



Family Caregiving

A husband feeds, bathes and clothes his 70-year-old wife who is in the final stages of liver disease. A wife visits her husband daily in the nursing home, even though he no longer knows who she is due to Alzheimer's.

Family caregiving is everybody's business

A mother provides everyday care to her developmentally disabled adult son who lives with her.

A daughter-in-law visits her husband's parents daily to make sure they take their medication. While her husband pays his parents' bills and does their yard work, she cleans their house — and worries about what her teenagers are doing at home alone.

Many individuals identify themselves as family caregivers. The National Family Caregivers Association maintains there are only four kinds of people, those who:¹

- have been caregivers,
- currently are caregivers,
- will be caregivers, and
- will need caregivers.

What is caregiving?

Family caregiving often starts with running errands and helping shop or manage legal and financial affairs.

Caregiving differs according to need, community resources and caregiver capability. Some may provide 24-hour care in their home, while others provide guidance and support via long-distance phone calls and correspondence. Some offer care after work or on weekends; while others supplement care in a nursing home or have help from a local hospice organization when caring for a family member.

Such care ranges from administering medicines and physical therapy to taking care of daily needs — dressing, bathing, toileting and feeding. Family caregivers help with household tasks and provide the much-needed emotional support essential for healing and coping with long-term disability, degenerative disease, chronic or terminal illness.

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Weekly hours of caregiving
Percent of U.S. family members providing care, 1997



- Less than 8 hours/week
- 8 hours/week
- 40 or more hours/week

Nationwide, of all individuals needing long-term care:³

- More than half (about 53 percent) — 6.4 million — are retirement-age adults 65 and older.
- Less than half (44 percent) — 5.3 million — are working-age adults 18 to 64.
- The rest (3 percent) — 400,000 — are children under age 18.

Of older adults with long-term care needs; about 30 percent — 1.5 million — have **substantial long-term care needs**. This means they need help with three or more activities of daily living such as walking, dressing, eating, using the toilet, bathing, and getting in and out of bed.

Of these, about 25 percent are the oldest adults age 85 and older, and 70 percent report they are in fair to poor health.⁴

Some caregivers find themselves caring for a loved one with dementia. **Dementia** is defined as the loss of intellectual functions — such as thinking, remembering and reasoning — that interferes with an individual’s ability to live alone safely. The most common form of dementia is Alzheimer’s disease.

Alzheimer’s and other dementias are more prevalent among the oldest adults. Nearly half (48 percent) of those with dementia are age 85 and older. However, just because someone grows older does not mean they will experience memory problems, have Alzheimer’s disease or any form of dementia.

In Wisconsin, an estimated 103,000 adults age 65 and older have some form of dementia. Most of these (84 percent) live in the community.⁵

Individuals needing long-term care by age groupings
Percent of U.S. population needing caregiving, 1999³



Individuals with dementia in Wisconsin

State population with dementia is a summary of county populations calculated from U.S. Census data for 2000.⁵ See county figures on page 6.



Who are family caregivers?

Individuals do not readily identify themselves as caregivers. Unless a sudden accident or illness intervenes, the caregiver role evolves over time, and gradually turns into a major time-consuming responsibility that can be stressful.

Nearly 1 out of every 4 U.S. households — 22.4 million (23 percent) — are involved in caring for a person age 50 or older. By 2007, that number is projected to reach 39 million households — nearly doubling in less than a decade.⁶

Of older adults living in the community and needing long-term care:⁷

- Only 8 percent relied solely on **formal caregivers** — paid help.
- Nearly two-thirds (64 percent) depended on family and friends — **informal caregivers** — as their only source of help.
- About a third (28 percent) received both formal and informal care.

Who provides care?

Percent of caregiver type for older adults needing care, 1982-1994



Women have assumed informal caregiving with their roles as mother, spouse, daughter and daughter-in-law. Many female caregivers (40 percent) are raising their own children, and two-thirds also work outside the home, mostly full time.⁸ Many new studies show that men are assuming caregiving responsibilities.

Why are families providing care?

Families have always stepped in to provide care to family members, regardless of where they live. An increasing number of families find themselves in more intensive caregiving roles. Nearly **1 in 4 Wisconsin households** (23 percent) have an older adult age 65 or older.

Medical technology has preserved and extended life expectancy, increasing the number of older adults who need assistance or live with severe conditions.

Medical practices, plus changes in Medicare reimbursement laws and private managed care programs, see individuals being released from hospitals earlier and needing more care.⁹

Family caregivers are learning to administer multiple medications and use equipment such as feeding tubes and respirators at home.

Caregivers must also learn to navigate the health care system and become advocates for their loved ones.¹⁰

Regardless of their health or need for assistance, older adults prefer to live independently. Of Wisconsin adults age 65 and older in the 2000 U.S. Census, most (92.7 percent) lived in the community:

- **Family household-head of household** — 33.3 percent
- **Family household** — 27.9 percent
- **Live alone** — 22.4 percent
- **With a non-family member** — 9.1 percent

Only about 5 percent lived in a nursing home, and 2 percent in other group quarters. Compare these with county figures on page 5.

Families are having difficulty managing caregiving responsibilities:

- Families are smaller, with fewer members available to provide care.
- Families are geographically dispersed, separated by distance.
- Many women also work full- or part-time outside the home.

What are the costs of caregiving?

According to conservative estimate, the economic value of the unpaid **informal care** friends and family provide nationwide is **\$257 billion a year**. This figure dwarfs annual national spending for:¹¹

- **Formal home health care** — **\$33 billion.**
- **Formal nursing home care** — **\$83 billion.**

Wisconsin family caregivers provide almost \$4 billion in caregiving services annually. This ranks Wisconsin 18th in the nation for dollar value caregivers contribute.¹²

In 2002, close to half (42 percent) of U.S. workers provided some form of caregiving. In a study of employers, more than two-thirds (70 percent) reported staffing problems related to caregiving increased in the last 10 years. Yet two-fifths (40 percent) had no plan in place to assist caregivers.^{13, 14}

Where older adults live Wisconsin

Percent of Wisconsin population age 65 and older, *Census 2000*



What caregiving costs employers
All costs to U.S. employers, 1997

Type of cost	Cost per employee*	Total employer costs
Replacing employees	Not available	\$4,933,816,305
Absenteeism	\$69	\$397,596,918
Partial absenteeism	\$86	\$488,298,715
Workday interruptions	\$657	\$3,765,122,333
Eldercare crisis	\$189	\$1,084,355,232
Supervisor’s time	\$141	\$805,133,760
Total annual costs	\$1,142	\$11,474,323,263

* Total annual cost per employee does not include the cost of replacing an employee who may resign due to caregiving responsibilities.

This lack of planning costs U.S. businesses dearly. Employers lose an estimated **\$11 to \$29 billion each year**, and attribute this loss to their employees’ need to care for family members over age 50.¹⁵

What caregiving costs families

When caregiving demands intensify, caregivers take leaves of absence, reduce their work hours or quit their jobs. These decisions take a heavy toll financially.

One study states that a caregiver can lose **more than \$650,000** in wages, Social Security benefits and pensions during the course of a family caregiving “career.”¹⁶

Another recent study found that besides personal income and benefits lost, about half (44 percent) of terminally ill patients reported that the cost of their medical care was a **moderate or great economic hardship** to their family.¹⁷

Family caregivers have other costs beyond financial, including loss of health and well-being. Caregiving takes a heavy emotional toll. Caregivers report chronic stress, family conflicts, and failure to meet their own personal and emotional needs. They also often report feeling alone and isolated.

Caregiver stress can lead to depression, burnout, self-neglect, excessive use of drugs or alcohol, and even neglect or abuse of the care recipient. Of the caregivers who provide more than 21 hours of care a week — **intensive caregiving** — more than half (61 percent) suffer from depression.

Yet caregivers do not access community resources and supports meant to help family caregivers take care of themselves and assist with caregiving tasks. Caregivers are often unaware of community resources, maintain they can manage on their own, and feel uncomfortable with outsiders coming into their home.

Caregivers often become ill, incapacitated or die because they attend to caregiving responsibilities rather than taking care of themselves. Without the family caregiver, the care recipient may need to be institutionalized prematurely.¹⁸

Who will provide care in the future?

A shrinking number of family members in a growing number of households will need to provide more care with fewer to share caregiving as Wisconsin’s population ages.

Wisconsin already has more adults age 65 and older (13 percent) than the national average (12 percent).¹⁹

From the 1990 to the 2000 U.S. Census, the oldest adults age 85 and older increased by 29 percent — three times the increase in Wisconsin’s total population (9.6 percent) that decade.

Based on census data, Wisconsin can expect the older adult population to increase rapidly. In 2011, the first post-World War II baby-boomers turn 65. By 2030, more than a fifth (21percent) of Wisconsin’s population will be age 65 or older — meaning **1 in 5** people will be retirement age.

As the number of households providing care to older adults soars, families are getting smaller. The 1990 U.S. Census found **11 potential caregivers for each person needing care**. By 2050, the number of potential caregivers per recipient is projected to plummet to **4 to 1**.²⁰

This shortage of family caregivers will have major ramifications for families, communities and health care providers.

How does Pepin County fare?

No matter where you live — in a city, the suburbs or on a farm — family members step in to care for their spouses or aging relatives. Caring for someone with medical problems such as Alzheimer’s and other diseases takes time away from family activities and creates stress for the primary caregiver and other family members.

Sometimes family caregiver concerns are invisible in the community. The following county data can help community leaders plan for local family caregiver needs, and let family caregivers know they are not alone.

From 1990 to 2000, the greatest increase in older adults was among the oldest, age 85 and older. In Pepin County, the number of individuals age 85 and older grew by 11 — a 5.6 percent increase during that decade.

Population figures in this fact sheet are based on 1990 and 2000 U.S. Census data.

Older adults in Pepin County

How state populations are aging, *Census 1990-2000*

Older and oldest adult populations	1990	2000	Increase/ decrease	Percent change
Age 65 and older Pepin County	1,322	1,215	-107	-8.1%
Age 65 and older Wisconsin	651,221	702,553	51,332	7.9%
Age 85 and older Pepin County	195	206	11	5.6%
Age 85 and older Wisconsin	74,293	95,625	21,332	28.7%

The oldest adults age 85 and older represented 14.8% percent of the older adult population — all those age 65 and older — in 1990. That changed to 17.0% percent in 2000.

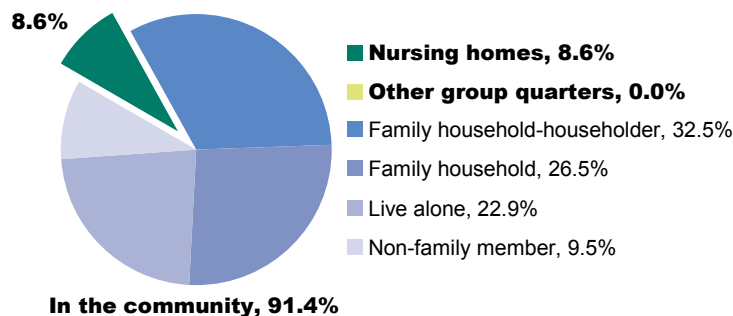
Where do older adults live?

The 2000 U.S. Census found that of Pepin County adults age 65 and older, most (90 percent) live in the community. Regardless of their health or need for assistance, older adults prefer to live independently. They do not seek help until a crisis occurs, such as a fall or other medical emergency.

Where older adults live in Pepin County

Percent of county population age 65 and older, *Census 2000*

Compare these with statewide figures on page 3.

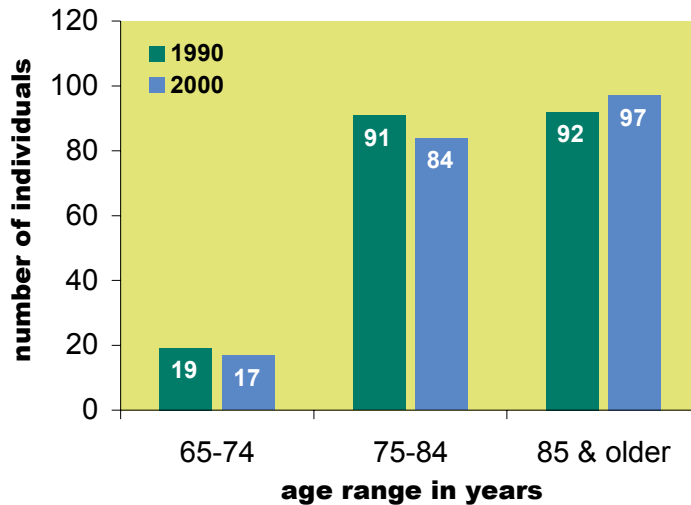


How many have dementia?

In Pepin County, an estimated 198 individuals age 65 and older have some form of dementia. The oldest, those age 85 and older, make up 49.1 percent of all older adults with dementia, yet are only 14 percent of the older adult population.²¹

Individuals with dementia in Pepin County

County population with dementia is calculated from U.S. Census data for 2000.²¹ Compare these with statewide figures on page 2.



Research indicates that caring for someone with dementia is more stressful than caring for someone without dementia. Family caregivers have a greater need to use community supports such as adult day care and in-home respite care, and could benefit from support groups and community educational programs.

With the number of oldest adults age 85 and older increasing — and many of them needing family support because of dementia — communities can plan and develop ways to help these families.



How can you help?

Communities can support family caregivers in many ways. Here are some ideas.

Individuals can:

- Volunteer to help family caregivers through organizations that reach out to them, such as hospice, church or inter-faith respite programs, and other community groups.
- Contact the county or tribal aging office and ask about other volunteer opportunities to support family caregivers.
- Offer companionship to family caregivers, or help them network with other family caregivers to support one another.

Employers can:

- Develop plans, policies and procedures for family care that support employees, such as flexible use of sick leave, vacation and family leave for eldercare crisis and end-of-life situations.
- Provide educational workshops, informal discussions and information on family caregiving issues and resources.
- Provide referrals for information and advice on medical, legal, financial and family communications, or counseling or bereavement services.
- Encourage wellness efforts that help family caregivers ease stress and maintain their own health.

Community resources — county or tribal aging office, health and other care professionals including doctors and nurses, human services, church, temple and inter-faith agencies and volunteers — can:

- Make supports for family caregivers known throughout the community and easy to access. Target information on caregiving issues, concerns and resources for anyone, especially isolated spouses, aging immigrants, and those who work full-time in the home.
- Refer family members to other community resources and information for family caregivers.

Communities can:

- Provide support services such as support groups, respite care and in-home health care services, educational programs and written information.
- Help build awareness of these support services, family caregiver issues, concerns, and other resources in the community.

These supports help a family caregiver keep the care recipient at home, and avoid or postpone institutionalization. They also provide information, education, services, and support to family caregivers so they can continue being a caregiver.

Community resources for family caregivers

Community and web-based resources are available to family caregivers, providing information, educational programs and direct services. If you do not have a computer, try your local library. Most libraries have a free computer connected with the Internet. Or call the U.S. Administration on Aging Eldercare Locator toll-free (Spanish help available):

(800) 677-1116 —
Weekdays 9 a.m. to 8 p.m. EST

Start with these:

AARP is a national organization with a state office and local chapters in every state. They provide information and promote the independence of older adults. Their free online seminar, *Planning for the Care of Aging Parents*, is just one example of the educational resources they provide on family caregiving. www.aarp.org/learn/course/Articles/a2003-06-13-planningparentsdescrip.html

Alzheimer's Association is a national organization with a network of chapters in every state, providing information, education, support and referral. To locate the chapter that serves your community, call toll-free, any time (Spanish and other language help available): (800) 272-3900, www.alz.org

County and tribal aging offices answer questions about needs, services and opportunities for older adults and their families. To locate your county or tribal aging office, consult: www.dhfs.state.wi.us/aging/contacts/COAGOF.HTM

University of Wisconsin-Extension has local offices in every county, and provides educational resources through classes, publications and web sites. To locate your county UW-Extension office, consult: www1.uwex.edu/ces/cty

University of Wisconsin-Extension provides leadership to the **Wisconsin Alliance for Family Caregiving**, which provides fact sheets and other educational resources plus links to additional web sites for family caregivers and the professionals who support them: www1.uwex.edu/ces/flp/caregiving

Wisconsin Alzheimer's Institute (WAI) is an academic center within the University of Wisconsin Medical School. WAI develops innovative education and training programs, coordinates research, and provides technical expertise for health care providers caring for people with Alzheimer's disease and related dementias:
www.medsch.wisc.edu/wai

Notes

- ¹National Family Caregivers Association. *Family Caregivers and Caregiving Families*. 2001: <http://www.nfcacares.org>
- ²National Alliance for Caregiving and AARP (formerly American Association of Retired Persons). *Family Caregiving in the U.S.: Findings from a National Survey*. June 1997: <http://www.caregiving.org>
- ³The Henry J. Kaiser Foundation. *Long-Term Care: Medicaid's Role and Challenges*, Publication 2172, Washington, D.C. Nov. 1999.
- ⁴*Ibid.*
- ⁵Wisconsin population with dementia is a summary of county populations calculated from U.S. Census data for 2000. See note 21.
- ⁶National Alliance for Caregiving and AARP. *Op. cit.*
- ⁷Liu, K., Manton, K.G. and Aragon, C. Changes in home care use by disabled elderly persons, 1982-1994. 2000. *Journal of Gerontology: Social Sciences*, 55B (4), S245-253.
- ⁸Gutheil, Irene, and Roslyn Chernesky, *Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models*. 2000. Ravazzin Center for Social Work Research in Aging, Fordham University Graduate School of Social Service.
- ⁹National Family Caregivers Association. *Op. cit.*
- ¹⁰National Alliance for Caregiving and Partnership for Caring. *Toward a National Caregiving Agenda: Empowering Family Caregivers in America*. July 2001: <http://www.caregiving.org>
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- ¹²National Alzheimer's Association and Center for Policy Alternatives. *Elder Care: An Emerging Public Priority*, in *Family and Work: An Investment Strategy for Communities*: 1999: <http://www.stateaction.org/issues/workfamily/elder/index.cfm>
- ¹³Families and Work Institute. *Business Work-Life Study*. 1998: <http://familiesandwork.org/summary/worklife.pdf>
- ¹⁴Human Resources Institute. *Measuring the Impact of Caregiving Responsibilities in the Labor Force: Employer Perspective*. 2000. St. Petersburg, Fla.
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- ¹⁶Jayce, Elizabeth, editor. *Dimensions of Family Caregiving: A Look into the Future*. Monograph prepared for a national conference September 12, 2000. MetLife Mature Market Institute.
- ¹⁷Emanuel, E.J., et al. Understanding Economic and Other Burdens of Terminal Illness: The Experience of Patients and Their Caregivers. 2000. *Annals of Internal Medicine*. 132:451-459.
- ¹⁸Schulz, R, and S.R. Beach. Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. 1999. *Journal of the American Medical Association*; 282:2215-2219.
- ¹⁹U.S. Census, 2000.
- ²⁰University of California-San Francisco Institute for Health & Aging, for the Robert Wood Johnson Foundation. *Chronic Care in America*. 1996.
- ²¹County dementia data is calculated from 2000 U.S. Census data based on the formula identified by Denis Evans, MD, et al. "Prevalence of Alzheimer's Disease in a Community Population of Older Persons." *Journal of the American Medical Association*. 1989. 262(18). The Evans study shows that Alzheimer's disease afflicts nearly half (47 percent) of those age 85 and older, about a fifth (19 percent) of those 75 to 84, and 3 percent of those 65 to 74.

Family Caregiving Is Everybody's Business continues the series *Wisconsin Families and the Communities Where They Live and Work*. The complete list of titles is on the UW-Extension Family Living web site at: <http://www1.uwex.edu/ces/flp/demographics>

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