

# Family Caregiving Resources



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# How to Use This Section

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Family members (sometimes called family caregivers) often help their older relatives tend to personal care needs, find resources, make decisions about housing or medical/nursing care, and keep up with health exams and treatments. Family members who live close by may be called upon more frequently than those who live far away, but the long distance caregiver can also play an important role in supporting the older person.

This section of the toolkit provides family members with some information as a starting point—there are several local and national organizations that focus on family caregivers' needs.

Sometimes families want to get everyone who is involved together in one place to hold a “family meeting” around long-term care needs and end-of-life wishes. This section also offers information and tips on how to do that.

# Family Caregiver Resources

## Information and Services

- **CaregiverMN**

[www.caregivermn.org](http://www.caregivermn.org)

Web site offers multiple resources for family caregivers and is a service of DARTS (Dakota Area Resources and Transportation for Seniors).

- **Family Caregiver Alliance**

1-800-445-8106 or [www.caregiver.org](http://www.caregiver.org)

Provides information, education, services, research, and advocacy.

- **Catholic Charities Caregiver Support—Respite Program**

651-215-2246 or [www.ccspm.org/caregiver\\_support.aspx](http://www.ccspm.org/caregiver_support.aspx)

Trained volunteers provide a four-hour break once a week to family caregivers who provide 24-hour a day care for a person 60 years or older who is unable to stay alone for more than two hours and needs supervision and guidance with functional activities. *Fee is a sliding scale based on income.*

- **University of Minnesota Extension Service—Financing Long-Term Care Resource Center**

[www.financinglongtermcare.umn.edu](http://www.financinglongtermcare.umn.edu)

A resource to help families that are planning ahead make more informed decisions.

## Caregiver Support Groups

- **Eldercare Partners**

651-234-2262 or

[www.eldercarepartners.org/caregiverservices.htm](http://www.eldercarepartners.org/caregiverservices.htm)

Calendar of events on their Web site lists supports groups and programs by county.

- **Our Lady of Grace Catholic Church**

952-929-3317 or [www.olgparish.org](http://www.olgparish.org)

Memory loss support group for caregivers. Meets third Wednesday of the month, 7–8:30 pm in Parish library. Free and open to public.

- **Senior Community Services**

952-541-1019 or [www.seniorcommunity.org](http://www.seniorcommunity.org)

Facilitates caregiver support groups at various sites in west metro area. Free, on-site adult daycare available while group meets.

## Caregiver Training

- **ElderCare Rights Alliance**

952-854-7304 or [www.eldercarerights.org](http://www.eldercarerights.org)

(Click on How do you Care? on Web site.) A two-part training to prepare families and friends to build a collaborative caring network of support for an older person's care needs.

## Additional Resources in This Section

- Form 1: Family Meeting Agenda
- Form 2: Elder's Needs and Expected Caregivers' Activities
- Form 3: Caregiver Notes/Journal
- Form 4: Questions for the Doctor

Make copies of these forms as needed.

# Holding a Family Meeting

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Planning for long-term care needs (such as how to take care of daily needs when health declines) often requires cooperation among family members. Holding a family meeting is a good way to facilitate this process.

## Who Should Attend?

The family meeting may include only family members, or may include close family friends, neighbors, or paid caregivers. It is up to the senior and family to decide who should be there. In general, it is better to be inclusive of all relatives who could be involved, as families need practice dealing with tough issues as a group. The primary organizers of the meeting should ask themselves:

- Who will be affected?
- Who has resources to offer?
- Who is concerned?
- Who needs to know?

A decision must also be made about whether or not to include the elderly family member in the meeting. If the planning is to be proactive to anticipate future needs the elderly person should be there and may lead the meeting. If family members need to share thoughts/feelings that would be painful for the older person to hear, consider holding one meeting *with* the older person present and a second meeting to focus on those matters *without* the older person present.

## When Do You Need Outside Help?

It is sometimes helpful to engage the help of an outside facilitator to help the family communicate about difficult subjects during the meeting. It especially helps to have a neutral outside facilitator when families have trouble working together or coming to agreements or when the family is divided on an important issue.

Facilitators could be social workers from local senior service agencies, hospitals, or home health care agencies; ministers; private case managers; or therapists trained in family counseling. Discharge planners in hospitals and nursing homes can also help facilitate a family meeting or refer you to someone who can.

## **How to Begin?**

1. Prepare an agenda. Fax, mail, or email a rough draft of the agenda to all participants prior to the meeting so they can share their ideas and suggest other items to include.
2. Collect relevant medical, financial, insurance, or legal information prior to the meeting, as well as resource information (like the Senior & Family Caregiver Resource Directory section of this toolkit).
3. Set a location that is quiet and private.
4. Set a starting and ending time. Consider making plans for a follow-up meeting if more time will be needed.

## **The Meeting**

1. Start on time with others who live a long distance away “patched in” through a speaker phone if possible. Make sure everyone has the agenda.
2. Establish a time keeper and a recorder/secretary. Set an ending time.
3. Remind participants that the goal of the meeting is to work as a team in caring for the older person (even if there is conflict among family members in other areas).
4. Ask participants to use “I” statements (i.e., “I need/feel,” rather than “you should”).
5. Record problems in a list as they are identified or shared.
6. Work to share the load—each person has a set of tasks and is accountable to the elder and team to follow up.
7. At the end make sure everyone understands:
  - The issues discussed
  - Solutions (if they’ve been established) and the plan
  - Responsibilities agreed to by each participant

Family meetings should take place regularly or at least when the caregiving situation changes. Work toward consensus building. Recognize that not all the caregiving issues can be solved, and in these cases it is important to accept approximations of a good solution.

Be patient with each other, as issues can bring up strong emotions related to family dynamics, feelings about death, and concerns about the older person’s health status.

*Sample Agenda Items*

**1. Goals/purpose**

Examples: Set priorities for us as a family and as an elder person, identify key issues, share feelings and ideas, create a plan.

**2. Medical information/treatment**

What are the conditions, treatments, and ongoing medical care expectations?

**3. Current care/assistance needs**

What does the elder need?

**4. Current support provided by family or paid help**

Who is doing what? How is that going?

**5. Sharing feelings**

**6. Anticipating short-term (or longer-term) needs**

- Housing—Need to move? What are the options?
- Home maintenance, inside/outside—Who does the chores?
- Help with meals, daily activities—How much time is available to help?
- Financial concerns/issues—What are the options? How much will help cost?
- Legal concerns/issues—What legal documents/decisions need to be completed/made?

**7. Problem-solving and putting together a plan**

What are the tasks? Who will do them?

**8. Summary**

What did we accomplish? What more do we need to do, and when?

# Form 1: Family Meeting Agenda

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Use this form to set your own agenda for your family meeting. Make copies of the agenda for everyone at the meeting so they can take their own notes (or fax/email prior to the meeting).

<i>A G E N D A</i>
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Date: \_\_\_\_\_ Family: \_\_\_\_\_

1.

2.

3.

4.

5.

6.

7.

8.

# Form 2: Elder's Needs and Expected Caregivers' Activities

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Use this form to describe the older person's needs and the expected activities of the caregivers who are/will be involved. Needs could include help with such things as: rides to medical appointments, grocery shopping, medication management, bill paying, yard work, and home maintenance. For those planning for future needs, issues might include: financial planning, housing decisions, or tax assistance.

## Elder's Needs and Expected Caregivers' Activities

<b>Elder's Needs</b> (describe)	<b>Frequency</b> (daily, weekly, monthly)	<b>"Caregiver" or Primary Person Who Helps</b> (include paid help if applicable)	<b>Others Who Could Help</b>

# Form 3: Caregiver Notes/Journal

Use this form to keep notes on the older person's needs, particularly **changes observed** or **services provided**. This can be used by family members or paid staff.

Date	Description/Notes	Person Recording

Source: Minnesota Board on Aging, [www.mnaging.org](http://www.mnaging.org)

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# Form 3: Caregiver Notes/Journal (continued)

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Date	Description/Notes	Person Recording

Source: Minnesota Board on Aging, [www.mnaging.org](http://www.mnaging.org)

# Form 4: Questions for the Doctor

Doctor's Name: \_\_\_\_\_ Date of Visit: \_\_\_\_\_

Reason for Visit: \_\_\_\_\_

<b>Issues and Concerns:</b>	What has changed since your last visit? What would you like to tell the doctor? What's going on differently in your life?
<b>Key Questions:</b>	Jot down your questions and leave space for the answers.

Source: Minnesota Board on Aging, [www.mnaging.org](http://www.mnaging.org)

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# Form 4: Questions for the Doctor (continued)

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<b>Summary of Visit:</b>	List the doctor's comments or recommendations. Include new diagnosis, treatment, or medications. Include your own responses and decisions.
<b>Action Plan:</b>	Use this section to make a list of things to do, such as make follow-up appointments, order new medications, gather new information, or arrange or change services.

Source: Minnesota Board on Aging, [www.mnaging.org](http://www.mnaging.org)