



**AGING INTERNET INFORMATION NOTES**  
empowering users to explore internet resources

## Caregiver and Aging Issues

(See also [Caregiving Resources](#), [Grandparents Raising Grandchildren](#), [Long Term Care Services in the States](#), [Adult Day Services](#), [Hospice and Palliative Care](#))

Families have traditionally cared for their infants, children, and older adults without compensation or assistance throughout much of our history. Informal or unpaid care of the elderly has traditionally been estimated to account for 95% of all care given to older adults. Social changes in family size, in numbers of women in the workforce, and in the increased longevity of older adults have been affecting the ability of natural caregivers to meet the needs of family members. These Internet sites help define the extent of the current and future need for family caregiving. Public policy initiatives for support for family caregivers through government tax expenditures, respite care, education and training are being advocated by many of the organizations sponsoring the sites listed below.

[Fact Sheets](#)

[Federal Programs](#)

[Statistics, Research and Government Reports](#)

[Caregiver Issue Articles](#)

[Bibliography](#)

[National Caregiver Organizations & Centers](#)

### Fact Sheets

#### **Eldercare: An Emerging Public Priority**

(Center for Policy Alternatives)

<http://www.cfpa.org/issues/workfamily/elder/Eldercare.pdf>

#### **Work and Eldercare**

(Family Caregiver Alliance)

[http://www.caregiver.org/factsheets/work\\_eldercare.html](http://www.caregiver.org/factsheets/work_eldercare.html)

#### **President's Proclamation on Caregiving 2002**

(White House)

<http://www.whitehouse.gov/news/releases/2002/10/20021029-6.html>

#### **Eldercare – Women's Rights**

(American Federation of State, Community and Municipal Employees)

<http://www.afscme.org/wrkplace/wrfaq04.htm>

### **For Caregivers**

(U.S. Administration on Aging)

[http://www.aoa.gov/eldfam/For\\_Caregivers/For\\_Caregivers.asp](http://www.aoa.gov/eldfam/For_Caregivers/For_Caregivers.asp)

### **National Eldercare Locator**

(U.S. Administration on Aging)

<http://www.eldercare.gov/>

### **Working with Family Members of Persons with Memory Disorders**

(North Carolina Division on Aging)

<http://www.dhhs.state.nc.us/aging/alz3093.pdf>

### **Hospital Discharge Planning – Helping Family Caregivers Through the Process**

(United Hospital Fund of New York and National Alliance for Caregiving)

[http://www.uhfnyc.org/usr\\_doc/DischargePlan\\_Prof.pdf](http://www.uhfnyc.org/usr_doc/DischargePlan_Prof.pdf)

[http://www.caregiving.org/content/reports/Discharge\\_Planner\\_final.pdf](http://www.caregiving.org/content/reports/Discharge_Planner_final.pdf)

### **Caregiving Myths**

(Center on Aging Studies Without Walls, University Missouri at Kansas City)

<http://iml.umkc.edu/casww/myths.htm>

### **Family and Medical Leave Act of 1993**

(U.S. Department of Labor)

<http://www.dol.gov/esa/whd/fmla/>

## **Federal Programs**

Office of Personnel Management

### **Elder Care Responsibilities of Federal Employees**

and Agency Programs - March 2002

<http://www.opm.gov/wrkfam/Mar2002Rpt/toc.asp>

### **National Family Caregiver Support Program**

(see more reports [Statistics, Research and Government Reports](#))

### **National Family Caregiver Support Program (Description)**

(U.S. Administration on Aging)

<http://www.aoa.gov/carenetwork/NFCSP-description.html>

### **Implementing the National Family Caregiver Support Program (Menu)**

(U.S. Administration on Aging)

<http://www.aoa.gov/carenetwork/default.htm>

### **Family Caregiver Support: Policies, Perceptions and Practices Since Passage of the National Family Caregiver Support Program**

(Family Caregiver Alliance)

[http://www.caregiver.org/national\\_center/10\\_state.htm](http://www.caregiver.org/national_center/10_state.htm)

## **Maine Primary Partners in Caregiving Project**

(Maine Center on Aging, University of Maine)

<http://www.umaine.edu/mainecenteronaging/mppc.htm>

## **Medicaid Home and Community Based Long Term Care Waiver Programs**

(see also: [State Long Term Care](#))

## **Home and Community-Based Services 1915(c) Waivers**

(U.S. Health Care Financing Administration)

<http://cms.hhs.gov/medicaid/1915c/default.asp>

## **Section 1915(b)/(c) Waiver Programs**

(U.S. Health Care Financing Administration)

<http://cms.hhs.gov/medicaid/1915b/1915bc.asp>

## **State Waiver Programs and Demonstrations**

(Centers for Medicare and Medicaid Services)

<http://cms.hhs.gov/medicaid/waivers/waivermap.asp>

## **Promising Practices in Home and Community Based Services Assisting Individuals to Avoid or Move from Institutional Settings**

(Centers for Medicare and Medicaid Services)

<http://cms.hhs.gov/promisingpractices/transitions.asp>

## **Understanding Medicaid Home and Community Services: A Primer**

(Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services)

<http://aspe.hhs.gov/daltcp/reports/primer.htm>

## **National Institute on Aging**

## **Alzheimer's Project: Caring for Elderly with Alzheimer's Disease**

(California State University, San Marcos)

[http://www.csusm.edu/shamill/Alzheimer's\\_project.htm](http://www.csusm.edu/shamill/Alzheimer's_project.htm)

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(U.S. Department of Labor)

<http://www.dol.gov/dol/compliance/comp-fmla.htm>

## **Statistics, Research and Government Reports and Hearings**

**2003**

## **Early Release of Selected Estimates Based on Data From the January-September 2002 National Health Interview Survey**

(National Center for Health Statistics)

<http://www.cdc.gov/nchs/about/major/nhis/released200303.htm>

## Personal care needs

- [Figure 12.1](#). Percent of adults aged 65 years and over who need the help of other persons with personal care needs: United States, 1997-2002
- [Figure 12.2](#). Percent of adults aged 65 years and over who need the help of other persons with personal care needs, by sex and age group: United States, January-September 2002
- [Figure 12.3](#). Age-sex-adjusted percent of adults aged 65 years and over who need the help of other persons with personal care needs, by race/ethnicity: United States, January-September 2002
- [Data tables for figures 12.1-12.3](#)

## **California's Family Caregiver Support System: Findings & Recommendations (January 2003)**

(Center for the Advanced Study of Aging Services)

Executive Summary: [http://cssr.berkeley.edu/aging/pdfs/CFCS\\_ExecSumm.pdf](http://cssr.berkeley.edu/aging/pdfs/CFCS_ExecSumm.pdf)

Full Report: [http://cssr.berkeley.edu/aging/pdfs/CFCS\\_FINAL.pdf](http://cssr.berkeley.edu/aging/pdfs/CFCS_FINAL.pdf)

## **Local Caregiver Needs Assessment Under California's Family Caregiver Support Program**

(Center for the Advanced Study of Aging Services)

<http://cssr.berkeley.edu/aging/pubdetails.asp?name=localcare>

## **A Profile of Family Caregivers: Results of the California Statewide Survey of Caregivers**

(Center for the Advanced Study of Aging Services)

<http://cssr.berkeley.edu/aging/pubdetails.asp?name=famcareprofile>

## **Need Is Growing, But Little Funding Available To Provide Long-Term Care At Home - Field Poll**

(Family Caregiver Alliance)

[http://www.caregiver.org/national\\_center/20030304\\_field\\_poll.htm](http://www.caregiver.org/national_center/20030304_field_poll.htm)

## **Together We Care: Helping Caregivers Find Support**

(National Council on Aging)

<http://www.ncoa.org/attachments/caregiver%2Epdf>

## 2002

## **Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners**

(Family Caregiver Alliance)

[http://www.caregiver.org/national\\_center/resource\\_inventory.pdf](http://www.caregiver.org/national_center/resource_inventory.pdf)

## **The State of the Art: Caregiver Assessment in Practice Settings**

(Family Caregiver Alliance)

[http://www.caregiver.org/national\\_center/state\\_of\\_the\\_art.pdf](http://www.caregiver.org/national_center/state_of_the_art.pdf)

## **Chronic Conditions – Making the Case for Ongoing Care**

(Partnership for Solutions, Johns Hopkins University)

<http://www.partnershipforsolutions.org/DMS/files/chronicbook2002.pdf>

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(Family Caregiver Alliance)

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**Self-Awareness in Family Caregiving**

(National Family Caregivers Alliance)

<http://www.nfcacares.org/documents/AARPSurveyFinal.pdf>

**State Family Leave Benefit Initiatives in the 2001-2002 State Legislatures: Making Family Leave More Affordable**

(National Partnership for Women and Families)

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**Faces of Aging: Personal Struggles to Confront the Long Term Care Crisis  
Hearing Testimony**

(U.S. Senate Special Committee on Aging)

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(Center for the Advanced Study of Aging Services, University of California at Berkeley)

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**Shared Work/Valued Care: New Norms for Organizing Market Work And Unpaid Care Work**

(Economic Policy Institute)

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(Australian Institute of Health and Welfare)

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(FP5/IST/Systems and Services for the Citizen Persons with Special Needs)

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Final Report Prepared for the Area Agency on Aging of Pasco & Pinellas, Inc.

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(National Family Caregivers Association)

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(U.S. Senate Special Committee on Aging)

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## **National Caregiver Organizations & Centers**

### **Adopt An Elder**

<http://www.adoptanelder.org/>

### **Center for Family Caregivers**

<http://www.familycaregivers.org/>

**Direct Caregiver Association**

<http://www.tucsonhealthlinks.com/dca2.htm>

**Family Caregiver Alliance**

<http://www.caregiver.org/>

**Institute for Caregiver Education**

<http://www.caregivereducation.org/>

**National Alliance for Caregiving**

<http://www.caregiving.org/>

**National Clearinghouse on the Direct Care Workforce**

[http://www.directcareclearinghouse.org/worker\\_assoc.jsp](http://www.directcareclearinghouse.org/worker_assoc.jsp)

**National Family Caregivers Association**

<http://www.nfcacares.org/>

**National Organization for Empowering Caregivers**

<http://www.nofec.org/>

**National Partnership for Women and Families**

<http://www.nationalpartnership.org/index.cfm>

**Rosalynn Carter Institute for Human Development**

<http://rci.gsw.edu/>

**Thou Shalt Honor Foundation**

<http://www.thoushalthonor.org/>

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