Wisconsin
Family and Caregiver
Support Alliance

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FOR IMMEDIATE RELASE
Date: 2/21/2020

The Wisconsin Family and Caregiver Support Alliance recognizes February 21, 2020 as National Caregiver Appreciation Day!

In Wisconsin, 580,000 caregivers provide more than 480,000 million hours of care to loved ones each year: a $6.9 billion value. February 21 is National Caregiver Appreciation Day, and the Wisconsin Family and Caregiver Support Alliance invites you to hear from local caregivers during its press conference at 11:00 am on Friday Feb. 21 at the Fox Valley Memory Project, located in the Goodwill Building #2, 1800 Appleton Road, Menasha, WI.

Caregivers deliver a variety of services from personal care to medical services with compassion and professionalism, yet they often go unrecognized. Their days may be long and demanding, but they provide support to those who need it most – this could be your child, sibling, spouse, parent, or other friends and family. National Caregiver Appreciation Day recognizes caregivers providing quality, compassionate care every day.

Caregivers deserve respect and support. Take time to thank a caregiver by using some of our suggestions below:

- **Say "Thank You**
- **Write a letter or card to express your gratitude**
- **Offer your help**
- **Give them a little gift**
- **Give them the day off:**
- **Remind them to take time for themselves**

Following our press conference, we invite you to join us at an Open House for the Fox Valley Memory Project's "Mindworks" Program from 11:00AM to 12:30PM at the Goodwill Center Building #2, 1800 Appleton Road, Menasha, WI. Mindworks is a facilitated, classroom-style program for individuals experiencing cognitive decline, early stages of dementia, or other memory loss disorders. The program focuses on overall health, well-being, and relationship building, and provides much needed respite time for caregivers and family members

The Wisconsin Family and Caregiver Support Alliance (WFACSA) focuses on the needs of families who provide care, improve resource coordination, increase access to family supports and sustain Wisconsin families into the future. To find out more or want to become involved go to our website at http://wisconsincaregiver.org/alliance

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NATIONAL CAREGIVERS DAY INFO.

National Caregivers Day is observed annually on the third Friday in February. Across the nation dedicated health care professionals serve those who require long-term or hospice care. National Caregivers Day honors those men and women dedicated to providing these vital services.

Caregivers deliver a variety of services from personal care to medical services with compassion and professionalism, yet they often go unrecognized. Their days may be long and demanding, but they provide support to those who need it most – this could be your child, sibling, spouse, parent, or other friends and family. National Caregivers Day recognizes caregivers providing quality, compassionate care every day. Today is a great day to show your appreciation to caregivers across the lifespan.

WISCONSIN

It is estimated that in Wisconsin, 580,000 caregivers are providing 490,000 million hours of care to loved ones annually, valued at nearly $6.9 billion dollars.[1] It is imperative we do what we can to support family caregivers as the options to find reliable care for a loved one is growing tougher due to the growing direct care workforce crisis.

In fact, while Wisconsin's population of adults over the age of 65 is projected to grow 72 percent between 2015 and 2040, the pool of people in their prime caregiving years is shrinking. Those looking for paid help are already having a difficult time recruiting workers due to the state's low unemployment rate and stagnant wages. That forces family members to take on major caregiving responsibilities at home, and an estimated 56 percent of those caregivers keep working full time.

Rosalyn Carter said *"There are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers."*

IDEAS ON HOW TO OBSERVE

Caregivers are heroes and are deserving of our respect and unwavering support. Take time to thank a caregiver by using some of our suggestions below:

1. **Say "Thank You"**: It may seem simple but think about the last time you stopped and just said 'thanks'. We can get so lost in our busy day-to-day that we forget

that the words “thank you’ can go a long way. If you have a caregiver, or if any of your loved ones are caregivers, give them a call or pull them aside in person and tell them how thankful you are for all that they do.

2. **Write a letter or card to express your gratitude**: Receiving a heartwarming card or letter can bring a big smile to any caregiver’s face. Writing a personal note of gratitude sends a powerful message of appreciation. It shows you recognize their hard work as a family caregiver.
3. **Offer your help:** A fantastic gift for a family caregiver is to lessen his or her burden. Just the offer of help (even if they don’t take it) can mean a lot. And try to be specific. Offer to pick up groceries, run errands, or simply spend time with the person they care for so the caregiver can take a break.
4. **Give them a little gift** (flowers, spa gift cards, cup of coffee, whatever they like!): Make it a surprise or ask them what they would like. Whatever it is – give them a gift to say thank you.
5. **Give them the day off:** Tell a caregiver that you’ll take it from here! Don’t take no for an answer! Have them give you a date and hold them to it – make sure they take the time off to do something for themselves.
6. **Remind them to take time for themselves:** This may surprise you, but caregivers need help and support too! To demonstrate how much you value you them – help them take time for themselves, such as offering to fill in for them for a few hours. Whether it’s napping, showering, or reading a book- it is so important that they find some ‘me’ time.

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Accompanying Documents: WFACSA Handouts.

Fox Valley Memory Project Mindworks Program

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Vision Statement
Our communities will be accepting places for people of all ages and abilities to live with the supports needed for the person, their families and caregivers. Our communities are stronger when we work together to support each other.

Mission Statement
Our mission is to raise awareness of family and caregiver support needs and increase the availability of and access to services and supports (both paid and unpaid) which will keep people across the lifespan engaged in their community as long as they desire.

Goals
The Wisconsin Family and Caregiver Support Alliance has five primary goals:

- Increase Outreach and Awareness
  Through purposeful outreach, the Alliance will raise awareness about the breadth of caregiving and family support needs in our state with the goal of improving understanding and acceptance and identifying solutions.

- Promote Policy and Advocacy Efforts
  The Alliance will inform public policy and engage in dialogue with policymakers and state agencies to advance solutions that result in the implementation of new, effective strategies.

- Improve Systems Navigation and Access
  The Alliance will consult with a diverse group of families, caregivers and professionals to identify gaps in resources and service provision with the goal of leading to concrete improvement in access to essential supports, information and resources.

- Expand Family and Caregiver Support
  The Alliance will expand the availability of supports for families and caregivers, in part by advancing collaboration and communication between aging and disability systems.

- Strengthen Community Support

> Members of the Alliance will work in communities to promote better understanding of local challenges that prevent families from accessing quality care from paid and unpaid caregivers and to promote the societal value of supporting caregivers.

Along with the Steering Committee, members of the Alliance are working to achieve goals through the following workgroups:

- **Expanding Respite Options & Providers Workgroup**
  Expand the availability of respite services to families who need it.

- **System Navigation and Access Workgroup**
  Improve family access to necessary information and resources; Increase the level and quality of assistance families receive to coordinate services and navigate through the service system.

- **Employer Engagement Workgroup**
  Create a more flexible and supportive employer environment for employees who are supporting and caring for family members.

- **Underserved Families Workgroup**
  Improve supports for families of color and other underserved populations.

- **Future Planning Workgroup**
  Make affordable, high quality futures planning available to all families in Wisconsin who need it.

- **Peer Supports Workgroup**
  Ensure that families receive the emotional, personal, and peer support they need.

- **Background Check Workgroup**
  Explore the possibility for making culturally necessary exceptions to background checks and professional credentials.

Membership:
Disability and Aging advocacy groups and organizations are invited to be listed as members of the Wisconsin Family and Caregiver Support Alliance. The WFACSA does not engage in lobbying activities but seeks to educate its members about public policy and other issues related to improved supports for caregivers. If you would like to sign on to WFACSA as an organizational or individual member, follow this link. WFACSA Membership or contact Co-Chairs Lisa Pugh Pugh@thearc.org or Lynn Gall Lynn.Gall@dhs.wisconsin.gov for more information.

See a current list of Member organizations on our website:
http://wisconsincaregiver.org/alliance

**The idea for the formation of the Wisconsin Family and Caregiver Support Alliance originated at a conference of disability and aging advocates convened by The Arc Wisconsin at The Johnson Foundation at Wingspread in Racine, Wisconsin in August 2017.*

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2019 Family Caregiver Survey

Purpose: To collect information on how family caregivers find and utilize resources to help care for self and the loved one they are caring for.

Caregiver Overview

Family caregiver respondents:
- 612 respondents
- 68% are age 45+
- 91% are female
- 74% never ask for help for themselves
- 66% have been caring for loved one for greater than 5 years

Family member being cared for:
- 25% are a parent or in-law
- 37% are a son/daughter
- 13% are a spouse/partner
- 30% caring for someone age 60+; 6% for age 45-59; 22% for age <18
- 46% have I/DD; 20% have Alzheimer's Disease or Dementia

Caregiving difficulties:
- 73% not meeting their own personal needs
- 63% not balancing caregiving and work
- 60% not balancing needs of their other children and family members
- 53% not understanding government programs such as Medicaid, Medicare, SSI, etc.

Personal impacts:
- 72% tired/worn out a lot of the time
- 64% social life has decreased
- 90% indicate their emotional and/or physical health has worsened
- 53% relationships with friends and/or family have suffered

Employment:
- 70% are employed outside the home
- 28% indicate caregiving has had no effect on employment
- 23% quit or changed their job
- 21% have decreased work hours

Positive highlights include:
- 51% say their employer/supervisor is accommodating when they have to leave work unexpectedly.
- 56% indicate they have gained empathy about others' situations.
- 42% have become an active advocate.
- 34% made new friends with people in similar situation.

"It's very difficult, stressful, rewarding, challenging, learning experience, gratifying, emotional roller coaster"…Family Caregiver

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2019 Family Caregiver Survey

Data comparison of family caregivers caring for someone under 30 years of age = ***<30****;*
and caregivers caring for someone age 30 and older = ***30+***

The data below is broken out into key issue areas mirroring the larger caregiver survey summary and highlights the top issue as reported by family caregivers.

Care-giving Difficulties

- < 30: 81% not meeting their own personal needs.
- 30 +: 70% not meeting their own personal needs.
- ***Greatest disparity: Finding reliable care workers (<30 = 60%; 30+ = 30%)***

Service use in past year

- < 30: 40% inquired about services but they were not available.
- 30 +: 30% inquired about services but they were ineligible or did not quality.
- ***Greatest disparity: Waiting list for services (<30 = 30%; 30+ = 9%)***

Information sources

- < 30: 52% report getting information from other families in similar situation.
- 30 +: 60% report getting information from doctors or healthcare providers.
- ***All report biggest challenges is not knowing what it is they need.***

Respite care utilization

- < 30: 56% report using respite care services.
- 30+: 22% report using respite care services.
- ***Greatest disparity: Lack of available workers (<30 = 35%; 30+ = 9%)***

Impacts of Care-giving

- < 30: 78% report being tired/worn out a lot of the time.
- 30+: 68% report being tired/worn out a lot of the time.
- ***Greatest disparities: Making new friends w/people in similar situations (<30 = 52%; 30+ = 20%)***

Impacts on employment

- <30: 30% report having to decrease their hours at work.
- 30+: 40% report caregiving has had no effect on their employment.
- ***Greatest disparities: Changing or quitting jobs (<30 = 41%; 30+ = 16%)***

"It is a blessing to be able to be a caregiver, but one must ask for help. Thankfully, help is available."…Family Caregiver

CAREGIVING

2015–2017 Behavioral Risk Factor Surveillance System (BRFSS) Data from adults in 44 States, Puerto Rico, and the District of Columbia

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

1 in 5 adults are caregivers

CAREGIVING CAN BE

LENGTHY
Nearly half
have provided care for at least two years

INTENSE
Almost a third
have provided care for at least 20 hours per week

HOW DO CAREGIVERS HELP?

80% manage household tasks

Over 50% assist with personal care

WHO ARE CAREGIVERS?

58% are women

19% are 65 years old or older

1 in 3 are caring for a parent or parent-in-law

9% of caregivers are providing care to someone with dementia

FUTURE CAREGIVERS

1 in 6
NON-CAREGIVERS expect to **BECOME CAREGIVERS** within 2 years

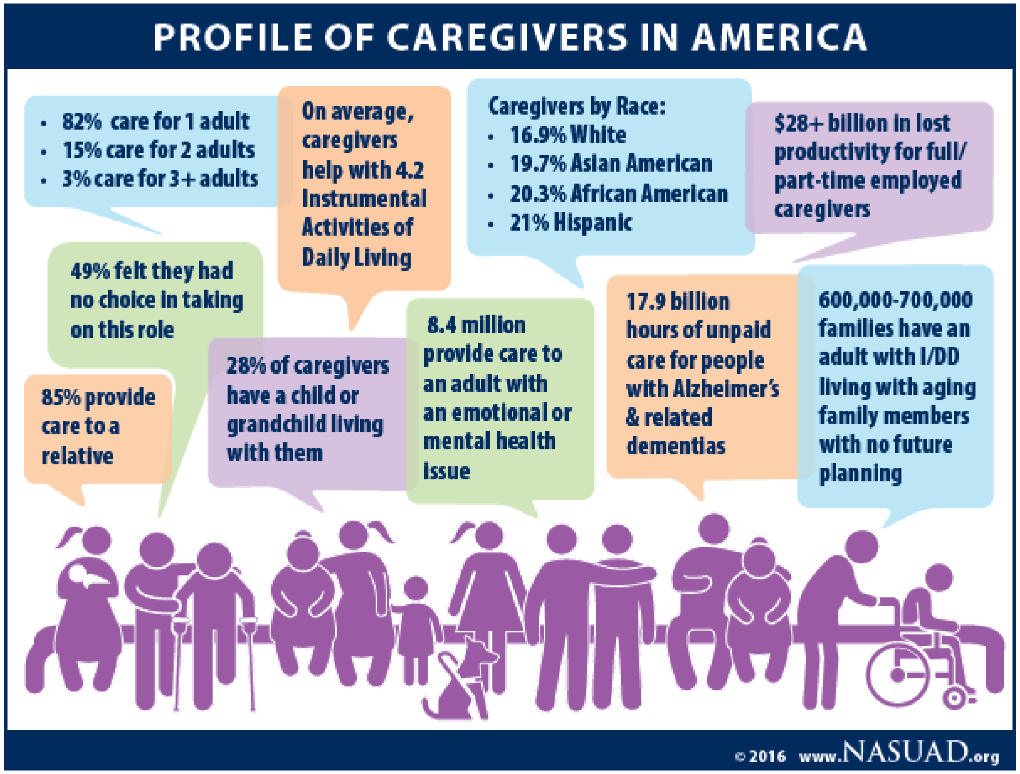
U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

cdc.gov/aging

CS 294325-A February 2019

Wisconsin Family and Caregiver Support Alliance

The State of Family Caregiving in Wisconsin and Nationally



Definitions

A **caregiver** - sometimes called an ***informal caregiver*** - is an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks.

Formal caregivers/Direct Care Workers are paid care providers providing care in one's home or in a care setting (day care, residential facility, long-term care facility). For the purposes of the present fact sheet, displayed statistics generally refer to caregivers of adults.

Heavy Reliance on Family Caregivers in Wisconsin

In Wisconsin a shortage of formal caregivers or direct care workers has created a crisis for people with disabilities, older adults, and their families. The need for direct care workers is projected to increase by an additional 20,000 workers by 2026[1]. In 2016, a statewide survey of more than 500 people who rely on direct care services and their families found 85% did not have enough workers to cover all their shifts 60% said they get sick more often when they do not have enough staff[2]. Families are the backbone of the caregiving industry in Wisconsin, providing an estimated 80% of all care.

Local Caregiver Feedback: The Family & Individual Needs for Disability Support Survey[3]

How does caregiving affect employment?

- 92% caregivers reported going in late or leaving early because of caregiving responsibilities.
- 83% of respondents worked for pay outside of caregiving responsibilities in the 12 months prior to the survey.
- 71% of caregivers reported cutting back hours.
- 52% reported giving up working.
- 42% turned down a promotion.
- 36% did not take job opportunities that require moving out of state.
- 31% reported losing benefits.
- 21% received warnings about attendance or work performance.

How is caregiving affecting parents?

- 98% report some level of stress. 50% are very or extremely stressed.
- 94% report challenges finding time for self-care.
- 91% report challenges balancing other family responsibilities.
- 83% report out-of-pocket expenses related to their family members needs of more than $1,000 per year.
- 65% report challenges meeting their own health needs.

What worries caregivers about the future for their family member?

- 93% worry the quality of support will go down if they are not there to advocate.
- 90% worry she/he will have to live somewhere she/he does not want to live.
- 86% worry she/he will not have enough friends and social activities.
- 85% worry she/he will have difficulty advocating for what she/he needs.
- 85% worry she/he will not be able to contribute to major life decisions or receive support for self-determination.
- 84% worry there is no one else to provide the support they are giving.
- 82% worry her/his health will deteriorate.
- 82% worry some form of abuse or neglect might occur.

1. State of Care: Wisconsin's Home Care Landscape. PHO. 2017. https://phinational.org/resource/state-of-care-wisconsins-home-care-landscape/
2. Survival Coalition Consumer Survey, November 2016. http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf
3. Family & Individual Needs for Disability Support Report 2017 (Institute. on Community Integration and The Arc of the United States)