



The Missing Link: Integrating Caregivers for Better Health Outcomes

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How's your morning?



Why Are We Here?

Goal:

Equip caregivers to navigate their caregiving journey with Resilience and Clarity.

Professionals will enhance their understanding of the complexities caregivers face, enabling them to provide targeted support that fosters caregiver well-being and improves health outcomes for the whole family.



It all started when...





Self-Realization: Embracing a New Life

**And we found others like us...
about 53 million give or take.**





Eureka: Caregivers are the missing link

Understanding Family Caregivers



- Definition:
 - "Informal" caregivers, also called family caregivers, are people who give care to family or friends usually without payment. A caregiver gives care, generally in the home environment, for an aging parent, spouse, other relative, or unrelated person, or for an ill, or disabled person.
 - "The Invisible Workforce"
- Connection to Care Recipients:
 - Often have a personal and emotional connection those they care for.
 - This connection goes beyond tasks and involves relationships.





Who Are They?

- By the Numbers:
 - 53M – Unpaid caregivers (2020)
 - 15.4M – Active duty & veteran caregivers (2024)
 - 5.4M – Caregiving youth (2020)
- Demographics:
 - Gender
 - Race
 - Culture
- Critical role in healthcare:
 - Impact clinical outcomes
 - 26 hr/wk average
 - 600B in economic impact

Caregiver Roles and Responsibilities

TO DO LIST

- **Advocacy and Communication:**
 - Advocate, Communicate with Healthcare Providers, Ensure recipient's needs are met
- **Safety:**
 - Ensure safety, Identify/Minimize Hazards
- **Financial and Legal Responsibilities:**
 - Manage Finances, Legal Matters, Bill Payment and Insurance
- **Care Coordination:**
 - Organize care, Coordinate healthcare, Doctor's appointments
- **Record Keeping:**
 - Maintain records, Treatment progress, Medical history
- **End-of-Life Care:**
 - Provide comfort, Palliative and Hospice care, Support
- **Emotional Well-Being:**
 - Nursing emotional health and managing emotional needs
- **Assistance with Activities of Daily Living (ADLs):**
 - Bathing, Dressing, Grooming, Toileting
- **Medication Management:**
 - Administer, Tracking dosage & Schedule
- **Monitoring Health and Vital Signs:**
 - Temp, Blood Pressure, Vitals
- **Meal Planning and Preparation:**
 - Meal planning, Grocery shopping, Cooking
- **Mobility Support:**
 - Transfers, Mobility aids, Assistance with mobility
- **Emotional and Social Support:**
 - Companionship, Emotional support, Social Interaction
- **Housekeeping and Home Maintenance**
- **Transportation**



The Impact of Caregiving

- Personal
- Professional
- And everything in between!

The Impact of Caregiving: Emotional, Physical & Mental Challenges



- Emotional Impact:
 - Sadness, anger, helplessness, grief
- Physical Symptoms:
 - Fatigue, sleep disturbances, frequent illness
- Mental and Cognitive Symptoms:
 - Forgetfulness, lack of concentration, feeling overwhelmed
- Guilt & Resentment:
 - Self-neglect, isolation, withdrawal

The Impact of Caregiving



- Employment
 - Absenteeism, presenteeism, PTO, lost promotions, reduced hours, job loss
- Relationship
 - Strain, conflict, isolation, care recipient, loss of family and friends...and yourself
- Spiritual
 - Challenge your beliefs or practices
 - Crisis of faith / disconnect from spiritual community
 - Impact overall sense of purpose and well-being

NEW REPORT: FAMILY CAREGIVERS STRUGGLING FINANCIALLY

\$7,242

Average Out-of-Pocket Expenses for Family Caregivers in 2021

Family Caregivers in the U.S. Provide \$600 Billion in Unpaid Care

Source: Valuing the Invaluable 2023 Update

More than three in four family caregivers (78%) are incurring out-of-pocket costs as a result of caregiving

78

\$10,525

Average expenses for caregivers with two or more work-related strains

26

Family caregivers are spending, on average, a quarter of their income on caregiving activities

26%

AFRICAN AMERICAN

HISPANIC/LATINO

ASIAN AMERICANS & PACIFIC ISLANDERS

\$6,746

Average Out-of-Pocket Expenses in 2021

34%
of income on average spent on caregiving activities

\$7,167

Average Out-of-Pocket Expenses in 2021

47%
of income on average spent on caregiving activities

\$8,368

Average Out-of-Pocket Expenses in 2021

22%
of income on average spent on caregiving activities

The Impact of Caregiving: Financial

Other Obstacles Faced by Caregivers

- Resource scarcity and access to support
- Impact of Social Determinants of Health (SDoH) on caregiving
 - Conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.
 - 5 Domains
 - “Get Upstream” to improve health and reduce health disparities



The Need for Integration

- Why caregivers should be included in service planning
- Shifting from a peripheral to a central role in health care
- Benefits of engaging caregivers in the health ecosystem
 - Outcomes
 - Satisfaction
 - Cost Savings
 - Extend resources and community capacity



Strategies for Integration

- Identify caregivers early and recognize caregivers as part of the team
- Involve caregivers in decision-making
- Establish a welcoming environment
- Provide training and resources
 - Equip caregivers with necessary skills to feel confident and competent. Then validate!
- Connect or create support networks
 - Facilitate peer support



Question For the Group

- What has been your experience integrating caregivers into the system?
- Other integration ideas?



Enhancing Support for Caregivers

- Respond to their needs (Personal/SDoH)
- Services that integrate caregiver support
 - Respite, Coaching, Training, Parent Education
- Role of human service professionals and volunteers
 - Advocate for caregiver rights and inclusion in all care discussions
 - Connect to resources – Paid/Unpaid
- Strategies for enhancing communication and collaboration
 - Establish regular check-in feedback mechanisms
 - Listen and be curious



Support for One, Support for All



- Government entities and programs
- Organizations who support caregivers
- Training
- Search engine 101
- Online groups
- Technology apps and devices
- Newsletters
- Caregiver Podcasts! Seriously!
- ASK! A friend or a stranger

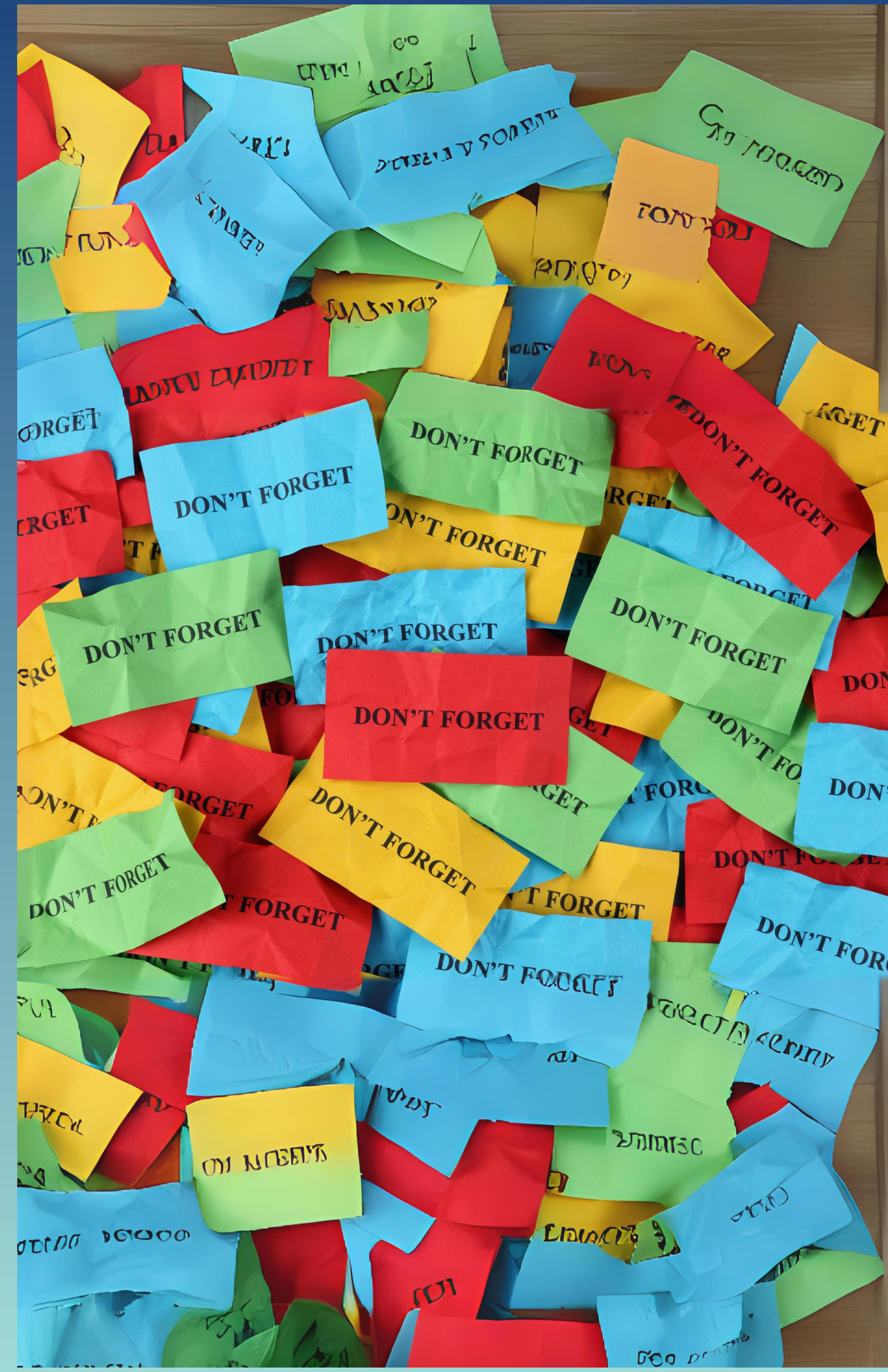
Questions For the Group

- What's missing?
- What does support look like to you?



Key Takeaways

- Recognition of caregiver value.
- Acknowledge the challenges caregivers face and offer supportive services and resources.
- Implement practical strategies to actively involve caregivers in care planning and decision-making processes.
- Advocate for the creation of robust support networks and resources that empower caregivers.



Let's Talk



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**Some Poppin'
Resources for
Caregivers
(and YOU!)**



Caregiver Resource

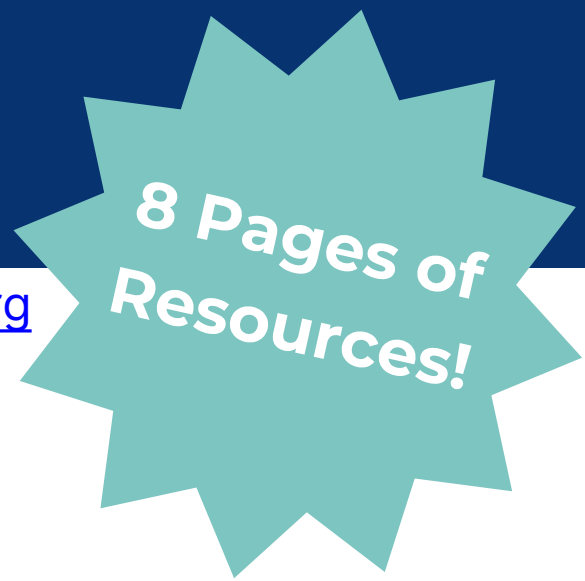
The podcast is based on the caregiving experiences of me and my sisters, who care for our mom, who has been living with Parkinson's Disease for over 20 years, and my husband, an HPV related Head and Neck Cancer survivor.

Our reluctance is not based on a lack of desire to support these family members but on our feelings of doubt, insecurity, guilt, and fear of failing those we love. Our first episode dropped on January 24, 2023.



**Relate.
Educate.
Inspire.
Laugh.**





Benefits Checkup

BenefitsCheckUp® connects millions of older adults and people with disabilities with benefits programs that can help pay for health care, medicine, food, utilities, and more by simply entering your zip code.

www.benefitscheckup.org

CaringBridge

CaringBridge is a FREE social network keeping families connected during any type of health event.

www.caringbridge.org

USA.gov Caregiver Support

This resource helps find programs and services from the government and around your local community to help both the caregiver and care recipient.

www.usa.gov/disability-caregiver.com

National Council on Aging

NCOA provides resources, tools, and best practices based on your role as caregiver or care recipient.

www.ncoa.org

AARP

AARP is a nonprofit, nonpartisan organization that empowers people to choose how they live as they age.

www.aarp.com

Administration for Community Living

The Administration for Community Living was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities.

www.acl.gov

Caregiving.com

Caregiving.com is an excellent resource for support, forums to meet other caretakers, and helpful articles that assist in the everyday issues of family caregiving.

www.caregiving.com

Eldercare Locator

A public service of the U.S. Administration on Aging connecting you to services for older adults and their families.

www.eldercare.acl.gov

Care.com

Care.com helps families source independent caregivers for short and long term in home care.

www.care.com

Eldercare Solutions

Elder Care Solutions helps families face the challenges of long-term care. We empower families by providing a bird's-eye view of all your options for facing your unique long-term care situation.

eldercaresolutionsinc.com

Find Balance while Caregiving: Self-Care

Self-Care: The deliberate and purposeful actions individuals take to promote their own physical, mental, and emotional well-being.

Self-Care as a Foundation: Is a cornerstone of mental health.



Self-care can include activities such as:

- exercise
- relaxation
- healthy eating
- sleep
- hobbies
- social connections
- seeking professional support
- other practices that contribute to a person's overall health and happiness.

What does balance look like?

- **Pursue Personal Interests:** Carve out time for personal interests and hobbies to maintain a sense of self and personal fulfillment.
- **Respite Care:** Utilize respite care services to take breaks from caregiving, recharge, focus on well-being and engage in activities that bring joy and relaxation.
- **Regular Checkups:** Caregivers should prioritize their own health by attending regular checkups and addressing any health concerns promptly.
- **Open and Effective Communication with Loved Ones:** Clear and open communication with care recipients is crucial to understanding their needs and providing quality care.
- **Setting Boundaries:** Establish clear boundaries to avoid becoming overwhelmed. Recognize your limits and learn to say no when necessary.
- **Remembering the Relationship:** Sometimes you NEED to be a spouse, mother, daughter, son, father.
- **Finding, Accepting and Embracing your new normal.**



Strategies: Survive & Thrive

Seek Support: Emotional support from friends, family, or support group can provide a valuable outlet for expressing emotions and concerns. Therapy or counseling can be highly beneficial for caregivers to address emotional challenges. Professional support offers a safe space to discuss and manage emotions effectively.

Practice Mindfulness and Relaxation Techniques: Mindfulness exercises techniques include meditation, deep breathing, and progressive muscle relaxation. Daily relaxation routines, even if just for a few minutes can reduce stress and provide moments of respite.

Understand and Cope with Caregiver Grief: Caregivers often experience a form of grief as they witness the decline in their loved one's health. This grief can manifest as sadness, loss, and anticipatory grief.

Allowing Emotions: It's essential for caregivers to acknowledge their grief and allow themselves to experience the range of emotions it brings. Suppressed emotions can lead to increased stress.

Deal with Guilt and Stress: Many caregivers experience guilt, feeling that they should be doing more or making different choices. Practice stress management techniques such as deep breathing, mindfulness, and exercise to reduce the emotional strain of caregiving.



Feeling Frazzled? Take 10 “Go To” Strategies



Deep Breathing: Take a moment to focus on your breath. Inhale deeply for a count of four, hold for a count of four, and exhale for a count of four. Repeat this several times to calm your nervous system.

Mindful Meditation: Spend a few minutes practicing mindfulness meditation. Focus on your breath and let go of intrusive thoughts. You can use guided meditation apps or follow your own breathing rhythm.

Progressive Muscle Relaxation: Tense and then release each muscle group in your body, starting from your toes and working your way up to your head. This technique can help release physical tension and stress.

Quick Stretching: Stand up and stretch your arms, legs, and back for a few minutes. Stretching can help relieve physical stress and improve blood circulation.

Visualization: Close your eyes and imagine a peaceful and calming place. Visualize yourself there, focusing on the sights, sounds, and sensations.

Mindful Walking: Take a short walk, focusing on the sensation of each step. Pay attention to the world around you, whether it's nature, architecture, or even just the sky.

Digital Detox: Disconnect from electronic devices for a short period. The break from screens and notifications can reduce stress and anxiety.

Mini Yoga Session: Practice a few yoga poses or stretches to release physical tension and promote relaxation.

Coloring or Doodling: Engage in some creative activities. It can be a simple yet calming way to de-stress.

Breath Counting: Count your breaths and aim to reach a specific count, like 10 breaths in a minute. This can help regulate your breathing and reduce stress.

Aromatherapy: Use essential oils or scented candles to create a calming atmosphere. Scents like lavender, chamomile, and eucalyptus are known for their relaxation properties.

Listen to Calming Music: Put on your favorite soothing music for a few minutes. Slow tempo and instrumental pieces can be particularly relaxing.

Quick Journaling: Jot down your thoughts and feelings in a journal or on a piece of paper. Expressing your emotions can be a cathartic release.

Positive Affirmations: Recite positive affirmations to yourself. Repeating positive statements can help shift your mindset and reduce stress.

Laughter: Watch a short funny video or call a friend who can make you laugh. Laughter is a great way to reduce stress and improve mood.

"Take 10" NRV Caregiver Conference Survey Summary

- Awareness moment
- Bible Study
- Breathe
- Breathing Exercises
- Brush my Hair
- Cleanse my face & Hydrate my skin
- Close eyes and take a deep breath
- Close my eyes
- Close my eyes and zone out
- Coffee and Facebook (mentally disconnect for a second)
- Crossword Puzzle
- Dance
- Daydream
- Deep Breathe
- Draw and Relax
- Eat a snack
- Eat a treat
- Fiddle Around
- Garden - pull weeds
- Go for a walk
- Go outside - walk, stand in the sunshine, feel fresh air, hear the birds
- Go outside and breathe Deeply
- Go outside and do nothing
- Go outside and ground myself (feet bare on the earth and deep breathe /pull in fresh air)
- Go outside and look at my flowers
- Go outside for a walk
- Go outside/enjoy surroundings
- Go outside and appreciate the lawn, trees, plants, shrubs
- Go outside and feel sun on face
- Knit while listening to classical music
- Laugh
- Lay down and close my eyes and reflect/rest
- Listen to music like 80's songs, favorite songs, and Christian music
- Listen, sing, and hum to the music
- Look at cell phone/waste time
- Look at Pinterest
- Make a to-do list
- Meditation
- Pet the cat and dog
- Pet therapy dog and breathe deeply
- Play a game
- Play a mental puzzle game
- Play piano
- Play video games
- Power nap
- Pray
- Qgong Moves
- Quilt / Sew
- Read a book, a poem, the bible, fiction, and positive affirmations
- Reflect on what I read on theology
- Relax on the floor on back
- Remember your purpose
- Renewal of mind via prayer
- Rest
- Scream/cry/breathe and keep going
- Scroll social media
- Self-massage
- Send a positive message to a friend, child or sibling
- Sing
- Sit and relax
- Sit down and turn on my foot massage
- Sit down and turn on tv oldies
- Sit in my car alone in silence
- Sit on couch and use breathing exercises
- Sit on the front porch barefoot or with feet in the grass
- Sit on the porch with plants
- Sit outside
- Snuggle with dog or cat
- Spinal cord breathing
- Stare out window
- Straw breathing
- Stretches, especially back and neck
- Take a bath
- Take a breath and focus on one step
- Take a shower
- Take a walk
- Talk to myself
- Turn to the lord/prayer
- Walk in the woods
- Walk outside and pray
- Walk outside and take a break from everyone
- Watch TV, funny videos, Golden Girls highlights
- Watch sunrise
- Water my plants
- Work in yard & smile at my flowers
- Work on a craft
- Work outside in yard
- Yoga moves
- YouTube shorts

What would you do with 3 to 4 hours?

NRV Caregiver Conference Survey Summary

- Arts, crafts
- Bible study
- Binge watch TV and favorite movies
- Bottle of wine & watch the deer for a couple of hours
- Call and catch-up with friends
- Go to church/be with God
- Clean the house
- Coffee and snack
- Do laundry
- Watch funny YouTube videos
- Get a massage, pedicure, facial and/or haircut
- Get outside
- Go for a hike
- Go on picnic
- Go to a craft brewery after taking a nature walk
- Go to a movie and eat salty buttered popcorn
- Go to animal rescue and donate
- Go to gym
- Go to lunch with my sister-in-law and shop
- Go to the country
- Go to the pool and float in the water
- Go to yoga class
- Go visit family
- Have some hot tea with milk, honey and cookies
- Landscaping/yard work
- Laser tag in woods
- Lay in bed and eat snacks while reading
- Listen to a podcast
- Listen to music
- Long bubble bath with relaxing scents
- Lunch with friends
- Nap, go out to eat favorite food
- Watch Netflix
- NOTHING AT ALL
- Photography
- Play disc golf
- Play tennis
- Play with dogs
- Purge, sort, organize a closet
- Quiet time on the water with music and wine
- Quilt/sew
- Read or listen to a good book (fiction)
- Ride bikes
- Ride motorcycle
- Scroll social media
- Sewing machine time, embroider, or work on something
- Shopping and eating out
- Sit on patio swing
- Sleep
- Spend time with spouse / family
- Study and write
- Take a drive
- Take a long shower
- Take a nap, shower and watch a movie
- Take a walk
- Take a walk in woods by stream
- TV and junk food
- Visit friends
- Walk the dog
- Water Aerobic
- Work on a jigsaw puzzle
- Work on something that brings me peace
- Yard sale (and hit starbucks on the way!)



Best Resources

NRV Caregiver Conference Survey Summary

- Local Area Agency on Aging
- Adult day services
- Alzheimers Support Group in Patrick County
- Brain Injury Services
- Caregiver Action Network
- NRVAAA Caregiver conference
- CarePal App
- Carilion Clinic Hospice
- Church Support Groups / Faith based resources
- Community Partners
- Community for Respite Support
- DARS
- District III info for Alzheimers
- Facebook groups
- Family
- Family physician
- Family physician
- Findhelp.org or Reddit forums
- Google, online
- Group conversations through commonwealth
- Home Health
- Hospice services
- Local caregiver of Parkinsons group – meets once per months
- Local department of social services
- Local rec center (senior programs)
- Medicaid waiver
- Medicare guidebook
- Meet other caregivers who care for LOs with similar diagnosis
- NRVV Disability Resource Center
- Omsbudsman
- Online support groups
- Online support groups
- Palliative Care
- Podcasts
- Professional Contacts
- Respite care
- Conference and events where you can get info
- Support group for families of dementia patients
- Talking to a person who has "been there, done that"
- The Cancer Center
- Right benefit plan to meet the needs of loved one/Care recipient
- there is training available
- VA Navigator site
- VT ECCA
- WIOA

What is the one thing you wish you had known about Caregiving? NRV Caregiver Conference Survey Summary

Number 1: Caregiver care info is out there but you have to look to find it. More help is available than you realize. There are so many resources for individuals of all ages.

- Assisted Living Facilities can disappoint you
- Be an advocate for your loved one – don't be afraid
- Be aware the impact of caregiving can have on your family
- Be kind to everyone
- Becoming a CNA was very helpful
- Use a broker to help select best health plan
- Check out long term care insurance
- Get counseling for yourself to cope
- Don't expect relatives to help
- Engage with hospice sooner versus later
- Find a hotline (Caregiver Action Network)
- Find the best hospital for the medical condition
- Get comfortable answering uncomfortable questions
- Go with the flow.
- Learn to better prepare for the future
- How to navigate getting help; How to get a caregiver
- How to handle financial matters; aspects of estate planning
- How to properly use search engines
- Learn from your own caregiving journey to plan for your own
- Limitations of the Loved One's Health Plan
- Look for support groups
- Pace yourself
- Paid caregiver services through Medicaid
- Qualified Income Trust (QIT)
- Recognize you are not alone!
- Respite/Day Care Programs
- Share your story
- Take stock, Reality checks
- That others are going through the same thing as me!
- There are support groups in my area
- This is a marathon not a sprint
- Treat others as you would want your family to be treated
- Understand hospice care
- Understand legal rules
- Understand more about cancer treatments
- Understand my LO's disease better
- Understand the terms and what to expect from the agencies to hold them accountable
- Use your FMLA
- Wish I had known to ask question to get dementia diagnosis quicker
- You are not alone
- You can't care for others if you don't care for yourself.

What's your *Favorite Guilty Pleasure?*

NRV Caregiver Conference Survey Summary



Hobby Time!

- Crochet
- Exercise
- Video / Online Gaming
- Jet skiing
- Laser tag
- Learn more about plants
- Learn something new on the guitar or write a song
- Play jigsaw puzzles online
- Sit on the porch and knit
- Write/release thoughts

Eats & Treats!

- Chocolate
- Chocolate Ice Cream & a Glass of Wine
- Eat Chocolate and drink Diet Sunkist
- Having a gin and tonic
- Sit, drink glass of wine and eat chocolate
- Have a cup of hot tea with something sweet
- Dark Chocolate
- Wine
- Ice cream
- Reese's Cups
- Get a Milkshake

Personal Time!

- Get a massage
- Aromatherapy
- Pedicure/Manicure
- Get a haircut!
- Paint my nails
- Hot Tub
- Imagine a future after caregiving
- Workout/exercise
- Listen to a podcast
- Listen to music
- Listen to music and sing loud
- Personal dance party
- Time to Read
- Taking time for myself and not feeling bad for doing so

TV & Online Time!

- Watch Days of our Lives
- Watch Instagram videos and laugh
- Watch YouTube videos
- Watch Basketball
- Watch pimple popping videos
- Watch Westerns
- Movies
- Netflix and wine
- Wordle
- Shop on Facebook Marketplace

Go Somewhere!

- Visit a Craft Brewery
- Dinner out
- Enjoy a fun outing with family/ friend
- Shopping
- Read a magazine at Barnes & Noble
- Visit Starbucks
- Go on a motorcycle trip
- Getting away with my Wife
- Go to the lake - Claytor Lake
- Get a tattoo
- Hang out poolside
- Going out to eat / Spend time with my spouse
- Going to the Gym
- Play Tennis
- Watch the Sunset in a Hammock with Wine
- Sit at the barn with cold beer
- Time in Nature
- Staycations (trip to Roanoke, NC, WV)
- Take time to pray and walk for 20 minutes
- Playing with dogs
- Teach others about plants