



Caring for the Caregiver

A presentation as part of the Pierce County ADRC
"Hot Topics" series

MATTHEW M. SANTELLI
EDUCATION AND OUTREACH SPECIALIST
PIERCE COUNTY AGING AND DISABILITIES RESOURCE CENTER



07/06/2023 Pg. 1

1

Disclaimer

The information provided during this presentation is not intended to serve as an exhaustive list of caregiver situations. Caregivers needing support should consult with their physicians, family members, and other trusted individuals to develop a plan for self-care.



07/06/2023 Pg. 2

2

How do we determine who is a caregiver?



- Today we will consider unpaid family and friend caregivers.
- A caregiver is giving the care and a care receiver is getting the care,
- The definition of “what is a caregiver” changes over time as family dynamics, the economy, and our longevity changes. Technological changes have also imposed an additional burden on caregivers, along with greater risks of financial exploitation that caregivers must monitor. “Giving care” as a caregiver can be defined in many different aspects, as noted on the following slides.



07/06/2023 Pg. 3

3

Caregiver duties include, but are not limited to:



- Managing care receiver finances including paying bills, filing taxes, shielding against financial scams;
- Understanding and effectively using online platforms for access to care receiver bank accounts, investment accounts, tax filing, and email communication with friends, family, and professional service providers;
- Purchasing and delivery of groceries and household items;
- Scheduling/transportation to medical/dental/vision appointments;
- Housekeeping services including vacuuming, sweeping, laundry, bathroom and kitchen cleaning, yard maintenance, scheduling of furnace/plumbing/electrical maintenance/phone/computer maintenance and repairs;
- Motor vehicle maintenance and cleaning;
- Purchase/installation of supportive medical equipment at home;
- Prompts and direct assistance for care receiver personal hygiene including dressing, bathing, toileting, foot care, medication management, meal preparation, vision care, dental care;



07/06/2023 Pg. 4

4

More caregiver duties



- Locating, understanding, and filing for benefits including Social Security retirement/disability, Medicare/Medicaid, and so on;
- Locating, understanding, and filing for Durable Power of Attorney forms, Protective Payee forms, Advance Directives, POLST Forms, Last Will and Testament, and so on;
- Emotional support and companionship;
- Having meals together;
- Watching TV programs or sports together;
- Working in the yard together;
- Taking walks together;
- Car rides together;
- Attending faith services together;
- Arranging the COVID-19 vaccine for caregiver and care receiver at 253-649-1412.



07/06/2023 Pg. 5

5

How did I know that I had become a caregiver for my parents?



I knew that I had become the caregiver for my parents when the activities I was doing with my parents were no longer the things I *WANTED* to do *WITH* them, but instead were the things I *NEEDED* to do *FOR* them.



07/06/2023 Pg. 6

6

Caregiving by the numbers



- In the United States alone, **millions of people provide support and care to ill or impaired loved ones** including parents, spouses, children, and non-relatives. Special care is necessary for those who live with limited physical, mental, or cognitive abilities.
- The U.S Census Bureau and Center for Disease Control both note that 1 in 5 Americans lives with a disability totaling 22% of the U.S population.
- About 13% live with a mobility disability.
- 10.6% have a severe disability that affects concentration, remembering things and making decisions.
- Another 6.5% experience difficulty with independent living.
- 4.6% are blind or nearly blind.
- 3.6% cannot perform everyday self-care needs like bathing or dressing.
- With the rise in the number of disabled people in the US, caregivers are needed now more than ever before, and the challenge often falls upon unpaid caregivers.



07/06/2023 Pg. 7

7

More caregiving by the numbers



In general, unpaid caregivers make up 43.5 million people in the United States. The amount of people in unpaid care roles continue to increase for both child and adult patients. When caring for an adult age 50 or older, about 34.2 million Americans will take an unpaid caregiver role.

More debilitating conditions like Alzheimer's or other forms of dementia cause about 15.7 million family caregivers to step into unpaid support roles lacking proper training.

Age

Caregivers tend to vary in age much more than care recipients. While 48% of caregivers are 18-49 years old, only 14% of patients fall into the same age range. The average age of a caregiver sits at about 49 years old. This could reflect parents living longer and adult children then becoming caregivers for their parents.



07/06/2023 Pg. 8

8

Even more caregiving by the numbers



Gender

The [Institute on Aging](#) found that women are more likely to be caregivers. They make up about 75% of all caregivers. Female caregivers spend up to 50% more time with their care receivers than male caregivers.

Race

The [National Alliance for Caregiving](#) notes that Latin-Americans are more likely to take on the role of caregiver when compared to other groups. In fact, 21% of caregivers are from the Latin-American community. African Americans the same at 21%, Asian Americans at 19.7% and finally, White Americans make up 16.9% of caregivers

The LGBTQ+ Community

A report called [Out and Visible: The Experiences and Attitudes of LGBT Older Adults](#) details the LGBTQ community's experiences with aging. LGBT male caregivers report an average of 41 hours spent in their caregiving roles. In comparison, heterosexual men report an average of 29 hours.



04/06/2023 Pg. 9

9

Challenges facing caregivers



Healthcare

Due to new technology and modern medicine, **the number of older adults who need care is rapidly growing.** In fact, the fastest growing group of people in the United States are those who are 80 years or older. This leaves fewer young family members to provide adequate care and support for elders.

Furthermore, about half of caregivers are employed, which makes adequate care even more difficult to provide. Dual income households are increasingly more common, leaving less time for caregiving. People are having fewer children or none at all, there are higher divorce rates, more people are opting out of marriage, and blended families are growing.

All of these factors mean that **fewer people can act as caregivers** for family members and loved ones. If patients do not have a family member to care for them, they are forced to pay privately for care in the home, apply for government sponsored care in the home, or seek placement in a care facility. Professional care facilities are often the only option for family members seeking consistent quality care for loved ones.



07/06/2023 Pg. 10

10

More challenges facing caregivers



Physical, Emotional and Mental Health

Caregivers endure physical, emotional, and mental health complications at an increasingly high rate. Of this group, family caregivers who support older adults are most likely to experience depression, anxiety, and social isolation. Between 40-70% of caregivers live with significant depressive symptoms.

Anxiety and depression are known to be prominent among caregivers, and as the patient's functional abilities decline, the caregiver's depression worsens. These higher levels of depression typically occur when someone is caring for a patient with dementia. In fact, 30-40% of dementia caregivers experience strong emotional stress levels. Physical health takes a toll, too. Caregivers are at a heightened risk for elevated levels of stress hormones and experience higher rates of chronic disease. An increase in stress puts caregivers at risk for increased drug and alcohol use. Caregivers are more likely to use prescription and psychotropic drugs than non-caregivers.

Lack of preparation/understanding of LTC planning for home or facility care

Caregivers often neglect long-term care planning due to their lack of knowledge of financial options to pay for care, uncertainty about different types of care programs, and feelings of obligation to the care receiver.



07/06/2023 Pg. 11

11

Two examples of caregiver situations



A mother with three chronically disabled sons

Example of a mother caring for three adult sons, all of whom were mentally ill. At age 62, she became ill very quickly and died, failing to manage her own health while devoting herself to caring for her sons. After months of struggle trying to live on their own, all three sons ended up living in separate group homes for the mentally ill.

A husband needing cancer treatment caring for a disabled wife and disabled son

Example of a husband caring for a chronically ill disabled wife and developmentally delayed son. He became ill himself from cancer and could not undergo life-saving treatment while caring for himself and caring for his wife and son. With the support and guidance of his cancer treatment social worker, he arranged for his wife to move to an Adult Family Home for care. The husband survived and all of them thrived, once all were receiving the proper care.

Overall, 30% to 70% of caregivers die before their care receivers die.



07/06/2023 Pg. 12

12

Some ideas to make the home of the care receiver safer and more accessible



- Proper heating/cooling systems, well-maintained with safety covers for thermostats.
- Grab bars, ramps, adjustable beds, lift recliner chairs, door alarms.
- Locks on access to stairwells, electrical panels, water heaters.
- Removal of car keys from the home.
- Shower chairs, bath benches, detachable shower heads, toilet seat risers, shoe horns.
- Medication containers in a safe place, walkers for in the home, walkers for outside the home, wheelchairs, crutches, different types of canes, adjustable beds, power lift chairs.
- Securing and/or eliminating loose carpets and throw rugs.
- Weighted utensils, colored plates with food guards, smoke detectors (monitored if possible), amplified phones, closed caption phones, door alarms.
- Personal Emergency Response systems, safe return bracelets, location trackers for shoes, reminder devices with family voice recordings.
- Robotic pets and robotic babies for dementia clients.

More useful ideas at Alzheimer's Store, www.alzstore.com or 1-800-752-3238.



07/06/2023 Pg. 13

13

Some important health and safety tips for caregivers



- First AID classes,
- Fundamentals of caregiving classes,
- Back and leg and arm supports,
- Private caregivers,
- Respite care in the home or outside the home at Adult Day Health programs,
- Relaxation techniques such as yoga, meditation, aromatherapy, massage, and
- Having the necessary documents in place for Durable Power of Attorney for Health Care and Financial decision-making, POLST forms, Advance Directives for Health Care, Last Will and Testament, Burial/Cremation Plans.



07/06/2023 Pg. 14

14

Even more important health and safety tips for caregivers



- Learn and use stress-reduction techniques, e.g. meditation, prayer, yoga, Tai Chi.
- Attend to your own healthcare needs.
- Get proper rest and nutrition.
- Exercise regularly, even if only for 10 minutes at a time.
- Take time off without feeling guilty.
- Participate in pleasant, nurturing activities, such as reading a book, taking a bath.
- Seek and accept the support of others.
- Seek supportive counseling as needed, talk to a trusted counselor, friend, or pastor.
- Identify and acknowledge your feelings, you have a right to ALL of them.
- Change the negative ways you view situations to avoid despair.
- Attend a caregiver support group in-person or online.
- For COVID-19 vaccine information including current booster availability, please contact your local pharmacy. Also consider the Influenza vaccine and the RSV vaccine.



07/06/2023 Pg. 15

15

Even more important health and safety tips for caregivers



Vaccine update

All CDC-recommended vaccines and current boosters along with are free of charge or billable at no charge with your Medicare benefit.

Includes Shingles, Influenza, Pneumonia, RSV, Tetanus, COVID-19, others.

If you test positive for COVID-19, talk to your physician about treatment with Paxlovid.



07/06/2023 Pg. 16

16

Help with Medicare questions



Washington Statewide Health Insurance Benefits Advisors (SHIBA)

- A division of the Washington State Office of the Insurance Commissioner.
- Statewide phone contact: 1-800-562-6900 and website address: <https://www.insurance.wa.gov/contact-shiba>.
- Pierce County phone contact: 253-212-3519 and website address: <http://www.soundoutreach.org/>.
- Helping people of all ages and backgrounds with their Medicare questions and options.



07/06/2023 Pg. 17

17

Help with legal documents



WashingtonLawHelp.org

- Their website is maintained by staff at the Northwest Justice Project.
- Website for information: www.washingtonlawhelp.org and for free legal help: <https://nwjustice.org/get-legal-help>.
- Washington Law Help offers free civil legal services for low-income persons and elders in Washington. Their site's legal education materials and tools give you basic information on a number of legal problems, and in some cases, detailed instructions and forms to help you represent yourself in court.



07/06/2023 Pg. 18

18

More help with legal documents



WashingtonLawHelp.org (cont'd)

From the website, click on "Legal Topics" and then "Planning Ahead/elders":

- Alzheimer's / Dementia
- Power of Attorney
- Guardianship of an Adult
- Planning for Death
- Healthcare for elders
- Social Security



07/06/2023 Pg. 19

19

Local caregiver support programs



Pierce County Aging and Disability Resource Center provides three types of caregiver programs available to support caregivers and care receivers in their homes.

1. **COPES program:** Medicaid-funded program to provide in-home care for elder/disabled clients unable to meet their daily personal care needs.
2. **TSOA program:** Medicaid-expansion program to provide more limited in-home care for clients ages 55 and over unable to meet their daily personal care needs.
3. **FCSP program:** Non-Medicaid program to provide support and respite care to unpaid family caregivers who provide care to an adult friend or family member.



07/06/2023 Pg. 20

20

Even more caregiver support programs



- **MSHH Donor Closet:** located 3635 So Lawrence St, Tacoma. Phone 253-327-1033. Website <http://www.mshh-donorcloset.com/>
- **The Alzheimer's Store:** Phone 1-800-752-3238 Website www.alzstore.com
- **Washington Connection:** Website <https://www.washingtonconnection.org>
- **Trualta (Caregiver Information):** Website <https://wacaregivingjourney.com>
- **Dementia Legal Planning Project:** Phone 425-780-5589 Website <https://www.dementialelegalplanning.org>
- **Pierce County Veterans Program:** located 3602 Pacific Ave, Suite 200, Tacoma. Phone 253-798-7449 Website <https://www.piercecountywa.gov/veterans>
- **WA Cares (Washington Long-Term Care Trust Act)** for active workers only! Website <https://wacaresfund.wa.gov/>



07/06/2023 Pg. 21

21

For more Information, here are some useful resources:



Pierce County Aging Disabilities Resource Center at
253-798-4600 / www.pierceadrc.org (information on COPES, TSOA, and the Family Caregiver Support Program)

Pierce County Long-Term Care Ombudsman (information on care facilities) at
253-798-3789

Caregiver support group information at:
www.multicare.org (Multicare Good Samaritan caregiver support group in Puyallup meets on first Wednesday every month, contact Brian Holtvedt at brian.holtvedt@multicare.org)
www.chifranciscan.org
www.alz.org



07/06/2023 Pg. 22

22