



With Confidence

**A Self-Help Guide for
Your Caregiving Journey**

A collaborative publication of Eldercare Partners,
FamilyMeans and the Metropolitan Area Agency on Aging

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Who are Caregivers?

You might not think of yourself as a caregiver. *After all*, you're just doing what a good daughter does for her mother; a friend does for a friend; or a husband does for a wife. You may not even like the term. However, if you are helping a friend or older family member who can no longer manage needs they once handled themselves, you have become a caregiver.¹

Life has changed. You've assumed this role along with the other roles in your life. Though there are many rewards to caregiving, balancing responsibilities may, at times, be frustrating; you may feel guilty, anxious, meet resistance where there should be thankfulness, feel alone, or angry that others don't know what you're experiencing. Balancing your multiple roles and being aware of your feelings while gaining some strategies and resources are keys to the ability to continue providing care. This booklet has been designed to help.

Let's Take a Look at Caregiving in Your Life

Have you ever really thought about the many roles you play and the amount of care you give to others? Consider this short checklist² – you might be surprised.

What roles do you play?

- | | | |
|--|--|--|
| <input type="checkbox"/> Caregiver | <input type="checkbox"/> Husband/Wife | <input type="checkbox"/> Mother/Father |
| <input type="checkbox"/> Aunt/Uncle | <input type="checkbox"/> Grandma/Grandpa | <input type="checkbox"/> Son/Daughter |
| <input type="checkbox"/> Son/Daughter in law | <input type="checkbox"/> Partner | <input type="checkbox"/> Friend/Acquaintance |
| <input type="checkbox"/> Best Friend | <input type="checkbox"/> Employee | <input type="checkbox"/> Organization member |
| <input type="checkbox"/> Brother/Sister | <input type="checkbox"/> Other: | <input type="checkbox"/> Other: |

Kinds of caregiving provided:

- Household management (cooking, shopping, cleaning, housekeeping)
- Providing or managing transportation
- Personal care (bathing, dressing, grooming, toileting, ambulating)
- Medical care (assistance with medications, dressings, oxygen)
- Supervision for safety
- Emotional support and companionship
- Financial management and decision-making assistance
- Coordination and management of care provided by others (doctors, therapists, homemakers)
- Regular assistance to more than one family member
- Other:

¹ AARP

² FamilyMeans

"If you do these types of activities, you're one of thousands of other Minnesotans who are family caregivers. Caregiving usually begins with simple, everyday tasks such as cleaning and shopping. As the person becomes more frail, caregiving becomes more intense and time consuming.

Family caregiving may be one of the most important roles you will undertake in your lifetime. Typically, it is a challenging role, and it isn't one that most of us are prepared for.

Many of us will struggle with juggling several responsibilities, our own families, jobs and commitments. It's not easy, and there's usually no clear-cut time frame. For some, caregiving may last a few weeks. For others, it may last years.

So many family caregivers say they wish they had known more about how to provide care, what resources exist, how to get help for their loved ones and themselves, and what to do to make sure that their own quality of life is optimal."³

Please remember, you are not alone, in fact:

- In one of every four households, someone is involved in providing care to a relative or friend age 50 and over.
- 64% of caregivers are in the workforce full or part-time.
- In Minnesota, families provide 95% of all assistance needed by older adults living in the community.

Estimates suggest that the value of family caregivers to the health care system is about \$196 billion each year, compared to \$32 billion per year spent for home care and \$83 billion per year for nursing home care. This represents your worth in dollars – your worth in loving care is invaluable. **Family caregivers are a critical part of the healthcare system.**

Advice From Caregivers

"Seek advice of others with caregiving experience. Find out how they coped and what worked for them."

*Used with permission from the
Minnesota Board on Aging*

³ Minnesota Board on Aging

Caring for Yourself

Caregivers use their internal resources and abilities – sometimes with almost superhuman effort. As a result, caregivers may become ill because they have neglected their own needs. It is ironic that studies show caregiver exhaustion, illness and death are the most common reasons for nursing home placement of the care receiver. Keeping yourself healthy both physically and emotionally is important – this is a necessity – not a luxury.

A Caregiver Self-Assessment⁴

Please answer each item as honestly as possible. The “care receiver” is the person to whom you have been providing care. Use the following scale for your answers.

3	2	1	0	NA
Nearly always	Frequently	Sometimes	Never	Not applicable

- _____ 1. I feel closer to my care receiver than ever before.
- _____ 2. My faith has been a source of strength and comfort for me while caring for my care receiver.
- _____ 3. I feel that, because of the time I spend with my care receiver, I do not have enough time for myself.
- _____ 4. I feel stressed over trying to care for my care receiver and still carry out my other responsibilities.
- _____ 5. I feel angry and frustrated about caring for my care receiver.
- _____ 6. Caring for my care receiver gives me a sense of satisfaction, because I am able to return some of the love he or she has given me.
- _____ 7. I am a better person as a result of caring for my care receiver.
- _____ 8. Caring for my care receiver negatively affects other important relationships with family and friends.
- _____ 9. My physical health suffers because of caring for my care receiver.
- _____ 10. I have learned a lot by caring for my care receiver.

⁴ “A Caregiver Self Assessment” with permission from Winter Park Health Foundation, *As Families Grow Older*

- _____ 11. I feel that I should be doing more for my care receiver.
- _____ 12. Sharing the duties of caring for my care receiver has brought our family closer together.
- _____ 13. I feel that I have lost control of my life, since I began caring for my care receiver.
- _____ 14. I admire my care receiver for the way he or she is handling the situation.

The purpose of this self-assessment is to give you a general idea of the level of burden and level of benefit you feel as a result of caring for your care receiver. There are no right or wrong answers. Feelings can change often based on the circumstances you are currently facing. To assess how you're feeling now, add up your answers below:

Record your responses for each of the questions listed here:

- Question #3: _____
- Question #4: _____
- Question #5: _____
- Question #8: _____
- Question #9: _____
- Question #11: _____
- Question #13: _____

Total = _____
(out of possible 21 points)

This total represents the degree of burden you feel in caring for your care receiver at this time.

Record your responses for each of the questions listed here:

- Question #1: _____
- Question #2: _____
- Question #6: _____
- Question #7: _____
- Question #10: _____
- Question #12: _____
- Question #14: _____

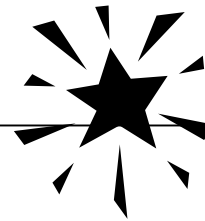
Total = _____
(out of possible 21 points)

This total represents the degree of benefit you feel in caring for your care receiver at this time.

Do the burdens and benefits of caring for your care receiver balance each other? Or is your scale tipped in one direction?

As a Caregiver I have the right:

- To take care of myself – to rest when I'm tired, to eat well and to take breaks from caregiving when I need them.
- To recognize the limits of my own endurance and strength.
- To seek help from family, involved parties, and the community at large.
- To socialize, maintain my interests, and to do the things I enjoy.
- To acknowledge my feelings, whether positive or negative, including frustration, anger and depression; and to express them constructively.
- To take pride in the valuable work I do, and to applaud the courage and inventiveness it takes to meet the needs of my care receiver.



⁵ Family Caregiver Support Project, Northwest Regional Council/Area Agency on Aging

Tips for Caring for Yourself⁶

Rosalynn Carter states in her book, *Helping Yourself Help Others*, "...if you ignore your own health, you won't be much help to your loved one...you're entitled to care and attention too." She urges caregivers to care for themselves with as much dedication as they show to the person receiving their care. But how? Here are some tips to get you started:

1. Feeling healthy is always a good place to begin. Treat yourself to consistent eating, sleeping and exercising habits.
2. Organize your time, set priorities, and decide which tasks merit your best effort and which are less important.
3. Find a creative outlet you enjoy. A hobby like gardening, in which you see progress and results, can be very satisfying.
4. Celebrate your successes and efforts. *Idea: reward yourself with flowers.*
5. Practice relaxation techniques such as deep breathing, stretching tense muscles, or surrounding yourself with things pleasing to your senses.
6. Focus on the positive. Express your negative feelings to someone you trust, and then consciously try to replace them with more productive thoughts.
7. Extend your attention to someone besides the care receiver. Do something nice for a stranger, friend or yourself.
8. Arrange for time away and spend it with people who boost your spirits.
9. Have people with whom you share your burdens and joys.
10. Involve yourself with others experiencing similar situations. Try a caregiver support group.
11. Don't be shy. Ask for assistance so that caregiving becomes a partnership in which you share responsibilities with others.
12. Acknowledge your human limitations, and let go of situations that are out of your control – moving on frees you to conquer what you CAN manage.
13. Learn about available resources so you know who to contact when you need help.
14. Include your care receiver in planning for the future.
15. When possible, use this time to enjoy your care receiver to build and recall special memories that will comfort you in years to come.
16. Live for today.

⁶ www.caregivermn.org. Visit the site to see many more resources for caregivers.

Assessing the Situation

A common source of caregiver stress is being unsure of what kind of help or how much help the person you're caring for really needs. Caregivers often wonder, "Am I doing the right things?" A thorough assessment of the situation can help you move forward with confidence.

Where to Start⁷

An assessment is a review of several important aspects of the care receiver's life. Taking a good look at the person's strengths and needs in these areas gives you a "bird's eye view" of the situation and helps you focus on the most important things.

You may assess the situation yourself or seek the help of a professional. Care managers, who are usually social workers or nurses, provide comprehensive assessments and then guidance in putting the resulting plan into action. No matter how you approach the assessment process, there are two valuable tips to keep in mind.

1. Include the person you care for in the discussion and decision-making as much as possible. This allows the person to retain control they may feel is slipping away and sets the tone for a positive team approach. You may not be able to meet all the person's wishes, but asking about care preferences will help you come to mutually agreeable plans.
2. Notice and honor the person's strengths. Strengths might be evident in ways they've coped in the past, their ability to make needs known, their willingness to use supportive services, or the strong relationship they've fostered with a neighbor, for example. Talking about strengths encourages everyone to consider the whole person rather than focusing only on current difficulties, and it helps to come up with creative solutions.

Assessments usually cover the following general areas:

Physical Health

- Current health status

⁷ www.caregivermn.org. Visit the site to see many more resources for caregivers.

- Medical conditions under treatment, medications
- Recent hospitalizations
- Health professionals involved
- Vision, hearing and other senses
- Use of alcohol and drugs
- Nutritional status

Daily Living

- Ability to move around the home
- Managing personal activities such as dressing, bathing, eating, using the toilet
- Other life skills such as using the telephone, preparing meals, transportation, household chores, money management

Thinking Skills, Mental Health and Emotional Well-Being

- Changes in memory or thinking ability
- History or symptoms of depression, anxiety or other mental illness
- Grief or sadness
- Hopes and aspirations
- Coping skills
- Spirituality

Environment

- Condition and safety of home
- Housing preferences
- Maintenance and outdoor chores

Legal, Financial

- Income and assets
- Status and location of legal documents (Powers of Attorney, Wills, Health Care Directives)
- Insurance information

Support System

- Others who will help, what they do, and how frequently
- Involvement with organizations and faith communities
- Contact information for key family members, friends, neighbors

Advice From Caregivers

"I have learned the meaning of the word patience."

*Used with permission
Minnesota
Board on Aging*

Tools for Gathering Information

On the following page, you can list vital information about the person you care for. Having this information in one place can be useful when seeking services, when you have someone other than yourself at home with the care receiver, or in an emergency situation. You may want to write this in pencil – things may change.

CARE RECEIVER VITAL INFORMATION

Date Updated: _____

Name: _____ Phone: _____

Address: _____

Date of Birth: _____ Social Security Number: _____

Health Insurance, Medicare, Medical Assistance and ID numbers :

List of prescription medication(s): _____

Dates of recent hospitalizations, hospitals and related medical info: _____

Physician name(s), specialties and numbers: _____

Emergency contact name and number(s): _____

Services currently being used and who is providing them: _____

Total Assets: _____ Yearly income: _____

The following documents may be needed when accessing services or making other arrangements: Do you know where they are?

Birth Certificate	Citizenship Papers
Social Security Card	Medicare Card
Medical Assistance Card	Health Insurance Policy
Bank Book, Check Book	Will/Trusts Info
Pension/Retirement Info	Property Deeds/Titles
Mortgage	Auto Titles/Registration
Auto Insurance Policy	Prepaid/Funeral Instructions
Burial Property Certificate	Military Papers
Powers of Attorney	Marriage/Divorce Papers
Health Care Directives	Durable Power of Attorney

Now What? Developing Your Action Plan⁸

You have done your homework in an effort to assess the situation. You've looked at your personal situation – its stressors and benefits. You've assessed your care receiver's situation – their condition and their needs. Now what?

Often (but not always) caregiving seems to fall on one person – usually a spouse or a daughter – and other family members may do relatively little. Doing all of the caregiving by yourself may not be the best idea for you – or your care receiver. This next exercise can help you sort through and prioritize needs and help identify where family, friends and/or community resources can be of value:

Advice From Caregivers

"Surround yourself with supportive friends and family who will nurture you during the experience. You would do the same for them."

*Used with permission from the
Minnesota Board on Aging.*

1. List all of your caregiving related tasks that need to get done such as cooking meals, mowing the lawn, filing insurance forms, going to the doctor, bathing, dressing, laundry, etc.
2. Group your list into categories such as: personal care, transportation, household chores, healthcare, etc.
3. List your caregiving worries. Who will help Mom if she falls and no one is around? Where will we get money to pay for John's medications? Who will care for Mary if I get sick?
4. Group your worries. Possible categories might be: emergency worries, financial worries, health concerns.

⁸ Adapted from http://agrability.sdstate.edu/care/caregiver_tips.htm

5. Pat yourself on the back. Sorting through all of your responsibilities isn't an easy thing to do. You've reached a milestone on the "getting help" path. You are getting closer to being able to ask for *PRECISELY* the kinds of help you need.
6. Review your lists with the idea of sorting the current items into four new categories:
 - things you really think you can't hand off to someone else;
 - those tasks you enjoy or which give satisfaction;
 - responsibilities you find difficult/impossible; and
 - miscellaneous

Review your new lists and decide which items you need to ask someone else to do. If you can't come up with any items that someone else can do – **look again**. The idea is to help you improve the quality of your life and that of your loved one as well.

7. Now think of all the people in your life who might be willing to help in some way. Try to have fun with this list, and brainstorm until you run out of names. Consider writing down family members, friends, neighbors, co-workers, sorority sisters, lodge members, and so on. Don't forget to include your loved one's circle of friends and supporters, which may be different than your own.
8. Do it! Take a deep breath and actually ask someone to help with one of the tasks on your list or ask for guidance in resolving a persistent worry. Rather than, "Can someone take over for me once in awhile?" try, "I need one weekend a month to myself. Who will fill in for me with mother?" Start with something small. It might take a little practice – remember to curb a desire you may have to criticize your helpers (after all, they may not do things exactly the way you might) – but they are there for you – because of you.
9. Be sure family members who live at a distance know that even phone calls offering emotional support are a way to share the care. They can also help immeasurably by relieving you completely for a week or two at a time once or twice a year.
10. You've done **good work for yourself and for your loved one**.

Advice from Caregivers

"Letting go of some of the care does not diminish your role as a caregiver, wife, daughter, son, etc., or mean that you care less about the person."

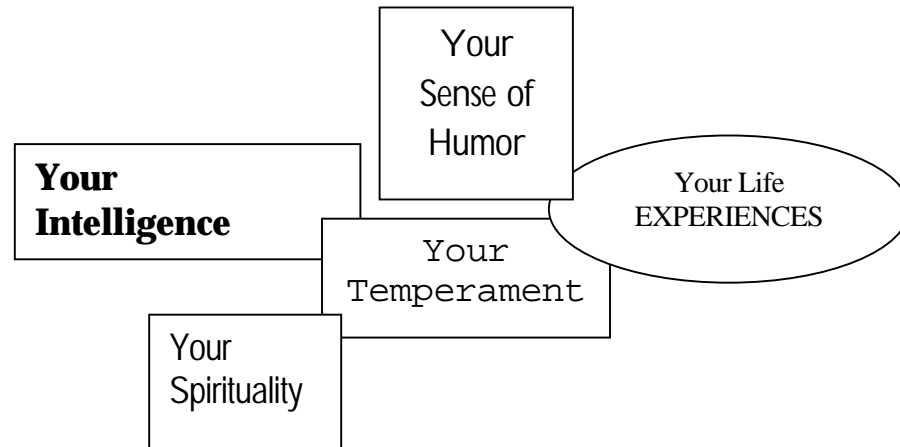
Used with permission from the Minnesota Board on Aging.

It's likely that not everyone will share the same sense of responsibility you feel for the person you care for – but then again you may be surprised. Remember, just because others can't help, doesn't mean you *must* do it all. You can still supplement your resources with help from community services.

Finding Resources

“As important as it is to know that you are not alone as a caregiver, you must also learn to recognize and tap your own inner resources. You have always relied on your inner resources to solve problems and get through tough times. Celebrate the power you hold within you.”⁹

All of us possess personal sources of courage and vision like those below. What are some of your inner resources?



Your own inner strengths and the help of family and friends can get you a long way down the caregiving path. Supplementing those resources with services from community agencies can further ease the journey. You will find descriptions of such resources beginning on page 14, or you can contact the Senior LinkAge Line® to get started at 1-800-333-2433.

Tips for Researching Services

When arranging for services, it may be useful to reference the Care Receiver Vital Information sheet you filled out earlier in this booklet. You may end up calling a number of companies and organizations to find services that meet your needs. The following Contact Sheet can help you organize your efforts.

⁹ Adapted from Winter Park Health Foundation, *As Families Grow Older*

CONTACT SHEET¹⁰

Date: _____

Agency name/address

_____ Phone: _____

Name of the person with whom you spoke: _____

Conversation:

My name is _____

I need _____

Can you help me? _____ Yes _____ No

If not, can you suggest someone else to call? _____

If so, what services do you provide? _____

What are the costs? How are they paid? _____

What are the eligibility requirements? _____

How long must we wait? _____

Can you send a brochure or application? _____ Yes _____ No

When should I expect that in the mail? _____

Are there additional steps I need to take? _____

Notes:

¹⁰ Adapted from a Contact Sheet designed by FamilyMeans

Internet Starting Points

The Internet holds a wealth of information useful to caregivers. You will find web sites about specific diseases, sites that explain public benefits, sites about housing options, sites that help caregivers connect online, and much more. The first three sites below are a good place to start locally. In addition to providing helpful information, each site includes links to other web-based resources.

www.caregivermn.org – is a comprehensive web site for caregivers of seniors featuring Care Pages on topics critical to caregivers, confidential assistance from an online advisor, descriptions of publications and other resources, a bulletin board for caregiver sharing and support, and categorized links to other valuable web sites. This site is a service of DARTS, which provides caregiver education and support in the community and the workplace.

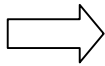
www.tcaging.org – is the web site of the Metropolitan Area Agency on Aging (MAAA). The agency offers assistance in linking elders and their families to a variety of services. Click the “Caregiving” button for a number of helpful articles and checklists, or the “Links” button to be directed to other aging and caregiving-related resources on the Internet.

www.mnaging.org – the web site of the Minnesota Board on Aging. The board listens to senior concerns, researches solutions, and proposes policy addressing senior needs. Go to “Caregiver Main Page” for additional web site resources and book lists.

www.eldercare.gov -- this national web site can direct you to providers of senior services information and referral anywhere in the United States. It also contains links to other caregiver Internet resources.

Descriptions of Available Resources

To support caregivers in their roles, many communities offer services that help seniors and their families. The description list below offers information on typical community resources under their most generic name. Please remember that services may have associated fees, which are established by the provider. These descriptions will help you identify services that may be available to you in your community.



What are services focused on the needs of the caregiver?

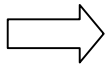
Adult Day Services centers provide structured programming that addresses the health, social and support service needs of the older adults while giving caregivers a break.

Caregiver Coaching Services offer an expert on aging issues to assist you to: build on your strengths, manage caregiving challenges, access training, work effectively with family and guide you to clear solutions.

Caregiver Education/Training helps people increase their confidence and comfort in their caregiving roles. Sessions cover topics such as legal and financial questions, self-care, and community resources. Many home health care agencies and others provide training to increase caregivers' skills in physical or medical tasks.

Caregiver Support Groups bring caregivers together to discuss concerns, share knowledge, and provide mutual support. Professionals generally facilitate the groups.

Respite Care provides temporary care or supervision of an elderly person so primary caregivers can have relief from their caregiving responsibilities. Services may be provided in the home, a nursing home, adult foster home, or a residential facility.



What services can assist me with legal/advocacy issues?

Adult Protection is a county service responsible for investigating complaints and providing protection against abuse, neglect or financial exploitation of vulnerable adults.

Conservatorship/Guardianship is when a court-appointed individual or agency acts on behalf of elders who can no longer act for themselves. The arrangement may be made for matters of the person, the estate, or both.

Health Care Directive (Advance Directive) is a written tool used to guide health care decisions when an individual can't do so because of an incapacity. This tool combines the general purposes of the living will and durable power of attorney for health care.

Legal Assistance provides legal advice, counseling, and representation by an attorney or other person under an attorney's supervision. Services can be provided by elder law attorneys in private practice, or who work for non-profit organizations.

Ombudsman Services provide advocacy for seniors when disputes arise between the elder and service providers such as nursing homes, hospitals or in-home health services. Ombudsman services are offered through the state and some cities.



What are some financial assistance/help options?

Benefits Check-Up is a National Council on Aging website to help elders and their families identify programs they may qualify for and where to apply for them. See www.benefitscheckup.com

Elderly Waiver/Alternative Care Grant are financial support programs that help eligible elders cover the cost of services they choose to receive at home rather than move to a nursing home. Covered services may include home health care, home-delivered meals, adult day services, chore services and others. Application is made through county social service or health departments.

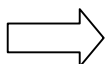
Medical Assistance is a federally funded, state operated program that provides medical benefits for people with very low incomes. It is often referred to as “MA” or Medicaid. This program may be helpful paying for nursing home care.

Medicare is a national health insurance program for people 65 years of age or older and for people under 65 who have a permanent disability.

Money Management Services provide professional staff to help with bill paying, balancing checkbooks, review of medical bills and insurance filing, organization of important papers, and other business matters.

Other Financial Aid programs include federal housing assistance, food stamps, energy assistance, refugee cash assistance, supplemental security income, Minnesota supplemental aid, telephone assistance, general assistance, and general assistance medical care. For those who own their home, a reverse mortgage may be an option to obtain additional resources.

State Health Insurance and Assistance Program (SHIP) allows Medicare-eligible individuals and their families to consult with certified health insurance counselors about Medicare, supplemental insurance, Medical Assistance, and other health insurance questions.



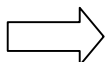
What community services are available to help with keeping up a home? What housing options are out there?

Chore Services provide help with typical household duties such as housecleaning, yard work, snow removal, and minor home repairs.

Home Modification/Repair adapts people's homes to address such things as mobility, safety and energy saving concerns.

Homemaker Services are light housecleaning, shopping, laundry, some food preparation, and other household duties. Some programs may provide social support and companionship.

Housing options include independent senior housing, board and care, housing with services, assisted living, continuing care retirement communities, federally-subsidized rental, adult foster care, nursing home, memory care suites, and shared housing.



What services can assist with long term care planning?

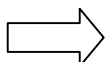
Care Management provides assessment to identify strengths and weaknesses, determine eligibility for assistance, and plan for needed services. Care managers may also assist with arranging and monitoring in-home services on an on-going basis.

Long-Term Care Consultation is a free in-home assessment process that helps identify the elder's needs and assists in developing a plan of care to meet these needs. Consultation is available through human service departments in your county.

Advice From Caregivers

"Seek the advice from professionals and don't worry about pleasing everyone else."

Used with permission from the Minnesota Board on Aging



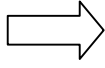
When nutrition is an issue – what's out there?

Grocery/Delivery Services deliver groceries, prescriptions, and other items for a small delivery fee.

Meals on Wheels delivers a well-balanced meal to people who are homebound.

Nutrition Counseling offers a one-on-one consultation with a dietitian to assess nutritional needs in light of medical or other issues. Offers nutritional education and information.

Senior Dining Programs offer meals in group settings at many places in the community including senior centers, churches, community centers and apartment complexes.



What personal care and community nursing services are available?

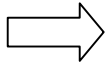
Home Health Care services offer nursing care (administration of medication, wound care, and health monitoring), therapeutic care (physical, speech and occupational therapy), and home health aide services (assistance with bathing, eating, toileting, mobility, etc.).

Hospice Care is specialized care for people who are facing life-limiting or life-threatening illnesses or conditions. The care provided emphasizes comfort over cure and includes pain and symptom management and a variety of other services. Care can be provided in the home, assisted living facility, or nursing home.

Living at Home/Block Nurse Programs are community programs using professionals and volunteers to provide information, support, nursing, social, and other services for the elderly.

Parish Nursing Programs minister to individuals and families within faith communities. Service includes a combination of nursing and ministry. Some programs offer this service to non-members of their faith community.

Public Health Nursing Services provide health and wellness assessment, education, screening, follow-up patient care, and home health care.



What services are available for safety/emergency issues?

File/Magnet of Life provides vital information about the elder to emergency personnel in a crisis situation.

Personal Emergency Response System provides a call button that the elder can activate in an emergency, alerting family, friends or emergency personnel to the need for assistance.

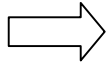
Telephone Reassurance provides well-being checks by calling the elder or having the elder call in at a specified time during the day.



What are some opportunities for socialization?

Companion Services and Visiting Programs provide companionship, friendship and support to people with special needs, especially elders who are homebound.

Senior Centers are located in communities throughout the Twin Cities' metropolitan area and provide recreational and leisure activities, adult education, health education, health screening, and other activities of interest to seniors.



Can anyone help with transportation?

Transportation Services assist people with travel to and from community resources and facilities for needs such as medical appointments, social functions, or senior dining programs. Providers include public transit programs, hospitals and clinics, senior centers, social service agencies, county services and private companies.



Is there somewhere I can call that can help link my needs to services?

Senior LinkAge Line® is Minnesota's comprehensive senior Information and Assistance telephone line to help people find local support services. Senior LinkAge Line® staff can access the **ATT Language Line** to assist with translation when needed.

Eldercare Locator is a national toll-free directory assistance program provided by the U.S. Administration on Aging to help elders and their families find local services. Call 1-800-677-1116 or visit www.eldercare.gov

Minnesota Relay provides telecommunications access for people who are deaf, hard-of-hearing, speech impaired, deaf and blind, or mobility impaired. Calls can be initiated by dialing 1-800-627-3529 for TDD, and 7-1-1 or 1-877-627-3848 for speech-to-speech relay services.

Call Senior LinkAge Line® 1-800-333-2433



It's a Gift to Participate with Mom in the Process of Aging¹¹

A caregiver's story:

My mother, who is 88 years old, asked me to take her shopping the other day to buy a Mother's Day card for her mother. She wanted a card to express the love and gratitude she feels for her mother who is an active presence in her life. She sees and talks to her mother often and recently sent her a beautiful card at Easter. Her mother has been dead for 37 years.

My mother has dementia and lives in a south Minneapolis nursing home. Every day she fights a frustrating battle to hang on to her reality. Her ability to experience her mother's presence in her life is the best part of her deteriorating mental state. The other aspects – the paranoia, anxiety, disorientation and lethargy – are not nearly so pleasant for her or for me.

Until she became sick and could no longer care for herself, my mother lived a fiercely independent life. At 85 years, she still drove a car, opened and closed her lake cottage by herself and loved a good game of poker or gin rummy. She was the caretaker for many friends and their link to church and other outings.

Then, slowly, month by month, she began losing her ability to negotiate daily life. Balancing her checkbook, remembering to take her medicine or baking her favorite cookies became an insurmountable task. She moved from her own home, to assisted-living, to my sister's home. Last September, she came to Minneapolis to be in a nursing home.

A difficult blessing

Having my mother near me during this final period of her life has been a real blessing, but it has not been easy. In fact, much of the experience has been extraordinarily difficult – the time demands, the emotional roller coaster, the sadness and hopelessness at watching someone lose their mental faculties and physical well-being, and the constant feelings of never doing enough.

At the same time, the opportunity to participate intimately with a loved one in the process of aging has been a true gift. With each encounter I am challenged to be a better person – more compassionate, more loving and more giving.

When I bathe my mother each Sunday afternoon, I enter into a kind of sacred relationship with her body, her privacy and her dignity. When I take her out to sit in the sunshine or hold her hand when we visit, I am reminded of the meaning of the simplest gestures.

¹¹ Star Tribune Newspaper, published Sunday, May 13, 2001

When my mother and I talk and her mind is clear, I rejoice in the give-and-take, the chance to tease her and even to get her to smile. When her mind is fuzzy, I appreciate the opportunity to just be there – listening, getting her to smile, helping her to re-enter the world and connect with me. When her mind is completely gone, I actually enjoy entering into her fantasy world and going anywhere it takes me.

I like to hug my mother now and feel her body (which all her life she protected and controlled) melt into mine and experience some release. I like to kiss her, never knowing if her lips will be rigid or tender. When she is responsive, her kisses have such sweetness and impish gratitude.

I am grateful that my mother's presence and vulnerability reminds my husband, children and me, what it means to be a family. Every day we look into the fragility of human existence and can celebrate the simple things – love, compassion, trust, touch, surrender and gratitude. When I am 88 years old, I hope to be sending a Mother's Day card to my mother who has taught me so much.

Pam Costain, of Minneapolis, is Director of the Resource Center of the Americas. Her mother, Martha, lives in the Jones Harrison Residence.

Martha passed away January 30, 2002.