

# *Share the Care* A Family Caregiver Journal



*Minnesota*  
**Board** *on Aging*



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*The Minnesota Board on Aging wishes to thank the following organizations for their advice and support in creating “A Family Caregiver Journal.”*



# Introduction

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Family caregivers find creative and smart approaches for bringing personal satisfaction and reward, a balanced lifestyle, or a steady ability to cope and survive with a duty they feel is theirs. A practical approach to coping with the caregiving experience is through a Family Caregiver Journal.

Use this Family Caregiver Journal to plan, organize, or reflect about your personal caregiving experience:

- ❖ Keep track of things about your family member's condition
- ❖ Journal your personal thoughts and feelings, life's events or special moments or relationships
- ❖ Write about things that matter to you and things you are grateful for

This journal is designed in a flexible format. Tabbed sections offer structure to common areas:

- ❖ Health—general health and daily care
- ❖ Meds—medications and treatments
- ❖ Life—family lifestyle
- ❖ Thoughts—personal thoughts
- ❖ Calendar—for activities and appointments
- ❖ Reference—for important numbers and resources

You may want to use this journal to share information with family, volunteers, or your physician. Take it with you to physician appointments, when you travel, use it in case of emergencies, or to check health insurance claims. Or, you may just want to keep the journal for yourself.

This is your Family Caregiver Journal. Let it work for you.

## Caregiver Tip:

Use this journal to help you make decisions, change ways you provide care or find new services.

As you need more, make copies of the following pages and charts.

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*“What lies behind us and what lies before us are tiny matters compared to what lies within us.”*

*—Ralph Waldo Emerson*



# General Health & Daily Care

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Changes often occur in a family member's condition. Sometimes these can be hard to pinpoint unless they are written down.

In this section, write about how your family member is doing:

- ❖ What are his or her symptoms?  
How long are they present and how often?
- ❖ What is her or his activity level? Can the person move around easily and well?
- ❖ Are there mood or behavior changes?
- ❖ Has she or he lost weight?
- ❖ What is he or she saying about how they are feeling?

Use the "Questions for the Doctor" page 3 attached to plan for your next visit. Jot down a summary of the visit and your action plan.

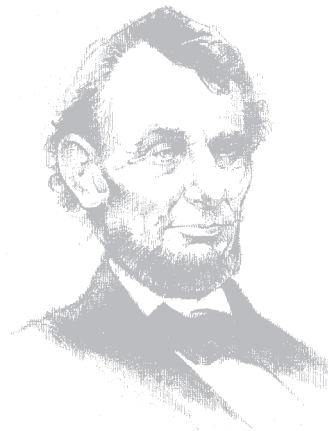
As a caregiver, you probably have your own way of doing things. Jot down your preferences, so when others provide care, you will know things are being done the way you normally do.

Also, use the "Activity Chart" attached to keep track of daily routines and activities. Share useful tips.

## Caregiver Tip:

Use this section to jot down questions you have for the nurse, physician or others. Leave a space for the answer.

*"The best thing about the future is that it comes one day at a time."—Abraham Lincoln*



# Questions for the Doctor\_\_\_\_\_

Doctor's name \_\_\_\_\_ Phone: \_\_\_\_\_

Date of visit \_\_\_\_\_

Reason for visit \_\_\_\_\_

Issues and Concerns:      What has changed since your last visit? What would you like to tell the doctor?  
What's going on differently in your life?

Key Questions:      Jot down your questions and leave a space for the answer.

Summary of Visit:      List the doctor's comments or recommendations. Include new diagnosis, treatment or medications. Include your own responses and decisions.

Action Plan:      Use this section to make a list of things to do, such as follow-up appointments, order new medications, gather new information or arrange or change services.

Date      Comments & Observations

Date	Comments & Observations

# Activity Chart

This chart is for keeping track of daily activities and care routines (such as reading, napping, bathroom, hobbies, dressing or eating), the assistance needed, and useful tips.

Activity & Time (e.g. nap at 2 p.m.)	Assistance Needed	Useful Tips



# Medications & Treatments



Medications are an important part of one's health and daily treatment plan. It is common for medications and dosages to change frequently, and it can be confusing to keep track. Adequate drug information and routine tracking of results are necessary to best manage your family member's medication regimen.

Use this section to write down medications and treatments, their purpose, and scheduled times. Write down things you notice about your family member's condition.

- ❖ Is the medication working well?
- ❖ Is pain being adequately relieved?
- ❖ Does your family member have a mood or behavior change?
- ❖ Is your family member eating, drinking fluids, sleeping well, and able to move around?

If you like, share this information with your physician, pharmacist or others helping with the care.

Also, keep track of lab tests, x-rays and hospital visits using the chart attached.

## Caregiver Tip:

If your family member's medication schedule is confusing, ask your pharmacist if unit dose packaging is available.

*“When you get to the end of your rope, tie a knot and hang on.”—Franklin D. Roosevelt*





# Medications & Treatments Chart

This page is for keeping track of your family member's current medications and treatments. Don't forget to list allergies, side effects, or if a medication or treatment is discontinued and why.

Medication/ Treatment Date Started	What It's For	Dose/ Time Given	Observations/Side Effects

# Lab Tests, X-Rays & Hospital Visits

This section is for keeping track of your family member's lab tests, x-rays or diagnostic tests. Also include any hospitalizations, emergency room, or urgent care visits.

Lab tests, X-rays or Hospital Visits/Date	Results	Comments/Follow-up

# Family Lifestyle

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## *Family life changes with caregiving.*

Sometimes when a person becomes ill or frail, our *perceptions* of him or her change. We may focus on the disease, the person's frailty or the new routine of caregiving. How can you give care and honor your family member's individuality?

Remember the things that make this person special. *Why is he or she unique? What are his or her personal preferences and needs?*

On the next page write about the positive aspects of your family member's life, including:

- ❖ What major events or activities shaped his or her life?
- ❖ Where were his or her favorite places?
- ❖ Who were his or her best friends?
- ❖ What did he or she like and dislike?
- ❖ What sports or hobbies did he or she enjoy?
- ❖ What made him or her happy?

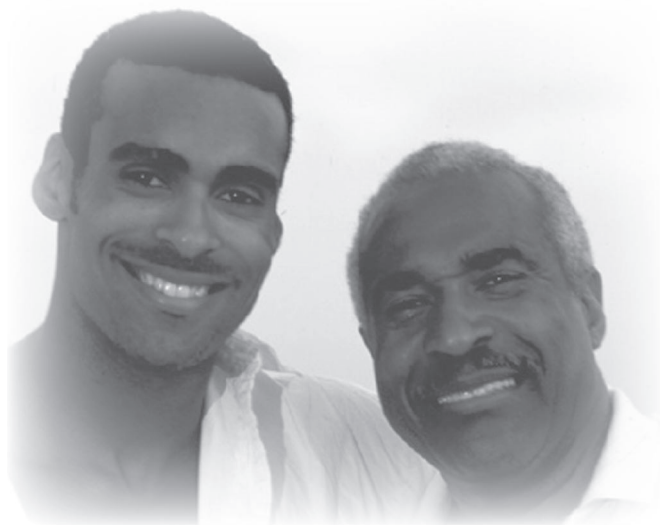
Write about the things that will create special memories for you and your family.



### Caregiver Tip:

Ask other family members to journal special memories in this section.

*"Hugs are the universal medicine."—Author Unknown*



Date Notes About Family Member

Date	Notes About Family Member

# Personal Thoughts

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For many, this section of the *Caregiver Journal* may be the most helpful because it focuses on *you*—the family caregiver.

Taking care of frail or ill family involves many tasks and responsibilities. These can have an enormous impact on your life. Many caregivers describe this as a time of:

- ❖ Emotional “ups” and “downs”
- ❖ Lifestyle changes for the whole family
- ❖ Changing family roles and relationships
- ❖ Juggling tight schedules
- ❖ Loss and grief

Even with its ups and downs, this experience also brings families closer together and gives personal satisfaction to caregivers.

What are your personal experiences with caregiving?

- ❖ Has caregiving changed your life or family relationships?
- ❖ What are you doing for yourself to get a break?
- ❖ What do you feel sad or happy about?
- ❖ What is working well? What things would you like to change?
- ❖ What are your personal goals, your future plans?

Use these questions to guide you during your caregiving experience. Give yourself permission to seek help when you need it. There is help and support available!

## Caregiver Tip:

List five things you're grateful for each day.

*“Every day may not be good, but there's something good in every day.”—Author Unknown*



Date	My Thoughts, Goals & Future Plans
<p>How are you doing? Are you taking care of yourself? What have you learned? What advice do you have for other caregivers?</p>	

# Caregiver Checklist



Here are things to help you with your caregiving duties:

- Are you seeking information about the disease or condition?*
- Have you created a circle of support by maintaining family relationships and friendships?*
- Do you set realistic goals?*
- Do you share with family & friends and invite them to help you give care?*
- Are you using community resources?*
- Are you taking breaks from your caregiving duties?*
- Are you eating well and getting enough sleep?*
- Do you relax each day?*
- Have you laughed today?*

Use the "Calendar" on page 14 to jot down appointments and outings. Don't forget to schedule time for yourself. Also, use the "Reminders" sheet on page 15 to jot down things to do. (*Copy more pages as you need them.*)

## Caregiver Tip:

If you are beginning to feel overwhelmed call the Senior LinkAge Line® at 1-800-333-2433 to learn about help available.

Seek advice from a friend, relative or neighbor with caregiver experience.





(Month)

(Year)

Sunday

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday


# Reminders

Date	Things To Do

# Important Phone Numbers

Family Member's Name	Social Security Number
Health Insurance Carriers/Policy Numbers	Phone Numbers
Doctors Names/Clinics	Phone Numbers
Hospital/Urgent Care	Phone Numbers
Pharmacy	Phone Number
Police	Fire
Poison Center	Senior LinkAge Line® 1-800-333-2433
Power of Attorney-Names and Numbers	Living Will or Health Care Directive? <input type="checkbox"/> Yes <input type="checkbox"/> No
Emergency Contacts	<i>Phone Numbers:</i> Daytime: Evening: Mobile:
Home Care Services	Phone Number
Other Services or Helpers	Phone Number

# Family Caregiver Resources

## *Get Connected*

### **Call the Senior LinkAge Line® to find local resources**

**1-800-333-2433** Senior LinkAge Line® is a free service that helps seniors and their families locate needed resources, including personal and in-home services, and respite services, including adult day care. The LinkAge Line is sponsored by the Minnesota Board on Aging and your local Area Agency on Aging.

### **Resources available on the Web**

- *Minnesota Board on Aging* - [www.mnaging.org](http://www.mnaging.org) Learn about caregiver resources, how to arrange care, the Minnesota Health Care Directive, the Ombudsman program and much more.
- *Benefits Checkup* - [www.benefitscheckup.org](http://www.benefitscheckup.org) Log on to learn about state and federal assistance available for seniors.
- *Family Caregiver Alliance* - [www.caregiver.org](http://www.caregiver.org) - This California-based site has information on caregiving in crisis, communication with doctors and much more.
- *Minnesota Department of Human Services* - [www.dhs.state.mn.us](http://www.dhs.state.mn.us) - Learn about state programs that assist seniors, such as Elderly Waiver and Alternative Care Programs and Minnesota Prescription Drug Program.



### **Books by Minnesota authors**

- Ted Bowman  
*Finding Hope When Dreams Have Shattered.*  
Available by writing to author at:  
2111 Knapp Street, St. Paul, MN,  
55108 or by sending an e-mail to  
[bowma008@tc.umn.edu](mailto:bowma008@tc.umn.edu).
- Wayne Carron, Ph.D., James Pattee, M.D.,  
and Orlo Otteson, M.A.  
*Alzheimer's Disease. The Family Journey.*  
Plymouth, MN: Northridge Press.  
Available through the Alzheimer's  
Association, 1-800-232-0851.
- James Sherman, Ph.D.  
*Creative Caregiving.*  
Golden Valley, MN: Fairview Press.
- Pat Samples  
*Daily Comfort for Caregivers.*  
Minneapolis, MN: Fairview Press.
- Warren Wolfe  
*Checklist for Aging: A workbook for caregiving.*  
Contact author at P.O. Box 131866, Roseville,  
MN 55113 or visit Web site at  
[www.checklistforaging.com](http://www.checklistforaging.com).

### **Other books**

- Nancy Mace and Peter Rabins  
*The 36 Hour Day*  
Baltimore, MD: John Hopkins Press.
- Virginia Morris and Robert Butler  
*How To Care for Aging Parents.*  
NY, NY: Workman Publishing Company.
- Maggie Callanan and Patricia Kelley  
*Final Gifts: Understanding the Special Awareness,  
Needs and Communications of the Dying.*  
NY, NY: Bantam & Double Day Publishing

*(Resources continued on page 18)*

# Family Caregiver Resources

## Educational Resources

### *Community Education classes & resources*

- Contact your local community education center or your local extension office to find out about caregiving classes and resources in your area.
- Contact your local library for finding caregiver books.
- Contact the lending library at DARTS, Inc. (Dakota Area Resources and Transportation for Seniors) at (651) 455-1560 or log on to their Web site at [www.caregivermn.org](http://www.caregivermn.org).

## Caregiver Support Groups

- Call the Senior LinkAge Line® at 1-800-333-2433 to learn about caregiver support groups in your area.

## Hospice Care

- Hospice Minnesota  
1-866-290-4321 or 651-659-0423 for information about hospice care and hospice programs, or log on to [www.mnhospice.org](http://www.mnhospice.org).

## For Health Information and Resources

### *Alzheimer's Disease*

- Call the Alzheimer's Association Minnesota-Dakotas Chapter at 1-800-232-0851 or visit their Web site at [www.alzmdak.org](http://www.alzmdak.org).  
This site also has a caregiver resource page.

### *Arthritis*

- Call the Arthritis Foundation Minnesota Chapter at 1-800-333-1380 or visit their Web site at [www.arthritis.org](http://www.arthritis.org).

### *Cancer*

- Call the American Cancer Society at 1-800-227-2345 or visit their Web site at [www.cancer.org](http://www.cancer.org).

### *Diabetes*

- Call the American Diabetes Association at 1-800-342-2383 or visit their Web site at [www.diabetes.org](http://www.diabetes.org).

### *Heart Disease*

- Call the American Heart Association at 1-800-242-8721 or visit their Web site at [www.americanheart.org](http://www.americanheart.org).

### *Lou Gehrig's Disease*

- Call the ALS Association at 1-888-672-0484 or (612) 672-0484 or visit their Web site at [www.alsmn.com](http://www.alsmn.com).

### *Lung Disease*

- Call the American Lung Association of Minnesota at 1-800-642-5864 or (218) 726-4721 (Duluth office) or visit their Web site at [www.mnlung.org](http://www.mnlung.org).

### *Multiple Sclerosis*

- Call the National MS Society - Minnesota Chapter at 1-800-582-5296 or (612) 335-7900 or visit their Web site at [www.mnms.org](http://www.mnms.org).

### *Parkinson's Disease*

- Call the Parkinson Association of Minnesota at (763) 545-1272 or visit their Web site at [www.parkinsonmn.org](http://www.parkinsonmn.org).

### *Stroke*

- Call the Minnesota Stroke Association at 1-800-647-4123 or (612) 879-0015 or visit their Web site at [www.strokemn.org](http://www.strokemn.org).

**Note:** Call the Senior LinkAge Line® to find additional resources in your area.



# Advice from Caregivers:



*“Try to keep a sense of humor. Find things to laugh about. It is your best defense!”*

*“Assemble a caregiving team. Divide chores into categories i.e., personal care, transportation, errands, help around the house, personal affairs, etc., and delegate them to others you trust.”*

*“Learn to adapt—maybe you cannot go out to eat, but you could have a picnic at home or bring in a meal.”*

*“Set priorities and spend your energy wisely.”*

*“You must develop a personal support system, just for you. Create a telephone support network.”*

*“Routinely schedule time for just yourself; go out with friends, go for a walk, go out to dinner, or shopping, join a club and meet new friends, go to work. Focus on the activity, enjoy yourself, and don't worry or feel guilty.”*

*“DO NOT hesitate to ask for help from family and friends. Tell them what you need help with. Be specific. Tell them your frustrations. Let them help you.”*

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

*“Seek advice from professionals and don't worry about pleasing everyone else.”*

*“Seek advice of others with a caregiving experience. Find out how they coped and what worked for them.”*

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



# Caregiver Journal—*Comments & Suggestions*

1) *On a scale of one to five, how useful was this journal to you?*

Not Useful

Extremely Useful

1

2

3

4

5

2) *The most useful section or sections to me.....(please describe)*

3) *Was the format easy for you to follow and use (e.g. journal entries, charts and phone sheet)?*

*Please check one.*       Yes       No *(Please describe):*

4) *Are there topics or issues that you think should be added or deleted?*

No       Yes *(Please describe):*

5) *Any other suggestions or ideas about improving this journal to make it more useful for caregivers like yourself?*

*Thank you for your time!*

*Please fold this sheet and mail it to*

*Caregiver Journal*

*Minnesota Board on Aging*

*444 Lafayette Road, St. Paul, MN 55155-3843 or*

*e-mail your comments in to us at [www.mnaging.org](http://www.mnaging.org).*