



Supporting Family Caregivers

Amy Kowinsky, RDN, CDP



Dementia's Two Fold Impact

People Living with Dementia

- Compared to those without dementia,
 - 2x as many hospital stays
 - 4x likelihood of nursing home placement
- 80-90% experience behavioral symptoms, increasing both their distress *and* risk of move to nursing home
- Recent diagnosis associated with short term higher suicide risk

Family Caregivers

- Health:
 - **1 in 3** dementia caregivers say their health has gotten worse due to their care responsibilities
 - Caregiver strain is independent risk factor for mortality of caregiver
- Time:
 - Avg 23 hours of caregiving/week
 - 8.6 billion hours annually, valued at **\$244 billion**
- Work:
 - 6 in 10 say they had at least 1 impact to their employment as a result of caregiving
- Finances:
 - 1 in 5 experience high financial strain
 - Annual per capita costs for Medicare beneficiaries with ADRD are **3-5x greater** than those without it

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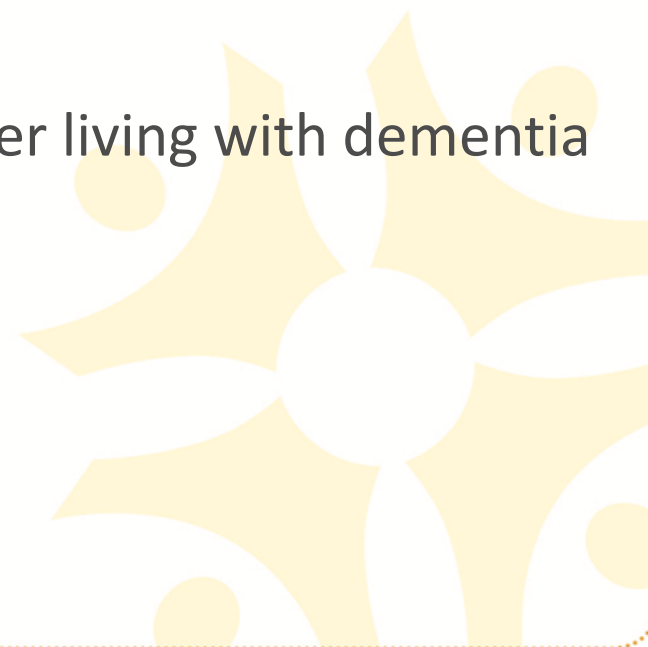
The Quiet Voice of the Family Caregiver

My sister lives alone and refuses to take her medications and is no longer completing hygiene tasks. She has become incontinent won't change or wash her clothes. Her apartment has an odor. She becomes very combative and belligerent with me and *I don't know what to do.*

- 94 year old caring for her 90 year old sister living with dementia



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The Quiet Voice of the Family Caregiver

It's just the two of us all the time now. It's hard for me to take her out. We used to go to church because that was really important to her, but people started looking at us sideways when my wife would get restless or make noise during the service. So we quit going because we didn't feel welcome. *I miss it, and now she doesn't leave the house at all.*



The Quiet Voice of the Family Caregiver

I don't know if you saw on the news but Bob wandered out of the house and was missing for 2 days. They found him over an embankment. He's ok and he's at the VA now getting treated but *I don't think I can do this anymore.*



The Quiet Voice of the Family Caregiver

I feel the pressure of it every day; am I making the right decision for my mom? Should I be doing something different? *I feel like this is a second job, that I wasn't trained in and don't feel competent at.*



The Quiet Voice of the Family Caregiver

I am exhausted because I get up at 4am every day to do things that need done around the house because as soon as she is awake she needs my undivided attention. I shower with her to make sure she is properly cleaned and I now also have to clean her after she uses the bathroom. *The other day was really hard and at one point we just looked at each other and we both started to cry.*



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Where Do Families Turn?

PCP's, but...

- **Training is limited**
 - 65% who had dementia training in residency said it was “very little”
 - 27% are never/sometimes comfortable with questions about dementia
- **Office Visit Time is Limited**
 - 29% have talked to their doctor about what they need to care for their family member
 - 13% have talked to their doctor about what they need for own well-being

Friends and Neighbors

Dr. Google



Dementia is a medical diagnosis...

That impacts functional abilities

That has emotional implications

That has social implications

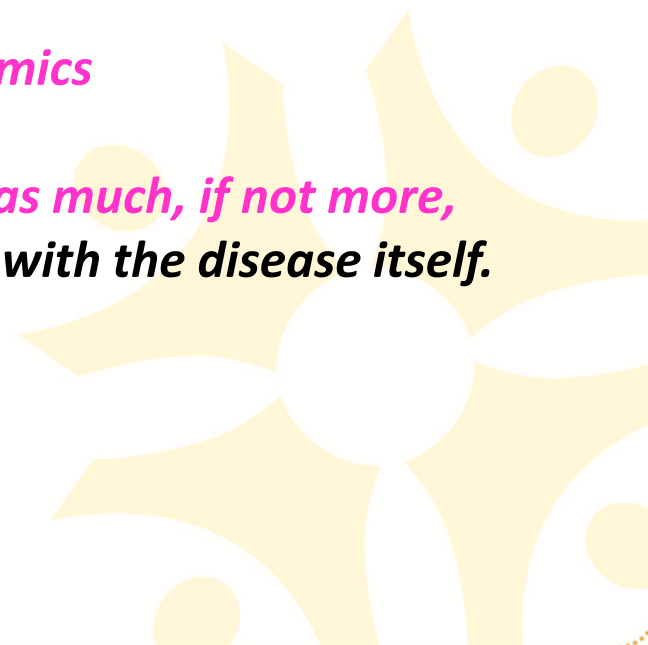
That has relationship implications

That affects family dynamics

That impacts the family caregivers' lives as much, if not more, than it impacts the life of the person living with the disease itself.



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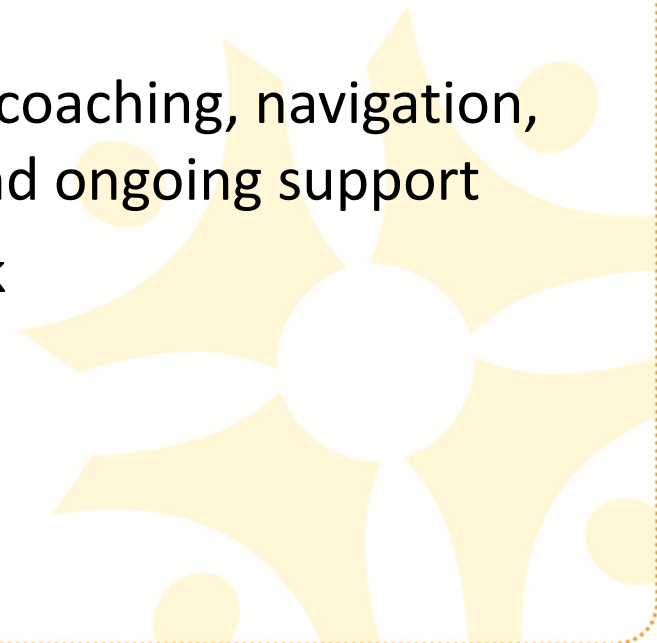
Dementia360

- ...because life doesn't prepare *anyone* to be a dementia family caregiver
- ...because family caregivers often feel alone and unprepared for the challenges they face
- ...because it is possible to help families live better in the context of dementia



Dementia360 Can Help

- What is it? Comprehensive, ongoing support program to help families caring for people living with dementia at home
- Goals:
 - Extend the length of time the person living with dementia can comfortably and safely live at home
 - Prevent crisis situations
 - Give families a life that is better because they have confidence, skills, and support to be successful
- Dementia360 team provides education, coaching, navigation, connections to community resources, and ongoing support
- Part of Presbyterian SeniorCare Network



Dementia360

Because helping the family caregiver helps the person living with dementia

Dementia Education
What to Focus On
What to Let Go Of
“Problem Solving”
Managing behaviors
Planning

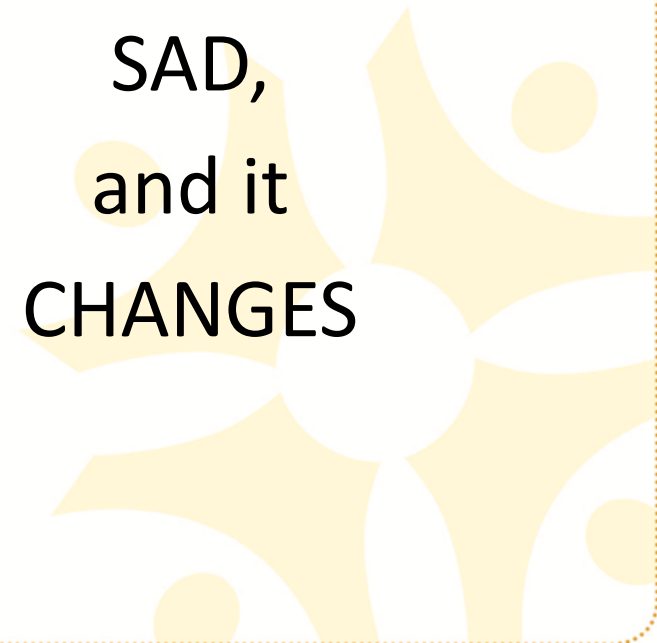
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Ongoing support for
the family caregiver(s)
because this is...

HARD,
SAD,
and it
CHANGES

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More About Dementia360

- Program foundation is the **intensive relationship** between family and the Care Coordinator
- Process starts with a **home visit**
- Involve the **entire family** ~ diagnosis impacts *everyone*
- Maintain a **dual focus** ~ present & future



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Dementia360: Because dementia impacts *everything*

Its education and resources... but its also personal

She hasn't bathed in months.

He has thrown out every caregiver we've brought in.

I'm not comfortable with lying to her.

What happens to him if my cancer comes back?

The kids think I should place her.

Caregiver is blind... and he wanders.

His incontinence is getting worse.

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Can we still travel?

He has me up all night.

Is he still safe to _____?

She keeps overfeeding the cats.

We want to keep her living in her own house as long as she can.

This isn't what I thought our life would be like.

She won't eat/All he wants to do is eat.

She keeps calling me grandpa.

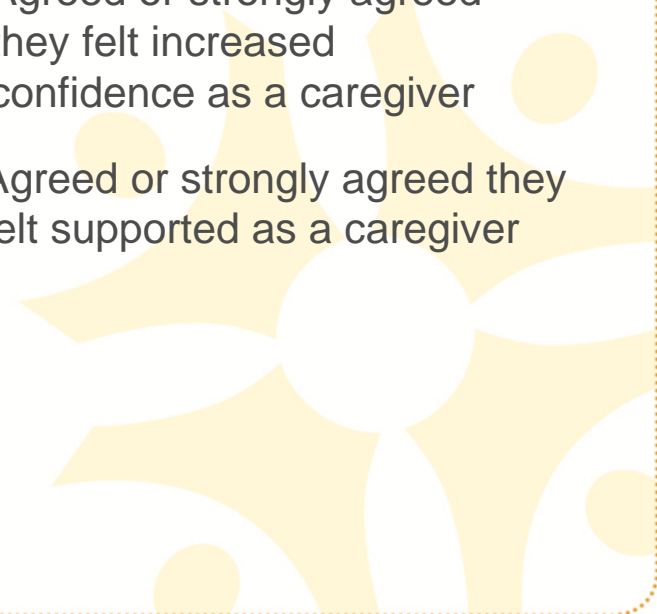
Dementia360 Program Results

Of the people living with dementia who participated in the program:

- 79%** Experienced equal or fewer falls
- 96%** Experienced equal or fewer ER visits
- 80%** Experienced equal or fewer hospitalizations
- 67%** Experienced an improvement in nutritional status

Of the caregivers who participated in the program:

- 60%** Experienced decrease in caregiver burden (even with progression of the disease)
- 43%** Experienced an improvement in their overall well-being
- 100%** Agreed or strongly agreed they felt increased confidence as a caregiver
- 100%** Agreed or strongly agreed they felt supported as a caregiver



Challenges and Lessons Learned

- Caregiver Level
 - “I should be able to do this myself.”
 - Asking for help too late
- Community Level
 - Dementia360 awareness
- Payer Level
 - Private pay program
 - Upcoming pilot with a payer



Questions?

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