



NC Department of Health and Human Services

“Give Me A Break!”

NC’s Lifespan Respite Program

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Topics We Will Cover Today

- The what, why, where and how of respite
- A focus on caregivers
- The benefits of respite
- Helping caregivers access and use respite effectively
- The Lifespan Respite Voucher Program
- How to learn more about respite and respite options
 - “Planning and Using Respite” on-line modules as continuing education for recertification

What is Respite?

Respite is a break for unpaid caregivers who provide ongoing care for an individual of any age who needs help, care or supervision due to disability, chronic condition or other special needs. Respite is intended to provide relief to the caregiver.



SOURCE: NC Lifespan Respite State Advisory Team, 2017

Where is Respite Provided/Who Provides It?

- Respite care can be provided at home by:
 - a friend, neighbor, or another family member;
 - a volunteer from a faith-based community or other community organization; or
 - a paid worker from an agency.
- Respite may also be provided in a group care setting, such as a respite center, an adult day care/day health center, or in a residential facility. Day or overnight camps and caregivers' day out programs also provide group respite options.

How do you pay for respite services?

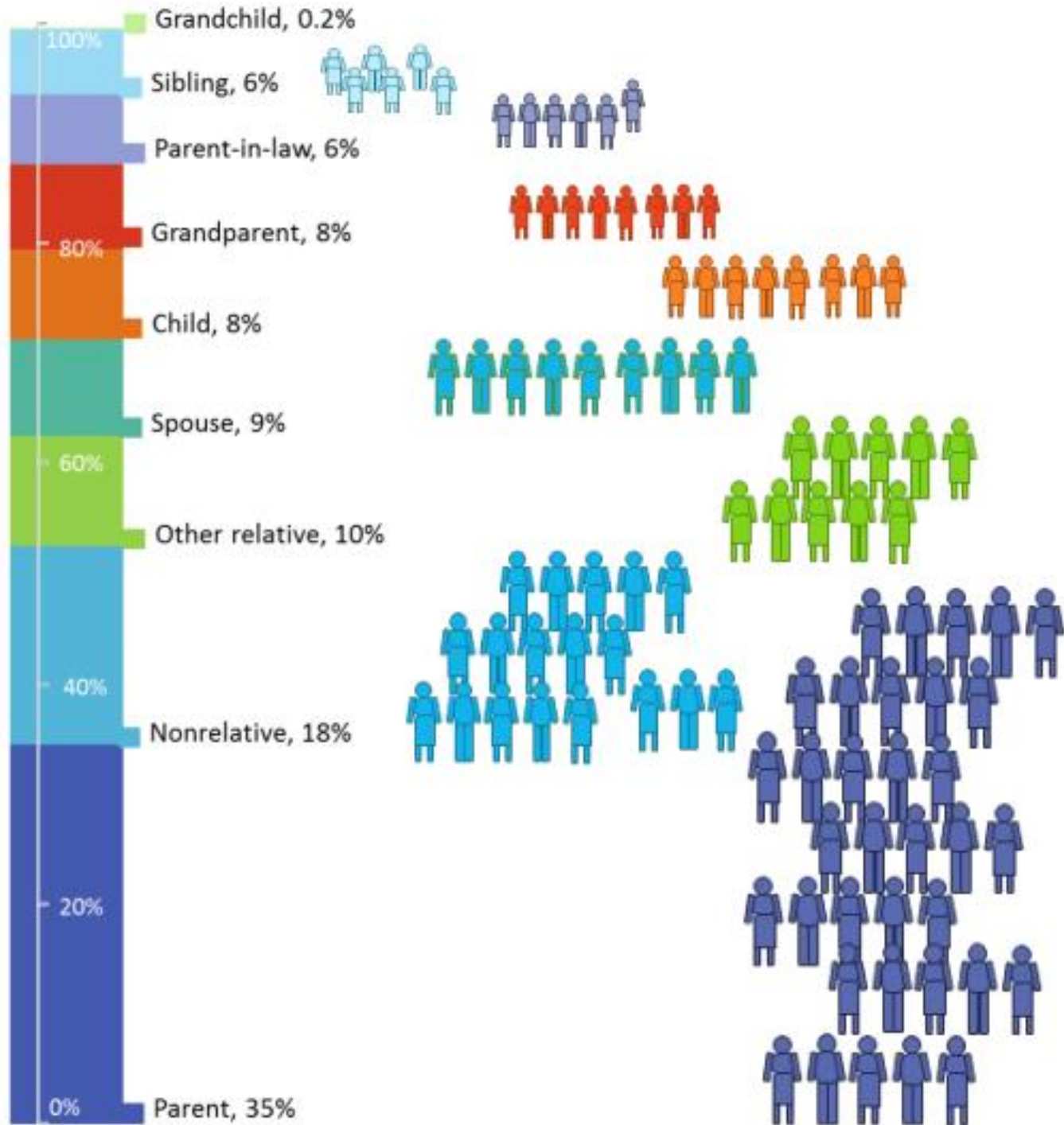
- Private pay
- Hospice Medicare Benefit
- Medicaid Waiver programs
- State Adult Day Care Fund
- Home and Community Care Block Grant
- Family Caregiver Support Program
- Project C.A.R.E.
- Veteran's Administration
- Donations/awards from non-profit organizations
- **Lifespan Respite Program Voucher**



Caregiving in North Carolina

- 1 in 5 adults reported in a recent Behavioral Risk Factor Surveillance Survey that they had been a caregiver to someone with special needs within the previous 12 months.
- About 471,000 NC grandparents age 65+ have primary responsibility for their grandchildren.
- 66% of older persons with chronic diseases are cared for by a family member.
- 71% of adults with intellectual/developmental disabilities in NC live at home (First in Families of NC 2014).
 - 25% of their caregivers are age 65+.

Who receives the care?



What Care Do Caregivers Provide?

- Assistance with personal care needs (e.g., dressing, bathing, bathroom help)
- Household chores (cleaning, meal preparation, laundry, etc.)
- Transportation for shopping, errands, medical appointments
- Medication management
- Communication with health care professionals
- Relaying information to other family members
- Providing emotional support/companionship
- Managing finances
- Providing supervision for safety and/or management of challenging behaviors

Increasing Complexity of Caregiving

- In addition to assistance with ADLs and IADLs, more and more caregivers are performing tasks that nurses typically perform.
- Almost 60% of family caregivers are performing medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions.
- These tasks include:
 - managing medications, including administering intravenous fluids and injections;
 - tube feedings;
 - catheter and colostomy care; and
 - wound care.

SOURCE: Caregiving in the U.S., AARP and National Alliance for Caregiving, 2015

More About Caregivers

- Caregivers can experience profound grief, feelings of anger, guilt, fear and isolation.
- Nearly half are clinically depressed at some point.
- 53% of caregivers who said their health had gotten worse also said the decline has affected their ability to provide care.
- *Not all caregiving is a bad experience.* Many caregivers report surprising rewards and renewals of relationships as a result of their caregiving role.

The Why of Respite: Caregivers Are at Greater Risk



- Depression
- Guilt, anger, denial
- Declines in physical health
- Strained social and family relations
- Sleep disorders
- Anxiety about aging
- Difficulty carrying out responsibilities
- Neglect of self and others
- Less marital closeness
- Work absenteeism and job loss
- Exhaustion
- Loss of friendships

How Respite Can Help

- Gives caregivers time to run errands, spend time with family and friends, go to the doctor, participate in community activities, or just relax
- Reduces stress
- Supports family stability and preserves caregiver-care recipient relationships
- Reduces caregiver burnout and delays out-of-home placements
- Prevents potential abuse and neglect
- Provides care recipients with a break from their usual caregivers and an opportunity to interact with others
- Promotes health and well-being for both caregivers and care recipients

Respite is the most requested service on the caregiver menu, yet a very small number of people use it.

AARP surveys show approximately 85% of family caregivers have never used respite. Why?

- See caregiving as a family duty, not a role they share with others
- Hear about “caregiver services” or “respite” and don’t think they need it
- Report that my “fill in the blank” won’t let anyone else in the house to help
- Feel that no one else can do it right
- Can’t afford to pay for it and can’t find it at low or no cost
- Have tried it and it was still a stressful experience for them
- Are saving it for an emergency
- Have been awarded respite or can pay privately, but can’t find a worker who is adequately trained or available when they want them

Strategies to Help Caregivers Use Respite

- Don't wait for caregivers to self-identify or request respite. Reach out and tell them about the benefits.
- Suggest a trial plan to try out respite care “just in case” it might be needed in an emergency situation down the road.
- Help caregivers plan and set goals for the use of their respite time.
- Learn more about respite and respite options available for caregivers in NC.
- For those caregivers who “fall through the cracks” in eligibility for other services or are on waiting lists, submit a Lifespan Respite Voucher Application.

Helping Caregivers Set Goals

- Studies show that when caregivers use their respite time to do what they intended to do, they may feel less burden and more satisfaction with the caregiving role.
- Use of the tool “Setting Goals to Maximize Your Respite Time” was shown to significantly lower caregiver burden scores in a study done in NC during 2012.

Setting Goals to Maximize Your Respite Time

On this sheet of paper, please write down one to three specific goals of what you would like to accomplish during your respite time this week/month. Your goals can be anything (e.g., sleeping, cleaning, going to lunch with a friend), but they must be attainable during the respite time that is available to you. We recommend that you choose activities that:

- you have always enjoyed doing;
- you did before you became a caregiver but may not have been doing lately;
- have religious or spiritual meaning to you;
- may improve satisfaction with caregiving;
- may reduce the stress you might feel from caregiving;
- may increase your respite time;
- encourage you to use your respite more regularly.

Goals:

How to Learn More about Respite

- Publicly Funded Respite Options for Caregivers in NC
- United Way 2-1-1
- On-line Lifespan Respite Modules



The screenshot displays a presentation slide titled "Planning Principles and Tools" from the North Carolina Lifespan Respite Project. The slide features a central image of a laptop with a yellow pencil resting on it, displaying a website interface. To the right of the laptop, there is a text box that reads: "On the North Carolina Respite Care Coalition website you can click on the link 'Respite Resources for Family Caregivers' to see a document listing statewide resources for all ages. Click on the picture of the site to open it in a new browser window." The slide also includes a navigation bar at the bottom with "PREV" and "NEXT" buttons. On the left side of the slide, there is a "Menu" section with a "Respite" dropdown menu containing various topics such as "Time for a Plan", "What Do Caregivers Know about Why a Plan?", "Local vs Satisfaction", "Respite Best Practices", "How Do Caregivers Use Respite?", "Maslow's Hierarchy", "First Reaction: Barriers & Essential Elements", "Appropriateness/Accessibility", "Affordability", "Accessibility/Availability", "Change is Difficult", "Barriers Good and Bad", "I know...", and "Don't say".

On-line Lifespan Respite Modules

- *Planning and Using Respite: Working with Caregivers across the Lifespan*
 - Introduction: About Caregiving, Caregivers and Respite
 - Engagement and Screening
 - Assessing Caregivers
 - Planning Principles and Tools
 - Planning Examples and Following Up
- As a certified Options Counselor, you can go to <http://tmslearn.unc.edu> and access the modules through your account.
- Remember that these modules count toward Options Counseling recertification.

NC Lifespan Respite Voucher Program

- Part of North Carolina's Lifespan Respite Care Project
- NC has applied for and received six Lifespan Respite grants from the US Administration for Community Living since 2009
- Purpose of the funding has varied from building a respite infrastructure, increasing sustainability of state respite services, enhancing and increasing quality and/or access to respite, to providing direct service dollars to provide more respite to caregivers across the lifespan

Things to Know about Lifespan Respite Vouchers

- The Lifespan Respite Voucher Program reimburses up to \$500 in respite services per year to unpaid primary caregivers caring for an individual of any age.
- The program is consumer-directed: caregivers who are awarded vouchers can choose from a variety of options to provide their respite services.
- The program is intended to serve those caregivers who are “falling through the cracks” because they are unable to access other sources of publicly-funded respite and cannot pay privately.

- The NC Division of Aging and Adult Services contracts with the High Country Area Agency on Aging to manage the Lifespan Respite voucher process.



Applying for a Voucher

- Vouchers are accessed through an on-line application process found at www.highcountryaging.org.
- Applications are not accepted directly from caregivers; they must be completed by a referring agency professional.
- Referring agency professionals are those who work with caregivers in need of respite, including:
 - County Departments of Social Services/LME-MCOs
 - Physicians' offices/hospitals
 - Area Agencies on Aging/ senior centers
 - Schools/Children's Developmental Services Agencies
 - Community agencies
 - **OPTIONS COUNSELORS**

Who is Eligible for a Voucher?

- The caregiver must be 18 years old and a NC resident.
- The caregiver must be providing *unpaid* care for an individual of any age.
- Neither the caregiver nor the care recipient can be receiving ongoing publicly funded in-home care or respite care, including adult day care services.
 - Those who are on waiting lists for these services are eligible.
 - Exceptions can be made if there are emergency situations or special circumstances.

More Voucher Information

- Priority for Lifespan Respite Vouchers is given to:
 - caregivers with the greatest economic need;
 - caregivers who provide direct care for their loved one; and
 - caregivers who have not received a publicly funded respite break within the past 6 months.

- Caregivers must be able to:
 - use the respite voucher within 90 days;
 - screen and hire their own respite provider;
 - pay for services in advance if bill arrives prior to reimbursement; and
 - complete required paperwork (Respite Provider Agreement, Record of Respite Services).

Help Give a Caregiver a Break!

- The Lifespan Respite Voucher application and program description are available on the High Country AAA website.
- Apply at www.highcountryaging.org.
- Look for the services tab at the top, and select “Lifespan Respite” on the dropdown menu.
- Hit green “Apply Now” button at top right side to open application.
- Complete application and hit “Send” at bottom of application.
- A pdf application is available if you prefer to mail.
- Questions??? Call Pat Guarnieri at 828-265-5434, x 139.

Why it matters



- The voucher allowed me to have some relief from caring for my elderly mother. It helped my husband and me take some time away to refresh our own selves. This program is much needed for caregivers as we lose ourselves in caring for our loved ones.
- My respite getaway was to NYC to visit my daughter and her family for Mother's Day.
- Although the respite time went by so fast, it really seemed great to feel normal again. My husband and I were able to get out and do the simple things in life that had been lost to us.
- The time of rest and doing things we might not be able to do without respite care is such a time of regeneration that affects the whole family.

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