healthsmart

Caregiving at Home for the Elderly, Chronically III or Disabled

Are you caring for a family member or friend who is chronically ill, disabled or elderly? If so, you're not alone. According to the National Family Caregivers Association, 50 million Americans face the enormous financial, personal and health demands of caring for someone other than themselves. This *HealthSmart!* offers resources to help guide you through successful caregiving for yourself and your loved one.

Before home care begins

If your loved one is hospitalized, gain as much information as possible from doctors, nurses, social workers and therapists prior to discharge so you can develop a care plan and strategies for effective home caregiving. Before your loved one leaves the hospital, ask your health care team the following questions:

- How long will the illness or injury last?
- How will the person's condition improve or worsen?
- Will the person fully recover from his or her condition or illness?
- Is physical, occupational or speech therapy necessary for recovery, and who will provide the service? If necessary, will therapists train caregivers how to move/

transfer the patient until home health or the therapist arrives?

- How will any medical emergencies that might occur be handled?
- What types of care will the person require and what is the best way to provide them?
- Will any special equipment be needed to deliver oxygen, monitor health indicators or provide intravenous feeding? Find out who will train you to operate it and what type of maintenance might be required. Be sure to have a number to call if equipment fails.
- Ask your doctor or pharmacist about required medications. Find out when and how long the medication should be taken, what the possible side effects are and whether interactions may occur with any other medications the patient is taking. Ask what time the next dose of medication needs to be given after discharge.

Setting priorities and goals

In committing to home care, it is important to set priorities and goals with your loved one and to recruit as much support as possible.

 Form a care team that includes health care workers, friends, family, community organizations and volunteers.

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- Create a care plan journal to keep track of new developments or changes in your loved one's needs and track his or her progress.
- Include your loved one in decisions about her care as much as possible.
- Learn as much as you can about your loved one's condition so you can communicate appropriately with the health care team.

Preparing the home

It is important to take precautions when setting up your loved one's environment. Home modifications can be minor or major depending on the nature of the injury or illness. The following are home modifications that may be necessary, but consult with your health care team to determine other special needs.

- Set up a bedside table to keep important items within reach, such as medications, water and a bell to call for assistance.
- Depending on the person's mobility, you may need a bedpan, a handheld urinal or a portable commode chair that contains a removable bedpan.
- Improve lighting and visibility by installing lighted switch plates, using high-wattage lightbulbs in stairways and hazardous areas, installing a voice- or sound-activated adapter to turn on lights, or using motion-sensitive lighting.
- Remove loose rugs around the home and install nonslip surfaces in the bathroom and kitchen.
- Install a shower or tub chair, handrails and grab bars in the shower and next to the toilet. A booster seat for the toilet may also be necessary.
- Converting a ground-floor room into a bedroom may make assisting your loved one easier and offer better access to the restroom and kitchen.
- Replace round doorknobs with lever handles.
- Install an emergency response system.

Resources for caregiving at home

It may become too difficult to care for your loved one by yourself. If you determine that professional in-home assistance is needed, options are available. Home health care services range from skilled nursing assistance to transportation and meal assistance.

Home health agencies

Home health agencies provide a wide range of services, such as registered nurses, nurses aides, physical and occupational therapists, speech therapists, and nutrition counselors. These services may be appropriate if your loved one needs constant medical supervision and/or assistance with wound care, injections, tube feeding or colostomy care. Your doctor, social worker or discharge planner can recommend services for your situation.

Personal care services

Personal care services provide assistance with bathing, food preparation or transportation. Companions, housekeeping and assistance with daily living are provided by various organizations. Home health agencies may be able to provide such assistance; friends, neighbors, local volunteer organizations, church groups or senior citizen centers may also be sources of help. Ask your doctor or social worker for recommendations.

Meal services

Meals on Wheels is a volunteer-based program that provides home delivery of meals. This service is often provided through senior citizen centers, local government agencies, church groups and national associations such as the American Red Cross.

Transportation services

Many community organizations provide transportation services for seniors and the disabled to medical appointments or community locations. Ambulance service may be used as well and is appropriate for people who can't use other transportation methods. Transportation services may be offered through home health agencies, local volunteer organizations, church groups or senior citizen centers.

Adult day care programs

Adult day care includes programs, services and

facilities designed to help physically or mentally impaired adults remain in their homes. These programs provide an alternative to placement in a residential institution and give caregivers a break from having to provide constant attention. Some local governments, community organizations, senior citizen centers or church-related groups provide this service. Your doctor or social worker may recommend an adult day care program in your area.

Drugstores and medical supply companies

These stores carry a wide selection of home care equipment and supplies for purchase or rent. Equipment ranges from hospital beds and wheelchairs to urinals and bedpans. Some providers may deliver and set up the equipment in the home and demonstrate how to use it properly. Talk with your social worker, discharge planner or doctor for recommendations.

Hospice

Hospice services meet the needs of people who are terminally ill. Care can be delivered in the home or hospital. A doctor's authorization is required for hospice care. Talk to your doctor and health care team to see if hospice is right for your loved one.

Geriatric Care Manager

A geriatric care manager specializes in issues relating to elder care and can help families navigate the health care system. A geriatric care manager can help develop a care plan, monitor home help services, and assist with legal and medical issues. To learn more, visit the National Association of Geriatric Care Managers Web site at www.caremanager.org, or ask your doctor for a recommendation.

Elder Care Locator

The Elder Care Locator is a public service financed by the U.S. Administration on Aging to help older adults and their caregivers find community resources. For more information, call 1-800-677-1116 or visit www.eldercare.gov/Eldercare/Public/Home.aspx.

Finding the right home health care provider and services

Choosing a home health care provider requires research. No matter what type of care your loved

one needs, ask any potential provider the following questions and be sure to interview several providers before committing to one:

- Is the provider licensed, bonded and registered with the appropriate regulatory agencies in your state? Check with your state's department of public health or department of social services.
- Is the provider accredited by an appropriate agency? Accrediting agencies include the Accreditation Commission for Home Care, the Community Health Accreditation Program, The Joint Commission (accredits health care organizations such as hospitals and other medical facilities), the National Committee for Quality Assurance, and the National HomeCaring Council Division of the Foundation for Hospice and Homecare.
- How long has the provider been in operation?
- Ask friends, neighbors and your health care team about the provider's reputation in the community.
- What are the fees for the services you require? Will your health insurance cover these fees? What are the billing procedures?
- Is the provider Medicare-certified?
- How does the provider hire, screen and train staff members? Are criminal background checks and drug screenings performed?
- Does the agency provide the required equipment?
- Do staff members train family members to perform caregiving duties?
- Are staff members available on weekends and holidays?
- How does the provider handle emergencies? Does it have 24-hour emergency assistance?
- How does the provider handle questions and complaints from customers?

While interviewing the provider, outline and explain upfront all the tasks you would like the provider to perform. Make sure both parties have a clear understanding of what is required.

Paying for home health care

Medicare, Medicaid, state-funded health care, private insurance plans, the Department of Veterans Affairs, Workers' Compensation and managed care plans are a few providers that offer assistance for home care services. Be sure to talk with your doctor, social worker, hospital discharge planner and insurance agent to determine the benefits for which your loved one qualifies.

Medicare

If your loved one is 65 or older and needs skilled nursing or rehabilitation care at home, Medicare may cover it. Minimum qualifications in addition to physician orders for care are typically required. Medicare only covers home care provided by a Medicare-certified home health care agency. To find out more, visit Medicare's Web site at www. medicarebenefits.com or call 1-800-633-4227.

Medicaid

Medicaid is a state program that provides health insurance for low-income or disabled residents. Covered services may include part-time skilled nursing care, home health aides, medications, and medical equipment and supplies. Eligibility varies from state to state, so please check with your local Medicaid office to find out which services are covered for you. To find out more, visit the Center for Medicare and Medicaid's Web site at www.cms.hhs.gov or call 1-800-633-4227.

Department of Veterans Affairs

The Department of Veterans Affairs covers the cost of home health care for eligible veterans who are at least 50 percent disabled, if the disability is service-related. To be covered, home care must be authorized by a doctor and provided through a VA hospital. Contact your closest Department of Veterans Affairs Regional Office for additional information about benefits and eligibility. Call 1-800-827-1000 or visit their Web site at www.va.gov.

Long-term care insurance

Long-term care insurance is usually available only to people who are in generally good health at the time they purchase the policy. Coverage varies considerably from one policy to another. Check your policy or talk to your insurance representative to determine the benefits for which you qualify.

Workers' Compensation

Workers' Compensation may cover the cost of home care services needed as a result of a work-related injury or illness and also covers the cost of rehabilitation. If your loved one has a work-related injury or illness, contact his or her employer's personnel office or human resources department for information on eligibility for benefits and how to file a claim.

Community and volunteer organizations

Community organizations and local service clubs, such as Rotary, Elks and Kiwanis often offer assistance to those in need. Other helpful resources include national volunteer health organizations such as the American Cancer Society, the Easter Seal Society, the United Way and the Alzheimer's Association. For more information about services available, contact your local chapter.

Preparing for doctor and hospital visits

As a caregiver, you will most likely be responsible for communicating with the health care team. Being prepared for your visit will help you, the patient and the health care team experience the best possible outcomes.

- Prior to a hospital visit, be sure to have the patient's medical records, a list of the patient's allergies, current medications and dosages, and names and phone numbers of the health care team with you.
- Make a list of your concerns and specific questions prior to talking with the health care team.
- Be clear and concise. State clearly and briefly what your question or concern is, what you need and what you expect.
- When you hear something you do not understand, ask for clarification.
- Write down as much as you can when speaking with the health care team.
- Ask the doctor or other care team members to put in writing any instructions, explanations, resources, medications or information that is important to your loved one's care.

Legal issues

Medical privacy laws place great protection on patient information. Having the proper legal documents will help you advocate for your loved one. Examples of the following legal documents may be obtained through your hospital, social worker, attorney or your state attorney general's office. Signed copies should be given to your family doctor and placed in the hospital chart each time your loved one is hospitalized.

Durable power of attorney for health care

Also known as a health care agent or proxy, this person can be appointed to make decisions about the person's medical care if they are unable to speak for themselves.

Advance medical directive

An advance directive informs doctors and family members what kind of care your loved one wishes to receive in the event that he or she can no longer make their own medical decisions.

Living will

A living will is a written document signed by a competent adult that contains the person's advance directive about medical care in the event that he/she becomes incompetent to make such a decision. Unlike a durable power of attorney for health care, a living will speaks for the person who signed.

Laws regarding living wills and advance directives vary by state. The National Hospice and Palliative Care Organization provides a link for caregivers to download state-specific advance directives. For more information: www.nho.org.

Care for the caregiver

Caregiving can place great strain on the caregiver. Remember that caring for yourself is just as important as caring for your loved one.

 Support groups allow caregivers to come together and discuss information and resources, share experiences, and receive emotional support from others who are experiencing the same thing. Support groups are available in a variety of forms, including online discussion groups and personal meeting groups. Many associations have support groups that deal with specific illnesses. The UK HealthCare Web site provides links to a wide variety of support groups available in or near Lexington. To view this list, visit **ukhealthcare.edu.org/patients/listofgroups**.

- If you are working, be sure to talk with your employer to let them know about your new responsibilities. They may be able to work with you for necessary paid medical leave. Consult your human resources department for specific policies and available resources.
- Don't be afraid to ask for help. It's natural for you to need assistance with and breaks from your caregiving responsibilities.

Resources

Family Caregiver Alliance

Provides a wide array of services and publications based on caregiver needs.

1-800-445-8106

www.caregiver.org

National Family Caregivers Association

Provides information, education and support for caregivers.

1-800-896-3650

www.nfcacares.org

National Alliance for Caregiving

Offers brochures, education and research for family caregivers and organizations.

www.caregiving.org

Family Caregiving 101

A Web site offering caregivers education, tips and resources for family caregivers. Sponsored by the National Family Caregivers Association and National Alliance for Caregiving.

www.familycaregiving101.org

American Cancer Society

Offers information, support and community resources for cancer issues.

1-800-227-2345

www.cancer.org

Alzheimer's Association

Provides local offices, 24-hour support line and resources for finding home care.

1-800-272-3900

www.alz.org

American Red Cross

National volunteer association that provides education and support services.

1-800-733-2767

www.redcross.org

The United Way

Local United Way chapters assist with funding assistance, education and support. www.liveunited.org

1-703-836-7112.

UK HealthCare

Offers a variety of resources and education about specific illnesses and injuries along with a comprehensive list of support groups.

859-257-1000 or 1-800-333-8874 (toll free) ukhealthcare.uky.edu

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