How Will We Care?

Denise M. Brown
founder of The Caregiving Years Training Academy

How Will We Care?

It's not about whether or not
family caregivers self-identify.

(If you aren't reaching family caregivers,
you aren't speaking their language
and/or offering what they need.)

How Will We Care?

We're not hidden or invisible.

The system does not have a way
to reimburse itself for supporting
and helping us.

(This is changing.)

How Will We Care?

It's not a self-identification issue.

The systems see us.

It's a reimbursement issue.

They aren't paid to help us.

How Will We Care?

The Numbers

6,000: Number of hospitals

920,000: Number of hospital beds

1 million: Number of physicians

2.2 million: Number of home care workers

4.2 million: Total number of RNs

53 million and growing: Individuals caring for a family member

How Will We Care?

Family caregivers are the largest group
of health care professionals in the world.

How Will We Care?

Caregiving will remain a part of our lives.

How Will We Care?

Will there be enough?

- Money to hire care?
- Care to hire?
- Services and programs to access?
- Money to retire?
- Family members to help?

How Will We Care?

Our shortage of health care professionals will impact everyone regardless of where care happens.

Shortage = Higher costs

Shortage = Wait lists

How Will We Care?

In-home health costs rose by 14.2 percent between March of 2023 and March of 2024.

How Will We Care?

692,000 individuals were on wait lists for Medicaid home- and community-based programs in 2023 per KFF.

Starting in July 2027, most Medicaid beneficiaries can see a primary care provider within 15 business days of booking an appointment. It's 10 days for mental health and substance use care.

How Will We Care?

The average wait time for new-patient, non-emergent appointments across five specialties is 26 days, up 8% from 2017 per Merritt Hawkins.

How Will We Care?

Our Solution: We train our program participants how to help clients manage a wait list and manage when a benefit ends.

How Will We Care?

We will work rather than retire.

How Will We Care?

Children will grow up
in caregiving situations.

How Will We Care?

A caregiving experience will be a threat
to our basic needs.

How Will We Care?

Our stress = the overlooked epidemic.

Our stress = 4.10

on a scale of 1 to 5 with 5 being most stressed

1,296 family caregivers surveyed

How Will We Care?

In our survey of 112 family caregivers, we asked family caregivers:

How tired are you?
71% selected 1 or 2 on a scale of 5.

1 is Fatigued, 5 is Energized.

No one selected Energized.

How Will We Care?

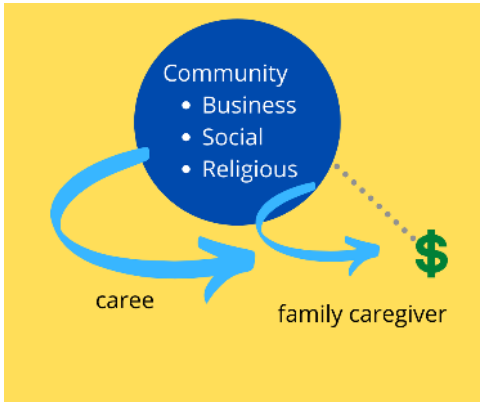
What tires you?

- Coping with all that's happening -- I feel like I just can't cope with one more situation or issue: 56%
- Scarcity -- there's not enough time and/or money and/or help: 47.32%
- Loneliness -- I feel so alone: 43.75% 49
- Grief -- I'm so sad by all these losses and declines: 42.86%

How Will We Care?

What energizes you?

- Solitude -- having time for myself: 75%
- Connections -- spending time with others who understand and support me: 70%
- Productivity -- accomplishing work and goals outside of my caregiving responsibilities: 58%



Cost to the Community

What expenses have decreased for you due to caregiving?

Entertainment: 77.78%

Travel: 55.56%

Dining out: 44.44%

Cost to the Community

What's the impact?

"Quality of life"

"The impact is that my caregiver's exhaustion does not get cured because I don't have time, energy, or freedom to go on trips."

Cost to the Community

What factors influence your spending decisions as a caregiver?

Your stress level: 90%

Your energy level: 70%

A day's level of difficulty: 60%

Cost to the Community

Do you feel guilty about spending money on yourself while caregiving?

No: 70%

Cost to the Community

15% of population within a community of 100,000 may be in a caregiving situation.

Each family caregiver once spent $20 a week visiting local restaurants and shops.

When that spend stops because of caregiving responsibilities, **the monthly cost to the community is $1,200,000.**

(The math: 15,000 x $20 x 4 weeks = $1,200,000.)

That's a significant loss of revenue for both businesses and the local municipality.

How Will We Care?

The Family Caregiver's Perspective

How Will We Care?

It's about the money and who it serves.

How Will We Care?

It's about what we see and its impact on us.

How Will We Care?

Money will stay in the family.

- Concerns about spending money because of the budget.
- The system will provide “moment in time” solutions.
- Family will be the 24/7 solution.
- An inability to find help to hire.
  - Help isn’t available.
  - Help is too expensive.

(We offer free monthly planning sessions to help families hire family members to provide care.)

How Will We Care?

Money will be spent on and with organizations that make a difference.

- Diversity.
- Family caregiver representation.
- Direct care workers receive living wage and benefits

How Will We Care?

Money will be spent to keep organizations accountable.

- If you speak my language and understand my experience, I'm with you.
- If not, I'm out.

How Will We Care?

Could families form an LLC with annual investments from family members to pay the primary family caregiver who becomes a Certified Family Care Manager?

- The LLC pays the Certified Family Care Manager (CFCM) who also receives benefits.
- The CFCM also provides virtual help to other family caregivers as a Certified Caregiving Specialist, generating revenue for the LLC.

How Will We Care?

Will family members take turns taking a leave of absence from work to provide care?

- Each family member uses FMLA for three months each year.
- What's the cost to the business?

How Will We Care?

Family caregivers will want to work where diversity and inclusion matters.

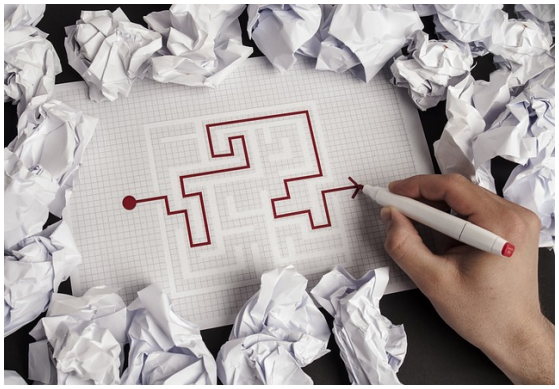
- They understand what it's like to feel marginalized.

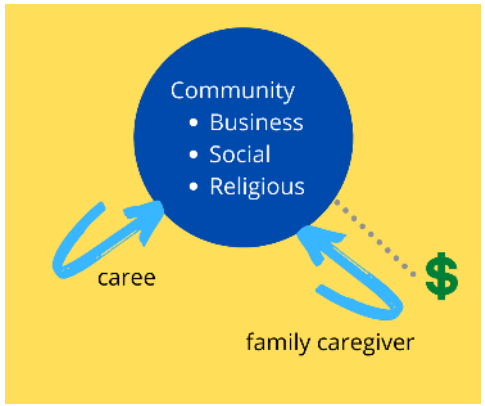
How Will We Care?

Family caregivers will distrust the systems but look to individuals they can believe.

How Will We Care?

Family caregivers will want a solution tied to an individual rather than an organization.





How Will We Care?

AI

- Easier to find resources, receive instructions, get training

How Will We Care?

The value of the learned experience

- Trained and certified auxiliary personnel like our Certified Caregiving Consultant
- Payers reimburse auxiliary personnel for providing support and navigation services

How Will We Care?

The value of the learned experience

- Professional Listening Artists who offer an affordable option for individuals who want immediate relief after a terrible day, a difficult conversation or a trying situation.
- Our goal: Professional Listening Artists become a benefit offered through Employee Assistance Programs and Flexible Savings Accounts.

How Will We Care?

Medicare introduced new Medicare Part B services in 2024:

- **Support for social factors that impact health**
  These support services can be provided for patients and family caregivers **by auxiliary personnel**.
- **Support for patients with an illness that puts them at risk for hospitalization, nursing home placement or sudden worsening of symptoms**
  These support services can be provided for patients and family caregivers **by auxiliary personnel.**

How Will We Care?

Medicare introduced new Medicare Part B services in 2024:

- **Training for family caregivers**

How Will We Care?

The systems will change not from within but because of outside forces (us).

Consider the advocacy efforts of parents in Indiana.

How Will We Care?

Gofundme:
Raised over $5 billion since 2010

"Customers Buy Out Doughnut Shop Early Every Day So Owner Can Be With Sick Wife"
~ CBS LA

How Will We Care?

Fund the Family Caregiver

How Will We Care?

Family caregivers are the health care system.

- What if the Certified Family Care Manager also received reimbursement and training (training now happens!) from a payer (like Medicare)?
- What if local communities created guaranteed income for family caregivers?

How Will We Care?

Acute Care

- "Hospital at home"
- Certified Caregiving Consultants
  - Patient Care Team
  - Palliative Care Team
  - Hospice Team

How Will We Care?

Local Communities

- Community Gardens house a Caregiving Department which naturally create a co-op
  - Share care
  - Reduce costs (buy in bulk)
  - Force efficiencies
  - Deploy the Mobile Caregiving unit throughout neighborhoods

How Will We Care?

Local Communities

- The Caregiving Department staff completes annual Family Emergency Planning sessions with residents
  - The staff are family caregivers and former family caregivers who have completed training

How Will We Care?

Home Care Shift

- Client isn't an individual but a community
- Virtual visits from home health aides

How Will We Care?

Long-Term Care Shift

- Will we feel comfortable with a placement decision?
- Will a ltc facility still be a viable employer?

How Will We Care?

Long-Term Care Shift

- The truth about placement services
  - Money spent on placement services better spent on patient care

How Will We Care?

Entertainment

Venues accommodate family caregivers and carees so they stay in business.

(Caregiving friendly restaurants)

How Will We Care?

Businesses

Businesses accommodate us as employees and as customers or go out of business.

(Southwest)

How Will We Care?

Houses of Worship

What if worship services happened throughout the week and not just on weekends?

Services accommodate caregiving families just like parenting families.

How Will We Care?

Employers

Work hours becomes flexible because customers will need that flexibility.

We need our work.

Our economy needs our work.

Our communities need our business.

How Will We Care?

Every organization will need:

Chief Caregiving Officer

Caregiving Support Program

How Will We Care?

Cases involving eldercare increased 650% over the last decade.

Men are nearly three times more likely to bring cases involving eldercare as compared with childcare: nearly 40% of cases involving eldercare were brought by men. Employees are less likely to win eldercare cases because workers have better legal protections with respect to childcare than eldercare. Still, there is plenty reason for employers to be concerned.

How Will We Care?

The Protecting Family Caregivers from Discrimination Act, introduced June 5, 2020, would prohibit employers from firing, demoting, mistreating, refusing to hire, or taking other adverse employment action against workers who are caregivers for loved ones. The bill would also prohibit employers from retaliating against a worker for seeking enforcement of these discrimination protections and establish a grant program to assist in preventing and combating such discrimination.

How Will We Care?

Family caregivers will comprise the greatest number of customers, employees and community members.

How Will We Care?

Our future caregiving experience will change because our economy will depend on it.

How Will We Care?

Join us:

Certified Caregiving Consultant

Professional Listening Artist

Certified Family Care Manager

Care and Share: Our Big Ideas

Caregiving Support Benefit on CaringOurWay.com

How Will We Care?

Questions?

How Will We Care?

Denise Brown
CaringOurWay.com
CareYearsAcademy.com
denise@careyearsacademy.com
773-343-6341