My Journey: What Older Adult Well-Being Means to Me
“There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver.”

— Rosalyn Carter
Family Caregivers: Who They Are

- Average Age: 49
- Time Spent Caregiving: 24 to 41 hours per week
- Length of Time Caregiving: 4 to 5 years
- Cost if Paid: $400-$522 billion annually
## Family Caregivers: What They Do

<table>
<thead>
<tr>
<th>Direct Care</th>
<th>Less Visible</th>
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<tbody>
<tr>
<td>Transportation</td>
<td>Keeping them safe</td>
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<tr>
<td>Meals</td>
<td>Monitoring symptoms</td>
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<tr>
<td>Dressing</td>
<td>Assisting with decisions</td>
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<tr>
<td>Making and keeping appointments</td>
<td>General vigilance</td>
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<tr>
<td>Medications</td>
<td>Promoting social inclusion</td>
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<tr>
<td>Shopping</td>
<td>Maintain activities and relationships</td>
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<td></td>
<td>Maintain dignity and independence</td>
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<td>Finding and overseeing paid caregivers</td>
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Family Caregivers: Caring From a Distance

- Increasing number
- Multiple generations
- 25% primary caregiver
- Average distance 450 miles
- Expenditures ($400-$670/ month)
- Average 2-3 visits/month
- 80% working
- 30% miss work days (more women)
Employed Caregivers

- 23% of all employees provide care (at least!)
- 64% of Wisconsin workers surveyed
- $33 billion in lost productivity (U.S.)
- $2100/year/employee
- 60% have interrupted work (late, early, absent)
- Higher employee health care costs/illness
- 22% or retirees retired early
What Do Family Caregivers Say About Caregiving?

Challenges

Need for assistance/not quitting

Rewards

Desire to continue
# Challenges and Consequences for Caregivers

<table>
<thead>
<tr>
<th>Lack Of Preparation</th>
<th>Other Consequences</th>
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<tbody>
<tr>
<td>Difficult conversations</td>
<td>Isolation</td>
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<tr>
<td>Anticipating what is up ahead</td>
<td>Income loss</td>
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<tr>
<td>Knowing when and how to ask for help</td>
<td>Family dynamics</td>
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<tr>
<td>Responding to behavior changes</td>
<td>Maintaining older person’s independence and quality of life</td>
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<tr>
<td>Deciding when/where/how to relocate</td>
<td>Rewards</td>
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<tr>
<td>Training/education (AARP)</td>
<td>Stress/sleep loss</td>
</tr>
</tbody>
</table>
Family Caregivers: What They Need

- Well timed
- Relevant
- Support decision making
- Safe, paid assistance
- Prepare for likely decisions
- Anticipating what’s ahead
Why it Matters for Care Recipients

- Ability to stay home
- Improved quality of life
- Maintain relationships
- Accepting assistance
Not Always Able to Stay Home
Paid Caregivers: Different Settings

- Home & Community
- Housing with Services
- Nursing Home
Paid Caregivers: Who are They?

Source: PHI
Challenges for Paid Caregiving Workforce

- Wages
- Hours
- Education
- Work/Family conflict
- Working conditions
What Professional Caregivers Need

- Preparation for setting
- Training/education
- Organizational support
- Staffing
- Hospital discharge
### Caregiving: Public Policies and Proposals

<table>
<thead>
<tr>
<th>Family Caregiving</th>
<th>Paid Caregiving</th>
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</thead>
<tbody>
<tr>
<td>- Filial obligation laws</td>
<td>Nursing Homes</td>
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<tr>
<td>- 100 bills in 32 states (21 passed)</td>
<td>- 8 hours/day of RN (DoN)</td>
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<tr>
<td>- Hawaii family caregiver support</td>
<td>- Staffing sufficient to provide quality care</td>
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<tr>
<td>- Tax incentives</td>
<td>- 75 hours</td>
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<tr>
<td>- Family medical leave (12 weeks)</td>
<td>- ADA: least restrictive environment</td>
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<tr>
<td>- Social Security Caregiver Credit Act of 2015</td>
<td>Assisted Living</td>
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<td></td>
<td>- Fastest growing</td>
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<td></td>
<td>- Wide state variation</td>
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<tr>
<td></td>
<td>- Minimal nurse/physician oversight</td>
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<tr>
<td></td>
<td>Group Homes/family homes/ CBRF</td>
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</tbody>
</table>
Caregiving: Using Nursing Research to Meet Needs

eCARE

Helping You Help Your Older Adult.

Get Started

Make it Work
Find ideas, tips, stories from experts, families and friends helping older adults.

Consider Options
Confront your concerns and support your older adult’s independence and quality of life.

Address Changes
Organize, track, and share what needs to happen to manage successful transitions.

Support for Older People with Intellectual Disability:
A Manual for Promoting Health
Providing support, education and orientation
Reducing turnover
Increasing attraction of environment
Guiding organizational support
Training and supporting mentors
Supporting Healthy Aging for People with Intellectual Disability

Support for Older People with Intellectual Disability:
A Manual for Promoting Health
Evidence-based App for Family Caregivers

- Anticipatory guidance for family caregivers
- Decision support
- Identifying options/paths and likely consequences
- Preparing for challenges and preparing for choices
- Support for communicating with family members
- Guiding difficult conversations
- Increasing confidence
Our Mission
Through nursing leadership, discovery, education and practice, the Center for Aging Research and Education (CARE) improves the health and well-being of older adults.

Our Vision
To transform quality of life and quality of care for older adults and their caregivers.

Are you a family caregiver? Ask us how you can help inform the eCare project!

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