

Families Providing Care to an Elderly or Ill Family Member¹ Jeffrey E. Tranel²

Many families reach a point when they recognize that an ill or older family member needs help. There are usually warning signs: difficulty with daily activities; memory problems; trouble with banking and finances; multiple falls; problems with driving; forgetting medications, etc. Sometimes the family member needs more than occasional assistance — they need full-time care.

Who will provide the care needed by the family member? The answer is often close to home: an adult child or grandchild. A family member might become the caregiver by default, or one is selected because he or she lives closer or has fewer family responsibilities of his/her own. Even though family members may want to help and feel a sense of duty to care for a loved one, it is a job with heavy time commitments and responsibilities. The person providing care for a family member is likely to make significant sacrifices. He or she will experience a change in lifestyle which may include giving up a job with wages and benefits, changing commitments to other family members, foregoing a social life, etc.

What is the value of the provided care to the care recipient and to other family members? The care provider may be willing to do some things for free while other activities or assistance should be paid or reimbursed. Family dynamics and relationships will help determine who or if a family member will provide the care and the amount of compensation.

The family should note that a non-family member or organization providing the care would likely charge a fee for the service.

Families Discussing Personal Care

It can be stressful for a family to discuss providing care to a parent. The elderly person may be resistant to receiving help or moving out of his or her home; there may not be an obvious choice about who will provide the care; there may be a lack of trust within the family; and money may be an issue. Additionally, some families may not have experience (or have had bad experiences) talking about complex and sensitive issues.

One method for discussing difficult topics is to hold a family meeting. The family meeting should be just that — a meeting with an agenda and notes taken as to the topics discussed, decisions made, and work to be accomplished. A well-organized meeting can provide everyone with shared support and a better understanding of the decisions to be made. It is important to include all necessary family members in the meeting. In some cases, a non-family person may be desired to facilitate the meeting.

Some topics needing to be discussed during the family meeting include:

 What care needs to be provided? There should be a clear listing of the caregiver's role and tasks.
 The care recipient's perception of his or her

¹ The purpose of this fact sheet is for educational purposes only. Changes in the law may have occurred since publication. No statements should be considered as legal advice. People should consult with a licensed attorney about their individual cases.

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quality of life and independence should be taken into consideration when identifying the care to be provided.

- What will be the compensation for providing the care? The compensation rate and timing of payment should be stated. Some families have sufficient funds to compensate the care provider on a regular basis, while other families may need to compensate the care provider from the estate of the care recipient.
- Who will serve as the backup care provider? A
 person or persons should be identified that can
 provide temporary care to the family member
 when the regular care provider is unable to
 provide care due to becoming ill, taking
 vacation, or other reason.
- Who holds any Powers of Attorney? Some families may want the care provider to have a Medical Power of Attorney. Other families may want to separate legal authority from other responsibilities.
- Is there a Health Care Directive? The care recipient should have a legal copy of any Health Care Directive. The care provider and family members should be aware of the declarations and instructions contained within the document.
- Are there Medicaid "spend down" or "look back" considerations? The care recipient and family should be aware of implications and possible restrictions of Medicaid. The family should contact all appropriate government officials before finalizing their decisions.
- What is the plan if or when it becomes time for placement in a residential facility? A plan outlining the circumstances when it becomes necessary for the care recipient to move to a residential facility (elder day care, assisted living, nursing home, hospice, etc.). Also, there should be consideration as to the care provider's plans when he or she no longer needs to provide care. This may be especially true if the care provider gives up other employment and/or has to move to another community.

Personal Support Service Agreement

One way to protect the care recipient, care provider, and the family is to put the care relationship in writing. A personal support service agreement (also known as an elder care contract or family care can

help resolve concerns as it is being drafted and avoid future conflicts and misunderstandings.

The personal support service agreement should clearly state the services to be provided; compensation rates; other benefits allowed the care provider (such as room and board); time off; and other critical aspects of the services to be provided and compensation. An attorney may not be necessary, but one may be advisable when entering into any contractual relationship.

If a family member is providing care and the person being cared for is likely to eventually enter a care facility and/or need to qualify for Medicaid down the road for more extensive care, it is crucial that the personal support agreement be in writing to avoid problems associated with qualification for Medicaid.

In addition to being in writing, the agreement must, at a minimum:

- Be signed by the applicant for Medicaid (i.e., the person being cared for) or by his/her power of attorney or conservator/guardian.
- List an appropriate agent. The agent cannot be someone who is going to receive money under this agreement.
- Describe the caregiver responsibilities: What duties? How often? How?
- Detail caregiver compensation. Payment needs to be at least monthly, and the rate needs to be comparable to what others in the community would get paid. Also, the caregiver cannot get paid for what others are already getting paid to do.

Home Health Agencies

Although most home care is provided by family, friends, or volunteers, there may be need to hire paid professionals to provide the required care. Many such professional work for private agencies that provide health care.

Home health agencies deliver a variety of skilled services ranging from short visits to help with bathing and administering medicines to round-the-clock full-time care. Some agencies must be paid with private funds, while others are paid by Medicare and/or Medicaid.

Families should carefully interview the agencies in their area to assure a good match with the care recipient. Also, it is important to know how the agency will be paid.

Medicaid & Other Government Services

Medicaid, other government agencies, and nongovernment organizations (community, county, state, and federal) have many resources for elderly people and their families. Professionals from such organizations can help families determine care needs and evaluate options for providing care.

Medicaid will pay for many services for elderly people and others with qualifying needs. However, there are numerous restrictions and regulations associated with Medicaid. Families should consult — prior to making any final decisions — with the care recipient's health care provider, local Social Security Administration, a Medicaid planning professional, and organizations with the purpose of helping the elderly and their families.

Compensating a Family Member Care Provider

A person providing services to an elderly family member should be compensated for his or her time spent providing care. The time compensated should be that beyond the time a family member would spend simply visiting with and/or doing things for an elderly relative. Further, the care provider should keep a log of tasks performed and time spent accomplishing the tasks.

The total value of services rendered to the person receiving the care can be calculated by multiplying the time spent performing the service by an hourly rate. The hourly rate should be a "reasonable" rate acceptable to the provider, the person being cared for, and the recipient's family. There are myriad sources on the internet which can be useful in determining a reasonable rate.

A spreadsheet-based tool is available at www.ABM.extension.colostate.edu to help families calculate the compensation a person could receive for providing care for a family member.

Reimbursement for Personal Expenses Incurred

A care provider has reasonable expectations to be reimbursed for using his or her automobile to transport the care recipient to appointments, shopping, and other places important to the life of the care recipient. Reimbursement of mileage should be calculated by multiplying the number of miles by an acceptable per mile rate. There are myriad sources on the internet which can be useful in determining a reasonable rate.

A care provider and/or family member(s) may find it expedient to pay certain costs and be reimbursed for the costs incurred. Further, family members may find it necessary to pay certain costs which should be reimbursed from the care recipient's estate. It is important that the care provider, care recipient, and care recipient's family have open and honest discussions about which expenses will be paid and by whom and when the expenses will be reimbursed.

Summary

Families often struggle with paying someone to provide care to a family member. Some cultures have strong beliefs regarding a need for "the family to care for their own".

In those cases where a family member provides care to an elderly parent or grandparent, it is reasonable to expect compensation for providing the care. The care provider may have to quit his or her job, forego opportunities, move to another community, or otherwise experience a change in lifestyle to provide the required care.

The computerized spreadsheet based template accompanying this fact sheet may be a helpful tool in calculating such compensation and accounting for reimbursable expenses. Further, the information entered into the spreadsheet may serve as a useful record of time spent and expenses needing to be reimbursed.

The most important aspect of care being provided to someone is that the care provider, care recipient, and care recipient's family have open, honest, and frequent discussions about the care being provided and compensation.

Calculating Compensation for Personal Services



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| PERSONAL SERVICES | | Hours | Weeks | | Hourly | Total |
|---|---------------------------------|----------|----------|---------|---------|---------------|
| | | Per Week | Per Year | Years | Rate | Value |
| Personal Care | | | | | | |
| Visiting, "Checking Up On", Etc. | | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Bathing, Personal Hygiene | | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Exercise | | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Other | Description | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Household | · | | | | | |
| Food Prepa | aration/Serving | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Laundry | | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| House Clea | aning | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Other | Description | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Financial | , | | | | | |
| Paying Bills | 5 | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| | with Attorneys/Accountants/Etc. | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| _ | with Government Agencies | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| _ | with Health Care Providers | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Other | Description | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Transportation | | | | | 1 2 2 2 | , |
| • | entists, Other | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| - | Other Shopping | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Financial & Other Professional Counselors | | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| | iends & Recreation | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Other | Description | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Other | and the second | | | | 1 2 2 2 | , |
| Other | Description | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| Other | Description | 0.00 | 0 | 0.0 | \$0.00 | \$0.00 |
| REIMBURSEM Mileage | IENT FOR PERSONAL EXPENSES IN | CURRED | | | | Total Cost |
| Trip or Act | ivity 1 | | 0.00 | miles @ | \$0.56 | \$0.00 |
| Trip or Activity 2 | | | 0.00 | miles @ | \$0.56 | \$0.00 |
| Utilities | , = | | 0.00 | 65 | YOUR | φσ.σσ |
| Rent or Mortgage Payment \$0.0 | | | | | | |
| Electricity, Gas, Other Energy, Water, Sewer, Trash, Etc. | | | | | \$0.00 | |
| Television, Internet, Etc. | | | | | | \$0.00 |
| Telephone, Cellphone | | | | | | \$0.00 |
| Other | Description | | | | | \$0.00 |
| Auto | · | | | | _ | |
| Debt Payments \$0.00 | | | | | | |
| Insurance | | | | | | \$0.00 |
| Repairs & Maintenance | | | | | \$0.00 | |
| License Plates, Tags | | | | | \$0.00 | |
| Fuel | | | | | | \$0.00 |
| Other | Description | | | | | \$0.00 |
| Other | | | | | _ | |
| Long Term Care | | | | | | \$0.00 |
| Health Car | | | | | \$0.00 | |
| | (life, health, long-term care) | | | | | \$0.00 |
| Other | Description Description | | | | | \$0.00 |
| Other | Description | | | | | \$0.00 |
| | | | | | | |
| TOTAL COMPENSATION and REIMBURSEMENT \$0.00 | | | | | | |