



A Handbook For People Who Care

Caring for parents and other older adults

*MAINE
PRIMARY PARTNERS
in CAREGIVING
Project*

**For more info call your
Area Agency on Aging**

1-877-353-3771

FAMILY CAREGIVERS DEFINED

Family caregivers are the immediate family, close relatives, or life partners who provide care directly or manage the care of older individuals who are ill or disabled.

WHO ARE WE AS FAMILY CAREGIVERS?

As family caregivers we are a diverse group of individuals who are traveling a complex journey. Some of us thrive in the caregiving role, while others



encounter challenges that may seem too much for us.

For whom do we care? 48% of us care for spouses or life partners, 24% of us care for a parent, and 19% of us care for a child.

Most of us are female, and our average age is 46. In one in four American households, one of us is caring for a family member age 50 or older.

Close to two in three of us are working, 52% full time and 12% part time. Nearly half of us spend in excess of 40 hours a week on our caregiving tasks.

The caregiver journey has demanded that we shift roles. We have moved from spouse/life partner to caregiver, from son and daughter to caregiver, perhaps dramatically altering our lifestyle along the way.

We are daughters and sons, who have stretched our role as the child of our parents to become their caretakers. Most often we have extensive other family and life responsibilities.

Meals for Me Meals for Me provides nutritional meals delivered directly to your family member's home.

Personal Care Services A Personal Care Assistant (PCA) can provide assistance with the activities of daily living, such as dressing, bathing, and eating.

Respite Respite services provided by responsible, trained adults offer temporary relief from caregiving responsibilities, either in your home or at an adult day-care facility.

Senior Companion A volunteer program in which an individual comes to your home and provides companionship to your family member by talking, reading, playing games, or simply offering friendship.

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TERMS AND AVAILABLE SERVICES

Advocacy Advocacy is support for you as an individual as well as the provision of education and training on issues related to aging and caregiving.

Community Services We have individuals who can provide information and assistance regarding federal, state, and local programs that may make benefits and services available to you and your family.

Home-Based Care Professional care services can be provided in your home. These include services from nurses, physical therapists, occupational therapists, and other individuals particularly skilled in working with family caregivers.

Homemaker Services Homemaker services provide assistance with the daily tasks of caregiving such as light housekeeping, meal preparation and laundry.

We are traveling a road that for us is uncharted. Map makers have not put markers along this road, and we often find ourselves at dead ends, uncertain how to manage and feeling lost, frustrated, and anxious.

CAREGIVERS CAN BE DIVIDED INTO TWO GROUPS

We each experience different levels of felt obligation. There is no single caregiving role—rather, caregiving emerges from prior role relationships.

Primary Caregivers assume the largest share of caregiving responsibility for a spouse/life partner, parent, or child.

Secondary Caregivers are generally sons, daughters, and other family members who provide support and assistance to the primary caregiver.

Both primary and secondary caregivers are generally employed full-time outside the home and juggle jobs and other responsibilities with caregiving tasks.

Many of us are involved in cross-age caregiving—taking care of elderly family members while raising our children,



or taking care of spouses and life partners and caring for our grandchildren.

We are all challenged by the complex relationships that come to the arena of family caregiving.

At some point, each of us asks, “How can I care for

both of us, for my family member and for me?”



STRESSES UPON FAMILY CAREGIVERS

The stresses upon family caregivers can be considerable. Even when we have made a loving choice to accept this responsibility, it can be a difficult undertaking. We must remember that multiple stresses are cumulative, and can put our own health and well-being at risk.

Physical Health Concerns

Family caregivers are jugglers—with time, with energy, with the demands of our jobs, and with personal responsibilities.

75% of spousal caregivers are “going it alone” with few, if any, outside services.

Spousal caregivers are the least likely to ask for assistance.

We are often more able to attend to the needs of our family members than our own.

Many of us experience exhaustion, stress-related physical symptoms, and even stress-induced disease.

Mental Health Concerns

Few of us have an appreciation of the long-term effects of cumulative stress.

we have provided a list of terms and local services available for your use. Please call us for further information about any of these.

CONCLUSION

Caregiving family members is a complex, challenging task that entails many conflicting feelings and physical demands. Your Area Agency on Aging is staffed with individuals who understand, who care, and who are knowledgeable about the resources and services that are available to you and your family.

Many of us fear that by contacting agencies for assistance we will need to share more information than we wish to. We worry that our privacy will be invaded, that services will have a high cost, or that in some way we will be acknowledging failure in our caregiving capabilities. We understand these feelings; many of us have experienced them too. We will work with you to access the services

YOU need, not what we think you need. Your privacy will be respected, and you will only need to provide as much information as you feel comfortable providing.

Services at your Area Agency on Aging are free. Please call and let us help. Don't try to do this challenging task alone.





RESOURCES FOR FAMILY CAREGIVERS

We often don't know when we need help or what help is available for us. We fear being overwhelmed by outsiders who don't understand, can't do it as well, and who just aren't "family."

Remember, many of us have gone through this too. Many of us learned that this task is too much to manage alone, no matter how much we wanted to.

Asking for help and defining what help is needed is an important part of caregiving. It means you are caring not only for your family member but also for yourself. And when your own needs are being met, you can be a better caregiver to someone else.

Many of us in that "reachable" moment did not know what services were available. We didn't know what the terms meant, and we didn't have time to figure out who to call. For this reason, on the last pages of this brochure,

Few of us stop to appreciate the large responsibility we have assumed and the strain of decision making for another person.

Many of us feel a sense of isolation, of not being understood.

Some of us feel abandoned by other family members in the caregiving journey and harbor deep pain and resentment about this abandonment.

While many of us discuss these issues with friends, our discussions are more in the nature of commiseration rather than problem solving. Often our support community is disrupted by our isolation and preoccupation with caregiving tasks.



Few of us inform our primary care physician about the physical and emotional stresses we may be experiencing.

Few of us believe our primary physician has answers and can provide support.

SPECIAL ISSUES FOR FAMILY CAREGIVERS

Caring for family members with Alzheimer's disease and other dementias or for family members who live a long distance away can bring special challenges and unique stress responses.

Alzheimer's Disease and Other Dementias

Alzheimer's disease and other dementias produce a particular kind of reaction in caregivers. The reaction is



linked to grief over the psychological loss of the family member while the physical presence remains.

Many of us have experienced the grief of no longer being recognized or remembered by a family member.

Many of us have experienced the sorrow of gradually losing a family member to the disease.

Many of us doubt we can continue when bathing and toileting become part of our caretaking responsibilities.

And many of us worry that we too will succumb to the disease.

As caregivers of elders with a dementia, we are in need of significant social and institutional supports. Assistance is available, and we must reach out and access the support.

Long-Distance Caregiving

Caring for a family member who lives at a distance is stressful and challenging and very often requires support in two locations.

Many of us know the feeling of being out of the area, out of the loop, and out of control.

Many of us resolve to move the family member closer to us for ease in caretaking without realizing that our family member may be attached to their community and have significant supports there.

We need to find ways to ask for help, network, and explore our options. Relocation is one solution, but it may not be the best one.

Knowing When You Need Community Resources

We all have the “reachable moment” when we feel we have “hit the wall” and need help.

Many of us need to learn the skill of asking for help, particularly around family caregiving issues.

Asking for help is not a sign of weakness, failure, or lack of love. It is a recognition that more help is needed, temporarily or permanently.

All of us experience frustration, exhaustion, depression and sadness and perhaps sleep deprivation.

None of us function at our best when we are experiencing the cumulative stressors involved in caregiving.

None of us can give to others when the cup is empty. The cup of the self must be filled in order to maintain the energy and compassion to caretake.





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