

Desperate for Respite but Won't Say "yes."

**-- the role of faith community
"gatekeepers" in counseling family
caregivers.**

RESPITE IS

Temporary, short term breaks for anyone caring for someone dependent who can not be left unattended. Think: "Relax," "Recharge," and "Relief."

Lifespan respite is the focus of the S.C. Respite Coalition...

For family caregivers of all ages, regardless for whom they care:

- children with developmental disabilities
- children and adults with mental illness (an "invisible" group)





- adults with midlife degenerative diseases and head & spinal cord injuries
- This **midlife group** is of great concern - they have almost no public sources of respite funding.
- --older adults and those with dementias.

Today's focus is on family caregivers caring for someone with Alzheimer's disease or other dementias (ARDs).



*1 in 8 people 65+ have it.
Almost ½ of those 85+ do too.*

*In South Carolina in 2010, there
were 80,000 people known to
have ARDs.*

*This number will grow to at least
100,000 people by 2025.*

You know these people ...they are in your congregations. In fact, they're the ones dropping out.



Suffice it to say, a tsunami is on its way. Your counseling can help those who will listen!



Of people with ARDs, 80% are cared for by unpaid caregivers.



“SO WHAT,” you say!

**“Families have
always taken
care of their
loved ones”**

**And you are
right.**



But it's not like when Grandpa Walton moved in ... not any more

That was on TV. This is real life!

- **Caregiving goes on longer than ever before and few of us are truly ready.**
- **Life expectancy longer in ALL populations.**
- **Women are working...**
- **Families are smaller...**
- **And living farther apart.**

At first family caregivers do not realize how long this “journey” will be.

But YOU KNOW...

62% OF caregivers of elders with ARDs, report “high to very high” stress, compared with 39% of family caregivers of elders without it.



Why, of everything you are being asked to do, should respite be a priority for the faith community?



**Because you
are the next
best to kin!**

**Family
caregivers
trust you!**

Care giving affects more people in your congregations with each passing year!



Respite has emerged
as the top need of
family caregivers of
all ages, yet...

As desperate as they may feel sometimes

- They turn down offers of help.
- They do not know where to find it.
- They will not ask for it unless they can pay.
- They deny they need it.

THEY DO NOT REALIZE THAT IT WILL BE GOOD FOR THE LOVED ONE.



Caregivers do not ask for help because:

- of guilt,
- of fear of leaving their loved one with another person,
- of inability to manage the reaction if the loved one protests,
- of beliefs that families should care for their own,
- of no extra money to pay for respite
- of not wanting people to “know their business.”

**Studies show that as little as
4 hours a week of reliable
respite can improve the family
caregiver's health, reduce
abuse and neglect,
and forestall
institutionalization.**



Too often they withdraw and become isolated

They tend to allow only other family members in to help, IF they are near and IF they are willing.

You can do something, even if you can not provide respite or start new programs.



You can coach them to understand “respite,” and to accept and perhaps even seek help...

- Help them prepare for a longer “journey” than they expect.
- Persuade them to build a circle of support EARLY ... BEFORE A CRISIS.



Why do they “need” coaching?

- Spouses take longer to experience the “role tension” that leads them to understand that they are actually “caregivers,” that this is more than just “the worse” in “for better and...”
- Adult children experience “role tension” immediately and are uncomfortable.
- Parents DO NOT want to ask adult children for help until they just have to...often very late!
- They are not accustomed to “outsiders” in their homes. Many have never employed or supervised anyone in their lives.

Intervening EARLY is important... before the caregiver “gives up” their own activities.

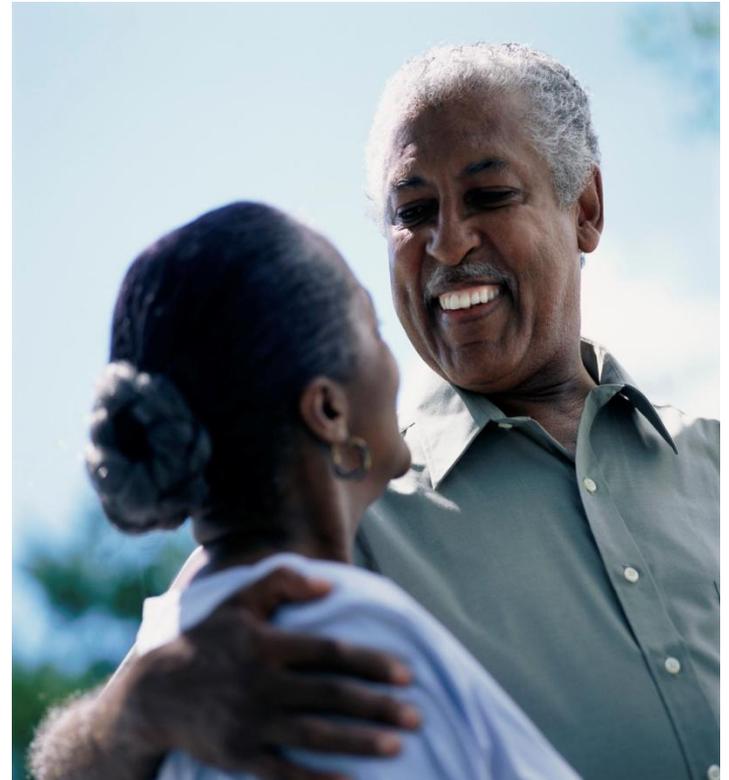


START WITH INCLUSION

- Ask about including the loved one in congregational life, so the family caregiver continues “normal” involvement.
- This may mean training a “shadow” for the loved one..
- OR creating a separate activity for them...
- OR finding someone to go by the house before they come...

Prepare for their resistance

- They are protective of their loved one – their dignity.
- *S/he may not want to wear “church clothes.”*
- Or may disrobe at times, especially once dressed for an outing while the caregiver tries to get ready.
- *Or may eat with their fingers or have to be fed.*



Listen. Express your love and care for the loved one.



- Reassure the family caregiver that **you accept the loved one just as s/he is**...formal clothing doesn't matter.
- Pledge to teach the congregation members about dementia and the changed person – **assure discretion and dignity.**
- **Remove obstacles** and objections if you can. “We will all eat with our fingers.”

Above all, BE INSISTENT that they not be the only person in their loved ones life or plan to do care alone!





Leeza Gibbons and her mother in 2002

Carlos Gibbons described the gift he AND his wife received from their couples dinner group that had grown out of an adult Sunday school class.

If inclusion will not work...

Look for other ways to get your foot in the door:



- Try to arrange for someone to bring a meal on a day when they have a doctor's appointment.

(Be sure to find out the loved one's preferences and dietary restrictions. And **ask who** the caregiver likes and does not like.)

- If that person will stay and eat with them, that **might** be welcome.

Prepare friendly visitors to take a role.

- If a member takes altar flowers after church on Sunday, let them deliver only to one household. Ask them to go in and see if anything is needed.
- If that member can be someone who the family caregiver knows and likes -- even better!!





- If the caregiver is still in their robe, suggest they offer to sit with the loved one while s/he takes a shower... goes for a walk. ..run an errand.
- Or suggest the visitor offer to run a quick errand, do some dishes, sweep the porch... little things that let the family caregiver know they are sincere when they offer help.

Teach the family caregiver to create a “circle of support”

- Help them prepare a list of ways others can help – have them keep it with them in case someone says: “let me know if there’s anything I can do.”
- Use online resources like “Lotsahelpinghands.com” to coordinate friends, neighbors and family members.
- **Be respectfully insistent....**



Keep reminding them that their loved one needs friends and supporters too.

- Research shows that family caregivers are so self-sacrificing that **they do not respond to “take care of yourself.”**
- Help them create a back up plan so others could take over in an emergency.



IF NECESSARY USE THE ULTIMATE ARGUMENT:

- “If not for yourself, use outside help for the sake of your loved one... WHAT WILL HAPPEN TO THEM IF YOU FALL OUT?
- THIS IS WHAT A RESPONSIBLE CAREGIVER OF SOMEONE THIS VULNERABLE DOES!”
- Respite can be a way for people to keep current on how to take care of your loved one!

If they will not accept help without paying people

- Suggest they put “respite” on their gift lists. (How many more bathrobes do we really need?)
- Counsel them that this is the “rainy day” for which they have saved.
- Help them to think of what assets they have to use.
- Our homes, if paid for, are a resource. Find information about reverse equity mortgages for homeowners 62+ (or recruit a congregation member to help with this)

- Guide them to elder care attorneys for advice and planning.
- Steer them to respite resources.
- Recruit someone to help them find private providers or nearby Adult Day Centers.
- Provide the number of the aging information specialist at the closest Aging and Disability resource center –
better yet, make that call WITH THEM while you are at the home. (start with 800-868-9095)

This is all easier said than done!

When they say,
“God never gives us
more than we can
bear,”
emphasize that it
does not show a lack
of faith to ask for help
from God’s people.



You may not be able to talk openly during your visit with the care receiver present.

- Ask the family caregiver to walk out with you.
- Arrange to talk later.
- Bring another person with you to take the loved one in another room.



Family caregivers are worn down. They may need coaching to be assertive

- Address resistance by the loved one to letting anyone else but the family caregiver provide care - children also resist having a babysitter, but it is necessary sometimes.
- Teach them a trick of hiring someone to clean house...
- Perhaps the caregiver needs to be needed so much they are fostering dependence! Often rigid standards for care are actually ways of preventing anyone else from succeeding.
- Teach that it is best to be direct with providers (paid OR volunteer) about what is working and what is not.

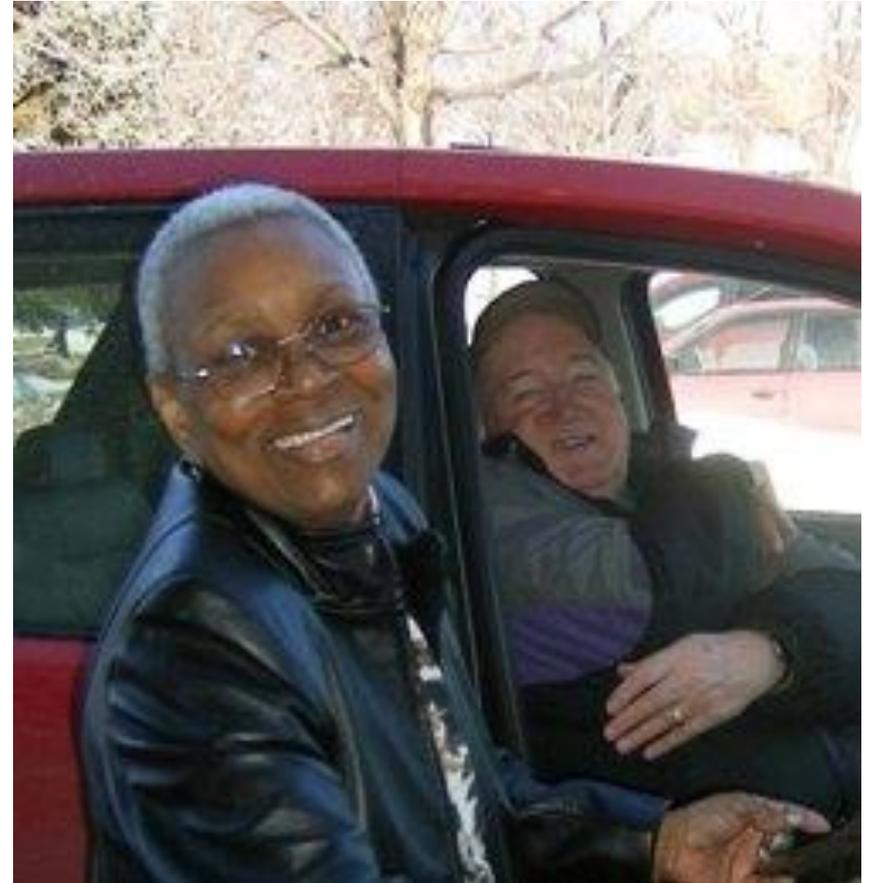
You will not succeed in many cases

- But please keep trying.
- Do not be deterred by the idea that if you can not provide support for all the family caregivers in your congregation, you should not do it at all.

Think of the little boy saving starfish that washed up on the beach.



If you succeed with just one or two families, you will have made a difference.

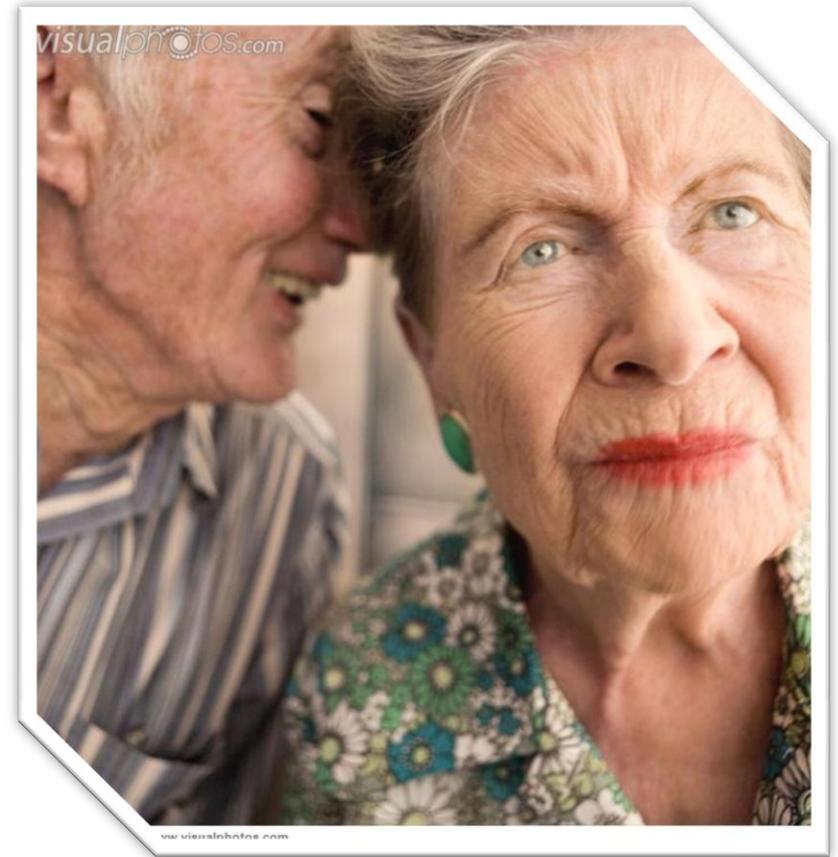


BEFORE A CRISIS Remind family caregivers:

- Having a plan in place is **RESPONSIBLE** and **UNSELFISH** -- something could happen to any of us at any time.
- **Regular respite providers are part of the back-up plan.**
- **Even busy adult children BENEFIT from being allowed and asked to help!**
- Respite will mean that someone besides the family caregiver knows the **CURRENT** needs, habits, and routine of the loved one.

To be sure, no-one can provide care like the family caregiver

- But doing it alone **DEPRIVES THE LOVED ONE** of others to care.
- **ASK THEM:**
“Is this about them or you?”



Love thy neighbor as thyself.

Leviticus 19:18



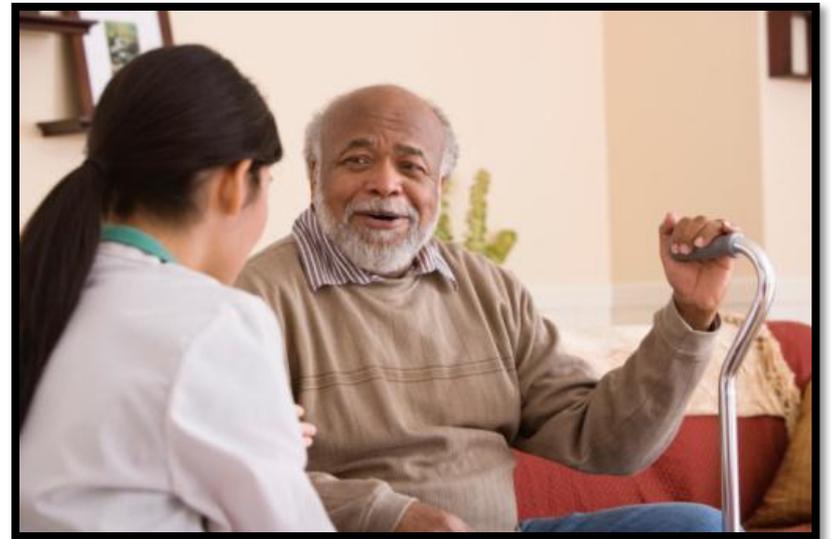
Not one of you
truly believes
until you wish
for others what
you wish for
yourself.

The Prophet Muhammad
13th of the 40
Hadiths of Nawawí



For I was hungry
and you gave me
food, I was thirsty
and you gave me
drink, a stranger
and you welcomed
me.

Matthew 25:35



The faith community is next best to KIN!

And you, who visit the families at home, are often the key to extending ministries to keep the family caregivers connected and to serve them. **Your coaching matters!** THANK YOU!

References

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