



The Coalition to Transform Advanced Care (C-TAC)
in Collaboration with
The D.C. Coalition to Support Caregivers

Listening Sessions to Identify the Needs and Concerns of Caregivers in
Washington, DC Ward 7 Community

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Background

Statistics show the ever-growing rate of unpaid caregivers. According to AARP's *2020 Report: Caregiving in the U.S.*¹, the number of unpaid caregivers grew 3% over the past six years (2015 to 2021), up from 18% to 21% of adults serving as unpaid caregivers. In Washington D.C., nearly one in five adults were caregivers in 2016 and of these caregivers, one in five had provided care for at least 20 hours per week.²

The Coalition to Transform Advanced Care (C-TAC) collaborated with the newly formed D.C. Coalition to Support Caregivers (D.C. Coalition) to identify the needs and concerns of caregivers living in Washington, DC- initially focused on Washington D. C.'s Ward 7 community. The D.C. Coalition to Support Caregivers is a group of faith-based leaders and community partners working to make a difference for and to support unpaid caregivers. Founding supporters and participants included: Progressive National Baptist Convention, INC.(PNBC), ARCHANGELS, and Capital Caring Health (CCH). Further there were several faith communities active in promoting the Listening Sessions. These groups included the following:

- Evergreen Baptist Church
- Holy Trinity United Baptist Church
- Johns Memorial Baptist Church
- Mount Baptist Church
- New Macedonia Baptist Church
- Pennsylvania Avenue Baptist Church
- Pilgrim Rest
- Southeast Tabernacle Church

C-TAC and the D.C. Coalition to Support Caregivers successfully designed and hosted two “Virtual” Listening Sessions with 30 community members in attendance.³ These efforts helped the organizations gain critical insight on the needs and concerns of caregivers. The results of the sessions will guide the D.C. Coalition to create education, provide resources, and garner support from other appropriate community partners.

¹ AARP & National Alliance for Caregiving. 2020. Caregiving in the U.S. 2020. Available at: <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>

² CDC. (2016). *District of Columbia Caregiving* (Infographic). <https://www.cdc.gov/aging/data/infographic/2016/district-columbia-caregiving.html>

³ Community members – caregiver representatives from faith communities, health care systems (including hospices), and other community partners.

The Project

Capital Caring Health (CCH), an advance illness care and hospice care organization and an inaugural member of the D.C. Coalition, has provided care for patients living in all of Washington, DC since 1998. In 2019, CCH served 963 patients in DC with 305 of those patients in Wards 7 and 8. In effort to expand its services and programs in the Ward 7 community, CCH partnered with The Progressive National Baptist Convention, Inc. (PNBC) to connect with the community and hear of their needs. Having the blessing and support of PNBC was critical as faith communities serve an essential role in building and bridging trust⁴ within communities that have historically been underserved and under resourced – primarily communities of color.

Goals

The goal of this project is to provide unpaid caregivers with support and resources – creating education and advocacy efforts from themes learned from the Listening Sessions. The D.C. Coalition is strategically and authentically led by Rev. George Gilbert, Jr, Associate Pastor of Holy Trinity United Baptist Church, located in Ward 7.

The following metrics were used:

- Number of Listening Sessions
- Attendance at events
- Feedback from Community Partners
- Response from Caregiver Intensity Index (CII) – Archangels
- Number of follow events and educational sessions

Where did we begin?

About Ward 7

This project's initial focus was on the Ward 7 community. Ward 7 is in the easternmost tip of the District of Columbia and is a predominantly African American community. According to DC Health Matters, 2021 Demographics for Ward 7's population is almost 91.7% African American and the Median household income is \$42,201.⁵ Regarding access to health care, about 86% of Ward 7 residents possess some type of health care coverage, however, health challenges show relatively high death rates due to heart disease, cancer, diabetes, and essential hypertension.⁶

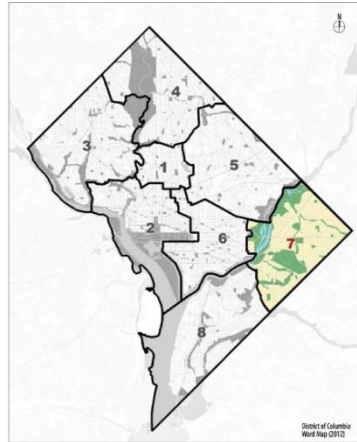
⁴ Nandyal, S., Strawhun, D., Stephen, H., Banks, A., & Skinner, D. (2021). Building trust in American hospital-community development projects: a scoping review. *Journal of community hospital internal medicine perspectives*, 11(4), 439–445. <https://doi.org/10.1080/20009666.2021.1929048>

⁵ DC Health Matters. <https://www.dchealthmatters.org/demographicdata?id=131494>

⁶ District of Columbia, Department of Health, Center for Policy, Planning and Epidemiology, State Center for Health Statistics.

https://doh.dc.gov/sites/default/files/dc/sites/doh/publication/attachments/Profile_of_Health_and_Socio_Economic_Indicators_Ward_7_2000.pdf#:~:text=Ward%207%20is%20located%20in%20the%20easternmost%20tip,residents%20possess%20some%20type%20of%20health%20care%20coverage.

Ward 7 is distinguished by its leafy streets, single-family homes, transit stations and above all, its greenspace. It is home to several Civil War fort sites that have since been turned into parkland and home to the largest city-owned park in the District, Fort Dupont Park.⁷ Ward 7 is also home to green spaces such as Kenilworth Aquatic Gardens, Watts Branch Park, Anacostia River Park and Kingman Island.



Working directly with the faith communities outlined previously as well as other community partners, two caregiver Listening Session were planned and held in the summer – August 24, 2021 and again in the Fall, October 14, 2021. To guide our efforts the D.C. Coalition used the *AARP Livable Communities: Roadmap to Livability: Community Listening Session Tool Kit*.⁸ This publication was a key guide in developing both Listening Sessions.

As supporters of the D. C. Coalition, Archangels⁹ provided participants with a link to a survey to assess and measure each attendees Caregiver Intensity.¹⁰ Also, within each session, there was a live presentation with PowerPoint slides to reference and to give attendees context, share key definitions and findings, and a summary of their intensity scores.



⁷ District of Columbia, Office of Planning. <https://planning.dc.gov/page/about-ward-7>

⁸ AARP. Roadmap to Livability: Community Listening Session Tool Kit <https://www.aarp.org/content/dam/aarp/livable-communities/livable-documents/documents-2018/Book-2-Roadmap-To-Livability-Listening-62518-Irspr.pdf>

⁹ Archangels. <https://www.archangels.me/>

¹⁰ Archangels. Washington, D.C. Ward 7 Caregiver Intensity Index. <https://www.archangels-cii.me/ward7care/>

More about Caregiver Intensity

The Caregiver Intensity Index was created by the ARCHANGELS to support two cases¹¹:

1. To reflect an individual caregiver's experience
2. To give the systems designed to support caregiver's sufficient data and detail to do so effectively.

Intensity is reflected by colors **Red**, **Yellow** and **Green**.

The initial findings¹² for **this** caregiver group revealed the following:

- Caregivers are two times more likely to be in the **Green** than other communities across the country. ARCHANGELS team believes this is due to the connection and support from faith-based groups.
- Overall Caregiver Intensity – **22% are in Red** (High Intensity). That is:
 - 91% have 1 or more adverse mental or behavioral health symptoms
 - 81% have symptoms of an anxiety or depressive disorder
 - 54% have had serious suicidal thoughts in the past 30 days
 - 49% see their day-to-day ability to do their work impacted due to the intensity of their caregiving

This group of caregivers from Ward 7 are .5x less likely to be in the Red than caregivers in other ARCHANGELS benchmark populations across the country.

- **15% are in the Green** (Low Intensity) Mental Health characteristics of caregivers with Low Intensity include:
 - 20% have 1 or more adverse mental or behavioral health symptoms
 - 15% have symptoms of an anxiety or depressive disorder
 - 6% have had serious suicidal thoughts in the past 30 days

This group of caregivers from Ward 7 are 2x more likely to be in the Green than caregivers in many other communities across the country. ARCHANGELS finds that caregivers from faith-based groups have lower intensity on average – though there is wide variation.

- Further, **52% of caregivers measure as being “on the edge”**. These caregivers find the following experiences to be more common:
 - Are experiencing regular crises as part of caregiving

¹¹ Archangels. <https://www.archangels.me/home-inside>

¹² Results are not definitive conclusions but provides directional insights.

- Are less likely than other caregiver types to not believe caregiving has positive benefits (making someone’s life better, doing a good thing, making the caregiver a better person)
 - Have widespread concerns about not having adequate free time
 - Do not typically have negative emotions such as shame, guilt and resentment related to caregiving
 - Often express concerns with caregiving interfering with productivity at work
 - Are more likely than other caregiving types to express concerns about paying their own bills, having less income, and worrying about future financial problems
 - Report access to information may be a significant concern: fewer than half report being able to get the legal information and help they need.
 - Are often not sleeping well.
 - Are feeling emotionally exhausted
 - Report family is a significant stressor
- **For 26%** of the caregivers in this sample from Ward 7, ‘feeling supported’ is the greatest buffer reducing intensity. Caregivers from this Ward 7 sample are close to 2x more likely to have support as their top buffer than other communities ARCHANGELS has worked with. We know from our research published by the CDC that feeling supported is THE more effective buffer for Caregiver Intensity.
 - The top driver of intensity for this group of Ward 7 caregivers is not having enough time for themselves. This was the top driver for **37%** of caregivers in the Ward 7 sample. Caregivers in the Ward 7 sample group were 1.3x more likely to have ‘no time for you’ as their top driver of intensity than other benchmark populations. The rate of ‘no time for you’ as a top driver is like that of populations who are primarily ‘double duty’ caregivers – meaning they are caring for people at work and at home.

These findings from the intensity score surveys were complimentary to the responses we obtained from the Listening Sessions.

The Support Team

To execute each Listening Session, a support team was created with designated roles and responsibilities. Further, prior to “go live” a practice session was held and after each session, a debriefing occurred. These two steps were critical in process, ensuring preparedness, comfort, and data capture. The following is a description of key roles and their responsibilities:

- **Facilitator:** It was important to the that the facilitators recruited was a member of the faith community and well respected amongst the core target group and, belonging to the same ethnicity/race.
- **Back Up Facilitator:** To serve as a backup/ co – facilitator if needed.

- **Notetakers:** Workgroup members wanted to ensure that participants felt comfortable in speaking freely; therefore, the group decided that the sessions would not be recorded. With the sessions not being recorded, it was critical to have good listeners and note takers available to capture the results and comments.
- **Timekeeper:** Each session included a timekeeper whose responsibility was to keep the facilitator on track. If questions or discussion ran long, the timekeeper would communicate to alert the facilitator to advance in the session.
- **Technical Support:** The technical support person was able to give easy instruction and tips on how to use the chat, raise hands, and mute or unmute participants, and share screen to advance slides.

Session Agenda/Schedule

Schedule (based on a 90 min session)

Time Allotted	Agenda Items
2 minutes	Zoom Tips
6-8 minutes	Welcome and Introductions – Opening remarks and related scripture shared by Rev. Gilbert, Jr.
2 minutes	Purpose and Agenda
2 minutes	Housekeeping
1 minute	Session Overview
2 minutes	Group Agreements and Questions
10 minutes	Presentation
45 minutes	Discussion
15 minutes	Priority Issues and Barriers
3 minutes	Closing and Next steps – Closing included prayer from Rev. Gilbert, Jr.

Discussion Questions/Participants Responses Compilation

The questions used for these sessions were designed to be both open and closed ended. The goal was to uncover the session participants' level of awareness and understanding of their role as a caregiver and uncover their core needs for support and education.

Questions on the caregiver experience included the caregiver experiences, buffers, and needs and community supports.

Questions on Experiences

1. How would you describe the person you are caring for?
 - a. Deteriorated so fast
 - b. Left out – felt like her loved one hid the seriousness of his illness from her
 - c. Lost husband while child was 2 years old
 - d. Process of getting guardianship for his wife; difficulty getting power of attorney (guardianship/POA, etc.)
 - e. He's getting weaker by the day because he also has a chronic illness
 - f. "I love to do this because she's my wife"
 - g. Surprised by the rapid decline
 - h. Started off manageable, then became very difficult.

2. Is it hard to plan for the care you are providing?
 - a. Hard to predict; for example, neuropathy in the legs and the day of the appointment she was complaining that her legs were hurting so she couldn't make it to the appointment
 - b. Another example – a phone call from a doctor that said he needed to amputate her father's leg, within 24 hours she needed to get him from Florida to DC; no time to plan
 - c. Hard to keep schedule and keep appointments
 - d. Feels over challenged
 - e. You must prepare for when you are not there. Prepare the food that the person likes, the medications etc. There is a lot of prep that goes into being able to leave to do something for me or to go to work – so that the paid caregiver has the things that will make the person being cared for feel well taken care of

3. Do you find that you must pay for things to provide the care for the person or people you care for? (poll) yes or no
 - a. Yes - 7
 - b. No – 1
 - c. Sometimes – 1

4. Is Caregiving a financial burden on you or your family? (poll) yes or no
 - a. Yes – 4
 - b. No – 3
 - c. It can be – 1
 - d. Example – she moved her mom from DC to Maryland immediately and sadly lost access to lots of benefits; it would be helpful to have a DMV collaborative effort – they depleted all her mom's savings and started to have to make up the difference themselves (herself, her spouse, and children)
 - e. Had to purchase a ramp; need a better ramp built; home is not accommodating because he is on second floor. DC provided lift and wheelchair, but resource limit was reached and unable to obtain other supplies needed.

- f. Kaiser was very supportive. Provided all she needed after Rehab. The only thing that changed was her taking on more duties and responsibilities.
 - g. State of Maryland did not provide any resources for equipment. They do receive meals
5. Do you experience disagreement about people not doing enough to help?
- a. Yes – difficulty among family members – “you know how your father is, don’t take him in” – very hard to get help
 - b. Thanks god for her church family; they contributed financially and practically; helped with resources
 - c. Hard to get family members to feel urgency and come and help
 - d. Family dynamics change, sometimes causing division/tension
6. Do you sometimes feel you should be doing more as a caregiver?
- a. Of course, always asking yourself “Am I doing enough”?
 - b. Not enough knowledge about the role of a caregiver – i.e., caregiver fatigue, dividing responsibilities, self-care, etc.
 - c. Not having enough information about resources available.
 - d. Echoes of “I don’t mind”- can be gathered that caregiving is becoming a burden and increasingly difficult to do.
7. Are there concerns about people not spending enough time with the person or people you are caring for?
- a. Never enough hours in one day; but you do the best you can
 - b. If you’re there most of the time
 - c. Hard to balance work responsibilities as well
 - d. You need to take care of “you”
 - e. Participant brought up “respite care” for hospice patients – need for resources to give caregivers a break
 - f. A lot of Christian growth from the caregiving experience – gives him the power to keep going
 - g. Idea from Geri – can you ask your neighbors to come sit with the individual?
 - h. Sick, while caring for the loved one.
 - i. This is a great concern, you want to give a lot of time, but you have other things you must do. You must have balance, and still do the things that you need to do, in addition to things you do for others.
8. How would you rate yourself as a caregiver? (poll??) 1-3 3- outstanding, 2 -average, 1- needs improvement
- a. 1
 - b. 2 = 4 people
 - c. 3 = 6 people

- d. 3 – Once I understood that my mom’s behavior was tied to physical challenges – them I was able to identify the subtle changes that meant she had a physical thing going on (e.g., time to check the lab results)
 - i. Being your loved one’s advocate is part of the role of caregiving
- e. 3 – “I gave it my all”

Questions on Buffers

1. Are you supported by friends and neighbors or family in your work as a caregiver?
 - a. Joy to see the great grandchildren observing and trying to understand what was going on – getting to know their great grandmother as she died and observing the family dynamic

2. Do you have someone to provide support when things get tough/difficult?
 - a. Yes – my daughter was my “mini-me”
 - b. Support of partners/spouses when caring for an elderly parent
 - c. Cousins
 - d. Eldest sister
 - e. Aunt
 - f. Close girlfriends allow her to vent
 - g. Having a support team is everything – especially if you’re working
 - h. The faith community
 - i. Sometimes they will and sometimes they won’t.
 - j. Sometimes family is scarce
 - k. Blessed to have a good level of support.
 - l. Complicated family dynamics

3. Let’s talk about the ability to navigate the health insurance benefits for the which person you are the caregiver?
 - a. You never understand all the nuances – example: limited in rehab care to what the insurance says are the best providers
 - b. What insurance pays for is not necessarily the “best” care
 - c. Not always able to ask the right questions. Have his niece – geriatric nurse- to take him to the doctor to get the right answer.
 - d. Mom’s last year was in nursing home. Got support and understanding from his sister and a brother was a doctor. Needed help with understanding nursing home bill

4. Do you have much Personal freedom as you would like?
 - a. No – 2 people
 - b. Example – difficulty trusting other people to care for your loved one – she would drop her dad off and he would come back worse than when she sent him (e.g., giving him drinks/food that raise his blood sugar)

- c. Respite care support is needed. Weekends are hard to find coverage. Sometimes 'just need some time to go sit in the truck'. Even if have great levels of paid caregiving or help from family, sometimes just need some time for a break or to do errands or back up when paid caregiver can't make it (rather than leave work).
- d. Uses husband's sleep time for her self-time.

Questions on Needs and Community Supports

1. If you could identify one thing/idea to make the caretakers role/life easier What would it be?
 - a. Call the insurance company – they listed resources in the DC area
 - b. Equitable resources – list of resources
 - c. Not familiar with the resources; help is needed
 - d. Misunderstanding about services/resources (e.g., hospice care)
 - e. Disagreement among family members
 - f. Ease of gathering community-based resources
 - g. Having legal documentation in place timely (Advanced Care planning)
 - h. "Listen to the person – they will help you care for them
 - i. Follow-up to make sure people are targeting their help
 - j. Information on resources for a blind person; where we can go; what will help him with eyesight
 - k. Weekend support to provide respite.
 - l. Caregiver education and training
 - m. Support obtaining meals- prepared meals delivered
 - n. How all of us as care givers can effectively communicate with those we take care of in a kind and loving way.
 - o. Education on the new regulations of DC to have time off to caregiver and Advocacy
 - p. Navigating Insurance
 - q. Advocacy

Top 4 Themes Identified by Caregivers

1. Caregiver support (physical support in the home)
 - a. Respite
 - b. Self-Care
 - c. Social Supports
2. Financial Strain
3. Lack of awareness of available resources/healthcare resources
 - a. Equitable sharing of resources
 - b. Understanding insurance – what is covered and what is not
4. Help navigating family relationships

How Did Individuals Rate the Themes?

1. Awareness of resource/insurances, 2. Caregiver Support, 3. Financial Strain and 4. Family relationships

- 1, 3, 4, 2 (caregiver support, then lack of awareness of resources, then family relationships and lastly financial strain)
- 3, 2, 1, 4 (lack of awareness/resources, then financial strain, then caregiver support and lastly family relationships)

**** Awareness of resources and financial strain/burden = top two concerns****

Priority Issues Identified

1. Difficulty with increasing caregiver needs as person gets sicker/declines
2. Hard to watch your loved one suffer or change
3. Caring for multiple people at the same time (children, adult parents, work responsibilities)
4. "A pleasure but also painful"
5. Unpredictability - hard to plan (2 people)
6. Financial strain of caregiving
7. The "church village"
8. Need for caregiver self-care (3 people)
9. Need for social support (family, friends, faith community)

Next Steps and Opportunities

After each Listening Session, attendees received a thank you email and a general resource list.

Based on our findings, the next steps will be for the D.C. Coalition and its members and supporters to design and host educational forums based on the themes and needs identified – in continued collaboration and partnership with various faith communities. Further, D.C. Coalition members and supporters are putting forth efforts to expand and resource our efforts for follow up based on the findings from the Listening Sessions including:

- **Capturing data and resource sharing**
ARCHANGELS will continue to have open and share the link to access the Caregiver Intensity Index tool. This tool measures the intensity of a caregiver's status and provides a score with their specific intensity buffers and drivers. The score helps to validate experiences and then connects the caregiver to resources based on their results.

This score first validates their experiences and then connects them to caregiver resources based on their results. The CII engages caregivers over time and across a spectrum of intensity.

- **Providing Educational Forums and Workshops**

Developing educational forums and workshops that support and reinforce messaging on the key themes identified in the sessions:

- Caregiver support
 - Respite
 - Self-Care
 - Social Supports
- Financial Strain
- Identifying, Understanding, and Navigating Caregiver resources
- Strengthening and supporting family relationships

- **Supporting Social Determinants of Health**

Capital Caring Health's Stay at Home Safely program support social determinants of health (SDOH) with a proactive approach and targeted interventions that address related systems of social, cultural, and economic factors by addressing the following:

- Home safety - Conducting home safety evaluations and repairs and modifications
- Transportation barriers – Providing transportation services via Lyft or necessary medical transport options for transportation to medical appointments
- Food insecurity, access to nutrition – Providing medically tailored home delivered meals

These efforts are all made possible by generous donors and foundations.

- **Training Congregational & Community Care Coaches to support caregivers**

Talk Early Talk often founder, Rev. Dale Susan will lead an effort: Navigating Uncertainty: The Congregation-Community Care Planning and Access Harbor (for those facing complex aging or serious illness)¹³. This effort will be a multipronged approach, with an intentional focus on supporting marginalized communities- utilizing program trained care coaches. Care Coaches will be trained in various areas to include:

- Supporting family caregivers to have “hard” conversations in advance care planning
- Empowering family caregivers to have confidence in shared decision-making with extended family and health care professionals
- Navigating the health care system and access to resources
- The role of faith leaders and congregations by normalizing difficult conversations surrounding progressive aging and serious illnesses in diverse communities

¹³ Project implementation is pending grant funding.

Acknowledgements

C-TAC and the newly formed, D.C. Coalition to Support Caregivers extends its gratitude and appreciation to the following individuals and organizations who made this project possible.

Project Funders

Cigna Foundation¹⁴ and the Ralph C. Wilson, Jr Foundation

Lead Organizations

- The Coalition to Transform Advance illness Care (C-TAC)
- Capital Caring Health
- Progressive National Baptist Convention. Inc. (PNBC)

Project/Program Leads

- Geri Feaster MS, RN – **Facilitator**
Board Member, C-TAC
Retired Nurse Executive and Certified Health Minister
- Altonia Garrett – **Project Manager/Operations**
VP, Public Affairs & Strategic Partnerships/Exe. Dir, Ctr. Equity, Inclusion & Belonging
Capital Caring Health
- Rev. George Gilbert, Jr, - **Project Organizer/Lead**
Associate Pastor, Holy Trinity Baptist Church
- Rev. Tyrone Pitts – **Strategic Advisor**
General Secretary Emeritus, Progressive National Baptist Convention, Inc.
Co-Chair, C-TAC's Interfaith Working Group and Equity Task Force

D. C. Coalition Members and Community Partners and supporters

- ARCHANGELS
 - Alexandria Drane, Co-Founder & CEO
 - Sara Stephens Winnay, Co-Founder
 - Erin Stolte, Operations
- Annabel Anderson, Intern - John Hopkins University
- S. Sabrina St. Clair, Bereavement Counselor - Capital Caring Health
- Rev. Karen Curry, Associate Minister & First Lady - Pennsylvania Baptist Church
- Rev. Dale Susan Edmonds, Pastor – Trinity United Church of Christ, Founder: Talk-Early-Talk-Often.com, and Steering Committee Member, Interfaith Working Group of C-TAC
- Donna Gayles, Capital Caring Health – Sr. Client Relations Exe. and Associate Director, Center for Equity, Inclusion, & Belonging– Capital Caring Health

¹⁴ Cigna Foundation helped make this project possible.

Appendix A

Listening Session Presentation

1

WELCOME

D.C. Coalition to Support Caregivers Listening Session

Thursday, October 21, 2021
6:30pm
Hosted by: Rev. George C. Gilbert, Jr.
Facilitated by: Ms. Geri Feaster MS, RN

1

2

Let's Talk about Caregiving!

D.C. Coalition to Support Caregivers



- The Coalition
- Who are Caregivers?
- What is Caregiver Intensity?
- Your Intensity Score?
- Discussion

2

3

D.C. Coalition to Support Caregivers

The D.C. Coalition to Support Caregivers was formed in April 2021 as a group of faith-based leaders and community partners working to make a difference for and to support unpaid caregivers.

3

4

D.C. Coalition to Support Caregivers: Founding Members and Supporters



4

5

D.C. Coalition to Support Caregivers Goals

- To Listen and Learn directly from you all the community and the caregivers about your needs for support and access to resources.
- Define caregiving and its meaning to you as an active caregiver.
- Encourage dialogue in around caregiving needs and to support one another. You are not alone in this journey.
- Advocate as a collective voice on local and federal legislation.
- Serve as a liaison between local community groups and caregivers.

5

6

Who is a Caregiver?

Picking up groceries for a loved one? Driving someone to doctor's appointments? Stopping by to check-in? **That's caregiving.** No one particular thing makes us caregivers – it all counts. Many of us don't even realize we are caregivers – instead we say, "I'm just a daughter," "just a grandson," "niece," "neighbor" or "friend, doing what I can to help out."

The CDC defines caregivers as: "Caregivers provide care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis. The recipients of care can live either in residential or institutional settings, range from children to older adults, and have chronic illnesses or disabling conditions."

- 43% of us are in the role of caregiver¹
- 54% of call caregivers are men.¹
- Can also be episodic/short term.
- We call caregivers – Heroes!

¹ Source: Center for Disease Control (CDC); https://www.cdc.gov/mmwr/odays/mm2024a1.html#res_cdrmm2024a1_w

6

What are Positive Impacts of Caregiving?

7

A sense of fulfillment

Establishment of extended social networks or friendship groups

Feeling needed and useful

Learning something about oneself, others, and the meaning of life

² Source: Center for Disease Control (CDC); <https://www.cdc.gov/aging/caregiving/index.htm>

7

What are the Physical and Emotional Impacts of Being a Caregiver?

8

Informal or unpaid caregiving has been associated with:

- Elevated levels of depression
- Worsening physical health
 - 53% of caregivers indicate that a decline in their health compromises their ability to provide care
- Increased financial burden and strain
 - 27% of caregivers of adults reported a moderate to high degree of financial hardship as a result of caregiving
- Isolation and Loneliness

Source: Innovation in Aging; <https://academic.oup.com/innov/advance-article/doi/10.1093/innov/31.01/5613043>

8

How to build Caregiving Resilience?

9

- Information at your fingertips is power.
- Evaluate your level of social support.
- Keep a gratitude journal.
- Sustain good lifestyle habits and invest in self-care.
- Give yourself mini breaks.
- Self-determination is an important mindset.
- Ask for help!

Source: AARP Caregiver Resources; <https://www.aarp.org/caregiving/basics/info-2021/well-being-caregiver.html>

9

Caregiver Intensity Score

10

Being a Caregiver can be Intense!

The Caregiver Intensity Index was created by the ARCHANGELS to support two cases:

1. To reflect an individual caregiver's experience
2. To give the systems designed to support caregiver's sufficient data and detail to do so effectively.

Intensity is reflected by colors **Red**, **Yellow** and **Green**.



Source: ARCHANGELS; <https://www.archangels.org/home-inside>

10

What is Your Caregiver Intensity Score?

11

Caregiver Intensity is **very real** and we all have a score!!!

Scores show that this group caregivers are 2x more likely to be in the Green than other communities across the country. ARCHANGELS team believes this is due to the connection and support from faith-based groups.

11

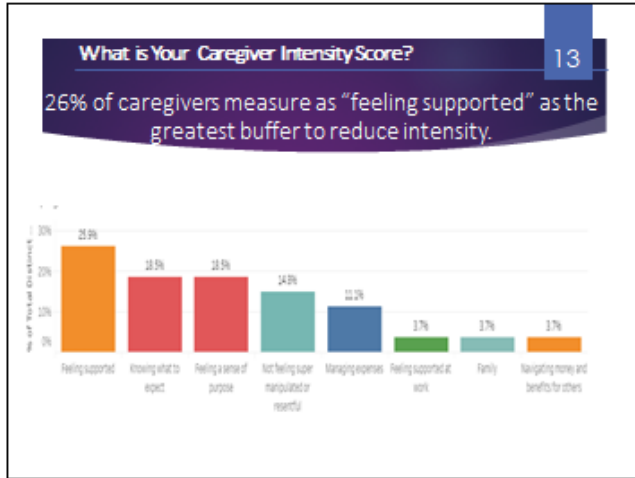
What is Your Caregiver Intensity Score?

12

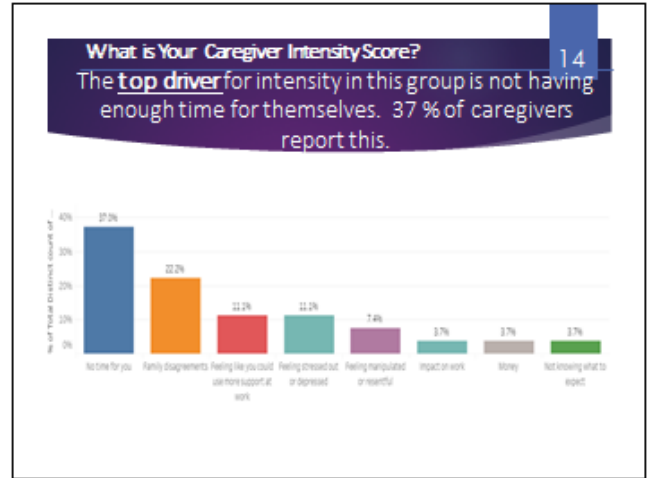
52% of caregivers measure as "on the edge".



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What is Your Caregiver Intensity Score? 15

Caregiver Intensity is **very real** and we all have a score!!!

Based on your answers, you'll find out if you are in the **Green**, **Yellow**, or **Red**, as well as the top two things making your caregiving harder and the top two things that may be making it easier. At the end, if you'd like, you can connect to free resources for support available in your area.

You can find out your score by taking a quick survey from our partner organization, ARCHANGELS:

Here is the link to take the survey: <https://archangelscsl.me/Ward7care>

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THANK YOU!!!

For more information, please contact
Rev. George C. Gilbert, Jr.

Email: georgegilbert01@gmail.com
Phone: 202-262-5053

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Discussion

The Caregiving Experience

Facilitated by: Geri Feaster, MS, RN

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Appendix B

Caregiver Resource Handout Snippets

D.C. Coalition to Support
Caregiver: Resource Guide

Family Caregiver Resources

Provided by DC Health Matters

(Click on each link to access more details)

General Resources:

- [DC Health Matters Connect](#)
 - **DC Health Matters Connect** is an online directory where you can search and connect with free or reduced cost social service programs in the Washington, DC metropolitan area. DC Health Matters Connect provides a straightforward way to find social services in our community and connect to them directly and electronically in every ZIP Code across the United States. Services and programs on the directory include federal, state, county, municipal, and local resources across the metropolitan area and the nation. DC Health Matters Connect was created to ensure that all residents are able to find appropriate and accessible resources to meet their needs. The platform provides open and free searches to allow everyone (whether it be a health care provider, a case manager, or a community member) to connect to appropriate and available services in our area. DC Health Matters Connect also supports nonprofits by allowing them to join the platform for free and provide free screening tools to encourage them to help people seeking help on the network.

Financial Resources

- [AARP Foundation's Benefits QuickLINK](#)
 - Find public benefits that can help you pay for food, medicine, health care, utilities and more by using AARP Foundation's Benefits QuickLINK tools.
- [BenefitsCheckUp \(BCU\)](#) (800-794-6559)
 - BenefitsCheckUp is a comprehensive, free online service from the National Council on Aging that connects older adults with benefits for which they are eligible.
- DC 311 (3-1-1 | 202-737-4404 calls outside D.C.)
 - 311 is a toll-free number and online service that allows people in the District to Columbia to request assistance with city services and information.
- [The Economic Security Administration \(ESA\)](#) (202-671-4200)
 - The Economic Security Administration, located within the Department of Human Services, determines eligibility for benefits under the following programs: Temporary Cash Assistance for Needy Families (TANF), Medical Assistance, Supplemental Nutrition Assistance Program (SNAP) (formerly Food Stamps), Burial Assistance and Interim Disability Assistance, among others.

Family Caregiver Resources for Washington D.C.

Food and Meal Services

Bread for the City: <https://breadforthecity.org/food/>

- **Food Pantries.** Each month, Bread for the City's two food pantries provide nutritious groceries — including fresh fruits, vegetables, and meats — to more than 8,400 clients living near the federal poverty line. Two monthly Farmers Markets offer fresh produce to the community at large, and as a [Grocery Plus](#) distribution site, Bread for the City offers an additional 30 lb. box of food to a small number of seniors. Our Sustainable Agriculture division both grows food and educates the community at our two rooftop gardens and three-acre orchard.

Food & Friends: <https://foodandfriends.org/>

- **Groceries - to - Go.** Groceries-to-Go, delivered every two weeks, is a service that includes fresh produce, frozen meats such as fish and poultry, frozen soups and entrees prepared in our kitchen, and pantry items. The service is available for individuals and families who live outside our freshly prepared meals delivery area. It is also available for those clients who are able to do light meal preparation, or who have a caregiver to do so.
- **Nutrition Counseling.** At Food & Friends, we consider nutrition to be a vital part of the treatment for our clients. Our community dietitians are available to provide individual nutrition counseling to all of our clients. In addition, within the community, we provide workshops on nutrition and wellness, on-site cooking classes, and educational materials.
- **Home-Delivered Meals.** Monday through Saturday, Food & Friends delivers nutritionally tailored, delicious meals directly to our clients' homes. Our community dietitians and professional chefs work closely to provide individualized services to our clients. Food & Friends offers 12 specialized meal plans to meet our clients' nutritional needs.

Manna: <https://mannapa.org/services/our-meals/>

- All MANNA meals are heart healthy, high in protein and moderate in carbohydrates, sodium, and fat. Meals may be modified to address

Veterans Administration

<https://www.caregiver.va.gov/>

VA Caregiver Support Programs

Caregiver Support Program (CSP) teams/Caregiver Support Coordinators are available at each VA Medical Center (VAMC) to help caregivers find the right support to meet their needs and to enroll in caregiver programs and services.

District of Columbia

District of Columbia	Caregiver Support Teams
<u>Washington, DC VA Medical Center</u> 50 Irving St., N.W. Washington, DC 20422	202-745-8000 ext. 55926