

Caregiver Handbook

Guide to Your Labor of Love



***ADRC of Brown County
can provide in-depth
assistance about
resources and more.***

***We are here to listen to
your story and help you
find answers and
solutions.***

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ADRC is a nonprofit, 501(c)3 organization

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Getting Started

This handbook is designed to help caregivers explore resources available in Brown County that can help 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.

ADRC of Brown County can provide in-depth assistance about the resources listed here and more. We are here to listen to your story and help you find answers and solutions.

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Our Mission:
***“Empower and enrich
the lives of older adults,
adults with disabilities
and their caregivers.”***

For more Information:

Visit our website:

www.adrcofbrowncounty.org

211 Community Services database:

www.get211.org

Who is a Caregiver?

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

Caregivers can come from all walks of life:

- An adult son who stops by to check up on his aging parents on the way home from work every day
- A mother of a child with a disability who stays home to provide 24-hour care
- A neighbor who gives an elderly friend a ride to the doctor or the store
- A wife who learns to give medication and manage medical equipment to help her terminally ill husband stay at home
- A husband who is caring for his wife and as to learn how to cook
- A grandparent now, unexpectedly, raising their grandchildren
- A sibling assisting with future planning for their sister/brother with disabilities

Feeling Stressed?

Caregiving is a labor of love. It can be very rewarding, but also very isolating, exhausting, and financially draining. It can also make it difficult to plan, so you need to learn how to be flexible.

Take a moment to complete the Caregiver Stress Test below. It can help you identify your feelings and specific areas that are causing you stress. Once identified, you can seek out resources to help!

- | | | |
|---|--------------------------|--------------------------|
| 1. I have a hard time getting enough rest. | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I don't have enough time for myself. | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I don't get out much anymore and feel lonely at times. | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I find myself becoming more easily irritated. | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I am having challenges with my own health. | <input type="checkbox"/> | <input type="checkbox"/> |

Scoring:

If you answered "Yes" to any of these questions, it may be time to begin looking for help caring for your loved one so you can focus on taking more care of yourself.

Contact ADRC 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, 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." 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 handbook) and check out the other resources listed. You owe it to yourself and to 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 allow caregivers the freedom to express their emotions without feeling guilty. You can vent anger, disappointments, and losses, as well as share successes in a safe, non-judgmental environment. Caregivers often feel comforted by sharing experiences with others who "get it."

You may also find hope from seeing that others have gone through similar challenges that you are now facing, and they have survived their caregiver experience. By forming new relationships with others, caregivers are provided honesty, encouragement, and moral support through their journey.

ADRC hosts several monthly caregiver support groups. There are many other support groups available throughout Brown County, including groups that address specific medical, physical, and emotional issues. To find a support group that may be helpful in your specific situation or to discuss counseling options that fit your needs, call ADRC 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 and help you learn coping strategies, work towards goals, identify your inner strengths, and support you through your caregiver journey.

Employee Assistance Programs

If you or a family member are employed, your workplace may have an Employee Assistance Program (EAP) that provides individual or family counseling. These counseling sessions are confidential (no one at work will know) and are usually on a short-term basis. To find out if EAP is an options for you, contact the Human Resource department at your workplace.

Educational Classes

Powerful Tools for Caregivers

Taking Care of You: Powerful Tools for Caregivers is a class for family caregivers that is offered by ADRC. It meets once a week 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, set goals, and cope with common emotions like anger, guilt, and depression.

For more information about upcoming classes, contact ADRC at (920) 448-4300 or visit us online, www.adrcofbrowncounty.org.

“Self-care is giving the world the BEST of you, instead of what’s LEFT of you.”
~ *Katie Reed*

Need a Break? Find Respite

What is Respite?

Respite is taking short-term breaks from tasks associated with caregiving. Respite is designed to serve caregivers who are caring for people with disabilities or other special needs, such as a chronic or terminal illness.

Types of Respite

There are a variety of respite services available that can either be provided in the home through use of home care agencies, palliative care, or hospice, or in an alternative setting such as an adult day care/service, assisted living facility, or nursing home.

Care at Home

Home care, home health care, and in-home care are all terms used for services brought into the home to provide individuals 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 Uses Home Care?

A person receiving home care services may be recovering from an illness, surgery, an accident, facing a terminal illness, in need of extra assistance due to a physical/cognitive disability, or an overall decline in health.

Finding a Home Care Worker

ADRC can provide you with a handout about home care options, which includes information about selecting a home care agency or hiring your own worker.

Some options include:

- Home Care Agencies - Home care agencies can provide housekeeping, meal preparation, companionship, personal cares, skilled nursing services, and in-home therapy. ADRC has a listing of all local options to help meet your caregiving needs. There are also 24/7 live-in caregiver agency options available in the community.
- Hiring your own worker -
 - Respite Care Association of Wisconsin has an online Wisconsin Respite Care Registry where you are able to conduct a search of home care workers or providers in your area. Visit their website at www.respitecarewi.org for more information.
 - Hiring your own worker based on newspaper/online ads or recommendations from friends is also an option.
 - See page 7 for tips on hiring your own home care worker.

Home Care 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, long-term care insurance, Medicare, Medicaid, Veteran's benefits, or publicly funded long-term care programs such as Family Care or IRIS. Caregiver grants may be available through ADRC, as well.

Tips for Hiring Your Own Home Care Worker

Taking time to find the right person is essential for your peace of mind and your loved one's safety.

Make sure you:

- Conduct an in-depth interview with each candidate. Screening applicants on the phone should always be followed with a personal interview.
- Be specific about all the tasks, skills, and schedules involved.
- Discuss compensation and payments schedules. Do not pay for services in advance.
- Request several work and personal references and check them carefully. Verify the information provided and ask all references about reliability, trustworthiness, punctuality, and the care provider's ability to handle stress.
- If possible, consider a background check. This could include:
 - Wisconsin Circuit Court
 - Wisconsin Caregiver Misconduct Registry
 - Department of Justice Wisconsin Online Record Check System
 - National Sex Offender Public Website
- Always include the potential care recipient in the screening process if they can participate, to ensure that both parties are comfortable and that your loved one's needs are respected.

Other Types of Home Care

Palliative Care

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

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

Hospice

Hospice care is a team approach to providing comfort and support to people of any age with a terminal illness 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 loved ones should receive the support they need throughout the process.

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

Types of Respite Care 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

Adult Day Care/Service is a non-residential, state-certified facility providing fun and supportive services for seniors and/or people with disabilities. Most centers provide meals, engaging social/recreational outings, and general supervision. Some specialize in Alzheimer's disease/dementia, people with a developmental disability, or frail elderly. Most operate during daytime hours, Monday through Friday.

In addition to the regular programs, most offer an additional fee for services such as hair care, foot care, bathing, and transportation. Program donations and funding from public and private charitable organizations help fund some local programs. Long-term care insurance, Veteran funding, Family Care, or IRIS may cover some of the cost of adult day care. For more information, contact ADRC at (920) 448-4300.

Short-Term Respite Care

Short-term respite is a service provided by Community Based Residential Facilities (CBRFs) and nursing homes that allow a person in need of care to be admitted for a short period of 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.

Most CBRFs and nursing homes charge a monthly fee that can be prorated for shorter stays. Funding options vary, though many providers accept private pay, private insurance, Family Care, IRIS, Medicare, and Medicaid.

Difference Between a CBRF and Nursing Home

A CBRF is a residential facility (type of assisted living) that provides supervision, personal care services (help with bathing, dressing, eating, toileting, grooming, and mobility), and some nursing services for adults with disabilities, mental health, or dementia who are no longer able to live independently.

Nursing homes are state licensed facilities providing residents with 24-hour 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 Medicaid funding, the respite stay must be at least 30 days. Other funding sources: private pay, Veteran funding, and private insurance.

Other In-Home Help

There are other ways to free up time, relieve stress, and be assured that your loved one is safe. It's nice to have time for just visiting that is not interrupted by chores.

Homebound Meals - ADRC Nutrition Program

Although Homebound 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. Homebound 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 community dining site, or have no one who can prepare meals for them.

Individual assessments are conducted to determine eligibility and if there are any other needs. Individuals under age 60 who have a disability may apply for a waiver for the program. Caregivers are also eligible for the meals. ADRC asks for a donation for each meal. No eligible participant is denied based on inability to pay.

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 find they 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 Resource 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 (FMLA) 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 a newborn child of the employee
- For the 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
- 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 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/general/topic/benefits-leave/fmla.

Financial Options

Providing care for a family member who is aging or has a disability can be costly. The following is a list of programs available to help caregivers. Some programs might allow for paying the caregiver and some programs might be able to provide medical coverage for caregivers.

Medicaid

Wisconsin Medicaid is a joint federal and state program that provides health care coverage, long-term care, and other medical services to Wisconsin residents. There are many types of Medicaid programs. Each program has different rules that you must meet to be eligible for the program. Full Benefit Medicaid programs can provide coverage for home health care, respite programs, and long-term care. Caregivers or their loved ones may both qualify for Medicaid. Call ADRC at (920) 448-4300 for more information.

Family Care and IRIS are Publicly Funded Long-Term Care options to help keep people with disabilities and older adults as independent as possible in the community by funding the supports they need. For more information on eligibility or questions about the program, contact ADRC at (920) 448-4300.

Medicare

Medicare is a national health insurance program, administered by Centers for Medicare & Medicaid Services. There are many ways a person can get their Medicare coverage and coverage differs according to each option. Contact ADRC at (920) 448-4300 for questions about your Medicare coverage.

Veterans

If your loved one is a veteran or the spouse of a veteran, there may be funding through the Department of Veteran Affairs. Connect with the Brown County Veterans Service Office at (920) 448-4450 to talk about potential benefits.

Additional Resources

Some people may have long-term care insurance policies or private health plans which might help with some services. There are also private pay agencies who will provide in-home care or respite care for a charge.

Financial Options, Continued

The purpose of the Caregiver Support Programs (AFCSP/NFCSP) are to provide grant dollars to help caregivers have access to community services. The funds are used by qualified individuals to purchase goods and services that will support them in caring for their loved one in their home as long as possible. Funds are limited for both programs and applications are required.

Support from these funds provides help to the caregiver for a variety of services:

- Daily home tasks (run errands, meal prep)
- Chore services (cleaning, yard work, heavy housework)
- Adult Day Programs and transportation
- Assistance with personal cares (dressing, bathing)
- Companionship

Alzheimer Family Caregiver Support Program (AFCSP)

The Alzheimer Family Caregiver Support Program (AFCSP) is a state funded program created in response to the needs of families caring for someone with Alzheimer's disease or other related dementias. Qualifications for the program are based on the person being cared for (care recipient):

- The care recipient and spouse's combined income
- Physician-verified diagnosis
- Currently residing at home
- Not receiving funding through Family Care or IRIS programs

National Family Caregiver Support Program (NFCSP)

The National Family Caregiver Support Program (NFCSP) is a federally funded program that provides a limited number of dollars to help individual families find and coordinate short-term respite options for the caregiver while they are caring for their loved one in the home. The NFCSP program is available to all qualifying caregivers regardless of their loved one's condition, including:

- Family caregivers
- Grandparents or older relative caregivers to children under the age of 19
- Grandparents or relative caregivers to adult children (between the ages of 19 - 59) with a disability

Respite Care Association of Wisconsin (RCAW)

Family caregivers of individuals who have long-term care needs and supports with personal care, supervision, and monitoring, find themselves in need of respite from their caregiver responsibilities. The purpose of this caregiver respite grant program is to meet planned and/or unplanned emergency respite care.

There are qualification guidelines for each of these programs. Please call ADRC at (920) 448-4300 to learn more and to apply.

Twenty-One 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 ADRC to talk about your situation.

2. *Develop a support system and talk with someone about your feelings and how you are 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 burnout.

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 time for yourself.*

This could mean bringing in someone to help while you get time to yourself. This lets you pursue interests, take care of yourself, maintain a healthy attitude, and recover from the stress 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 want to try yoga, which is a physical activity that 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.*

Eating a balanced diet will keep you healthy and energized.

8. *Drink enough water.*

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 your 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(s).

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: Vivent Health of Wisconsin (formally known as the AIDS Resource Center), The ALS Association, The Alzheimer's Association, The American Cancer Society, The American Diabetes Association, Autism Society, The National Multiple Sclerosis Society, and the Wisconsin Board for People with Development Disabilities (WI-DPDD).

12. Keep a medical log for your loved one.

Include an updated list of all medication, prescriptions, vitamins, and over-the-counter medications. This is a great place to jot down questions, concerns, changes you see in your loved one, and notes you might want to take while 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 this list with them. 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 your loved one and accepting help is a sign of strength because you have recognized the importance of your own health and 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 “Holding a Family Meeting” for information about how to plan and hold such a meeting. If conflict exists, it may be helpful to use a neutral party such as a social worker, counselor, or mediator to assist in 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. Laughter releases natural endorphins to lift our spirits and relaxes us. This could be as simple as watching a funny movie or TV show. You may even want to watch the comedy with your loved one.

19. Give yourself credit for the things you do well.

As caregivers, we tend to focus on our “mistakes” 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 go through as caregivers. Being able to connect with someone who can relate may help reduce stress and improve your emotional well-being. In-person support groups can be found in most communities. If you prefer online groups, Facebook alone has a number of available support groups for numerous conditions: mental illness, PTSD, physical, mental, and emotional abuse, anxiety and depression, and many more.

21. Recognize your own personal signs of stress 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.

Information is Power

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

ADRC Staff

ADRC staff can provide more information about the resources listed in this handbook. Staff are available to meet by phone, online, in person at the office, or in the home of the person you provide care for. There are also resources available through ADRC.

Hours: Monday - Friday, 8 a.m. - 4:30 p.m.

ADRC Website and Community Services Database 211

Check out the ADRC website at www.adrcofbrowncounty.org and click on "Resource Library" then "Caregiving" to view information about ADRC's caregiver support programs and other caregiving resources available in Brown County. You can also search the Community Services Database - 211 at www.get211.org. Click "Help Finding Services" on the left panel and then click "Community Services Database - 211."

ADRC Facebook

We realize family caregivers have different needs and prefer support in many different forms. ADRC's Facebook page is accessible 24/7 with information about caregiver supports and resources, connect with other caregivers, and receive tips for thriving, not just surviving, on your caregiving journey.

The page is updated regularly, so be sure to "Like" us to receive notices of updates. You can also post a comment or question for anyone viewing the page to respond to. If you would prefer to send us a message or questions that only ADRC staff can see, you can do that as well. Staff check the Facebook page regularly.

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, balance home and work, and how to communicate during a physician appointment. Many also offer online support groups and chat rooms. For an up-to-date listing of caregiver websites, contact ADRC at (920) 448-4300.

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