

Caregiver Chronicles

Spring 2024



Relatives caring for severely disabled adults ages 19—59 who live with them are eligible for Dane County Caregiver Program grants for respite and supplemental services.



Caring for an Adult Child with Severe, Life-long Disabilities

Across America hundreds of thousands of people with intellectual and developmental disabilities are being cared for at home by parents, siblings or other relative caregivers. As these caregivers age, they have concerns about their ongoing ability to provide care. While longterm planning is critical, some relative caregivers (ages 55+) for life-long severely disabled adults (ages 19—59) who live with them may be eligible for a Dane County Caregiver Grant as part of the National Family Caregiver Support Program (NFCSP). There is no income eligibility requirement for the program. Underserved communities and low-income caregivers can be prioritized for grant funding. For more information on a Caregiver Grant call 608-381-5733 or email caregiverspecialist@countyofdane.com.

In 2020, Christopher Booker of *PBS NewsHour Weekend* traveled to Rock County, Wisconsin as part of the “Rethinking Lifespan” series. He hoped to learn what steps were being taken to support families. See the full story as published in *Next Avenue* here: <https://www.nextavenue.org/challenges-caring-for-adult-child-with-disabilities/>.

Additional resources for caregivers of disabled older adults include:

Family Voices of Wisconsin: <https://familyvoiceswi.org/resource-library/able-accounts-what-families-need-to-know/>

WisconsinSibs: <https://wisconsibs.org/what-we-offer/journeyforward/>

WiscPact: <https://www.wispact.org/>



Click the photo above or visit this link to view the PBS NewsHour presentation, “Caring for An Adult Child with Disabilities in Retirement”: <https://www.youtube.com/watch?v=oIKc4VI6kO0>.



EMERGENCY PREPAREDNESS

FOR OLDER ADULTS AND PEOPLE WITH DISABILITIES

CREATE A NETWORK OF SUPPORT
TO HELP YOU IN CASE OF AN EMERGENCY.

PREPARE FOR A POWER OUTAGE IF YOU USE ELECTRIC MEDICAL DEVICES.



talk to a health care provider about what to do



identify an alternative power source for devices



inform your emergency contacts of the plan



Plan how you will **communicate** if you have a communication disability.



Plan for your **transportation** if you need help evacuating.



Plan how you will evacuate with any **assistive devices**.

WHAT TO INCLUDE IN AN EMERGENCY PREPAREDNESS KIT

- Contact information for important people and care providers
- A list of medicines you need, dosage instructions, and any allergies
- Styles and serial numbers of all medical and assistive devices
- Need-to-know information for first responders and others who might need to help you



Food, water, and essentials for you and pets or service animals



Medicines, medical supplies, batteries, and chargers



Copies of Medicaid, Medicare, and other insurance cards

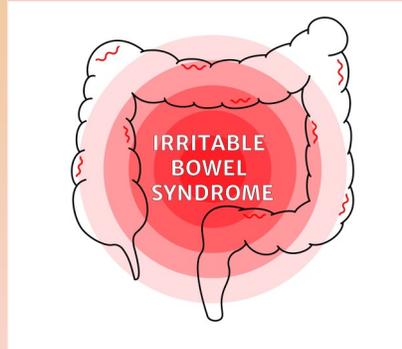


Learn more: acl.gov/programs/emergency-preparedness



Monthly MIPPA Moment: Preventive Services IBS

MIPPA (Medicare Improvements for Patients and Providers Act) has a goal of educating older adults on Medicare's cost-saving benefits & preventive services.



If you have irritable bowel syndrome (IBS) you are not alone. IBS is common and estimated to affect 10% to 15% of the population. Yet many people remain undiagnosed and unaware that their symptoms indicate a medically recognized disorder. IBS is a disorder characterized by abdominal pain or discomfort and altered bowel habit. Incidentally, 2 out of 3 IBS patients are female.

“**FODMAP**” foods (aka fermentable oligo-, di-, mono-saccharides and polyols) are a possible culprit for people with IBS. These are short-chain carbohydrates that are not easily absorbed and digested, which cause gas, bloating, and general pain. Doctors may treat irritable bowel syndrome (IBS) by recommending changes in your diet and other lifestyle changes, medicines, probiotics, and mental health therapies. You may have to try a few treatments to see what works best for you. Your doctor can help you find the right treatment plan.

Medicare Part B covers medically necessary tests ordered by your doctor to diagnose IBS, including an examination, diagnostic imaging studies such as colonoscopy or CT scan, and laboratory tests such as a stool test or lactose intolerance testing. If you are not at high risk for colorectal cancer, **Medicare fully covers a colonoscopy once every 120 months, or 48 months after a previous flexible sigmoidoscopy.** If you have Part B, Medicare generally pays 80% of allowable charges once you meet your Part B deductible. If you have Medicare Advantage, you may also have a copayment for these tests.

For more MIPPA Program information, call MIPPA Program Specialist, Leilani Amundson, at 608-240-7458.

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≡ **FREE Welcome to Medicare Seminars**

**Sponsored by: Area Agency on Aging of Dane County's
Elder Benefit Specialist Program**

What you need to know about enrolling in Medicare

If you are turning **age 64 this year**, the Dane County Area Agency on Aging wants to help you make informed choices about your Medicare options! Do you understand what Medicare is and isn't...how to avoid penalties for late enrollment in Medicare...and how to get the most out of your health and prescription benefit plans? **Some decisions and actions about Medicare can take place 3-6 months before you turn 65, so don't wait until you are turning 65 to understand all you need to know about this important benefit.**

Want easy to understand answers to all of these complex questions? Sign up to attend one of the following **Free Welcome to Medicare Seminars**. By attending a seminar, you'll walk away with the accurate and detailed information you need from unbiased experts in benefit programs. In-Person seminars have limited space so sign up early.

All dates are on Saturdays, 9–11:30 am

May 11, 2024 Virtual Seminar
Email AAA@countyofdane.com to
register by **5/3/24**

July 13, 2024 In-Person
UW Extension-5201 Fen Oak Dr,
Madison
Email AAA@countyofdane.com
to register by **7/3/24**

September 14, 2024 Virtual Seminar
Email AAA@countyofdane.com
to register by **9/6/24**

November 16, 2024 In-Person
Location TBD
Email AAA@countyofdane.com
to register by **11/8/24**





Taking Care of Yourself

INTRODUCTION

Research studies confirm what anyone who has cared for a chronically ill or disabled relative or friend knows firsthand – such a labor of love can exact an enormous physical, emotional, social, and financial toll. All too often those who provide care to others neglect their own need for self-care. Taking care of oneself is essential if the best care is to be provided to another person. Caregivers must learn how to balance their own needs with the needs of someone who needs care. There is no single recipe for ensuring that one remains a healthy caregiver but the following basic ingredients appear central:

EDUCATE YOURSELF ABOUT THE DISEASE OR MEDICAL CONDITION

Whether you care for someone with heart disease, stroke or dementia or whether care takes place in your own home or at a distance, many of the daily challenges are similar.

- Learn new information and skills and learn how to adapt to the challenges you encounter.
- Get up-to-date and accurate information through books, fact sheets and brochures regarding your relative's condition.
- Contact the appropriate disease-related organization, that can guide you to other resources such as hospital-based education programs and support groups.

FIND A DOCTOR OR ANOTHER HEALTH PROFESSIONAL WHO UNDERSTANDS THE DISEASE

Armed with some knowledge, you are capable of asking the right questions of the patient's doctor.

- Make a short list of questions and assert that you need such questions answered before you leave.
- Good doctors understand the impact of caregiving on you and should be willing to involve you in healthcare decisions that affect both your relative and you.

CONSULT WITH OTHER EXPERTS

You may need additional professional help to plan for the future. For instance:

- You may need legal authority to make healthcare and financial decisions on behalf of your relative.
- A certified financial planner may help you prepare for the possibility of expensive care for your relative in an assisted living facility or other chronic-care facility.
- Getting experts involved as soon as possible may save you a lot of worry later.
- If you are too busy to attend to this matter, make sure someone acts in your behalf to handle it.

TAP YOUR SOCIAL RESOURCES

Other family members and friends can play key roles in helping you to share in the care.



- Organize a family meeting so that everyone can get on the same page and find out what each person may or may not be able to offer. All potential sources of help need to be informed about the tasks at hand for both you and the relative in need of care.
- Make a plan with the family and then meet again a month later to evaluate progress.
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- Make a plan with the family and then meet again a month later to evaluate progress.

TAKE TIME FOR RELAXATION AND EXERCISE

Let's face it - helping another person can be hard work.

- Set aside time every day from the work of caregiving or you risk losing yourself to the exclusive needs of another person.
- Diversions are necessary in order to be renewed. Enjoy a hobby, see a movie, take a walk, ride a bike, or take part in any number of leisure time activities. You deserve a sense of normalcy. Something enjoyable should be built into every day, if even for just ten minutes, that reminds you that your needs are important, too. Take care of yourself in ways that are meaningful to you.

USE COMMUNITY RESOURCES

Unfortunately, most caregivers delay looking for help outside their social network until they are virtually exhausted.

- Check the local Area Agency on Aging, which administers state and federal funds to help older chronically ill persons and their family caregivers. To find your local Area Agency on Aging, contact the Eldercare Locator (1-800-677-1116 or go to <http://www.eldercare.gov>)
- Other local agencies target the needs of younger disabled people and their families. Such agencies can help you get a well-deserved break by paying for occasional in-home services by someone to relieve you or providing adult day services for your relative.

MAINTAIN YOUR SENSE OF HUMOR

There is nothing funny about a chronic illness, but being able to see humor in difficult situations can bring about much relief.

- Taking a lighthearted view can alter the meaning of a situation that might otherwise appear overwhelmingly depressing. Jokes, comics and funny movies can fill the void if you cannot find something funny on your own.

EXPLORE RELIGIOUS BELIEFS AND SPIRITUAL VALUES

Caring for someone with a chronic illness often evokes questions about faith, hope, God and the meaning of life.

- Organized religion may offer a fresh perspective, but spirituality runs deeper than any particular tenet or belief system.



- Individual and group prayer, rituals, meditation, inspirational reading and spiritual direction may shed light on matters of the soul.

SET REALISTIC GOALS

Accustomed to doing things in a hurry, you may be surprised to find out how little you can accomplish when you are responsible for another person.

- Be patient. Set small goals for yourself each day or week and build upon your successes instead of thinking about your failings.
- Learn to appreciate that you are making progress in ensuring that both you and your loved one are getting the best possible care. Finally, celebrate your achievements.

For additional information, contact the National Family Caregiver Support Program, U.S. Administration on Aging.

<https://acl.gov/DCWcenter/FamilyCaregiving>

Information provided in this fact sheet was adapted from materials submitted by Mather LifeWays Institute on Aging, Evanston, IL. For more information, visit their website

<https://www.matherinstitute.com/>

For more information about ACL

U.S. Department of Health and Human Services, Administration for Community Living, Washington DC 20201

Phone: (202) 619 – 0724

Fax: (202) 357 – 3555

Email: ACLinfo@acl.hhs.gov

Web: <http://www.aoa.gov>

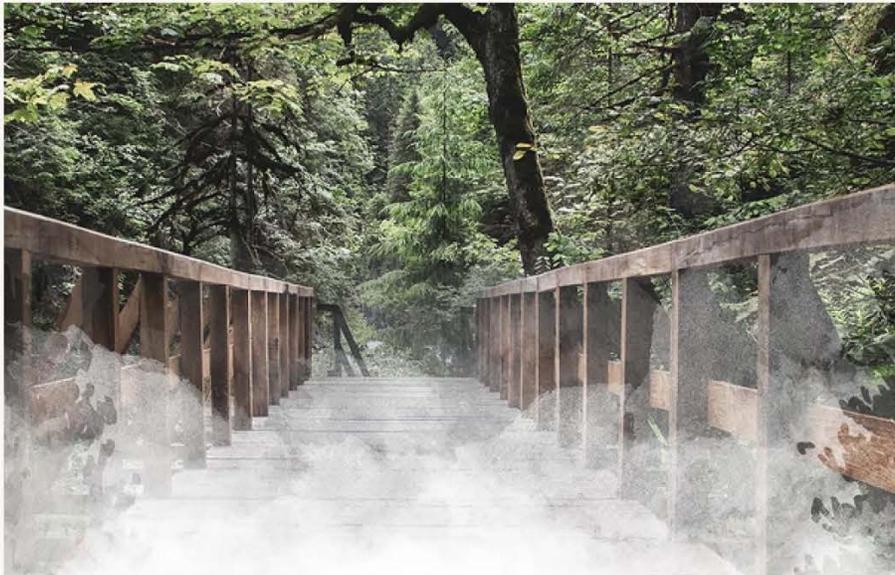




Crossing Bridges

An educational 4-week program for people who have mild memory loss or the early stages of Alzheimer's disease or dementia, and their primary care partner.

Learn coping skills, enhance family communications, and have some guidance toward developing plans for the future.



Dates and location vary throughout the year.
Contact us to find a program near you.



For questions or registration please contact us

608-240-7400

or by email danedcs@countyofdane.com

*Registration is required, and program space is limited.

Facilitated by the ADRC of Dane County



Hospice Care Myths

By the GWAAR Legal Team

When people think of the term “hospice,” many believe it means a person has given up on life or has just days to live. Many others think hospice is a type of facility, like a hospital or nursing home, that once a person enters they can never leave. However, hospice care is much different. The following are several common hospice care myths and the facts behind them.

Myth: Hospice is for people who have given up.

Fact: Hospice is for patients who are in the last phases of an incurable disease, but instead of focusing on curing an illness or prolonging death, the goal of hospice care is to relieve symptoms and give patients the best quality of life. The purpose of hospice care is to manage pain and other symptoms and to focus on the comfort and dignity of the person. And contrary to popular belief, research shows that in many cases, hospice care increases life expectancy, rather than decreases it.

Myth: Hospice is a place.

Fact: Hospice is rarely an actual location that people go to. Instead, the care almost always is provided where a person lives. Hospice patients are assigned a team of providers, such as a physician, registered nurse, home health aid, social worker, and chaplain. This team regularly checks in with the person, and works together to provide medical, emotional, spiritual and grief support to not only the patient but also their family.

Myth: People on hospice have to stop taking all medications.

Fact: This isn't always true. While it is true that hospice focuses on providing comfort rather than a cure, the decision to stop medication is usually left up to the patient. Depending on where people are in their diseases, it may be best to stop taking a medication that's a source of discomfort, but this is determined on a case-by-case basis. People are able to continue taking medications for pain and symptom control.

Myth: Once you sign up for hospice, there's no turning back.

Fact: Hospice doesn't mean a person is giving up control over their care or the ability to choose who provides it. A person can leave hospice and reapply at any time. For example, if a person on hospice wants to try a new drug trial or experimental therapy, they can always leave hospice and return at a later time, if needed.

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Myth: You can only be on hospice for a limited amount of time.

Fact: Eligibility for hospice care requires that two physicians agree that the person has six months or less to live, however, this does not mean a person has to die within six months. If the person lives longer than six months but doctors continue to certify that they're terminally ill, they'll receive hospice care for as long as needed.

For families that have used hospice care for loved ones, nearly all say they wished they'd known about it sooner. You do not have to wait for your doctors to bring it up – it is never too early to ask about hospice and what benefits it could provide.

For more information, visit:

<https://leadingage.org/common-myths-of-hospice-care-debunked/>

<https://www.npr.org/2023/12/28/1221648271/hospice-care-myths-jimmy-carter-end-of-life>



Monday through Friday
Call 7:45 am—4:30 pm

(608) 240-7400

Website: www.daneadrc.org

Email: ADRC@countyofdane.com

***Connecting People with the
Assistance They Need***



Jewish Social Services of
Madison is hosting a new



MEMORY CAFE

A meeting place designed for people
experiencing memory issues,
dementia, or Alzheimer's disease **and**
their caregivers

—
**Socialize, find support, and build
community without the stigma
associated with dementia**



When?

Every second Thursday
of the month
Begins March 14th!

1 - 2:30 PM

Where?

Temple Beth El
2702 Arbor Dr.
Madison, WI 53711

We offer transportation
assistance

Contact us:

(608) 442-4081

RSVP to Kate at
Kate@jssmadison.org

Website:
jssmadison.org

