

Expanding Caregiver Respite:



Creative Ways for Caregivers to Recharge



But first... It's important to note:

- RCAW is a 501(c)(3) non-profit charitable organization.
- Everything RCAW offers is free!
- RCAW is not a direct service provider, nor do we hire or employ respite care workers.
- Our programs are designed to work with existing program delivery systems and address gaps across the lifespan. Children to Adults to Older Adults.



RCAW

Respite Care Association
of Wisconsin

In a nut shell, what do we do?

GRANTS & PROGRAMS

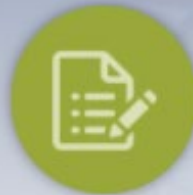
Our mission is to promote, support, and expand quality statewide respite care across the lifespan.



FREE TRAINING



GRANTS



REGISTRY



WEBINARS



RESOURCES

<https://respitecarewi.org/>

Training



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Respite Care Association of Wisconsin offers a variety of free online training courses for both caregivers and respite workers on many topics. These courses are divided into five categories: Respite Care Certificate Program, KIT for Caregivers, KIT for Respite Providers, Specialized Trainings, and Monthly Minis.

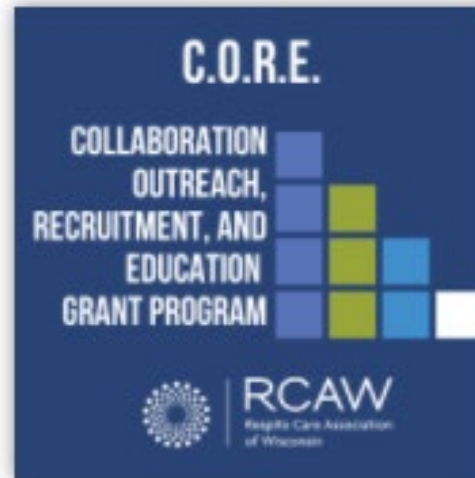
Coming Soon!

Free training opportunities via College of Direct Supports!

Grants



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Coming Soon!

Supplemental Respite Grant - Complimentary component to our Caregiver Respite Grant Program:

- PPE
- Household chores, Lawn care, snow removal, mileage reimbursement, etc.

WI Respite Registry



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This **FREE** registry connects those needing respite care with respite care providers. Direct care professionals or providers can register to be located on our registry. **Prerequisite** = Completion of our Respite Care Certificate Program.

Primary caregivers and agencies that support them can search this database for in-home or facility-based respite care providers that most closely meets their needs.

[FIND A RESPITE CARE PROVIDER](#)

[BECOME A RESPITE CARE PROVIDER](#)

Webinar Wednesday

Held on the 1st Monday of each month – sans holidays. These 60-minute webinars include an overview of RCAW programs, grants, FREE online training, and resources.

Additionally, each webinar features a different subject matter expert to inform & educate viewers on various respite related topics.

Our next Webinar Wednesday is October 7th, 2020.



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WISCONSIN
INDIANHEAD
TECHNICAL
COLLEGE

Careers in Gerontology

October 07, 2020

1:00 p.m. - 2:00 p.m. (CST)

During this 60-minute informative webinar, joiners will get a high-level overview of RCAW's grants, programs, and free training for respite care providers, and hear from our guest speaker.

Please welcome guest speaker!

Jennifer L. Ellis, MS, HS-BCP

*Gerontology - Aging Services Professional Program
Director at WITC*

Topics to include:

- The Dementia Care Pathway Certificate
- The Gerontology-Aging Services Professional Program
- The Gerontology for Healthcare Professionals Pathway Certificate

You can register by visiting
www.respitecarewi.org



Respite Resources

- Respite Resources – Children
- Respite Resources – Adults
- Respite Resources – Older Adults
- Various Tools & Worksheets

Examples (click for each):

- *Hiring A Respite Care Provider*
- *Getting To Know Care Recipient*
- *Training A Respite Provider*

Training A Respite Provider Worksheet 5 for Primary Caregivers TRAINING CHECKLIST

- Give a tour of the house/living space
Are there any areas that are off-limits to the respite provider or the care recipient?
- Rules about technology and screen time for the care recipient
Are there limits to the amount of time or the use of specific devices?
- Rules about the respite provider's use of technology
Do you have any rules on the respite provider's cell use?
Can the provider take pictures of the care recipient?
Can pictures be shared on social media?
- Introduction to siblings, roommates, or any pets
Does the respite provider have any responsibilities in regards to the people or pets of the house?
What are expected and allowed interactions between the care recipient and the people or pets of the house?
- Disability specific information
Common characteristics, allergies, medical information, seizures
Personal Care Assistance - how much help is needed on with what activities?
Communication devices - how to use, when to use
- Eating & Meal Information
G-tube information, if applicable
Food likes, dislikes, allergies
Meal routine and the amount of assistance the care recipient needs
- Medication information
When are medication given and where can they be found?
Is there a full list of medication in case of emergency?
- Activities
What activities does the care recipient like? Is a schedule needed? How much down time is ok?
Are outings ok and where? What about transportation? What can be expected in public?
- Challenging Moments/ Behaviors
What does this look like and what is the best way to respond? Is there a safety plan and how is it implemented?
What things can be done proactively to prevent or decrease challenging moments?
- Emergency Planning
Where are the emergency numbers, who should be called and for what purposes?



COVID-19 Resources



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ARCH Family Decision Guide

ARCH Respite Agency Decision Guide

RCAW's Respite Program Case Study:
'Respite in the Time of COVID-19'

Providing & Receiving Respite Care During COVID-19

Finding your New Normal During COVID-19

Help and Be Helped -
Sources for Caregivers, People and Provider Connection

"What is Your Plan?"
Document for Caregivers during COVID-19

Wisconsin Respite Care Registry

ARCH National Respite Network & Resource Center



Enough about us...

Yesterday and today, the ARCH National Respite Network hosted an International Respite Research Summit.

So much great information was shared! – One presentation really resonated & we thought it would tie in nicely with this presentation. We'll just share some of the highlights. The title of the presentation was:

**Respite Time-Use:
Research Findings Lead to Novel Intervention to
Maximize Benefit of Respite for Caregivers**

Presentation by Dr. Rebecca Utz





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So is it surprising to know...

About half of caregivers reported being
“not satisfied” with their respite time

Lund, D. A., Utz, R., Caserta, M. S., & Wright, S. D. (2009). Examining what caregivers do during respite time to make respite more effective. *Journal of Applied Gerontology*, 28(1), 109-131.

Interesting...



	<u>Desired Time-Use</u> (in hours)		<u>Actual Time-Use</u> (in hours)		% Whose Actual Time-Use was		
	<i>Mean</i>	<i>Std Dev</i>	<i>Mean</i>	<i>Std Dev</i>	<u>Less Than</u>	<u>Same As</u>	<u>More Than</u>
					<i>Desired Time-Use</i>		
<u>Respite Activities</u>							
1. Time with family	3.0	(5.8)	3.1	(6.2)	17	69	15
2. Housework	2.4	(4.0)	3.3	(3.6)	17	50	33
3. Rest and relaxation	2.0	(4.8)	1.3	(3.2)	20	67	15
4. Read or write	1.8	(2.5)	2.1	(4.4)	29	56	15
5. Help others	1.7	(3.3)	1.7	(3.5)	15	77	8
6. Watch TV	1.6	(3.5)	1.8	(4.0)	4	79	17
7. Sleep or nap	1.5	(6.2)	0.7	(1.6)	10	77	13
8. Cook	1.5	(2.2)	1.8	(2.2)	13	63	25
9. Eat	1.4	(1.9)	1.8	(1.8)	13	50	38
10. Shop	1.4	(2.2)	1.6	(1.8)	15	58	27
11. Time with friends	1.2	(1.9)	0.7	(1.3)	23	73	4
12. Hobby	0.9	(2.4)	0.5	(1.5)	15	81	4
13. Exercise	0.8	(2.0)	0.8	(2.0)	13	79	8
14. Personal or medical care	0.7	(1.3)	1.0	(1.6)	10	69	21
15. Listen to radio	0.6	(1.3)	0.6	(1.0)	8	77	15
16. Religious activity	0.5	(1.3)	0.4	(1.1)	6	88	6
17. Travel	0.5	(1.1)	0.6	(1.2)	4	83	13
18. Recreation	0.4	(1.1)	0.3	(1.0)	10	88	2
19. Attend support group	0.2	(0.7)	0.1	(0.4)	8	90	2

Source:

https://archrespite.org/images/Research_Consortium/Summit/PPTs/R_Utz_ARCH_research_summit_Sept_2020.pdf



So why didn't their
desired respite happen?

“I wasted my time watching television.”

“I wish I could have relaxed, but I had to help others and make visits.”

“I would like to stay home alone and work on projects that I never have time for.”

What does this tell us about respite care outcomes?

- If caregivers are not satisfied with their respite care, they're more likely not receive respite care in the future.
- Why is this bad?
 - ◆ *Respite care is a critical public health intervention. The effects of round-the-clock caregiving often lead the caregiver to feel isolated, fatigued, depressed, and anxious. The mental health toll on primary caregivers often exacerbates physical health conditions. Data shows that caregivers report chronic health conditions, including heart attack/heart disease, cancer, diabetes, and arthritis, at nearly twice the rate of non-caregivers. With the notion of pay now or pay later, we must move forward with increased funding to provide primary caregivers a break from their caregiving duties, so they can rest, refresh, and recharge.*



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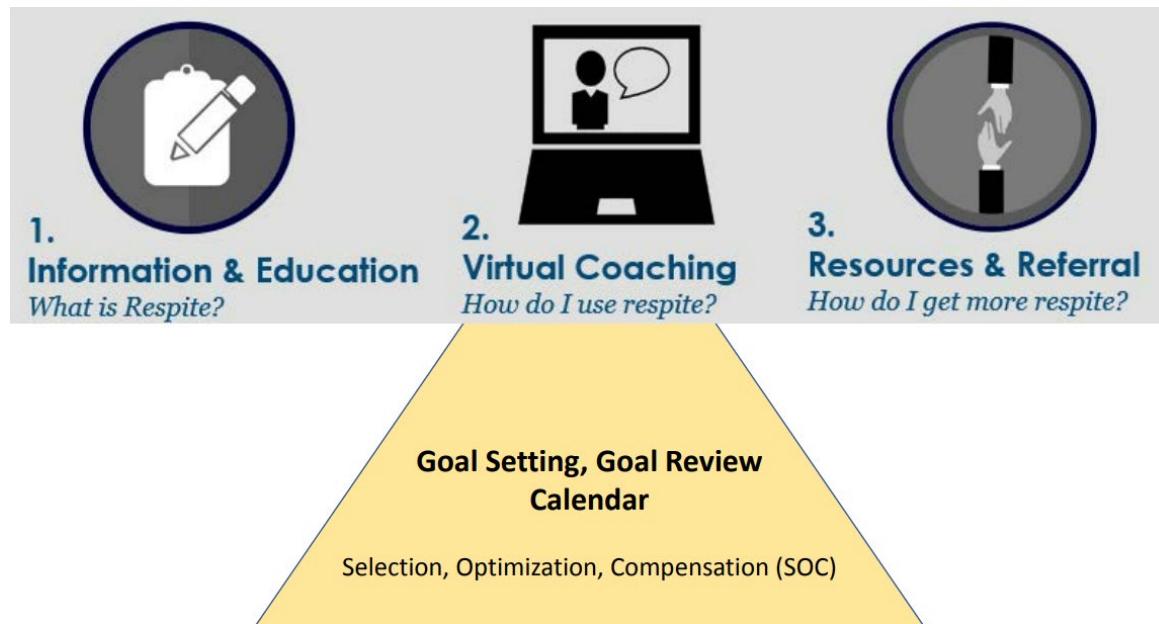


How can we help change that...

Intervention

Pilot
Project

Goal: to help caregivers maximize the benefit of respite by focusing on their time-use



Caregiver Feedback after intervention



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- *“I made a greater effort to find fun things to do and ACTUALLY got around to doing them...lead to other fun things which I did and will do in the future.”*
- *“It invigorated me. I am alive and not just living. I love feeling of success when I achieved my goals.”*
- *“I never had time for myself but since I set my goals, I feel obligated - like a promise I can't cut out.”*
- *“I was unconsciously sliding into a resigned death of my own until I started this study. This program really woke me up to the fact that I needn't give up – rather, that by setting goals, I can move forward and feel success even though my circumstances have not changed. I feel like a new, happier person!”*



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The participating caregivers recognized benefits to **identifying in advance how they wanted to spend their respite time** and **setting specific goals** helped empower them to act on their preferences.

Source: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4388419/#S5title>



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If you wish to follow the results of this pilot project, here is the place to go...



<http://tlc.gslc.utah.edu/>

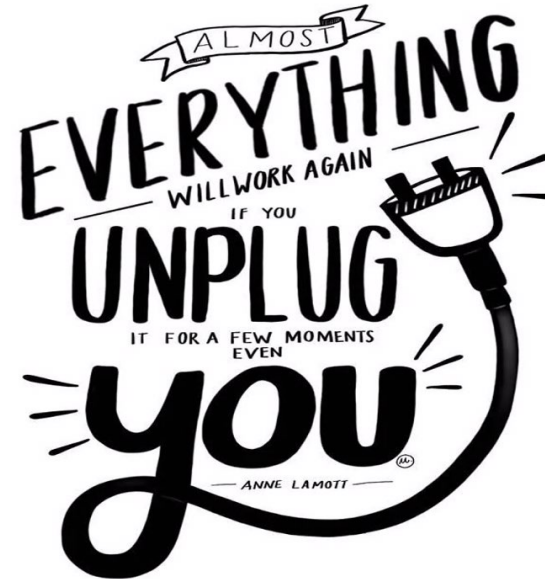


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Creative Respite Ideas



Meaningful Activities



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Outcomes...

(click for various examples)



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There are various ideas for specific populations, and at various stages in their disease.



Dementia products

From beautiful puzzles to games to play with the grandkids, we have a wide variety of goodies to find what's right for you.



Jigsaw puzzles

[Shop now](#)



Play together

[Shop now](#)



Stimulate the senses

[Shop now](#)



Get creative

[Shop now](#)



Sharpen the mind

[Shop now](#)



Spark memories

[Shop now](#)



Variety packs

[Shop now](#)



Best sellers

[Shop now](#)

Ways to reduce boredom and create meaningful moments



LISTEN TO THEIR FAVORITE
MUSIC



LOOK AT OLD PICTURES



MOVEMENT



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Person-Centered Memory Boxes



FIDGET MATS



How is this beneficial?

When there are person-centered activities planned for the care recipient, there is less guilt felt by the caregiver when "leaving" the care recipient in someone else's care.



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Unique Respite Ideas...

What does respite look like?

A while back when you registered for these caregiver coordinator trainings when they were going to be in person, you were asked to complete a survey, the following are the results/feedback from that survey.



Q#1: What types of respite have your caregivers found most helpful?

- Being able to take care out of the house and do the hobbies that they enjoy, attend events they enjoy, or taking a walk
- Having a family member or familiar person providing respite, or visits from friends
- Receiving In-home respite
- Having someone come into the home to allow the primary caregiver a chance to leave for a break overnight facility stays for their loved ones
- Helping with personal cares
- Helping with home chores like cleaning, snow removal, lawn mowing, etc.
- Attending Fresh Start, an exercise program - it gives them an opportunity to take care of themselves so they can continue to care for their loved one.
- Adult Day Services



Q#2: What has been the most unique/unusual type of respite you have approved for a caregiver?

- Coordinated a mix of paid & unpaid respite workers to allow caregiver to be with daughter who was going through chemotherapy.
- Paid for respite so that a caregiver was able to attend daughter's out of town graduation.
- Arranged time for a caregiver to get a massage.
- The respite provider taking the client out for fun activities and leaving the caregiver home to just rest. My kind of respite!!!
- Exercise program/membership

Others include:

- sidewalk repair so a mobile scooter could be used to visit with neighbors
- laid a walking path so PWD could walk to a barn to brush horses
- piano tuning for PWD who plays beautifully
- purchased a used power lift and slings
- purchased a used chair lift
- purchased a used mobility scooter
- purchased a 3-wheel bike
- purchased CBD oil



Q#3: We all need and use respite – what works for you?

- Reading a book, talking with friends and family.
- Someone offering to spend time with the care recipient doing things they used to enjoy doing together. i.e. what used to be deer hunting can now be a drive through some of the areas they used to hunt.
- Having a "she shed" that I go to for solitude watch a favorite TV program – comedies.
- Time away from work.
- Time with friends and family.
- Biking and walking.
- Painting.
- Gardening.
- Fishing with family.
- Spending time with grandkids.
- Sleeping in.



Q#3: We all need and use respite – what works for you? Cont'd.

- Putting energy into my health, i.e. dieting, exercise.
- Disengaged from social media to negativity.
- Focusing on my family as I have young children.
- Having an occasional cocktail.
- Watch a show on Netflix.
- Spending time outdoors.
- Shopping
- Going out to eat for a nice supper.
- My husband is disabled and has chronic pain and often grouchy. I love it best when he leaves on a Sunday morning to go walking in the woods.
- Seek relief from family members to give me time alone to recharge, take advantage of offers from others wanting to spend time with my children.

Our Favorite Ways to Relax



Most helpful respite ideas

Provide a respite caregiver that can join in the recipient's hobbies – take them fishing, talk about the war, play checkers etc.



Adult Day programs



Provide help with yard work such as lawn mowing, snow shoveling



Provide help with showering

Take the person on outings that they enjoy such as men's group, shopping, hikes, taking pictures



Provide help with household chores such as cleaning, meals

Have a familiar person come in to provide the respite

Personalize!

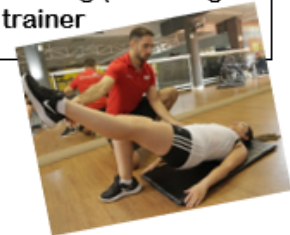
Basket full of favorite things that only take 10 minutes

Some unique respite ideas to consider



Sometimes the caregiver would like to stay home and have the care recipient leave

Pay for exercise program for recipient – boxing (including gloves), Fresh Start Exercise, personal trainer



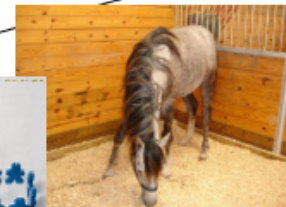
Personalize! –

- sidewalk repair so a mobile scooter could be used to visit with neighbors
- purchase a used power lift and slings
- purchase a used chair lift



piano tuning for recipient with dementia who plays beautifully

lay a walking path to walk to barn to brush horses



Maximize limited resources to best support Wisconsin caregivers



Cross Comparison of the AFCSP, NFCSP, CRGP

It is important to check with the AFCSP Coordinator before applying for NFCSP or other programs to avoid eligibility conflicts and to coordinate services.

	AFCSP Alzheimer's Family & Caregiver Support Program	NFCSP National Family Caregiver Support Program	RCAW Caregiver Respite Grant Program (CRGP)
Funding Source	State of Wisconsin GPR State and GWAAR distribute funds to counties	Federal AOA Program- State distributes funds to each Area Agency on Aging (AAA). GWAAR distributes funds to counties in its service area	State of Wisconsin GPR RCAW distributes grant awards to caregiver applicants.
Maximum Annual Allocation Per Applicant	\$4,000, but agencies may set a lower maximum service level in order to serve more families. <i>Actual service payment</i> is based on care needs.	None in federal policy, but local agencies often set their own limits. Participants are limited to 112 hours of respite per calendar year.	There is no maximum annual allocation per applicant, nor a limit to # of hours. Each request is reviewed on its own merits, needs of family caregiver and acuity level of care recipient. <i>Actual service payment</i> is based on care needs.
Eligibility Requirements	<ol style="list-style-type: none"> 1. Diagnosis of probable irreversible dementia: Alzheimer's, vascular dementia, Lewy body dementia, Parkinson's with dementia, Pick's disease, mixed or undetermined dementia, etc. 2. In-home, or can be used to provide caregiver respite and supplemental services for people living in a CBRF, RCAC or Independent Living arrangement. (Not for room & board) 3. \$48,000 max gross income of person & spouse 4. Not simultaneously enrolled in NFCSP or receiving caregiver respite through COP /Waiver, or Family Care 5. No asset test 	<ol style="list-style-type: none"> 1. Has significant cognitive or mental impairment or requires help with two or more activities of daily living 2. Resides in home setting (not facility) 3. Care recipient is age 60 or older – or has Alzheimer's or other dementia, <i>any age</i> 4. No income or asset test 5. Priority is given to low-income individuals and those with a diagnosis of dementia 6. Available to caregivers of all older adults aged 60+, even if the care recipient is enrolled in Family Care or another LTC program. Caregiver is the program recipient. 	<p>Applicants must meet all three requirements below:</p> <ol style="list-style-type: none"> 1. Be the primary family caregiver (does not need to live with care recipient) 2. Care recipients must live in Wisconsin. 3. Require respite care in the absence of any other funding source <p style="text-align: center;">AND:</p> <p>Care Recipient must meet both requirements below:</p> <ol style="list-style-type: none"> 1. An adult (18+) or a child (under 18) with special needs who requires care or supervision to meet the person's basic needs; prevent physical self-injury or injury to others or avoid placement in an institutional facility. 2. Has applied for, is in the process of applying, or been denied enrollment in any of the following Wisconsin Long Term Care Supports Programs (check only one below)



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			<ul style="list-style-type: none"> Family Care Include Respite I Self-Direct (I.R.I.S.) Children's Long-Term Care Support (CLTS) Children's Community Options Program (CCOP) National Family Caregiver Support Program (NFCSP) Alzheimer's Family Caregiver Support Program (AFCSP) Foster Care Support Services None of the above <p>If denied for a program – a copy of the denial letter must be sent to RCAW before completing an application or have the agency contact RCAW at 608-222-2033 or have them send an email to RCAW staff at info@respitecarewi.org.</p> <p>**If you do not meet any of the requirements above, please contact RCAW**</p>
How to Refer	<ul style="list-style-type: none"> Anyone may refer: ADRC staff, caseworker, medical staff, family member, friend.... The AFCSP Coordinator will assess eligibility, complete paperwork, and work cooperatively with case managers from other programs and dementia care specialists 	<ul style="list-style-type: none"> Anyone may refer: ADRC staff, caseworker, medical staff, family member, friend.... The AFCSP and NFCSP coordinators should meet regularly to determine the appropriate program for enrollment and maximize the number of families served by each program. 	<ul style="list-style-type: none"> Anyone may refer: ADRC staff, caseworker, medical staff, family member, friend.... The AFCSP and NFCSP coordinators should meet regularly to determine the appropriate program for enrollment and maximize the number of families served by each program

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	AFCSP Alzheimer's Family & Caregiver Support Program	NFCSP National Family Caregiver Support Program	RCAW Caregiver Respite Grant Program (CRGP)
Use of Funds	<p>Authorized by DHS Chapter 68 (For more detail http://docs.legis.wisconsin.gov/code/admin_code/dhs/68. Some things included are:</p> <ul style="list-style-type: none"> • Case management or service coordination • Intake and assessment • In-home respite/companionship • Adult day care/ Adult family home • Advocacy and legal assistance • Supportive home care - Help with personal care, bathing, medication monitoring/ chores • Safety improvements/ equipment • Caregiver training, including personal cares • Overnight respite in a facility • Specialized transportation and escort • Caregiver counseling and therapeutic resources • Housing and energy assistance • Community outreach and education • Crisis intervention • Protective payment or guardianship • Any other goods and services necessary to maintain the person with Alzheimer's at home 	<p>Authorized by Older Americans Act, Title IIIIE http://www.aoa.gov/AoA_programs/HCLTC/Caregiver/index.aspx</p> <ul style="list-style-type: none"> • Information and assistance to caregivers about available services • In-home respite/companionship (112/hrs/yr.) • Adult day care • Help with personal care, bathing, medication monitoring and chores • Home safety improvements/equipment • Caregiver training: incl. personal cares • Overnight respite in a facility • Transportation • Costs to attend or provide support groups • Other services as agreed by caregivers and the agency • Community outreach and education <p><i>Limits</i></p> <ul style="list-style-type: none"> • Supplemental services cannot exceed 20% of the grant expenditures. • No more than 10% of the NFCSP allocation can be spent on Grandparents Raising Grandchildren – Check your policy manual. 	<p style="background-color: yellow;">Funds can only be used to pay for respite services whether provided in-home, out of home, camp or the like.</p> <p>Funds can not be used for any other use.</p>

Cross Comparison of the AFCSP, NFCSP, CRGP

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Fund Dispersal	The maximum allocation for each family is determined using DHS eligibility worksheets. Payments are made using invoices and receipts. May pay a service agency directly or reimburse program participants or the primary caregiver/ representative for approved expenses.	Services must be approved by the administrative agency in advance in order for goods and services to be purchased using NFCSP funds. Payments to service providers are usually made monthly, but other timeframes are allowed.	Applicants are eligible to apply for a respite grant 1x every 90 days. Requests are based on care recipient needs, geographic location of services provided, and length of time respite is needed. Grants are awarded and paid to applicant (usually primary caregiver) so they can pay the respite care provider for services rendered. In circumstances where respite care is provided in a facility-based setting, we can pay the facility directly.
Details to note	<ul style="list-style-type: none"> • If all funding is allocated in a given year, a waiting list may be created to serve families if funding becomes available in the future. • Once enrolled in AFCSP, a person remains in the program until officially disenrolled by the AFCSP Coordinator (for reasons such as death, facility placement, switch to COP, Family Care, NFCSP, ineligible income, etc.) • The AFCSP Coordinator may apply for NFCSP on behalf of clients who have needs that surpass their maximum program allowance under AFCSP. (assuming there are sufficient NFCSP funds remaining) 	<ul style="list-style-type: none"> • Respite care is limited to 112 hours per calendar year. (Jan.-Dec.) • Before requesting NFCSP funds for a person with dementia, case managers should check with the AFCSP Coordinator to see if there are funds available through AFCSP, and if so, whether the person is eligible for AFCSP. • Best practice is to enroll a person with dementia in AFCSP first rather than NFCSP. If a family is eligible for AFCSP but funds are unavailable, they may enroll in NFCSP but should also be added to the AFCSP waiting list. 	<ul style="list-style-type: none"> • No limit of hours – must be reasonable • No limit on amount – must be reasonable • Can only apply 1 time every 90 days subject to funding availability.

Staff



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Respite Care Association
of Wisconsin



Lisa Schneider

Executive Director

Networking, budget, and fiscal management, contracts, strategic planning, representation of RCAW on councils and committees.



Rachel Watkins-Petersen

Project Manager

Marketing and communications, statewide presentations, webinars, and grant programs.



Val Madsen

Training & Development Specialist

Developing curriculums, specialized training development, statewide in-person training.



Margie Arpin

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First point of contact, information and referrals, data collection and management, and accounting.



Contact Information

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