



# RESPITE HANDBOOK



Toward Independent  
Living and Learning, Inc.

[www.tillinc.org](http://www.tillinc.org)



RewardingWork

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# TABLE OF CONTENTS

01

Introduction- Why Respite?

03

Medical Information

04

Emergency Information

10

Basic Information

20

Preparing for Respite

21

Preparing for Respite Outside Your Home

22

Preparing for In Home Respite

23

How to Select a Respite Provider

24

Setting Expectations

25

For the Caregiver- Taking Care of Your Own Emotional Wellbeing

27

Resources

# Introduction

## HOW TO USE OUR HANDBOOK

This handbook is designed to help family caregivers prepare for respite. We encourage you to complete and keep on hand the sections on **Emergency Information, Medical Information, and Basic Information**. Having all of this information in one place – easily accessible by your respite care provider – gives everyone piece of mind. Other sections include helpful tips, resources and encouragement. Preparing for respite in advance will help you relax and enjoy your time away!

## WHY RESPITE?

Respite care provides short-term relief for family caregivers, whether it's for an afternoon while you run errands or for several days while you're on a trip. The care can be in your loved one's home, the respite provider's home, at a day center or at a health care facility. The point of respite care is to make it easier for family caregivers to find more balance in their lives and take a break when needed.

It can be difficult to think about spending time apart. Entrusting the care of your loved one to someone else can cause feelings of anxiety but recognizing the importance of short breaks for everyone can provide many positive benefits for all family members. Your goal with respite is to take care of yourself, while ensuring your loved one is safe and secure.

## ABOUT TILL AND REWARDING WORK

Since 2004, Rewarding Work has helped people of all ages with disabilities and their families connect to caregivers who meet their unique needs. We operate a full-service online directory and job board in three states - CT, MA and KS.

Rewarding Work is a division of Toward Independent Living and Learning, Inc. (TILL), an innovative human service agency based in Dedham, MA. TILL provides services for individuals with specialized needs, including developmental disabilities, Autism Spectrum Disorder (ASD), Acquired Brain Injury, mental health and behavioral needs, throughout Eastern Massachusetts and Southern New Hampshire.

*TILL, Inc., developed this handbook as part of a Respite Innovations Grant program in Massachusetts, and is pleased to share it with family caregivers using RewardingWork.org.*

# \* Emergency Information \*

**Individual's Name:** \_\_\_\_\_ **Date of Birth:** \_\_\_\_\_

Address with Zip Code: \_\_\_\_\_

Phone: \_\_\_\_\_

**Language:** Verbal  Non-Verbal  Primary Language: English  Other

**Mobility:** Walks independently  Cane  Walker  Crutches   
(Please check all that apply)

Needs assistance – please describe \_\_\_\_\_

Wheelchair: Electric  Manual  1 or 2 person transfer  Prosthesis  type: \_\_\_\_\_

Brace  type: \_\_\_\_\_

## Family Contact Information:

**Parent/Guardian:** \_\_\_\_\_ **Relationship to Individual:** \_\_\_\_\_

Address and zip code if different from above: \_\_\_\_\_

Home Phone: \_\_\_\_\_ Work Phone: \_\_\_\_\_ Cell Phone: \_\_\_\_\_

## Day Program/Work/School:

\_\_\_\_\_ Phone: \_\_\_\_\_

Contact Name: \_\_\_\_\_

## Service Coordinator:

Contact Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Email Address: \_\_\_\_\_

Special comments/Instructions: \_\_\_\_\_

## Medical:

Height \_\_\_\_\_ Weight \_\_\_\_\_

Diagnoses Disabilities: \_\_\_\_\_

Seizure disorder? Yes  No

**Please list names of all medications individual is currently taking**

\_\_\_\_\_  
\_\_\_\_\_

# \* Emergency Information \*

**Insurance Company:**

Insurance Company: \_\_\_\_\_ Phone: \_\_\_\_\_

Member ID: \_\_\_\_\_ Group: \_\_\_\_\_

Prescription Coverage: \_\_\_\_\_ Bin: \_\_\_\_\_

**Doctor's Information (Primary Care):**

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Hospital Name: \_\_\_\_\_ Phone: \_\_\_\_\_

**Local Fire Department Phone:** \_\_\_\_\_**Local Police Department Phone:** \_\_\_\_\_**Local Ambulance Phone:** \_\_\_\_\_**Poison Control:** \_\_\_\_\_**Emergency Contact (if parent or guardian can't be reached):**

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Relationship to individual: \_\_\_\_\_

**Evacuation plan in case of disaster:** \_\_\_\_\_

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# Medical Information



Individual's Name: \_\_\_\_\_ Age \_\_\_\_\_ Ht. \_\_\_\_\_ Wt. \_\_\_\_\_

Disabilities: \_\_\_\_\_

TB Test Date: \_\_\_\_\_ Test Results? Pos.  Neg.

If Pos., results of Chest X-Ray: \_\_\_\_\_

Most recent Tetanus Shot: \_\_\_\_\_

**IMPORTANT – Please fill in the following information:**

Type of Provider	Name	Address	Phone
Primary Care Physician			
Pharmacist			
Psychiatrist			
Dentist			
(Other)			



## Medical Information



Please provide a history of all of the client's serious illnesses with their corresponding dates:

Date of Illness (From- To)	Type of Illness	Lasting Effects

Please provide a history of all of the client's previous surgeries with their corresponding dates:

Dates of Surgery	Type of Surgery







# Medical Information



Name of Medication	Strength of Medication	Dosage	Route	Time Given	Diagnosis for Use

Medication need to be crushed: Yes  No

Do medications need to be in food/ applesauce/ yogurt? Yes  No

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# Medical Information



## Seizure History:

Seizure Disorder?      Yes     No

If yes, frequency of seizures (e.g. daily, weekly, monthly, rarely, etc.)?

\_\_\_\_\_

If yes, duration of seizures (e.g. < 1 min., 1-3 mins., > 3 mins., etc.) \_\_\_\_\_

Precipitating Conditions: \_\_\_\_\_

Type of Seizures:

\_\_\_\_\_

## Seizure Safety:

1. Monitor for seizure activity at all times
2. Avoid feeding the individual during the seizure
3. Maintain upright or side-lying position during seizure activity
4. Do not restrain the individual
5. Protect the individual

## Documentation:

1. Note the time, movements and duration of activity
2. Document in the seizure log
3. Notify doctor if: \_\_\_\_\_

## When to call 911:

1. If \_\_\_\_\_ has ANY SEIZURE ACTIVITY lasting longer than \_\_\_\_\_ minutes.
2. If breathing or consciousness does not return to baseline after the seizure stops.

## When to go to the Emergency Room:

1. If injury occurs during seizure
2. Other: \_\_\_\_\_



# Medical Information



## Language:

Verbal  Non-Verbal

Primary Language: English  Other   
(Please write in primary language spoken)

**Mobility:** Walks independently  Cane  Walker  Crutches   
(Please check all that apply)

Needs assistance – please describe \_\_\_\_\_

Wheelchair: Electric  Manual  1 or 2 person transfer  Prosthesis  type: \_\_\_\_\_

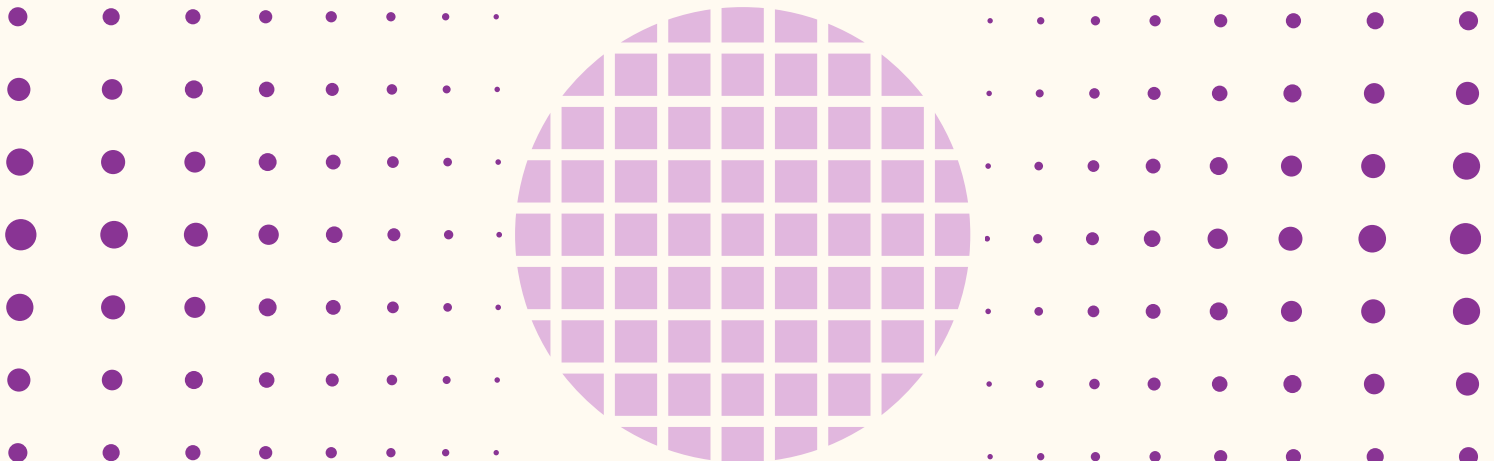
Brace  type: \_\_\_\_\_

## Insurance Information:

Insurance Company: \_\_\_\_\_ Phone: \_\_\_\_\_

Member ID: \_\_\_\_\_ Group: \_\_\_\_\_

Prescription Coverage: \_\_\_\_\_ Bin: \_\_\_\_\_





## Basic Information



**The following information will help respite staff provide support based on your loved one's needs:**

SAFETY	YES/NO	COMMENTS
Seeks assistance if injured, in pain or ill		
Seeks assistance when lost or needs directions		
Can exit house within 2 1/2 minutes in case of fire		
Walks safely with awareness of environment		
Crosses streets safely using crosswalks/walk signals		
Is aware of traffic		
Knows/reports own name/address/phone number		
Recognizes and avoids danger		
Recognizes and avoids objects or situations of potential danger		



# Basic Information



<b>FOOD AND KITCHEN SAFETY</b>	<b>YES/NO</b>	<b>COMMENTS</b>
Able to make appropriate food choices		
Understands special diet, if applicable		
Follows special diet, if applicable		
Preferences: Favorite foods		
Preferences: Dislikes /avoids		
Able to use stove/microwave		
Washes dishes by hand/dishwasher		

<b>DINING</b>	<b>YES/NO</b>	<b>COMMENTS</b>
Talks with mouth empty of food		
Uses napkin		
Eats appropriate amount, at approp. rate		
Asks for items/ Responds to requests to pass items		
Orders from menu in restaurant		
Able to locate restroom in public place		



## Basic Information



SELF CARE	YES/NO	COMMENTS
Brushes teeth thoroughly twice daily		
Showers/shampoos independently		
Combs/styles hair		
Toilets independently		
Shave daily, if applicable		
Manage menstrual hygiene, if applicable		
Puts personal hygiene supplies away and cleans up bath area		
Selects clean, neat, weather appropriate clothing		
Puts clothes away neatly; Puts dirty clothes in laundry; Hangs up clothing		
Choose appropriate makeup (if applicable)		



## Basic Information



<b>SMOKING/ ALCOHOL</b>	<b>YES/NO</b>	<b>COMMENTS</b>
Does not smoke		
Smokes in a safe manner and location		
Consumes alcohol in a safe and socially appropriate manner, if applicable		
Understands alcohol may not be consumed when taking certain drugs		

<b>COMMUNICATION SKILLS</b>	<b>YES/NO</b>	<b>COMMENTS</b>
Communicates needs and feelings		
Easily understood by familiar people		
Easily understood by strangers		
Follows directions		



## Basic Information



SOCIAL SKILLS	YES/NO	COMMENTS
Initiates conversations		
Responds to conversations initiated by others		
Takes turns when conversing in groups		
Is appropriate with strangers		
Works in cooperation with others		
Offers assistance to others		
Accepts assistance from others		
Enjoys being with other people		
Prefers to be alone		





## Basic Information



TELEPHONE/COMPUTER/MEDIA	YES/NO	COMMENTS
Uses phone/cell phone to make calls		
Uses cell phone to text		
Uses phone to access internet		
Uses computer/ gaming console		

HANDLING MONEY	YES/NO	COMMENTS
Holds money safely		
Can make cash purchases and waits for a receipt		
Can count change correctly		
Can judge if purchase can be made with available money		
Uses charge or debit card appropriately		



## Basic Information



GETTING ALONG WITH OTHERS	YES/NO	COMMENTS
Compatible with roommate/siblings		
Respectful of off-limit areas		
Able to apologize		
Does not interrupt others		
Does not tease or criticize others		
Does not threaten others		
Compliments others		
Helps others		
Gets excited easily		
Acts without thinking of consequences		
Denies problems when they occur		
Shows consideration for others feelings		
Able to pay attention to detail		
Very talkative		



## Basic Information



GETTING ALONG WITH OTHERS	YES/NO	COMMENTS
Prefers to be active at all times		
Shy/prefers to be by him/herself		
BEHAVIORAL STYLE	YES/NO	COMMENTS
<b>Is presently on a behavior plan, or are procedures developed to respond to behavioral needs?</b>		
<b>Are there identified reinforcers/motivators?</b>		
<b>What is the reaction and coping strategies when feeling?</b>		
• Stressed		
• Scared		
• Angry		
• Overexcited/overstimulated		
• When a peer is rude or inattentive		
• When not able to have preferred choice/activity		



## Basic Information



Please make a check mark or an X next to the activities listed below that the individual enjoys:

Leisure Activities / Interests		Leisure Activities / Interests	
Arts and Crafts		Knitting	
Baking / Cooking		Movies	
Bingo		Music	
Board Games		Picnics	
Bowling		Reading	
Card Games		Religious Services	
Video Games		Singing	
Crossword Puzzles		Sports	
Exercise		Storytelling	
Field Trips		Word Finds	
Groups		Parties	
Jigsaw Puzzles		Yoga / Meditation	



## Basic Information



In addition to those above, please identify other likes and any dislikes the individual may have:

Likes	Dislikes

**Describe the Nighttime routine:**

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**Describe the Morning routine:**

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Any sleep issues to be aware of:

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Indicate whether there are times of the day when the individual may have more or less energy, as well as any mood changes a caregiver should watch for:

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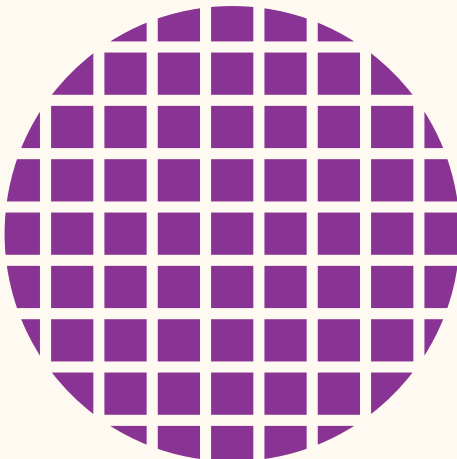


# Preparing for Respite



**The following tips will help you plan for respite.**

- If possible, plan respite in advance – arrangements can take a long time and space can be limited.
- Explain to your loved one what respite is and why you're going and/or they're going (you're not tired of them).
- Set expectations of how long they/you will be gone.
- Ideally visit the respite location or meet the respite provider ahead of time.
- Prepare clothing.
- Prepare medication. Keep the medications in their original bottles and in an easily accessible location.



# Preparing for Respite Outside Your Home

**Ask for pictures or visit the location ahead of time.**

## **Some questions to ask:**

- Is there medical oversight, medication administration?
- How is discipline handled?
- Are there regular health and safety inspections?
- What are the emergency procedures?
- Do you separate individuals who are sick – ie. Have a fever, cough etc?
- How many people will be caring for my loved one?

## **Assess the site:**

- Is it clean?
- Is smoking permitted? Does it smell like smoke?
- Do you see mold? Are hazardous materials locked up appropriately?
- Are there fire extinguishers and smoke detectors? Do they appear to be in good condition?
- Is it too warm/cold?
- Is it too loud?
- How does the staff interact with the residents?
- Where will my family member sleep?
- How are meals handled?
- What about TV or other electronics?
- Is there an outdoor space?
- What are the bathrooms like? How is toileting handled to ensure safety and privacy?
- Are hallways and doorways wide enough?
- Are there private bedrooms?
- Are doors to the outside locked? What's security like?

Get a packing list from the respite provider. Be sure to include comfort items.

# Preparing for In Home Respite

**Ask your respite provider to arrive early to go over information and ensure a smooth transition.**

**Provide a schedule for the day.**

**Share and post information about your home:**

- How to work the TV remote
- WiFi information including password for the internet
- Locking doors
- Location of lights
- Heat/AC
- Fuse box
- Water shut off
- Home address and phone number
- Security system information
- What to do if you get locked out

Secure valuables in a safe space.

Secure other medication in the home that is not intended for the individual.

Clarify whether visitors allowed and if so, who?



# How to Select a Respite Provider

## Sample interview questions:

- Are you trained in first aid and CPR? Are you med certified?
- Are you with an agency? (If important to you)
- Are you bonded (protects clients from potential losses caused by the employee)?
- Are you able to provide references?
- Are you available at the times needed?
- Are you able to provide back-up, if sick?
- Are you able to manage our specific health and behavioral care needs?
- Do you have a driver's license?
- Do you have reliable transportation?
- Have you worked with individuals similar to my family member before?
- How do you handle disagreements?
- What would you do in an emergency?
- Can I run a CORI check?
- What would you do if my family member is upset?

Be sure you understand the payment and scheduling system and that it works for you.



## Setting Expectations



### Clearly define the responsibilities of the respite caregiver:

- Is any housekeeping required/ expected?
- Who will do the meal prep?
- Will the respite provider administer medication?
- How will bathing, toileting, and other personal care needs be handled?
- If it's overnight respite, clarify if the caregiver can sleep and where?
- Will they be taking the individual out?
- What are the hours and days of care?
- Will the provider be driving the individual?
- What is the cost? How do you pay? When do you pay?
- Is there a cancellation fee?
- What happens if the provider needs to cancel – is there a backup option?
- What will the respite provider be reimbursed for – mileage, gas, entertainment, their own meal if dining out, etc?
- Rules around smoking, alcohol and drugs
- Transportation – how will the provider get to you or how will the family member get to the respite location?
- How far in advance can services be arranged?
- Be honest with the provider about difficulties that may arise, for example how to handle challenging behaviors.
- If issues arise during respite, do you want to be notified? Define what those issues are and how you'd like to be notified.
- Do you want a report of how the day/night went? How would you like this information to be communicated and how frequently?

Talk with your family member about their expectations and assess how respite went afterwards.

Ask for an assessment of how the session went and what could be improved upon for next time.



## For the Caregiver



Research shows that respite, which is personalized and planned, benefits not only the primary caregiver, but all family members including siblings, a spouse, or a partner. It's like putting on your oxygen mask first – it helps you be a better caregiver.

Family caregivers report higher levels of stress than people who are not caregivers. Some of the most common signs of stress are: mood swings, anxiety, skin problems, tiredness, muscle tension, poor concentration, poor memory, changes in sleep patterns, changes in eating patterns or indigestion, low self-esteem, sense of desperation or fear, and more frequent sickness. Respite is an important tool to help diminish symptoms of stress.

Benefits of respite include: socialization, time to rest and recharge, new opportunities for your loved one, avoiding burn out and time with other family members.

Remember respite is supposed to give the caregiver a break – don't make your life harder by preparing for respite in a way that detracts from that, such as excessively cleaning your house to prepare for respite.

There is no wrong way to spend your time away – reading, errands, sleeping, seeing friends – whatever feels like a break to you, is the right thing to do.

Make a plan ahead of time so you don't spend your respite time trying to decide what to do during your time off.



## For the Caregiver

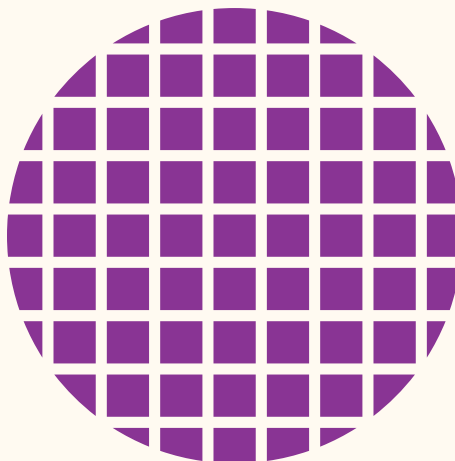


**Managing guilt:** It's normal to feel some guilt, but remember your loved one is in good hands with a caregiver you personally chose. You can also periodically check in with the provider for a status update.

**Staying connected:** Time apart does not have to mean you are completely disconnected. There are several ways to stay connected, whether it's via phone call, video chat or text. You can teach your loved one how to navigate technology or ask the provider to help them.

**Listening to your body:** You may feel pressured to see as many people or participate in as many activities as possible. However, if you feel tired and worn out, it's important to listen to your body and spend that time relaxing instead.

**Preparing for duty:** Like with any job, returning to duty after a break can be challenging. Take time to mentally prepare yourself. Practice self-care or determine what changes need to be made to prevent future burnout or stress.



# Resources

ARCH National Respite Locator Service: [Archrespite.org/resource-library/Medicaid-waivers](https://archrespite.org/resource-library/Medicaid-waivers)

ARCH Lifespan Respite Care Program: [archrespite.org/lifespan-programs](https://archrespite.org/lifespan-programs)

Caregiver to Caregiver Respite Network: [fcsn.org/c2c/](https://fcsn.org/c2c/)

Community Resource Finder (AARP and the Alzheimer's Association): [Communityresourcefinder.org](https://Communityresourcefinder.org)

Easterseals: [easterseals.com/our-programs/adult-services](https://easterseals.com/our-programs/adult-services)

Eldercare Locator: [eldercare.acl.gov](https://eldercare.acl.gov) or 800-677-1116

Family Caregiver Alliance: [caregiver.org/connecting-caregivers/services-by-state](https://caregiver.org/connecting-caregivers/services-by-state)

Federation for Children with Special Needs Support Groups: [fcsn.org/outreach-team/](https://fcsn.org/outreach-team/)

Medicare Part A and Respite Coverage: [www.medicare.gov/coverage/hospice-care](https://www.medicare.gov/coverage/hospice-care)

National Adult Day Service Association: [www.nadsa.org/locator](https://www.nadsa.org/locator)

National Alliance for Care at Home: [allianceforcareathome.org/find-a-provider](https://allianceforcareathome.org/find-a-provider)

PPAL support groups: [ppal.net/support-groups](https://ppal.net/support-groups)

Rewarding Work: [rewardingwork.org](https://rewardingwork.org)

Veterans Affairs Caregiver Support Program: [www.caregiver.va.gov/support/Respite.asp](https://www.caregiver.va.gov/support/Respite.asp)

VA Caregiver Support Coordinator: [caregiver.va.gov](https://caregiver.va.gov) or 855-260-3274

## **Connecticut:**

Care for Caregivers: [portal.ct.gov/aginganddisability/content-pages/bureaus/care-for-caregivers#](https://portal.ct.gov/aginganddisability/content-pages/bureaus/care-for-caregivers#)



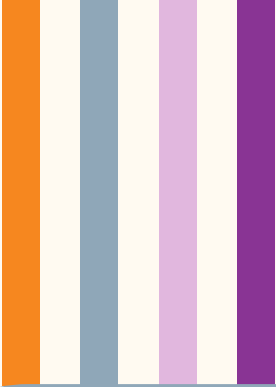
## **Kansas:**

Respite for Caregivers: [www.kdads.ks.gov/services-programs/long-term-services-supports/lts-training-resources/respites-for-caregivers](https://www.kdads.ks.gov/services-programs/long-term-services-supports/lts-training-resources/respites-for-caregivers)

## **Massachusetts:**

Massachusetts support groups for family caregivers: [www.mass.gov/info-details/support-groups-for-family-caregivers](https://www.mass.gov/info-details/support-groups-for-family-caregivers)

Family Caregiver Support Program: [www.mass.gov/family-caregiver-support-program](https://www.mass.gov/family-caregiver-support-program)



Respite is a resource to not only help ensure the health and well-being of you as a caregiver, but also for your family as a whole. The care you provide is important. It is equally important to take a break and rejuvenate.



Family caregivers can use [RewardingWork.org](http://RewardingWork.org) (an affiliate of TILL, Inc.) to find and hire respite workers and direct support in CT, MA and KS.

Learn more at: [www.RewardingWork.org](http://www.RewardingWork.org)

