

# Green County Caregiver Assessment Summary

# What we wanted to know and why...

- What is most stressful or challenging about caregiving?
- What is going well?
- What resources are lacking or needed to make their roles less stressful?
- What are Green County Caregivers experiencing in their own words and what would help?

# What did we learn?

- Communicating with professionals was challenging...
- Managing stress and finding balance in life were rated as significant challenges in the survey
  - A need for formal and informal respite help was talked about in the focus group as a solution and challenge
- Changing or non-normative relationships between the caregiver and care receiver made their role more stressful and difficult

# What else did we learn?

- We learned some things about what was working and wasn't for local caregivers
- Caregivers told us what they needed and wanted for resources
- These pieces of information have helped inform us as a coalition and as individual agencies and organizations where to focus our efforts!

# Communicating with Service Providers

- This was the most selected response regarding caregiving challenges in the survey
- Follow-up questions in focus group told us...

- Multiple providers to communicate with and keep track of
- Providers don't talk to each other
- Caregiver often is common thread, giving and keeping information from all providers and coordinating care – can be a very tough job

- Providers sometimes don't want to answer questions, or are too clinical
- Don't recognize how big and important the role of caregiver is
- Aren't as helpful and supportive as caregivers would like
- Caregivers want more information and guidance
- A knowledgeable resource person to help problem-solve and advocate

# Life Balance

Second and Third Biggest Challenges (survey responses):

- Balancing family responsibilities (kids, spouses, other relatives)
- Work schedules and responsibilities



# Self-care and emotional stress

Highest survey responses:

- Being upset and not managing emotions well
- Lack of time for themselves
- Not being able to sleep or exercise
- Exhaustion
- Lack of social life

# Need for Time Away

- “You know getting away to the grocery store can be really good. You know, I don’t hate grocery shopping like I used to. [lots of laughter] You know, you start to realize that going to the grocery store isn’t all bad.”
- “Yep, I remember walking in to Target and knowing that my husband was safe, that my daughter was with him. And walking in just like I was in... Candyland or something, and just taking some deep breaths, and you could enjoy yourself here.”

# Positive things

- 57% of survey respondents said they did not have too many caregiving responsibilities to be able to comfortably handle them

# More positive things

- caring for someone whom I love and/or care for a great deal;
- gaining satisfaction knowing that I'm providing the best care I can;
- feeling a sense of fulfillment of obligation to a family member;
- feeling appreciated by the person I care for;
- giving back to someone who gave to me.

# Changing and Non-normative Relationships

- Relationship with care receiver is significant source of positive feelings (previous slide)
- Also a significant source of challenge and emotional stress...

- “There were a lot of times when I’d have to walk away into another room and regroup myself a little bit before I could... respond. Because obviously they’re (care recipient) upset, they’re depressed, they’re frustrated.”

- “She’ll (her mother) tell one person one thing, and somebody else another.”
- “I have a brother and sister that are far away, and they’re always questioning everything we do...”

- “I couldn’t go to the grocery store because people would stop when my husband would start to hug me and cry. So I’d be hiding in the grocery store, and when I would come home, I wouldn’t have anything. Trying to get food and, and um, yah.”



- “Because mom, you know, I wonder if she’s not going to tell him things because I’m in the room. Such deep dark secrets that she holds in, you gotta know my mom. That she holds in that she can’t tell, she doesn’t need me to know, but maybe she would allow the doctor.”

- “Do I let her make that decision for herself that she’s not gonna go, or do I tell her that, you know this is what I do now, I make the appointments, you have to be here at this time. She’ll go, dragging... you know, but she’ll go. So, what’s my role? She’s eighty-seven, she’s fine, she should get to think for herself. She’s lived independently until last July, so what’s my role?”

- “Like my dad is 82 years old, and he’s trying to put in his new garage door opener. [Sigh.] You know it’s not an easy task, you gotta crawl up there and the leg, we have a hole up on the ceiling where the leg went through. [a bit of laughter] And as a child, you know you don’t want to treat him like a child and protect him and say, ‘Well Dad, you shouldn’t do that anymore, you shouldn’t be up there.’ He is independent, they are independent, as long as they’re competent. That’s a horrible role as a child to feel responsible, like you say, if you try to push, they’re gonna push you right back. So I think you hit it right on the head when it comes to elderly parents.”

- “Is it different if you’re the child or the spouse?”
- “Oh yeah, I’m sure it is.”
- “I mean, because would you resent, I mean think about your children, if they told you [that] you had to do something. I mean I think would you be, I mean, Oh my God!”
- “They’ll be telling you [that] you shouldn’t drive. And ‘you can’t drive here, Dad, we’ll come see you.’ The hell I can’t.” [Laughter]

# Barriers to finding or getting extra help

- Caregivers who may (or do) need care themselves have major worries and needs for help and resources
- Cost of formal services, in-home care
- Guilt about leaving care receiver
- Flip side is giving up paid work to provide 24/7 care
- What is a “qualifying event”?

# What do caregivers in Green County want/need?

- #1 – Education and support:
  - Skill-building for communication and coordinating care
  - Knowledge and resources to understand different diseases and illnesses
  - More about services available and how to access
  - Info and guidance to plan for the future, long-term care, financial education
  - Internet resources, brochures, workshops
  - Support groups

# More Resources Needed:

- Mentorship, sounding board, support group (ways to connect with other caregivers)
- Entity which would monitor and follow up with services providers and complaints
- Inexpensive respite care, more availability in evenings and weekends