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CAREGIVING FROM A DISTANCE

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While any caregiving situation can be stressful, long-distance caregiving is even more difficult. If you live more than a few hours away from your loved one, it's never too early to develop an action plan.

1) Begin a continual process of assessment.
2) Take a "family inventory."
3) Assess yourself.
4) Work to support independence.
5) Build support systems.
6) Consider residential care.
7) Investigate payment methods.

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1) Begin a continual process of assessment.

The **Needs Assessment Worksheet** (available at **www.CaregiversLibrary.org**) can help you make an initial evaluation, but as a long-distance caregiver, your primary responsibility will be to constantly monitor changes in your loved one's condition and arrange for necessary care.

- Call at least once a week. While a phone call can't tell you everything, it will give you a general idea about how your loved one is doing.

- Visit as often as possible. Even a quick look around can tell you a lot.

- Develop a support system in your loved one's community. Talk to friends and neighbors, or make sure someone stops by the house periodically.

- Encourage your loved one to allow his or her doctor to share medical information with you.

- Consider hiring a geriatric care manager based in your loved one's area. These professionals can assess the situation and make arrangements for necessary care.

2) Take a "family inventory."

It's probably best to arrange a family meeting so that your loved one can communicate his or her wishes and the entire family can develop of plan of care. Do this in person, if possible.

Here's a list of items to be covered:

- **Paperwork**: Make sure both you and another family member know where to find important documents in the event of an emergency.

- **Insurance**: Does your loved one have adequate health insurance? Is he or she eligible for Medicare and/or Medicaid?

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- **Financial Planning**: Many people don't like to discuss their personal finances, but try to get an accurate assessment of your loved one's status.

- **Legal Planning**: Stress the importance of wills and estate planning, as well as durable powers of attorney, which allow your loved one to designate a personal "decision-maker."

- **Medical History**: Forms for recording your loved one's personal health history can be found on the National Caregivers Library Web site. In a time of crisis, this knowledge can help doctors prescribe the proper treatment.

- **Housing Options**: If your loved one becomes unable to live independently, would he or she prefer to move in with you or move to a residential care facility? Explore options now.

- **Advance Medical Directives**: These legal documents allow your loved one to make decisions about his or her future medical care.

At some point, you may also need to discuss funeral arrangements. While this is a sensitive and difficult issue, you and other family members should be aware of your loved one's wishes.

- Remember that your loved one has the right to make decisions. You or other family members may not agree, but you need to be supportive.

- Avoid ill-considered promises. Your loved one, for instance, may want you to promise never to put him or her into "a home." But a promise like that can cut you off from necessary avenues of care in the future.

3) Assess yourself.

Can you meet the requirements of a long-distance caregiving role? While helping your loved one plan for the future, it's also a good idea to take stock of your own situation.

- Can you leave work on short notice and for long periods? If an emergency occurs, can you leave immediately?

- Will someone be available to take care of your children if you are suddenly called away?

- Can you afford to be a long-distance caregiver? Aside from the costs involved in paying for care, consider expenses like travel costs and long-distance phone bills.

- Also consider the emotional stress. Long-distance caregivers often feel a great deal of guilt and anxiety due to the fact that they can't be present to take care of their loved one's every need.

Talk about these concerns with other family members who can become involved in the caregiving process. Too often, one member of a family bears the brunt of caregiving responsibilities, even when others would be glad to help.

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4) Work to maintain independence.

Your loved one will probably want to remain independent as long as possible, and there are many services that can help you both achieve this goal. Locate your loved one's local Area Agency on Aging, which can tell you about these and other services in the community.

- **Home Modification**: This doesn't necessarily involve extensive remodeling. Often, a few simple repairs can make the home safer.
- **In-Home Aides** and **Workers**: There are a wide variety of home care workers who offer services ranging from light housekeeping to skilled nursing care.
- **Adult Day Care/Senior Centers**: These facilities provide needed services and the staff can let you know of any changes in your loved one's abilities or behavior.
- **Meal Services**: Many communities offer "Meals on Wheels" programs that deliver food. If such services are unavailable, try talking to local restaurants or grocery stores that may be willing to deliver.
- **Transportation**: Many communities also offer low-cost transportation services to elderly or disabled persons who aren't able to drive.

5) Build a support system.

Connecting with the right people and services is essential to ensuring the best care and comfort for your loved one. Cultivate your own system of friends, neighbors, and family members who can keep you up to date on your loved one's condition. See **Long-Distance Support Systems** at the end of this section.

6) Consider residential care.

If your loved one can no longer live independently, your role as a long-distance caregiver will change. While a professional staff may now be in place to make assessments and provide care, you will need to monitor the situation.

- Talk to your loved one frequently, and make sure that he or she is comfortable and well cared for.
- Develop a relationship with the facility's staff, and get regular updates on your loved one's condition.
- If you suspect that your loved one isn't being properly cared for, don't hesitate to voice your opinion.
- Keep in touch with the local long-term care ombudsman office. This federal program investigates complaints against long-term care facilities, monitors conditions and care, and fights for residents' rights.

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If distance prevents frequent visits, you may not be aware of diminishing faculties or abilities that could result in injury or crisis. If that's the case, you could be caught off guard when an accident occurs.

Here's how to put an emergency plan in place

1) Define roles and responsibilities.
2) Assemble necessary information.
3) Set up a phone tree.
4) Look at travel options.
5) Be aware of short-term solutions.

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1) Define roles and responsibilities.

Everyone in your long-distance support system should clearly understand his or her role. Be wary of assigning several people to cover the same task or of overlapping responsibilities. This may increase tension and stress in a crisis.

As you put your emergency plan into place, don't forget to:

- Take care of your own. If you have children or a pet, can someone else assume responsibilities for them? Will someone look after your home?

- Consider your employment situation. Lend extra support now to fellow employees so they will be more accommodating of your future needs.

2) Assemble the information.

Make sure that you or another family member has access to:

- Insurance policies for healthcare, disability, life, long-term care, home or apartment (fire, theft, liability), and cars

- Account numbers and institutions for savings and checking accounts stocks and bonds, profit sharing and retirement pensions

- Social Security number

- Safe-deposit box and key

- Legal description of real estate property (found on a property tax bill) and other assets or debts

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- Medical records including comprehensive lists of prescriptions, drug allergies, or other harmful reactions to treatment

- Will, living will, health care power of attorney, or other legal documents

3) Set up a phone tree.

Prepare a list of all the names, addresses, and phone numbers of your support system members, and prepare an additional list with other important numbers (doctors, lawyers, etc.). Then, set up a "phone tree." Decide "who calls who" ahead of time, and stress the importance of keeping all family and support system members informed.

- Make sure that members of your support system have a phone number where you can be reached in a crisis.

- Consider a pager, voice mail, or an answering machine you can check from another location. A cellular phone may or may not prove useful depending on your circumstances.

- Keep your loved one aware of this phone tree and explain how it will work. At the very least, this will offer additional reassurance.

4) Look at travel options.

You may be required to travel on short notice, and distance can be a factor. A three-hour drive might be less stressful than even a short flight with layovers or last minute delays. A quick hop on the metro to an outlying suburb might be faster and easier than negotiating city traffic.

- If you know a trip will require air travel, develop a relationship with a reliable travel agent who understands your situation and can make arrangements quickly.

- On the next visit, take note of your travel time and availability. If no one can reach you for a few hours, decide which family member will serve as primary contact while you are in transit.

- Always keep a bag packed. This can save energy, reduce stress, and give you time to deal with more immediate concerns in the event of a crisis.

5) Be aware of short-term solutions.

If an emergency room visit occurs in your absence and your loved one is cleared for discharge before you can get there, the hospital discharge planner can arrange for immediate care needs—cooking, dressing, bandage-changing, and so on—to be met by a home health aide.

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- Some companies provide employees with services or benefits that can help bridge the gap between an emergency and your arrival (see **Long-Distance Support Systems** in this section).

- Respite care can also serve as a short-term solution. This can be arranged through the local Area Agency on Aging.

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LONG- DISTANCE SUPPORT SYSTEMS

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As a long-distance caregiver, it's especially important for you to establish reliable support systems. Family, friends, neighbors, community agencies, and even employers can provide valuable support.

When developing a support system:

1) Recognize that no honest effort is too small.
2) Enlist friends and neighbors.
3) Contact local organizations and resources.
4) Check national resources.
5) Investigate employee assistance benefits.
6) Know your rights.

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1) Recognize that no honest effort is too small.

There are enough tasks related to long-distance caregiving that anyone who wishes to contribute can be significantly involved.

- Family members might be in a position to help with financial or legal matters that can be handled by phone or mail.

- Others can take charge of recognizing special occasions with cards, plants, or by sending your loved one photos and letters.

2) Enlist friends and neighbors.

In many cases, your loved one's friends may be wary of intruding in private family business. Neighbors may be worried about appearing "nosy" and hesitate to tell you about changes in your loved one's condition.

- Don't wait for your loved one's friends or neighbors to approach you. Give them your phone number and encourage them to call.

- Your own friends should also be aware of the situation; they might be able to step in for you if you are called away in an emergency. Approach them beforehand and be specific about what you'll need.

3) Contact local organizations and resources.

- **Adult Day Care** offers activities, and supervision in a group setting.

- **Adult Protective Services** will investigate possible abuse or neglect and provide short-term emergency support services.

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- **The Area Agency on Aging** can help arrange for low-cost care services.
- **Case Managers** can help develop a complete plan of services based on your loved one's needs.
- **Health Screening** and general assessment are freely available for persons over 60 years of age in some communities.
- **Hospice**, **Respite Care**, and **Personal Care Services** are also available.
- If your loved one has or had a favorite church, consult the clergy for referrals.

4) Check national resources.

There are any number of national organizations or foundations, like the Alzheimer's Association or the National Kidney Foundation, which can offer advice for meeting disease-specific health needs. The Red Cross, March of Dimes, and the American Heart and Lung Associations are additional possibilities. The resources located at **www.CaregiversLibrary.org** can help you.

5) Investigate employee benefit programs.

Many companies have shored up employee retention and productivity by making life easier for their caregiving employees. Ask your human resources representatives what services are currently offered, and inform them of any immediate or future concerns.

- Some companies provide subsidies for visiting nurses and emergency care.
- In dependent care programs, your employer sets aside a certain amount from your paycheck and places it in a non-taxable assistance fund.
- Some companies make allowances for time off with flex scheduling and leaves of absence

6) Know your rights.

Under the Federal Family and Medical Leave Act (FMLA), a covered employer must grant an eligible employee up to 12 workweeks of unpaid leave in a 12-month period to care for an immediate family member (spouse, child, or parent—but not an "in-law") with a serious health condition.

The FMLA law permits you to use—or your employer to require you to use— paid leave, such as vacation or sick leave, for some or all of the leave period.

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