Tips for Caregiving

This section has been reviewed and approved by the Cancer.Net Editorial Board [1], November / 2012

Listen to the Cancer.Net Podcast: Tips on Caregiving [2], adapted from this content.

Key Messages:

- Caregiving often involves different types of support and tasks, which can be overwhelming.
- There are several ways to help manage all the duties of a caregiver to help you provide effective care.

Suggestions for being an effective caregiver

The responsibilities of caring for a person with cancer may seem complex and overwhelming at first. Depending on the person's needs, you may provide emotional support; practical assistance, such as help with medical care, financial issues, or insurance issues; or serve as the communicator between the patient and the health care team. The following tips are designed to help you become a successful caregiver:

Remember that caregiving is a team effort [3]. A caregiver is a member of an important team that includes family members, friends, other volunteers, and the health care team. Each member of the team brings different skills and strengths to the group and is working towards a common goal?providing effective care. If you are the primary or lead caregiver, help each team member express concerns, opinions, and emotions, and make sure that the person with cancer has a central role in all discussions and decisions, if possible. It is very important for the person with cancer to have a sense of control and a way to be as proactive as possible. For example, Cancer*Care* provides a special website for caregivers called My Cancer Circle [4] to help caregivers organize the family and friends who want to help the patient or the primary caregiver. Find other online communities for support [5].

Create a list of tasks. Caregiving, like any responsibility, is made up of individual tasks of varying importance. Make a list of all of your caregiving tasks and use it to decide how to divide the tasks between friends, family, hired professionals, and community organization volunteers.

Be proactive. Being proactive means taking charge and planning as much as possible to prevent last-minute emergencies. This can also help provide a sense of control and order. Create schedules that list which relative, friend, or other volunteer is available when and for what tasks. Make sure that all of the caregivers involved have some time to be away without feeling guilty or concerned [6]. Long-distance caregiving takes even more planning. Find out more about how to be an effective long-distance caregiver [7].

Be a problem solver. To be a good problem solver, identify problems, find out what needs to be done, and follow through. Most importantly, do not be afraid to seek advice and help from others. Look for creative solutions that work for your situation.

Try to stay positive. Sometimes it?s easier said than done, but having a positive attitude can help set the tone for everything you do. You may not have control of what happens to you, but you can change how you react. Turn to members of the caregiving team, relatives, friends, religious or spiritual advisors, counselors [8], and health care professionals to help you cope.

Know yourself. Recognize your own strengths and limitations as a caregiver. This allows you to set boundaries and know when to ask for help. Setting limits can be beneficial to both the caregiver and the person receiving care; the person with cancer can exercise some independence, while the caregiver gets a needed break. Compassionate caregivers must recognize when they need a break so they don?t become overwhelmed or burned out. Read more about how caregivers can take care of themselves [9].

Consider professional and volunteer services. These services include professional home care, home-delivered meals, and help with everyday activities. Some community agencies have volunteers who can help with transportation or advocate for health insurance or other benefits. A local hospital or community social worker [10] is a great source for referrals to programs in your community. Learn more about different caregiving options [11].

Caring for the emotional well-being of the person with cancer

When caring for a person with cancer, it?s important to help them maintain a sense of control, as a person with cancer may feel that the diagnosis has limited their control over their life. Respecting a person?s independence can be as simple as asking them if you can help them with a specific task or decision instead of doing it on your own.

Communicate. One of the caregiver's most important jobs is to communicate openly with the person who has cancer. Choose a time that is convenient for both of you to talk. Provide assurance that he or she will be a central part of all discussions and decisions. Be open to the person?s feelings and opinions and allow enough time to fully explain your feelings.

Accept the limitations of a person who is seriously ill. For example, a person who just received chemotherapy may not be able to taste a meal you worked hard to prepare, or a person who is on pain medication may not notice all of the small things you do. Also, be aware that caregiving tasks may change as the person?s health changes.

Include the person with cancer in activities that provide meaning or pleasure. Even if the person with cancer is no longer able to actively participate in activities he or she enjoys, look for other ways to encourage involvement. It is important to help the person stay connected to the world beyond the cancer and to maintain a sense of normalcy.

Participating in medical and physical care

Gather information about the patient?s diagnosis, treatment, and prognosis (the chance of recovery). As a caregiver, learn more about cancer, including the patient?s type of cancer [12]. Many patient advocacy groups [13] also can provide information related to specific cancers. Ask the doctor about other reliable resources. In addition, you may want to keep a medical journal, which can include the patient?s medical appointments, test results, medications and dosages, symptoms and side effects, new questions between appointments, and names and numbers for resources. Find out more about managing a patient?s care [14].

Be an advocate. Take an active role in the patient's medical care. If possible, go with him or her to all medical appointments. It is helpful to write down questions for the doctor beforehand and to write down answers. In addition, give the doctor any new information that helps him or her make informed decisions. Learn more about communicating with the doctor [15].

Learn how to provide proper physical care. If a person requires physical care?such as bathing, dressing, feeding, using the toilet, and grooming?consider talking with a health care professional, or watching health care videos, or reading manuals or books that explain how to do these tasks. You may also want to hire professional help for these tasks.

Addressing legal and financial issues

Ask about being assigned an insurance case manager. Many insurance companies will assign a representative to help manage insurance concerns for a person with a serious illness. This representative can be a resource for determining which benefits are covered, deciding whether arrangements can be made to access out-of-plan benefits for medically necessary care, finding available home care, or troubleshooting insurance problems. Learn more about health insurance [16].

Determine financial status. Providing care for a person who is seriously ill can be financially challenging. For services that cannot be provided by family members?such as medical, pharmaceutical, or therapeutic services?determine who will perform these services and how they will be paid. Knowing the financial status of the patient can help guide future health care choices. Some community organizations may provide financial assistance for caregiving-related and treatment issues [17].

Have legal documents in place. Legal documents called advance directives [18] are an effective, legally binding way to communicate a patient's wishes. More importantly, a health care proxy (a person who can legally make health care decisions on another person?s behalf) can be designated to speak for the patient when he or she is unable to do so. Identifying a health care proxy is an important decision that should be made at an early stage and communicated to the professionals involved in care. Other documents, such as a durable power of attorney for health care and a living will, may also be needed.

More Information

Caregiving [19]

Caring for the Whole Patient [20]

Cancer Self-Advocacy [21]

Managing the Cost of Cancer Care [22]

Links:
[1] http://www.cancer.net/about-us
[2] http://www.cancer.net/patient/Multimedia/Podcasts/Files/Tips_on_Caregiving.mp3
[3] http://www.cancer.net/node/25032
[4] http://mycancercircle.lotsahelpinghands.com/caregiving/home/

[5] http://www.cancer.net/node/24634
[6] http://www.cancer.net/node/24491
[7] http://www.cancer.net/node/25234
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