



District of
Columbia
Caregivers'
Institute

Knowing What You Need and Finding Help in the District of Columbia

Part of the District of Columbia Caregivers' Institute Booklet Series
Caregiving: Practical Help, Practical Solutions



Part of the Senior Service Network
Supported by the D.C. Office on Aging

GOVERNMENT OF THE DISTRICT OF COLUMBIA

OFFICE ON AGING

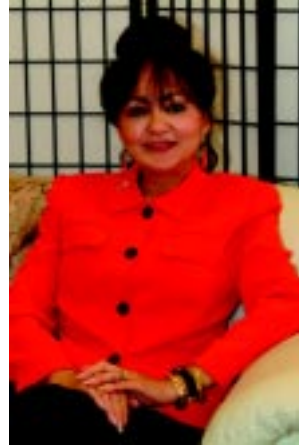


Dear Reader:

I am happy to present the first booklet in the District of Columbia Caregivers' Institute Booklet Series, *Practical Help, Practical Solutions*.

Most older persons are cared for by informal caregivers—those people who provide unpaid help to older persons, aged 60 and over, who need assistance with activities of daily living. You are a caregiver if you provide care for your daughter who has suffered a stroke, your husband who has Alzheimer's disease, a father who is crippled with arthritis, or your friend who has Parkinson's disease. You are a caregiver if you are a senior who provides primary care for a child less than 19 years of age. You are a caregiver if you are a family member, a friend, a neighbor, or a volunteer. You are a caregiver if you stay with the person 24 hours a day, 7 days a week, or only drop by en route to and from work.

The District of Columbia Caregivers' Institute is a 5-Star organization devoted to assisting caregivers by easing their caregiver burdens, thereby keeping their older relative or friend out of a nursing home. With support, training, and assistance, many caregivers are better able to care for themselves as well as their care receiver. If you are a caregiver, the Institute was designed to serve you.



We hope that you find some practical help and practical solutions in this booklet to make your caregiving burden a little easier.

Sincerely,

A handwritten signature in black ink that reads "E. Veronica Pace". The signature is fluid and cursive, written in a professional style.

E. Veronica Pace, *Executive Director*

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— *by Angela Heath* —

The District of Columbia Caregivers' Institute Overview

The District of Columbia Caregivers' Institute is a resource funded by the District of Columbia Office on Aging. The purpose of the “5-Star” Caregivers' Institute is to support unpaid caregivers residing in the District of Columbia who have primary responsibility for older, vulnerable DC residents. The District of Columbia Caregivers' Institute strives to be a one-stop, centralized resource to help caregivers make critical decisions, develop and implement a Caregiver Support Plan, advocate for themselves and the older person, and participate in activities designed for personal rejuvenation.

The “5 Stars” of the Institute refer to its five major activities, or branches, and its 5-Star philosophy. The five branches of the Institute include (1) Services, (2) Training and Technical Assistance, (3) Communication, (4) Research, and (5) Resource Acquisition. A “5-Star philosophy” drives the development of unique supports that respond to unique, individual needs. This philosophy was developed after extensive research and includes the guiding principles of (1) Flexibility, (2) Self-determination, (3) Coordination of Support Systems, (4) Empowerment, and (5) Self-care. In April 2002, the Caregivers' Institute began recruiting caregivers to participate in the Institute.

In June 2002, the Caregivers' Institute started its pilot test with 25 caregivers. These services included in-home assessments, establishment of Caregiver Support Plans, educational seminars, and reimbursement for approved caregiver-related expenses through Caregiver Flex Accounts. The Caregiver Support Plan concept allows program participants to have flexibility and choice in selecting the types of support that best meet their particular needs. Through the Caregiver Flex Account, participants receive reimbursement for respite care and supplemental services while selecting providers, including family and friends, and determining when and how the services will be delivered. In February



2003, the Institute rolls doubled to 50, and telephone support groups and case management services were made available to participants.

For further information or to become a participant in the District of Columbia Caregivers' Institute, call 202/464-1513.

Introduction

When my wife had her stroke, I didn't know what to do. She had always taken care of me; now, it was time for me to take care of her. Luckily, her sister told me to ask the hospital social worker about getting a helper to come into the home for four hours a day. It helps a lot but I still need more help. I told my wife that I would never put her in a nursing home. I really want to keep that promise, but I am getting sick myself—the doctor said it's my blood pressure, stress and exhaustion. I just don't know how much longer I can continue doing everything.

— John, 68 year-old caregiver

Although your caregiving situation might be quite different from John's, you probably share some issues of concern with him. You might have some help but think you need more. You may be determined not to move your older loved one into a nursing facility although you may be feeling the stress of providing care. Like John and many other caregivers across this country, you may not know where to turn for help and find accessing services to be time consuming, frustrating, and confusing.

The good news is that help is available for District of Columbia caregivers. This publication is one in a series, *Caregiving: Practical Help, Practical Solutions*, published by the District of Columbia Caregivers' Institute. This booklet is designed to provide information and tips so that you can get the help you need whether it is from family and friends or from services in the community. To do so, we will cover the following topics:

- Knowing your needs and the needs of the elder you help
- Asking others for help
- Getting the services you need
- Making sure services work for you

Knowing Your Needs and the Needs of the Elder You Help

When an older person needs assistance, it can include every aspect of his or her life. Caregiving can involve dealing with the elder's emotions and emotional needs, finances, physical limitations, mobility problems, medical conditions, dietary restrictions, personal care needs, housing adaptations, and spiritual needs. No wonder many caregivers find it difficult to know exactly what is needed and how best to meet those needs. In addition, you have your own needs and wants that also deserve your attention. While giving care to an elder, you also may be worried about your own health; how to balance caregiving and work; your relationship with your spouse, children, and other family members; the financial consequences of caregiving; and the rollercoaster ride of emotions that most caregivers experience. You may feel squeezed by the many demands you face and may be unable to find time to relax, socialize, and pursue your own interests.

The chart beginning on page 9 can help you. Periodically, use this chart to identify your needs as well as those of the senior you are helping. Simply place an "x" next to the statements that apply to you; then the chart will tell you about various options for addressing those concerns and summarize how services can benefit you. After you have completed this checklist, you will be better prepared to talk more specifically with family, friends, and service providers about your needs.

| Place an “x” here for your concerns | Statement of concern | Services available in the District of Columbia to help you | How the service can help you |
|--|--|---|---|
| | I don't know where to start. | Information and Referral | These services help you identify where you can get help. |
| | I need someone to teach me more about how to manage my caregiving responsibilities. | Education and Training | You can learn information to make caregiving easier. |
| | I need a break sometimes to take care of myself. | Respite | You must take a break in order to refresh yourself. |
| | My situation is so complex; I really need someone to help me make sense of everything. | Case Management | When an elder has several needs, case managers help you respond to them. |
| | Sometimes, caregiving makes me feel all alone. | Support Group | You can learn from others who are dealing with similar situations. |
| | The elder cannot be left alone during the day. | Adult Daycare or In-home Assistance | You will feel comfortable knowing the elder is supervised during the day. |
| | I am beginning to feel the physical effects of caregiving. | Physical Check Up, In-home Assistance or Adaptive Equipment | Take care of your own health and get help in the home. |

| Place an “x” here for your concerns | Statement of concern | Services available in the District of Columbia to help you | How the service can help you |
|--|--|---|---|
| | I can't afford to take care of the older person without help. | Financial Assistance, Caregiver Flex Account or Senior Discount Programs | Many programs can help you decrease the financial burden of caregiving. |
| | I wish other family members would help me more often. | Family Counseling or Case Management | Counselors can help your family develop a family plan of care. |
| | I could use some help with the elder's household chores. | In-home Assistance | You will have more time for other things. |
| | I am unable to keep up with the heavy chores at the elder's home. | Spring Cleaning | You will have more time for other things. |
| | I have some legal issues to handle for an older person. | Legal Counsel for the Elderly | You can make good decisions with legal advice. |
| | I have some health insurance questions pertaining to my senior relative or friend. | Health Insurance Counseling Program | You can better understand health insurance and your insurance rights. |
| | I need to find transportation for my older relative or friend. | Washington Elderly Handicapped Transportation Services and other senior transportation services | You will not always have to transport the elder. |

| Place an “x” here for your concerns | Statement of concern | Services available in the District of Columbia to help you | How the service can help you |
|--|---|--|---|
| | I want to start exploring a place for my older relative or friend to move that would provide some help. | Community Residential Facilities, Senior Housing, Assisted Living, or Nursing Homes | You can find supportive housing enabling the elder to live as independently as possible. |
| | My older relative or friend needs help with personal care such as bathing and dressing. | Home Health, Personal Care Attendant, In-home Assistance | Someone else can help you with daily personal needs of the elder. |
| | I need to know that my older friend or relative is OK when I am not there. | Personal Emergency Response System, Friendly Visitors, Senior Companion, Respite Aide, Telephone Reassurance | The elder will have a way to signal for help when something is wrong. |
| | I am concerned that my elderly relative or friend might have Alzheimer’s disease. | Geriatric Evaluation, Alzheimer’s Information, Personal Physician | A physician will evaluate and verify if an elder has Alzheimer’s disease and recommend treatment. |
| | My relative or friend is lonely and needs something to do. | Senior Centers, Wellness Centers, Nutrition Sites, Friendly Visitors, Senior Companions, Adult Daycare | The elder can socialize with his/her peers. |
| | My older relative or friend has 24-hour medical needs. | Private Nurse, Nursing Home Care, Assisted Living | The elder can receive the medical care needed. |

IMPORTANT NOTE: Many of the services listed on the preceding chart may only be available on a limited basis. Similarly, there may be waiting lists for services, and some may require the elder to meet certain eligibility criteria. Fees for these services vary. For further information on the services for caregivers in the District of Columbia, contact the District of Columbia Caregivers' Institute at 202/464-1513. To find services and resources for elders in the District of Columbia, contact the lead agency that covers the community where the elder lives. Lead agencies are funded by the District of Columbia Office on Aging and are listed on page 15.

Asking Others for Help

Once you know more precisely what you need, then you can find persons and organizations to help you meet those needs. Typically, there are people available to help you. However, you must first identify those persons, and second, ask them for help. Think broadly. Neighbors, life-long family friends, club members, local faith organizations, and even your family members are all potential helpers. Make a list of everyone you can think of and start contacting them.

Many caregivers refuse to ask for help, feeling that others, especially family, should know that they need assistance. Why should you ask for help? Ask because you need and deserve a hand. Care-giving can be very difficult and exhausting, both emotionally and physically. It is necessary for you to take a break and take advantage of what others can do for you and for the older person.

Another reason to ask family and friends to help you is because elders prefer to have people they know take care of them. Sometimes, they feel uncomfortable having "strangers" in their home helping them with very personal matters. You too may feel more comfortable having someone you are familiar with giving care to your older loved one. However, keep in mind there may be times when you may need to depend on someone you do not know to help with caregiving.

Asking for help means dropping your pride and forgetting what happened in the past. It can mean expecting that others want to help despite their insensitivity in the past. Do not drop hints about what would be helpful to you; ask for what you need. In asking, be specific. Below are a few examples of being specific in your requests:

- **Don't say**, "I am exhausted. Can you take Mom sometime so I can get some rest?"
- **Say instead**, "On Saturday afternoon, can you sit with Mom from 1:00 p.m. until about 7:00 p.m.?"
- **Don't say**, "It would be nice if you could help me with Dad."
- **Say instead**, "Can you help me by taking Dad to the doctor on Tuesday at 11:00 a.m.?"
- **Don't say**, "Grandma is having trouble cooking."
- **Say instead**, "Let's take turns cooking dinner for Grandma. How about you take one week and I'll take the next?"

By being specific with your requests, you make it easy for others to help you. Many times friends and relatives will say, "Call me if you need something." Such a vague offer may cause some caregivers to think that the offer is insincere, and they may fail to realize the other person's perspective. Often, family and friends may not know what to offer. They may feel that you will reject their suggestion or that you don't want them to help. The best way to find out if someone really wants to help you is to ask.

Keep in mind that just because people are unable to meet your specific request at one time does not mean they are unwilling to help. They just may have a conflict at that time or may feel they cannot make that specific commitment for a variety of reasons. And that is acceptable. Just remember, they may still be willing to help with other tasks. So be prepared to share with them a couple of other ways they can help and allow them to give what is comfortable and convenient for them. Keep a positive attitude; know that family and friends want to help you.

But what if they simply refuse to help you? Take the refusal in stride; at least now you know for certain whom you cannot count on in the future. Simply cross their names off your list of potential helpers and go on to the next potential helper. Don't waste a lot of time feeling depressed because someone refuses to help you. That is his or her issue; you have work to accomplish!

When you do ask for help, you must be prepared to accept assistance. This acceptance includes realizing that others will not do things the way you do them. You must respect the fact that a different approach to caregiving is fine as long as the older person is not hurt or harmed. Accepting help means you have to let go of control and focus on something else. **Very important:** remember to show your gratitude. A hearty “thank you” or maybe a card to express your gratitude is a welcomed touch. Kindness works every time. When people feel appreciated, they will help you more often.

Getting the Services You Need

After family and friends do what they can, you may find there are other areas where you need assistance. Now is the time to connect with the aging services network supported by the DC Office on Aging. Two agencies in the District of Columbia can assist you. The District of Columbia Caregivers' Institute can help you with your own personal needs and guide you to reduce your caregiving burden. The DC Office on Aging-funded lead agency serving the community where the elder lives can assist you in a number of ways. (To identify the lead agency in the elder's community, see page 15.) The lead agency can provide a social worker to help you understand what services are available and identify services for which you are eligible. In some instances, the social worker may be able to make a home visit to work with you. Your lead agency also will provide some services directly; for other services, staff may have to refer you to other agencies. Following is a list of lead agencies in the District of Columbia and the communities they serve:

Ward 1 — Barney Neighborhood House — 202/939-9020

Serving the communities of Columbia Heights, Park View, Mount Pleasant, Adams Morgan, Cardozo/Shaw, Lanier Heights, LeDroit Park, and Pleasant Plains

Ward 2 — Greater Washington Urban League — 202/529-8701

Serving the communities of Downtown, Mt. Vernon Square, Logan Circle/Shaw, Chinatown, and Penn Quarters

Ward 3 — IONA Senior Services — 202/966-2055

Serving the communities of Chevy Chase, Friendship Heights, American University Park, Spring Valley, Cathedral Heights, Palisades, Wesley Heights, Foxhall Crescents, Foxhall Village, Georgetown, Barnaby Woods, Hawthorne, Kalorama Heights, West End, Foggy Bottom, Georgetown Reservoir, and Dupont Circle

Ward 4 — Barney Neighborhood House — 202/939-9020

Serving the communities of Barnaby Woods, North Portal Estates, Shepherd Park, Brightwood, Lamond-Riggs, Petworth, Crestwood, Brightwood Park, Manor Park, Colonial Village, Ft. Totten, and Pleasant Hills

Ward 5 — Greater Washington Urban League — 202/529-8701

Serving the communities of Brookland, Brentwood, Eckington, Woodridge, Ft. Lincoln, Gateway, Trinidad, Carver-Langston, Edgewood, Bloomingdale, North Michigan Park, Michigan Park, University Heights, Old Soldiers' Home, Queens Chapel, Ivy City, South Central, and Arboretum

Ward 6 — United Planning Organization Senior Services — 202/610-3110

Serving the communities of Near Southeast, Capitol Hill, Lincoln Park, Kingman Park, Southwest Waterfront, Stanton Park, Navy Yard, North Capitol, Truxton Circle, Buzzard Point, Ft. McNair, Lincoln Park, and Near Northwest

**Ward 7 — United Planning Organization Project KEEN —
202/338-4280**

Serving the communities of Naylor Gardens, Randle Highlands, Fairfax Village, Penn Branch, Ft. Davis Park, Benning Ridge, Marshall Heights, Capitol View, Grant Park, Burrville, Deanwood, Lincoln Heights, Benning, River Terrace, Mayfair, Eastland Gardens, Kenilworth, Greenway, Central NE, Twining, Hillcrest, Ft. Dupont, and NE Boundary

**Ward 8 — Senior Citizens' Counseling and Delivery Service —
202/678-2800**

Serving the communities of Bellevue, Washington Highlands, Congress Heights, Douglass, Shipley Terrace, Knox Hill/Buena Vista, Sheridan, Woodlawn, Garfield Heights, Barry Farm, Hillside, Ft. Stanton, Historic Anacostia, and Fairlawn

The following tips will help you to prepare for the call to your lead agency:

- Think about the questions you want to ask in advance; be as specific as possible about the type of assistance your elder needs or the services you are seeking.
- Call when you have enough time to discuss the situation without being interrupted.
- Ask to speak with a case manager or social worker if possible. These persons can help you sort through issues to uncover hidden or unidentified needs your relative may have.
- Be prepared for a call back if someone is not available when you call.
- Have information about the elder handy such as his or her insurance information and monthly income. Although services funded by the DC Office on Aging are available to all seniors without regard to income, some other programs are income-based. The worker at the lead agency may need to ask for the elder's income and asset information to determine if he or she is eligible for other services.
- Ask about the various options for meeting your needs.
- Ask for a copy of the agency's service directory, if available.

After you have consulted with the elder’s lead agency, you may still need to call other agencies to arrange the services you need. This can be confusing and frustrating. Have a pen and a notebook ready and take good notes as you use the following tips to guide you through the maze of aging services:

- Mentally prepare yourself; you may be transferred, disconnected, and referred to different people before you reach the person who can help you.
- Use an upbeat, friendly, yet assertive tone with everyone to whom you speak.
- Introduce yourself and get the name and direct telephone number of everyone with whom you speak.
- Explain your needs as clearly as possible. The checklist in this booklet might help with this.
- Ask questions about eligibility criteria, waiting lists, fees for services, and various options for meeting your needs.
- Ask that program information and applications be mailed to you or your relative.
- If necessary, schedule a face-to-face interview.
- Before hanging up, repeat the information you have received to verify your understanding of issues discussed.
- Be courteous and extend a hearty “thank you” to persons who have been helpful. Flattery just might get you where you want to go.
- Report discourteous, rude workers to their supervisor.

Once you have completed your investigative telephone calls, you should have a clear understanding of what is available to address your caregiving circumstances. Remember: it is important to complete the follow-up instructions you received.

Making Sure Services Work for You

Now that you have succeeded in getting a particular service started for your older relative or friend, your worries may not be over. From time to time, there may be problems with the delivery of the service. For example, home health aides may not show up or may not complete the tasks required, or the respite care worker may show up late on an afternoon when you had planned a social outing. Likewise, senior transportation services may be late picking up your relative for a doctor's appointment. In any case, both you and your relative will need to be good consumers and share feedback to service providers about problems you encounter.

Exchange telephone numbers with a contact person for every service you are receiving. Find out, in advance, how you should handle voicing a complaint and to whom you should address it. Restate what you can expect from the service, how the service will be delivered, and when. If you have a problem, follow the agency's complaint process. Start with the person you interact with most and then go to that person's supervisor and continue all the way up the chain of command until your concern is addressed to your satisfaction.

Talk with your older relative or friend and make sure that he or she understands the services being provided. When a new service starts, you may want to be there the first few times so you can meet the service provider and begin establishing a relationship. Remember—a thank you note for good service will go a long way with service providers. If you really want to make an impression, send a thank you note to the provider's supervisor commending him or her for the great job. Again, always remember: gratitude will help you gain cooperation and support like nothing else!

Final Note

You must keep in mind that your caregiving situation will change over time. The elder's condition will change, and your ability to respond will change. Be prepared to learn as much about caregiving as you possibly can. Learn about the elder's condition and the various support services available in the future. Begin now thinking about how you will respond if you can no longer provide the help the elder needs. At the District of Columbia Caregivers' Institute, we can help you through educational seminars, support groups, financial reimbursement, and counseling. Call us at 202/464-1513.



The District of Columbia Caregivers' Institute

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