

Caregiver Things to Consider

Medical needs and understanding

- Knowledge and understanding. Some things seem clear on the surface, but then you realize that you understood them (from the doctor, from reading, from viewing, from friends) only superficially.
 - Take the time—and expect the doctor to take their time—to explain and describe and interpret information you are being given or heard elsewhere until it is so crystal clear to you that you will not forget it and will be able to make decisions based on it.
 - Read as much as possible on the topic. The CCC will give you a starting place for reading about most cancers. Realize that there is a lot of misinformation out there. Check one source with another of a very different nature; if they say the same thing, you can probably trust it. To be certain, ask your doctor.
- Medications
 - Be aware of the purpose of all medications, what the amounts taken mean, what taking more or less of each medication will do, what the side-effects are, and what cross-effects (mixing of medications) might be
 - Make sure you and the patient have an easy-access list to all medications and amounts because ERs, doctor office staffs, emergency medical personnel (fire departments, ambulances, etc.) will need a list and, in some cases, valuable time can be lost if a list is not readymade, such as in note on a cell phone (better than paper, but good to have both accessible)
- Information obtaining and sharing
- Interpreting and intervening/brain fog
- Emotional experiences of self and patient
 - Caregivers typically experience anger, fatigue, insecurity, depression, and a host of other emotions, some of them likely to be unusual for that particular individual. While time is limited while caring for a cancer patient near the end of life (denial that life is ending is also a typical emotion), it is important to understand and manage these emotions. Not doing so generally results in a stronger sense of grief, as well as regret, remorse, and self-recrimination that continue for a very long time after the patient dies.
 - If at all possible, get help from a professional. A psychologist who works with grief and end-of-life stresses has seen before what you are experiencing now and is distanced enough to provide perspective that you cannot see.

- Spiritual guidance, whether or not you have strong faith or any faith at all, can be as helpful as psychological counseling. Try a priest or a spiritual director or even both. They are not new to the experience of dying and navigating the waters approaching death and can often provide a surprising sense of calm and peace.
 - Remember that the patient is experiencing a host of unusual emotions, too. While some of those emotions may be in sync with yours, others will be very different: fear (of death, of falling, of being left out, of the results of not being in control of one's own body or life), vulnerability, processing the significance of existential, sense of isolation and loneliness even when surrounded by people (who else understands?), regrets about life decisions and incomplete bucket lists, and more.
- Self-care and self-awareness
 - Perhaps the most important part of self-care is adequate sleep, and it will generally be the most difficult component of self-care to get. Inadequate sleep leads to grumpiness, temper flares, resentment, stress, involuntary inattention (you could give the wrong medication or, as I did once, fall asleep at the wheel of the car), intensive desire for sleep that saps energy, and more unpleasantness.
 - Check your blood pressure routinely; the stress level of caregiving for a Stage 4 patient can be nearly debilitating. If your BP stays elevated even with medication, your doctor may want to increase the amount you receive. (It happened to me, and I thought I was nearly impervious to stress because of having held many highly stressful jobs without negative impact on my health. Caring for a Stage 4 patient is very different.)
- Recrimination and remorse
- Relationships of all sorts
- Dealing with the community on behalf of the patient
 - Receiving advice
 - Offers of help.
- Advocacy
 - It sometimes falls to a caregiver to enforce a patient's Advance Health Directive wishes.
 - It sometimes falls to a caregiver to obtain information about the range of treatments possible and to question or promote one or another kind of treatment.

THIS LIST IS INCOMPLETE AND WILL CONTINUE TO BE FLESHED OUT AS WELL AS LINKED TO SOURCES, RESOURCES, AND CANCER DIARY ENTRIES. CHECK BACK PERIODICALLY IF YOU NEED/WANT MORE OF THIS KIND OF INFORMATION—AND LET US KNOW OF YOUR SPECIFIC NEEDS THAT DO NOT SEEM TO BE COVERED HERE.

In the interim, here is suggested reading:

Snyder, Janice. *Survival of the Caregiver*, an alphabetized dictionary of caregiver topics.

[Available from MSI Press LLC.](#)

[Available excerpts](#)

Advice on Caregiving for Cancer Patients [from Southwest Women's Oncology](#)

Cancer Diary (MSI Press) [blog posts on caregiving](#)

[Family Caregiving](#) information, support, advice from AARP

There are hundreds of blogs on caregiving in general. Some will be right for caregivers of cancer patients. Scott Grant, a certified senior advisor, has combed through 400+ such sites and put together a list of what he considers the [37 best caregiving blogs](#).