

Family Caregiving in Oregon



Family caregiving is the foundation of Oregon's system of LTSS

- ♥ About 469,000 unpaid caregivers in Oregon
- ♥ Valued at \$5.7 billion per year
- ♥ 89% of people 65+ want to stay in own home.

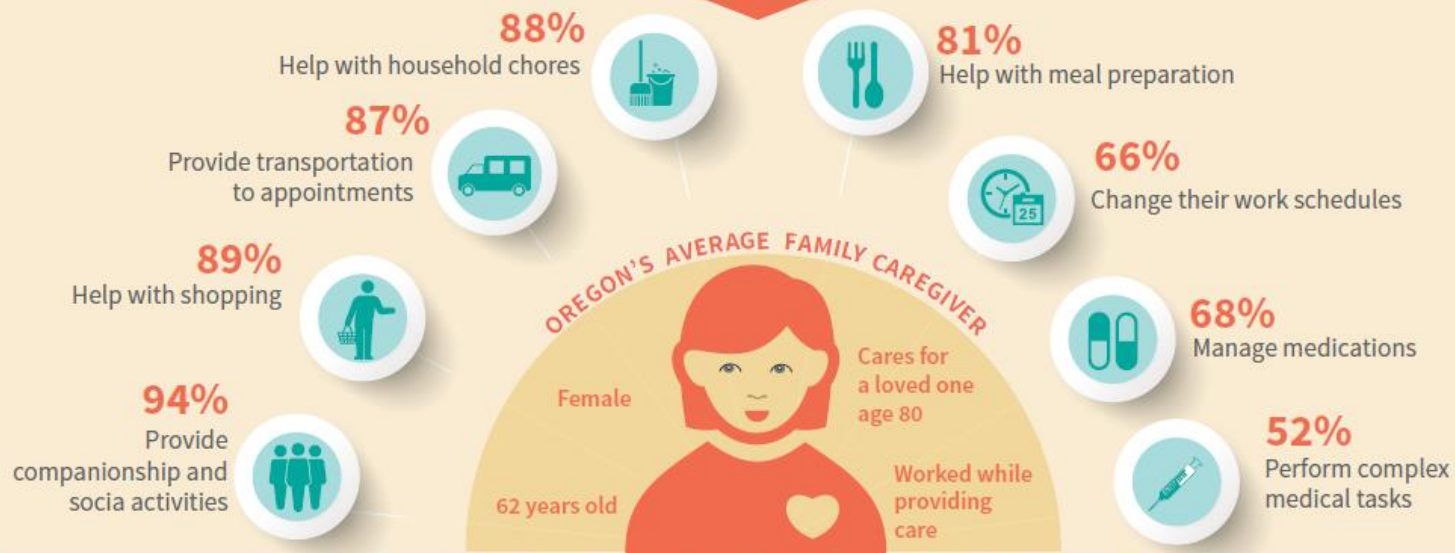
OREGONIANS ARE FAMILY CAREGIVERS

Across Oregon family caregivers take on big responsibilities, helping their parents, spouses, and other loved ones live at home. AARP recently surveyed 900 Oregon registered voters age 40+ about caring for their families. Here's what we learned:

49%  Current or Former Caregivers

53%  Likely Caregivers in the Future

Oregon family caregivers often have huge responsibilities. They:



Oregon family caregivers believe it's important to help their loved ones live independently at home, but they also face challenges:

57%
Use their own money to help.

71%
Emotionally stressed because of caregiving responsibilities.

64%
Stressed trying to balance job and family.

51%
Find it hard to get enough rest.

Source: 2019 Survey of 900 Oregon Registered Voters Aged 40-plus. Margin of error is ±3.27% <https://doi.org/10.26419/res.00259.021>

Respite is an identified unmet need

- ♥ 2014 AARP LTSS Scorecard ranked OR 41st for caregiver stress
- ♥ State Plan for Alzheimer's Disease in Oregon noted need for respite
- ♥ LTC 3.0 (SB 21) noted need for respite

What can help caregivers

- ♥ Training – Oregon Care Partners, Powerful Tools, etc.
- ♥ Support groups
- ♥ Paid family leave/flexible work schedules
- ♥ Some short breaks from caregiving (respite)

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Does it really help?

In a survey conducted by the Oklahoma Respite Resource Network:

- **88%** of caregivers agreed that respite allowed their loved one to **remain at home**
- **98%** of caregivers stated that respite made them a **better caregiver**
- **98%** of caregivers said respite increased their ability to provide a **less stressful environment**
- **79.5%** of caregivers said respite contributed to the **stability of their marriage**

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How do people get respite?

- ♥ Volunteer programs, friends, family
- ♥ Adult Day Programs
- ♥ Home care (agencies, Home Care Commission)
- ♥ Short term stays in long term care communities

Lack of Access

- ♥ About 20 Adult Day Centers in Oregon
- ♥ Too few home care workers
- ♥ LTC settings don't want short term stays

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Cost

- ♥ Home care can be about \$25 an hour
- ♥ Adult Day Centers less expensive, but still out of reach for many (about \$65-75 a day average)
- ♥ Short term stays in LTC is pricey for both consumer and facility

How is respite paid for?

- ♥ Out of pocket
- ♥ Medicaid – based on individual needs assessment and must qualify
- ♥ LTC Insurance – About 4.8% of Oregonians have it
- ♥ Veterans Administration (VA)
- ♥ Oregon Project Independence (OPI) - \$49,000 per biennium to Adult Day Programs
- ♥ Older Americans Act – Family Caregiver Support Program
- ♥ Some non-profits – like PRO, ALS, MS Society

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Awareness

- ♥ Don't identify as caregiver
- ♥ Unaware options exist nearby
- ♥ Unaware of the benefit of it
- ♥ The term "respite" doesn't connect
- ♥ Lack of conversation as a whole about caregiving

Resistance to using respite

- ♥ “I’m the only person who can...”
- ♥ “I promised mom we wouldn’t...”
- ♥ “Those places just plop people in front of TVs”
- ♥ “I don’t want some stranger coming into my home...”

Oregon Caregiver Respite Workgroup

- ♥ Formed after Respite Summit in April 2016
- ♥ Stakeholders from private, public, nonprofit sectors, including caregivers
- ♥ Reviewed research and literature

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Oregon Caregiver Respite Workgroup

- ♥ Held 14 community meetings around Oregon in June/July 2016



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Oregon Caregiver Respite Workgroup

♥ Key findings

- ♥ Emotional stress was top issue for most, but physical and financial stresses were noted by a majority, as well as lack of access to resources.
- ♥ A majority did not know about the ADRCs, even though many people who attended work for them
- ♥ People interested in all models – home care, adult day, short term stays

Oregon Caregiver Respite Workgroup

♥ Key findings (cont.)

- ♥ “Respite” doesn’t connect. “Short break” top, but “caregiving relief” also popular.
- ♥ Portland Metro and I-5 corridor said biggest barrier is not knowing where to find services.
- ♥ Elsewhere, top concern was lack of services.
- ♥ Cost a major concern across the state.
- ♥ Personal resistance also a major concern.

Oregon Caregiver Respite Workgroup

- ♥ Report published in November 2016
- ♥ Oregon Legislature Passed HJM 4 in 2017 which honors family caregivers, says the legislature will consider the work of the Workgroup, and urges Congress to pass the RAISE Family Caregivers Act

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Work Group Recommendations

♥ Education and Awareness

- ♥ Public awareness campaign about caregiving, value of getting breaks, and how to find respite. Need to use different terminology.
- ♥ Work with trusted messengers like medical providers to provide information about why to use respite and where to get it.
- ♥ **Work to encourage veterans to apply for benefits**
- ♥ **Improve data collection and analysis about respite**

Work Group Recommendations

- ♥ Increasing the supply of providers
 - ♥ **Revisit Adult Day Center rules (recently finalized)**
 - ♥ **Continue work on workforce development of home care workers**
 - ♥ Explore the creation of a new overnight model
 - ♥ Explore streamlining process for overnight stays in LTC settings while preserving protections

Work Group Recommendations

- ♥ Increasing the supply of providers (cont.)
 - ♥ **Explore colleges in underserved areas setting up programs, or collaborating with community partners**
 - ♥ Explore hospitals/CCOs developing programs or collaborating with community partners
 - ♥ **Explore using public funds for alternative models of respite, such as mobile programs, camps, etc.**
 - ♥ Provide funding for volunteer programs like Senior Companions

Work Group Recommendations

- ♥ **Make respite more affordable**
 - ♥ Expand funding for Family Caregiver Support Program and Oregon Project Independence considerably (**protected funding**)
 - ♥ *Explore a Medicaid 1115 waiver that would allow Oregon to provide respite to up to 400% of poverty level*
 - ♥ **Encourage employers to provide caregiver supports**
 - ♥ Create funding specific to “emergency respite” and establish protocols for making it available

Federal Activity

- ♥ RAISE Family Caregivers Act has been passed by Congress, signed into law.
- ♥ DHHS dragging their feet for implementation

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- ♥ Download the report at action.aarp.org/oregonrespite

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