

# Caregiver Handbook: A Resource Guide



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# The Caregiver Handbook

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## Getting started

This handbook is designed to help caregivers explore resources available in Brown County that can make caregiving easier. Some of these resources include respite care, financial assistance, and ways to connect with other caregivers. This handbook is meant to be a starting place for caregivers trying to figure out what their needs are, and what options are available.

Information and Assistance Specialists at the Aging & Disability Resource Center (ADRC) can also provide more in-depth information about the resources listed in this handbook. Call Monday-Friday, 8:00am-4:30pm at 920-448-4300 or visit the website: [www.adrcofbrowncounty.org](http://www.adrcofbrowncounty.org). Click on **Caregivers** to view information on caregiving resources.

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## ► WHAT IS A CAREGIVER?

A caregiver is someone who cares for and/or is concerned about a spouse, parent, child, sibling, or other relative or friend.

### **Caregivers can be many different people:**

- The adult son who stops by to check up on his aging parents on the way home from work every day.
- The mother of a disabled child who stays home to provide 24 hour care.
- The neighbor who gives an elderly friend a ride to the doctor or the store.
- The wife who learns to give medications and manage medical equipment to help her terminally ill husband stay at home.

## ► FEELING STRESSED?

Caregiving is a labor of love. It can be very rewarding, but also very isolating and exhausting. The special challenges of caretaking can wear you down and leave you feeling stressed out. Take a moment to complete the *Caregiver Stress Test* on the following page. It can help you identify your feelings and specific areas that are causing you stress. Once you identify them, you can seek out the resources that will best help you combat caregiver stress.



## Caregiver Stress Test

Read each statement and check the answer that most closely fits how you feel.

	Seldom True	Sometimes True	Usually True	Always True
1. I find I can't get enough rest.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I don't have enough time for myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I don't have time to be with other family members besides the person I care for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I feel guilty about my situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I don't get out much anymore.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I have conflicts with the person I care for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I have conflicts with other family members.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I cry every day.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I worry about having enough money to make ends meet.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I don't feel I have enough knowledge or experience to give care as well as I'd like.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My own health is not good.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Scoring:

If you answered "usually true" or "always true" to one or more of these questions, it may be time to begin looking for help with caring for your loved one and help in taking care of yourself.

Contact an ADRC Information & Assistance Specialist at 920-448-4300 to discuss your situation and learn about your options.

\*This test was adapted from materials provided by Kansas State University Research & Extension, <http://www.sedgwick.ksu.edu>



## ► There's not enough time

You might be thinking, "I don't have time to think about myself. I'm too busy as it is." Stress is serious business. The stress of family caregiving has been shown to impact a person's immune system, making it more likely that caregivers may become ill themselves. Caregivers also have higher incidences of sleeplessness, back pain, depression, and anxiety.

So, take a few minutes to read the "21 Tips for Caregivers" (at the end of this handout) and check out the other resources listed in this handout. You owe it to yourself and your loved ones to seek some help in reducing your stress. It will make you a happier, healthier person, and a more effective caregiver!

## ► NEED SOMEONE TO TALK TO?

### Support Groups

Caregiving can be isolating. Support groups offer a chance to get together with other caregivers to give and receive emotional support, learn caregiving tips from other people who are in a similar situation, have a good laugh or just sit and listen to the conversation.

The Aging & Disability Resource Center (ADRC) sponsors monthly caregiver support groups. They include:

- Caregiver Support Group
- Alzheimer's Caregiver Support Group
- Parkinson's Caregiver Support Group

There are many other support groups available in Brown County, including groups that address specific medical, physical, and emotional issues. To find out about other groups that may be helpful in your situation, contact an ADRC Information & Assistance Specialist at 920-448-4300.

### Educational Classes

♦**Taking Care of You: Powerful Tools for Caregiving** is a class just for caregivers and is offered by the Aging & Disability Resource Center. It meets once a week (2 hours each session) for 6 weeks and focuses on taking care of YOURSELF when you are caring for someone else. It provides tools to help reduce stress, improve communication, and learn from your emotions. For more information about upcoming classes, contact an ADRC Information & Assistance Specialist at 920-448-4300.



◆ **Living Well with Chronic Conditions** is also offered by the ADRC and is a class for people living with a chronic health condition. It meets once a week (2 hours each session) for 6 weeks. The class teaches relaxation and problem-solving techniques, techniques to deal with frustration, fatigue, pain, and isolation, and provides information on a wide variety of topics from exercise and nutrition to medication management and making informed treatment decisions. There is a small fee which includes a book and the 6-week session. For upcoming class dates, contact an ADRC Information & Assistance Specialist at 920-448-4300.

## **One-on-One Support**

There are a variety of counseling options available in the community. Counseling allows you to talk one-on-one with a professional who will listen and offer support. Counseling can help reduce stress, anger, and frustration, learn coping strategies, work towards goals, identify your inner strengths, and support you through your caregiving journey. The ADRC Information & Assistance Specialists can discuss counseling options with you. Call 920-448-4300 to speak with one.

## **Employee Assistance Programs**

If you or a family member are employed, your workplace may have an Employee Assistance Program (EAP) to fund individual or family counseling. The counseling would be confidential (no one at work would know). Usually EAPs offer a set number of counseling sessions per family member free of charge. To find out if EAP is an option for you, contact the human resources department at your workplace.

## **► NEED A BREAK? FIND RESPITE**

### **What is Respite?**

Provision of short term relief from tasks associated with caregiving. Services encompass home based care such as hiring a home health care agency, out-of-home care setting such as adult day services, and short term stays in an assisted living facility.

### **Types of Respite Help in the Home**

There are a variety of respite services available that bring help into your home or your loved one's home. These services may include **home care**, **palliative care** and **hospice**. Information about all of these services is available at the Aging & Disability Resource Center; 920-448-4300.



## ► Home Care

### *What is it?*

Home care, home health care and in-home care are all terms used for services brought into the home to provide individuals with assistance with daily needs. Home care can provide the help needed so people can continue living independently in their homes, with services ranging from simple household tasks to skilled nursing procedures.

### *Who does it serve?*

A person receiving home care services may be recovering from an illness or accident, facing a terminal illness, in need of extra assistance due to a physical disability, or frail due to age.

### *How do I find a home care worker?*

The Aging & Disability Resource Center (ADRC) can provide you with a handout about home care options which includes information about selecting a home care agency or independent home care worker.

Some options include:

- Utilizing the **ADRC In-Home Worker Referral Program**: a reliable referral service that links people seeking home care services with home care workers who have been recruited, screened, and interviewed by the In-Home Worker Specialist.
- Contacting **local home care agencies**: the ADRC has a current list of home care agencies and prices.
- **Hiring a worker on your own**: based on newspaper ads or recommendations from friends. Contact the Aging & Disability Resource Center for advice on hiring procedures.

### *What does it cost?*

Costs and payment methods vary depending on the type of home care services you need. Payment methods may include private pay, private health insurance, Medicare, Medical Assistance, or Community Options Program (COP) funding (see "Financial Concerns" section for more information on these programs).

## ► PALLIATIVE CARE

### *What is it?*

Palliative care is a team approach to improving the quality of life and providing comfort for people with serious illnesses and their families. Palliative care teams include social workers, nurses, chaplains, grief counselors, and volunteers. Under a physician's orders, palliative care teams may also provide consultation to reduce pain and other symptoms of serious illness.



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## Palliative Care, cont.

### ***Who does it serve?***

Palliative care services are designed to help people who have been diagnosed with a serious illness and their families regardless of prognosis. Palliative care can be given at any point in an illness from diagnosis on.

### ***What are the costs and funding options?***

Cost varies according to the services provided. Medical Assistance, Medicare, and private insurance may cover some treatments and medications. Some local palliative care programs may offer a sliding fee scale.

## HOSPICE

### ***What is it?***

Hospice care is a team approach to providing comfort and support to people with a terminal diagnosis and their families. The focus of hospice is on caring, not curing. Hospice teams include social workers, nurses, physicians, chaplains, volunteers and bereavement counselors. Hospice operates on the belief that people have the right to die pain-free and with dignity, and that their loved ones should receive the support they need throughout the process.

### ***Who does it serve?***

Hospice is designed to serve people of any age with a terminal diagnosis. Patients receiving hospice care are no longer undergoing treatments to cure their illnesses.

### ***What are the costs and funding options?***

Cost varies according to the services provided. Hospice care is covered under Medicare, Medical Assistance, most private insurance plans, HMOs, and other managed care organizations.



## ► Types of Respite Outside the Home

There are basically two types of respite care outside the home: **Adult Day Care/Service** and **Short Term Respite Care**.

### **ADULT DAY CARE/SERVICE**

#### ***What is it?***

A non-residential facility providing activities for elderly and/or handicapped individual. Most centers provide meals, social/recreational outings and general supervision. Some specialize in Alzheimer's Disease/dementia, people with a developmental disability, or frail elderly. Most operate during day hours, Monday through Friday.

#### ***What are the costs and funding options?***

Most programs charge a flat, per-day fee, with services such as hair care and transportation available at extra cost. Program donations and funding from public and private charitable organizations help fund some local programs. Long-term care insurance may cover some of the cost of adult day care. In Brown County, the Alzheimer's Family Caregiver Support Program (AFCSP) subsidizes NEW Curative Rehabilitation's adult day program, making it available at an affordable suggested contribution. For more information, contact the Aging & Disability Resource Center at 920-448-4300 to speak to an Information & Assistance Specialist.

### **SHORT TERM RESPITE CARE**

#### ***What is it?***

Short-term respite is a service provided by Community Based Residential Facilities (CBRFs) and nursing homes that allows a person in need of care to be admitted for a short period time. This can provide caregivers with a much-needed break. Some caregivers use short term respite stays to allow them to go on vacation, go on a business trip, attend to their own health needs, or just take a few days off of caregiving.

#### ***What is the difference between a CBRF and a nursing home?***

- A CBRF is a residential facility that provides supervision, personal care services (help with dressing, eating, toileting, grooming, and mobility) and some nursing services for adults who are unable to live independently.
- Nursing homes provide supervision and personal care services, but are equipped to provide more skilled nursing services than CBRFs. Nursing home short-term respite stays are not time-limited. If a person wants to use Medical Assistance funding, the respite stay must be at least 30 days.



***What are the costs and funding options?***

Most CBRFs and nursing homes charge a monthly fee that can be prorated for shorter stays. Funding options vary, though many providers accept private insurance, Community Options Program (CBRFs only), Medicare, and Medical Assistance. See the **“Financial Concerns”** section on page 11 to explore funding options.

**► OTHER IN HOME HELP**

**HOME BOUND MEALS—ADRC Nutrition Program**

***What is it?***

Although Home Bound Meals do not provide a short-term respite service, they do provide a break for the caregiver from planning and preparing meals. Meals are delivered daily, Monday through Friday to the participants’ homes by volunteers.

***Who does it serve?***

Home bound meals are available to people age 60 and older who are not able to prepare their own meals due to age or disability, are not able to get out of the house to go to a restaurant or a meal site, or have no one who can prepare meals for them. Individual assessments are conducted to determine eligibility within program guidelines. Individuals under age 60 who are disabled may apply for a waiver for the program. Caregivers are eligible for the meals as well.

***What are the costs and funding options?***

The Aging & Disability Resource Center asks for a per meal donation. No eligible participant is denied based on inability to pay.

**ST. VINCENT HOSPITAL FROZEN MEALS**

St. Vincent Hospital offers low-cost, precooked, frozen, microwaveable meals for purchase in the cafeteria. There are a variety of well-balanced meals available so stocking up on these frozen meals provides a healthy meal, giving caretakers a much-needed break from cooking.



## ► **BALANCING CAREGIVING AND EMPLOYMENT**

If you work outside the home, you've probably had to make some changes at work to find time for caregiving responsibilities. Many family caregivers, male and female, find the need to change their work schedules, come in late or leave early, and alter their work-related travel.

To help balance work and caregiving duties, talk with your human resources department. See if your employer has an eldercare program, Employee Assistance Program (EAP), or if they will work with you on a more flexible work schedule.

If you need to take time off of your job for caregiving duties, family and medical leave may be an option for you. The Family and Medical Leave Act provides eligible employees with up to 12 weeks of unpaid, job-protected leave per year. It also requires that their group health benefits be maintained during the leave. An eligible employee can use the 12 week leave for the following reasons:

- for the birth and care of the newborn child of the employee;
- for placement with the employee of a son or daughter for adoption or foster care;
- to care for an immediate family member (spouse, child, or parent) with a serious health condition; or
- to take medical leave when the employee is unable to work because of a serious health condition.

There are some restrictions regarding the number of employees your employer has and if you work part-time, the number of hours you work. You are not required to take all 12 weeks off at the same time. For more information about family and medical leave, visit the U.S. Department of Labor website at [www.dol.gov](http://www.dol.gov).

## ► **FINANCIAL CONCERNS?**

Providing care for a disabled or aging family member can be costly. Below is a list of programs available to help pay for some caregiving services.

### **MEDICAL ASSISTANCE (MA)**

#### ***What is it?***

Medical Assistance (MA) is a federal and state program that pays the medical expenses of people whose income and assets (such as savings, CDs, etc.) fall below certain limits.



***Who does it serve?***

To qualify for MA, a person must be 65 or older, **or** blind or disabled (of any age) and meet certain income guidelines.

***What kind of services does it cover?***

Through MA, funding is available to pay for medical expenses, including personal care. Personal care is medically oriented care that helps a person with the activities of daily living such as: dressing, bathing, toileting, and transferring to and from a wheelchair.

**COMMUNITY OPTIONS PROGRAM (COP)**

***What is it?***

Community Options is a state and county program offered through Brown County Human Services that helps people who need long term care stay in their own homes and communities.

***Who does it serve?***

COP serves people who need the same level of physical or mental health care as would be found in a nursing home, regardless of age or type of disability. While anyone may request a COP assessment and care plan, income guidelines are used to determine if COP will partially or fully pay for services. Other sources of funding (such as MA) are to be used before COP funds. There is usually a waiting list for COP funding.

***What kind of services does it cover?***

Some examples of COP services are home health care, respite, personal care, adaptive equipment, and housekeeping.

**COMMUNITY INTEGRATION PROGRAM (CIP)**

***What is it?***

Community Integration is a state and county run program funded through MA. It is also known as an "MA waiver." CIP helps fund services for developmentally disabled people living in their communities, and for relocating people with developmental disabilities from state centers and nursing homes back into their communities.

***Who does it serve?***

CIP funds are available to people with developmental disabilities.

***What kind of services does it cover?***

Some examples of CIP funded services are case management, counseling and therapeutic resources, day services, respite, and specialized transportation. Not all services are available for all CIP participants. Some services require a denial by MA before CIP can pay for them.



## **ALZHEIMER FAMILY AND CAREGIVER SUPPORT PROGRAM (AFCSP)**

### ***What is it?***

AFCSP is a state and county program that was created by the Wisconsin legislature to help reduce caregiver stress by providing financial assistance to caregivers of people with dementia.

### ***Who does it serve?***

Families caring for a loved one at home with any type of irreversible dementia are eligible for AFCSP services.

### ***What kind of services does it cover?***

In Brown County, AFCSP subsidizes NEW Curative Rehabilitation's adult day service program. The AFCSP subsidy allows Curative's adult day program to operate on a suggested contribution basis making it an affordable respite option.

## **NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM (NFCSP)**

### ***What is it?***

The National Family Caregiver Support Program (NFCSP) is a federally funded, county run program that provides funding for caregiver supports.

### ***Who does it serve?***

NFCSP services are available to any caregiver.

### ***What kind of services does it cover?***

In Brown County, NFCSP funds are used to support the ADRC's Information and Assistance Program, the general Caregiver Support Group, the six-week "Taking Care of You: Powerful Tools for Caregiving" class, and support of the ADRC website as a resource for long distance caregivers.

## **► WHAT KIND OF BENEFITS AM I ELIGIBLE FOR?**

The Benefit Specialists at the ADRC can provide information on MA, COP, and CIP to help you figure out if you are eligible. They can also explain application procedures and help you through the application process. There are two types of Benefit Specialists with different areas of expertise. Elderly Benefit Specialists have expertise on financial programs for persons age 60 and older. Disability Benefits Specialists assists persons age 18-59 with their benefits questions. To contact an ADRC Benefit Specialists, call 920-448-4300.



## ► INFORMATION IS POWER!

Seeking out information about your loved one's health condition and the resources available to you as a caregiver can help you gain control over your caregiving situation. There are lots of ways to find out more.

### **ADRC Staff**

The Information and Assistance Specialists at the Aging and Disability Resource Center (ADRC) can provide more in-depth information about the resources listed in this handbook. Call Monday-Friday, 8:00am-4:30pm at 920-448-4300. There are also other resources available through the ADRC.

### **ADRC Resource Room**

The ADRC resource room has a wide variety of materials about caregiving, specific medical conditions, and other topics. They are available to sign out for free. The resource room is open during the ADRC's regular business hours, Monday-Friday, 8:00am- 4:30pm.

### **ADRC Website and Community Services Database-211**

Check out the ADRC website [www.adrcofbrowncounty.org](http://www.adrcofbrowncounty.org) and click on "Caregivers" to view information on the ADRC's caregiver support programs and other caregiving resources available in Brown County.

You can also search the Community Services Database—211:

- Links can be found on the first page of the ADRC website by scrolling down or
- Click "Help Finding Services" on the left panel and then click Community Services Database-211

### **Caregiver Websites**

There are many caregiver organizations across the country. Their websites offer a wealth of information on lots of different caregiver issues including stress release tips, balancing home and work, and how to communicate during a physician appointment. Many also offer on line support groups and chat rooms. For an up-to-date listing of caregiver websites, contact an ADRC Information and Assistance Specialist at 920-448-4300.

## ► Medical Condition Related Organizations

There are many national, state and local organizations that provide information and assistance about specific medical conditions. Many have websites full of helpful information for caregivers. More information about many of these organizations can be found on the ADRC website's Community Services Database-211, or ask an ADRC Information & Assistance Specialist for a listing of medical condition related organizations.



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## 21 Tips for Caregivers

- 1. There is help out there...call and find out!** There are many programs and services that could help you and/or your loved one. Call the Aging & Disability Resource Center and ask to talk to an Information & Assistance Specialist about your situation and what options are available.
- 2. Develop a support system, and talk with someone about your feelings and how you're doing.** This may be a friend, family member, significant other, support group, counselor, clergy member or anyone else you are comfortable talking to. Don't keep your feelings bottled up, as this can lead to depression, resentment, and burn-out.
- 3. Take a break every day.** Even 10 minutes spent reading a book, listening to music, reclining in a quiet room, taking a bubble bath, or anything else that relaxes you can help improve your well-being and decrease stress.
- 4. Use Respite Care to get regular time for yourself** to pursue your interests, take care of yourself, maintain a healthy attitude, and recover from the daily stresses of caregiving.
- 5. Get enough sleep.** If you can't get a full eight hours, take a nap during the day. This is important for your own wellness and to help avoid burnout. Your loved one will benefit from you being well rested too.
- 6. Exercise.** This releases our natural endorphins that help us feel good. Physical activity is also a way to release stress. You may even want to try yoga which is a physical activity that also helps relax your mind. Be sure to check with your doctor before starting an exercise program to make sure it is appropriate for you.
- 7. Eat a balanced diet** to keep you healthy and energized.
- 8. Drink enough water** to stay hydrated so you have more energy and rid your body of natural toxins.
- 9. Acknowledge that you are human, have limitations, and make mistakes.** Having unrealistic expectations only adds to stress.
- 10. Carry out your personal interests and hobbies and make time for them each day.** This can be just 10 minutes of doing what you enjoy and will help maintain your emotional and physical well-being.
- 11. Learn about your loved one's health condition.** The more you know, the more you will be able to manage the present and plan for the future. Many illness specific organizations are available for information and support to people with the illness and their family members/friends. Some examples are: The American Cancer Society, The Alzheimer's Association, The AIDS Resource Center of Wisconsin, The ALS Association, The American Diabetes Association, and the National Multiple Sclerosis Society.



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12. **Keep a medical log for your loved one.** Include an updated list of prescription, over the counter, and natural medications in it. This is a great place to jot down questions for the doctor, concerns you want to bring up to the doctor, changes you see in your loved one, and notes you might want to take when talking with the doctor. Take this with you to each medical appointment.
  13. **Make a list of things you could use help with or that would make your life easier.** When someone asks, "Is there anything I can do for you?" share that list with him/her. Many times people want to help but don't know how. Having a few items for them to choose from can make it easier for both of you.
  14. **Communicate your needs to others.** If you don't let others know you need help, they may assume you don't.
  15. **Accept help.** This is often hard because we think we are the only ones who can care for our loved ones, or we may think accepting help is a sign of weakness. The truth is, others are able to care for our loved ones too, and accepting help is actually a sign of strength because you have recognized the importance of your own well being.
  16. **Get regular medical care for yourself.** Do not put your own health on the backburner because you are caring for a loved one.
  17. **Schedule a family meeting.** Family meetings offer an opportunity for individuals, their families and caregivers to communicate and work together to coordinate a plan. See the separate handout, *Holding a Family Meeting*, for information about how to plan and hold such a meeting. If any conflict exists it may be helpful to use a neutral party, such as a Social Worker, Counselor, or Mediator to assist with facilitating the meeting.
  18. **Keep humor in your life.** Our situations are not humorous but it is important to maintain balance in our emotions, and that means including humor and laughter. This may be as simple as watching a funny movie or TV show. Laughter releases natural endorphins to lift our spirits and relaxes us. You may even want to watch the comedy with your loved one.
  19. **Give yourself credit for the things you do well.** Often as caregivers, we tend to focus on our "mistakes" or "weaknesses" and never acknowledge our strengths.
  20. **Connect with other caregivers.** You are not alone! Even though everyone's situation is different, there are common experiences and feelings we experience as caregivers. Being able to connect with someone who can relate to you may help reduce your stress and improve your emotional well being. Support Groups and Internet Message Boards/Chat Rooms are great ways to connect with other caregivers.
  21. **Recognize your own personal signs of stress early before you are overwhelmed and burn out.** By recognizing your stress early and identifying where it is coming from, you can explore ways to decrease it before your own physical and emotional health suffer.