Pathways to Respite

FOR THOSE WHO PROVIDE SUPPORT TO AN OLDER ADULT OR SOMEONE WITH A DISABILITY



Pathways to Respite was created with funding from Federal ACL Lifespan Respite Grant 90LRLI0010-02-03 and developed by Informing Families, a resource of the Washington State Developmental Disabilities Council, in partnership with the Washington State Developmental Disabilities Administration, Aging & Long-Term Support Administration, and PAVE, which administers Lifespan Respite WA.



CONTENTS

Who is this Toolkit for?	2
What is Respite?	2
What Does Respite Look Like?	2
Caregiver Stress	3
Start Right Where You Are (quiz)	4
Bringing Someone New into Your Home	5
Medicaid-Funded Services	6
Lifespan Respite Voucher Program	8
Community Resources and Other Options	10
Checklist for New Caregivers	12
Assistive Technology Resources	13





Who is this toolkit for?

The information in this toolkit is for anyone who provides care and support to a family member or friend who is an...

- * older adult
- child or adult with a developmental or other disability
- adult with traumatic brain injury

Although you may have a hard time seeing yourself as a caregiver, that is what you are when you offer support to your family member or friend. Not only does it describe what you do—giving care—many programs use this term for identifying who can receive respite services and other forms of support.

What is respite?

Respite care is a short term break for both you and your family member or friend.

Being a caregiver does not diminish your family member or friend's value or ability to live as independently as possible, but it does acknowledge your need to take time for yourself.

For your family member, respite can provide an opportunity to expand their social support and explore new interests while you take time for yourself.

What does respite look like?

People, Activities, Technology

There are lots of different ways to find respite that fits your and your family member's needs—from paid caregivers to local community resources, smart technology, and simple ways you can have your time freed up to rest or do other things.

In addition to tips and templates for care planning, each section of this toolkit describes the people, activities and technology that may be available for you and your family member with the help of:

- Medicaid Funded Services
- Lifespan Respite WA
- Community Resources and Other Options

Caregiver Stress

Know the signs.

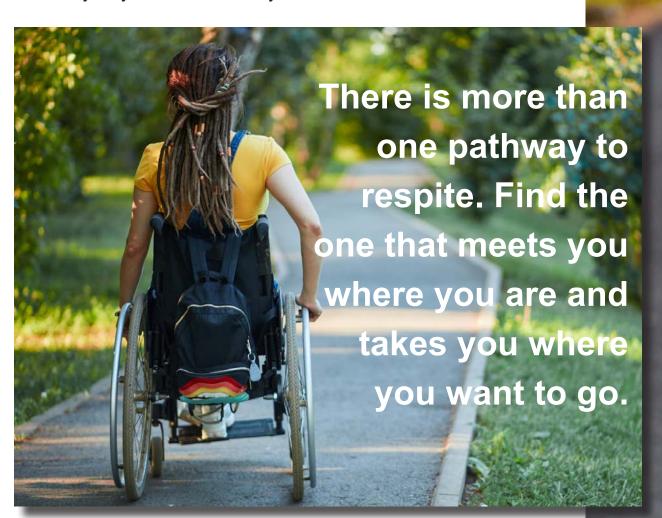
Putting the needs of everyone else before your own, may solve an immediate stress; however, in the long-term, it can lead to increased anxiety, frustration, overwhelming feelings, resentment, depression, burnout, and even illness.

Whether you think of yourself as a caregiver or not, these are all signs of caregiver stress.

No matter how many things there are to do, you are only one person.

Good self care means finding ways to tend to your physical, emotional and mental well being. If you won't do it for yourself, do it for your loved one. Because in order to be there for them, you need to be there for yourself.

Make self-care a daily habit. Whether it's taking a walk, listening to music, watching a movie, socializing with friends, allowing others to help you with chores and yard work, or hiring a paid caregiver, there are many ways to take care of yourself.





Start Right Where You Are

to make that happen.

Take a few moments explore what respite might

look like in your life and what needs to be in place



TIPS

When someone asks, "What can I do for you?" consider simple, time saving tasks that free you to do other things.

Something as simple as placing an order for incontinence supplies, wipes or other staples can save you a trip to the store.

Or maybe taking someone up on an offer to mow the lawn, do light housework or set up a meal train with others who want to help but don't know how.

If I had some time to myself, I would
If my family member or friend had someone to support them while I took time off, their favorite thing to do/person to see would be
I would like to take break, but I am concerned that
In order to feel comfortable taking a break, what I need to happen is
In order for my family member or friend to agree to the idea of having someone else provide support, they need to be able to
My biggest challenge to having some respite for myself and my family member or friend is

The person I feel most comfortable asking for help to get past

that challenge is

Bringing Someone New into Your Home Can Be Difficult

Bringing someone new into your home can be difficult.

Your family member or friend may be experiencing aging related stress. There may be cultural considerations or stigma related to having a care provider. And you may have concerns about the ability of someone else to understand and provide the kind of support you expect.

Involve Your Family Member or Friend.

Regardless of your family member or friend's age or disability, having a caregiver support you in your home or community can represent a loss of independence and control. Let your family member know that you need some help. Ask for their guidance on what kinds of support they would like.

Take it Slowly.

Your family member or friend may need to adjust to the idea of having someone new supporting them or you. You might also have concerns about a good match.

Start by interviewing the respite provider and get to know them. Have a clear understanding of want you want them to do and what kind of person would make a good match. Are there personal traits that would be a deal breaker? Clearly define their role and the expectations you have for them.

When testing things out, it's okay to stay at your home (do some work, or gardening, or hobbies, for example). You don't have to leave when the respite provider is there until you are confident in doing so. Trust your instincts. If it doesn't feel right, it's okay to look for another caregiver.

Create a Binder and Checklist

Create a binder that includes any assessments, medical concerns, communication needs, likes and dislikes. Include a plan and checklist with tips for how to care for your family member or friend, including their likes and dislikes. (See"Checklist for New Caregivers" on page 12 for ideas.)



Medicaid-Funded Services & Programs



HOW TO FIND CARE PROVIDERS

Carina Care

Carina Care is a free online service that helps connect clients receiving Medicaid funded home care with Individual Providers (IPs) who meet their needs and have been contracted through DSHS.

Learn more at:

carinacare.com

People You Know

People you know and trust can become a contracted respite provider. Visit informingfamilies.org/ip-contracting-dda to learn how it works for clients of DDA.

If your family member has a disability, or is an older adult, they may be eligible for Medicaid-funded services and supports that provide assistance with daily activities at home and in the community.

What does it look like?

People who Provide Respite

Paid respite services are provided by caregivers trained to assist people with disabilities and older adults at home or in the community. Some work as Individual Providers (IPs) and others work for agencies.

Services can be provided by someone you find through a referral resource, or by someone you know and trust who becomes a contracted provider for your family member.

Activities that Offer Respite

Some services are specifically called respite or relief care, but there are many forms that respite can take, including activities in the community. Depending on eligibility, activities for your family member or friend can include:

- assistance with daily living (from hygiene and housekeeping to cooking and shopping)
- * connecting with community resources & people
- recreational programs and activities, such as camp for people with disabilities

Technology

Technology (also called Assistive Technology) such as Personal Emergency Response Systems (e.g., fall detection, medication dispensers and reminders), as well as voice activated doors and switches and other kinds of smart home technology, can increase your family member's independence while also giving you some peace of mind.



Who is it for?

Seniors and Adults with Disabilities

Seniors age 65 who meet functional and financial eligibility can receive a variety of services through **Home and Community Services (HCS)**.

Unpaid caregivers of adults 55 and older who meet functional and financial eligibility can receive respite care and other needed support services like caregiver education, support groups, housework and errands and other services.

HOW TO APPLY

Contact your local HCS office or Area Agency on Aging. For a list of locations, visit <u>waclc.org</u>.

People with Developmental Disabilities (All Ages) and Children with Disabilities

Children and adults with developmental disabilities who meet eligibility criteria for **Developmental Disabilities Administration (DDA)** may be able to receive respite, personal care, assistive technology, community engagement support, and other services provided through Home and Community-Based Services waivers and Community First Choice (CFC).

Children with disabilities who are not DDA eligible may still be able to receive CFC through DDA.

HOW TO APPLY

Visit <u>dshs.wa.gov/dda</u> to request an application packet or for more information on DDA services and eligibility.

My son Gerik has always used all his respite and personal care from DDA. Then we added Community First Choice skills acquisition, then community guide. We self pay for therapeutic riding. All of this combined is helping create a good life for Gerik, and it's all respite for us." -Michelle W., Ellensburg

Lifespan Respite WA Voucher Program



Lifespan Respite WA offers support in the form of vouchers or mini grants for unpaid caregivers who are supporting a family member, friend, or neighbor who has a special need or condition. Recognizing the important relationship between a caregiver and a care recipient the program offers short-term breaks.

What does it look like?

Lifespan Respite WA provides vouchers or grants up to \$1,000 that a qualified caregiver may use with a registered Lifespan Respite provider.

People who Provide Lifespan Respite

In Washington State, it is essential that our registered providers have background checks for their employees, have proof of insurance and agree to additional requirements. The registered provider you select will then send invoices for services provided to Lifespan Respite and the voucher/grant amount will be used to pay these costs.

Activities Covered by Lifespan Respite Vouchers

- In-Home Services (including supervision, light housekeeping, laundry, light meal preparation)
- Day Camp
- * Overnight Camp
- Adult Day Services
- Recreation

Resources for Hiring a Provider

How do I interview a caregiver? What questions should I ask? What are some things to think about and look for when hiring? Find answers to these and other questions at: lifespanrespitewa.org/resources.





Who is it for?

Lifespan Respite vouchers or grants are for unpaid caregivers who provide 40 or more hours per week of care/ support to an individual of any age. Caregivers may be providing support to a family member, friend, or neighbor who we refer to as a care recipient.

Eligibility also includes:

- You are a resident of Washington State;
- Your family member is not enrolled in a Medicaid or other program that provides respite service, and is not scheduled to receive services within 30 days of application; and,
- ★ You cannot afford to pay privately for respite on your own.

Priority will be given to eligible families who have not previously received a voucher. While funding is limited, we make every effort to distribute funds to caregivers living on the eastside and the westside of the state.

From time to time, the program may obtain additional revenue for care recipients' conditions (e.g. Traumatic Brain Injury (TBI), Spinal Cord Injury/Paralysis, etc.).

How to Apply

Visit <u>lifespanrespitewa.org</u> to download an application.

For answers to questions or assistance completing the application email getrespite@wapave.org or call 1-800-5-PARENT, ext. 105.

Lifespan Respite Washington is administered by PAVE (Partnerships for Action, Voices for Empowerment.



Creative Options & Other Resources



Respite comes in all shapes and sizes, including free and low cost ways for you to take a break, get support and connect with others while your family member or friend does things they enjoy.

What does it look like?

Activities for Your Family Member

Many local organizations offer activities where your family member can socialize or exercise (in person or virtually).

Look for online listings for your local YMCA, Parks and Recreation, senior center, faith community, libraries, granges and more. Or, connect with other families through programs that provide information and resources for you (see next page on the right for program listings).

Support and Respite for You

Do things that give you energy, such as:

- Spending quiet time alone.
- Taking a walk, gardening, or listening to music.
- Connecting with your friends for support or fun.
- Being physically active or creative.

Whether it's just 30 minutes or an entire afternoon, evening or weekend, find ways to restore your energy. Do not underestimate the power of a nap or coffee with a friend.

We recognize that it can be hard and overwhelming to find solutions on your own, and equally hard to reach out. Consider connecting with other family caregivers who "get it" (see next page on the right) for support, encouragement and ideas.

Additional Respite Resources

Community Living Connections: waclc.org

ARCH National Respite Network: archrespite.org



Who is it For?

Adults with Disabilities

Family Caregiver Support Program (FCSP)

Limited respite for family caregivers who provide unpaid care to a senior or an adult with a disability. Services are provided through local Area Agencies on Aging. Visit <u>waclc.org</u> for local offices.

Children and Adults with I/DD

Parent to Parent (P2P)

For families of individuals with intellectual and developmental disabilities (I/DD). Many P2Ps offer Family Respite Night, which provides activities for the child while parents have a night off. Locate P2P near you: arcwa.org-parent-to-parent.

Children in Kinship Care

Kinship Caregiver Support Program (KCSP)

Resources and Kinship Navigators are there to support you and other grandparents and relatives raising children: dshs.wa.gov/kinshipcare.

Veterans

Department of Veterans Affairs

Up to 30 days of respite per calendar year for family caregivers of veterans in their centers or in their communities. Learn more: caregiver.va.gov.

Exceptional Family Member Program

Care and respite support for families with a member who has a special need or disability. Learn more at Childcare Aware: childcareaware.org/fee-assistancerespite



Checklist for New Caregivers

Create a binder that contains essential information for assisting your family member. Use the checklist below to organize all the information needed to help someone new coming into your home be the best fit for your family member and you.

Be sure to involve your family member or friend in making a list of things that are important to them. Pay attention to any discomfort or stigma they might feel about having someone support them. Ask for their help in problem solving so that you both get the support you need.

The following checklist items can help you start the conversation with your family member and help new caregivers get off to a good start.

	Your Family Member's Likes, Dislikes, Strengths, and Abilities
	Daily Routine (activities inside and outside the home)
	Transportation Scheduling and Contact Information
	Care Instructions (where needed) for:
	 eating and drinking supervision interpreting behaviors and other forms of communication
	 personal care lifts and transfers going into the community
	•
	Location of:
	○ Care supplies (incontinence pads, wipes, feeding tubes, gloves, masks, etc.)○ First aid supplies
	Shut off valves for gas/water/electric
	 Emergency Medical Data Sheet (to download a fillable form, visit: 911ready.org/documents/emergency_preparedness_docs/Emergency_Medical_Data.pdf.
	Strategies for Success: What works and what doesn't work?
	Risks and Concerns
	Cleaning and Infection Control Do's and Dont's
	Service Assessments and Plans of Care
	Emergency Plan

Assistive Technology Resources

Whether it's for communication or assistance, technology creates independence and access to places, people, and activities that enhance the lives of people with disabilities and older adults, while also providing caregivers some respite and peace of mind.

ABLELINK

Products to access technology for greater independence. Includes: travel app; daily scheduler; and instructions for daily tasks of all kinds. Learn more: ablelinktech.com.

NW ACCESS FUND

Low-interest loans for people to purchase assistive technology. Learn more: nwaccessfund.org.

OFFICE OF DEAF AND HARD OF HEARING

Provides equal access opportunities to effective communication. To learn more, visit: dshs.wa.gov/altsa/odhh/about-odhh.

QLINK WIRELESS

A leading provider of Lifeline, a free government benefit program that offers free cell phone service to eligible persons. Qualify through programs like SNAP and Medicaid, or based on your household income. Learn more at: glinkwireless.com.

TELECOMMUNICATION EQUIPMENT DISTRIBUTION (TED)

Free and low cost telecommunications equipment and training for people who are deaf, hard of hearing, or who have a speech impairment: <u>informingfamilies.org/ted</u>.

WASHINGTON ASSISTIVE TECHNOLOGY ASSISTANCE PROGRAM (WATAP)

Resources and services to help in the selection and use of assistive technology (AT) for school, work, home, and in the community. Learn more: watap.org.

DEPARTMENT OF SERVICES FOR THE BLIND (DSB)

DSB provides services for people of all ages who are blind or have low vision in the state of Washington: <u>dsb.wa.gov</u>.

Did you know that fall detection, medication reminders, smart home technology and other types of assistive technology can be provided through some Medicaid-Funded services? See pages 6-7, "Medicaid-Funded Services & Programs" on page 6.





informingfamilies.org