lesson Nine: Emotional/Psychological Support

The medical journey is an emotional and spiritual experience, as well as a physical one. The lesson is that both you and the patient are impacted and need emotional or psychological support. It can be found through support groups, individual therapy or through a variety of activities such as meditation or journaling. Resources for this support can be found through organizations associated with your patient's disease, such as the Heart Association or the Lung Association, through the local VA hospital or clinic, through large churches, temples or mosques, through your employer, or through non-profit groups. The medical team can provide referrals.

Lesson Ten: Self-care for Caregivers

Caregivers frequently develop "caregiver mentality," in which they don't believe that they are worthy of care since the people they are caring for are ill and they, the caregivers, are not. The tenth, and most important lesson is that caregivers need to have as much compassion for themselves as for the people for whom they are caring. They need to take care of themselves in order to remain strong for their loved ones. This means asking for help, taking time off of caregiving, and even creating a small support team for themselves.