

# Caregiving in the **Black Community**

INFORMATION AND RESOURCES TAILORED  
TO THE BLACK CAREGIVING EXPERIENCE



The Senior  
**Alliance**  
LIVE **YOUR** WAY



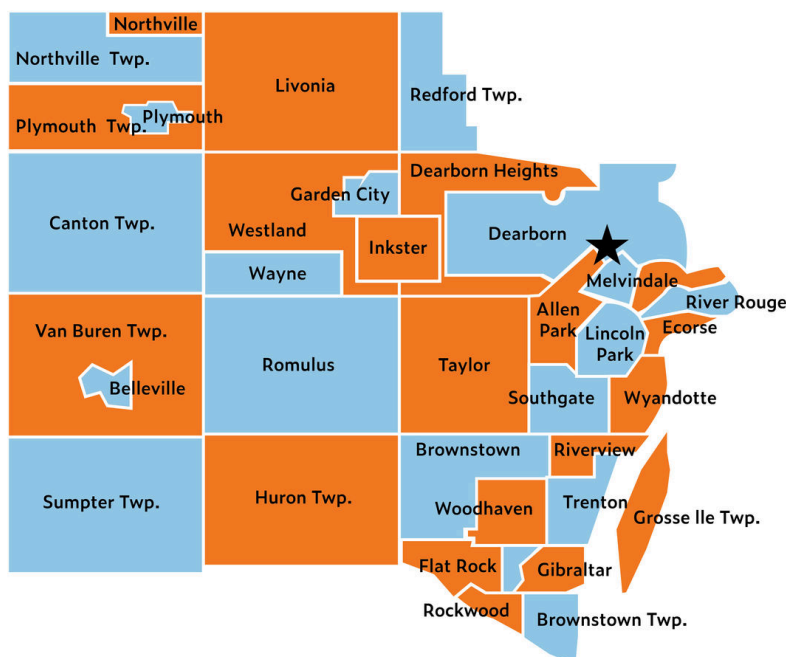
The Senior Alliance is dedicated to **enhancing and preserving the independence of older adults and individuals with disabilities, as well as providing support to caregivers.**

The Senior Alliance is a 501(c)(3) nonprofit agency designated as the Area Agency on Aging for the 34 communities of western Wayne County and Downriver. Our mission is assisting people to thrive as they live, age, and grow.

Our Caregiver Guide provides resources and information to help new and experienced caregivers better care for themselves and their loved ones.

Contact The Senior Alliance for additional information on local caregiver resources and services, or visit our virtual caregiver hub at [caregivinghaven.org](http://caregivinghaven.org).

Our Service Area



## Contact Us

[www.thesenioralliance.org](http://www.thesenioralliance.org) | [www.caregivinghaven.org](http://www.caregivinghaven.org)

734-722-2830

[info@thesenioralliance.org](mailto:info@thesenioralliance.org)





**The Healthier Black Elders Center encourages older African Americans to **participate in research** with the goal of **addressing health disparities**.**

The Healthier Black Elders Center (HBEC), located at Wayne State University's Institute of Gerontology, is dedicated to improving the health of older adults in metro Detroit and Flint. The HBEC brings together a diverse group of educators, community members, national advisors, and researchers with a shared goal of reducing health disparities through research and education. To increase participation of older African Americans in research, the program encourages them to join the Participant Resource Pool (PRP) and receive health education information.

HBEC hosts community-based events, such as Lunch & Learns, to promote health, prevent disease, and improve the well-being of older African Americans and their families. In collaboration with community organizations, HBEC removes barriers to research participation, develops innovative approaches for engaging minority populations, and works to improve health outcomes for older adults through education and research partnerships.

The Healthier Black Elders Center Consulting (HBEC-C) is a committee of seasoned Black adults that provide consulting services. Our mission is to collaborate and partner with institutions and/or organizations by advising and supporting the formulation, design, and dissemination of research studies and programs that promote the health and wellbeing of elder African Americans. HBEC-C was delighted to consult with the Senior Alliance to provide insight and feedback on this caregiver guide.

## Contact Us

<https://mcuaaar.org/cores/community-liaison-and-recruitment-core/healthier-black-elders-center/>  
313-664-2616

[vrora@wayne.edu](mailto:vrora@wayne.edu)



# Table of Contents

<b>Introduction</b>	<b>1</b>
<b>Caregiver Insights</b>	<b>2</b>
<b>Challenges</b>	<b>3</b>
Historical and Cultural Legacy	3
Finding Culturally Competent Care	4
Health Disparities and Access to Care	5
Handling Negative Health Care Experiences	6
Financial Challenges	7
<b>Self-Care</b>	<b>8</b>
<b>Getting Help</b>	<b>9</b>
Grow Your Network	9
Lean on Your Community	10
Lean on Your Faith	10
<b>Resources</b>	<b>11</b>
<b>Acknowledgements</b>	<b>13</b>
<b>References</b>	<b>14</b>





# Introduction



*How far you go in life depends on **your being tender with the young**, **compassionate with the aged**, **sympathetic with the striving**, **and tolerant of the weak and strong**. Because someday in your life you will have been all of these.*

*- George Washington Carver*



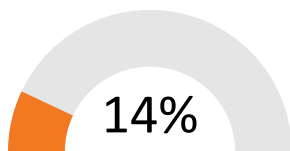
This guide is designed to **support Black caregivers** by addressing your unique **experiences and challenges**. By recognizing the influence of **cultural heritage, history, and systemic issues** like racism and discrimination, we aim to empower Black caregivers with knowledge and resources needed to **navigate care systems**, thus making the journey less challenging. Discover more information on caregiving topics, with additional guides, videos, and resources at **[caregiving haven.org](https://caregivinghaven.org)**.

# Caregiver Insights

If you regularly provide any form of assistance to someone, such as helping with **personal care, managing medical tasks, preparing meals, assisting with mobility, or offering emotional support and companionship**, then **you are a caregiver**. Caregiving encompasses a range of activities and does not require you to fulfill every possible care task. Your contributions are valuable and classify you as a caregiver whether your role is large or small.

Black caregivers spend about **1.3 more years** in caregiving roles and are over **2 years younger** than the national average. They also devote over **9 extra hours** per week to caregiving tasks, and the percentage of Black women in caregiving roles is 6% higher than the national average. While the percentage of Black caregivers caring for a relative matches the national average, these **relatives are 25% less likely to be parents**. These differences highlight the significant time and emotional investment required from Black caregivers and the importance of extended or chosen families in the community.

*Nearly 1 in 5 American adults (53 million) are family or informal caregivers...*



*of them, nearly 8 million (14%) identify as Black.*



**66% of  
Black  
caregivers  
are female**



**Average  
caregiving  
duration is 5.2  
years**

**48**

**Average  
Black  
caregiver  
age**



**31.2 hours per  
week spent  
on caregiving  
tasks**

Source: National Alliance for Caregiving, AARP, and IJERPH

# Challenges

Your caregiving challenges may differ from or be more intense than those of other caregivers due to historical and cultural factors. It is important to **find professionals who understand** these unique challenges so you can receive the support you need and deserve.

## Historical and Cultural Legacy

The historical and ongoing effects of racism add extra layers of difficulty to the caregiving experience, but the Black Community is **resilient**, and often draws upon family networks and kinship care to support one another. This practice can be seen throughout history, and many families continue to rely on these close ties.

Racism and discrimination can change the way burdens of caregiving affect you. Systemic barriers can limit your access to **healthcare, financial resources, and support services**, making caregiving more complicated. These barriers also lead to **higher stress levels** and **health disparities** for both you and your loved one (APA, 2015).



56% of Black caregivers have a hard time arranging care or services with healthcare professionals.

Source: Diverse Elders Coalition



## Finding Culturally Competent Care

Caregivers should require healthcare providers to provide **culturally competent care**. Doctors you work with need the skills to understand, respect, and work appropriately with your cultural background. This includes acknowledging the importance of **extended family networks, respect for elders, and the impact of historical health discrimination on trust and communication**. Culturally competent care creates trust, improves communication, and promotes healthcare practices that align with **your values**.



Finding a doctor you trust for yourself and your loved one can take time, but it can **improve healthcare experiences and health outcomes** (Musa, et. al, 2009). When searching for healthcare providers, explore online resources and seek referrals from community and cultural organizations. Narrow your search by using terms like "geriatrician," "senior health services," or "aging care specialist" to find professionals focused on older adult care. Once you have an appointment, look for physical signs of inclusivity such as diversity among the staff and patients, or pamphlets and magazines that cater to you.

During your visit, **consider asking the following questions:**

**Will you share any training you have received in delivering culturally competent care to Black patients?**

**How do you incorporate cultural beliefs and practices into your treatment plans?**

**How do you ensure effective communication with patients from diverse cultural backgrounds?**



## Health Disparities and Access to Care

Black caregivers often face **health disparities** that can complicate caregiving roles. These disparities are rooted in **systemic issues** such as racism, socioeconomic inequalities, and limited access to quality healthcare, which contribute to a higher prevalence of chronic conditions like hypertension, diabetes, and Alzheimer's disease (Ellis et. al, 2020). Managing your own health and the needs of your care recipient can intensify stress, with nearly 30% of Black caregivers reporting high levels of emotional stress, ultimately leading to poorer health outcomes (AARP, 2020).

**Discrimination** in healthcare settings, **lack of culturally competent care**, and **financial constraints** often hinder access to necessary medical and support services.

Many Black caregivers report negative experiences with healthcare providers, such as **not being taken seriously or feeling rushed** during appointments which may discourage you from seeking the help you need (Alexander et. al, 2023).



Black men and their caregivers may face additional challenges accessing healthcare due to a lack of trust in the system, making them hesitant to visit or change providers. This can be frustrating for caregivers, but talking openly and understanding your loved one's perspective can help. Share your concerns and work to find a solution that is comfortable for everyone.

### Caregiver Story

*My family has deep-rooted mistrust of doctors, and the health care system in general. My grandfather was medically experimented on when he was a child. My family was devastated when they found out what happened to him. Most of us have never been able to trust doctors. My dad is especially leery of doctors and avoids even routine health care.*

*It's a battle whenever I need to take my dad to the doctor. Recently, he's been losing weight and I'm worried something is wrong with him but struggle to get him to the doctor unless it's an emergency.*

**Henry, caregiver to his father**

## Handling Negative Health Care Experiences

If you perceive something as negative or discriminatory during a healthcare experience, know you have options and consider taking action. Your loved one **deserves** quality care.

### Prioritize Self-Care

**Take care of yourself.** The healthcare system can be physically, mentally, emotionally, and financially draining. If possible, briefly step away from the situation to **do something for yourself** to recharge. This might mean taking a walk, practicing deep breathing, or taking a moment to clear your mind.

### Advocate

Be firm and advocate for your loved one if you feel concerns are not being addressed. You may need to demand specific tests or actions. If you feel rushed or unheard, **assert your right** to a full appointment by saying, “I’m not finished here; I would like to utilize my full appointment to discuss this.” Clearly state your needs and, **if necessary, escalate the issue** by speaking to someone in charge.

### Document and Educate

**Keep detailed records** of your interactions and **become familiar with your patient rights**. Document dates, times, names, and the specifics of your conversations. You can also keep anti-discrimination laws printed to reference directly when needed.

### File a Complaint

File a civil rights complaint with the **Office for Civil Rights** by phone or email if you believe you or your loved one has been discriminated against. Find a new healthcare provider or request a different doctor who respects you and your loved one. **Reach out to your community** for trusted healthcare recommendations.

### Raise Awareness

Consider joining or supporting organizations that **advocate for health equity** and the rights of Black patients and caregivers. Your voice can help highlight the issues and push for meaningful changes.



## Financial Challenges

In 2021, family and informal caregivers across the United States delivered an estimated 36 billion hours of unpaid care, valued at around \$600 billion. Of this staggering total, caregivers in Michigan provided unpaid care valued at over \$19 billion (AARP, 2023).

**Caregiver's need enhanced financial support.** Despite caregivers' significant economic contributions, many face low wages and must balance employment and caregiving duties.

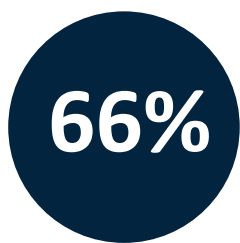
Black caregivers report spending a considerable amount of their income on caregiving-related expenses. With some studies indicating that Black caregivers spend **34% of their household income on caregiving costs**, highlighting the economic burden they face in comparison to the **national average of 26%** (Dozan et al., 2021).



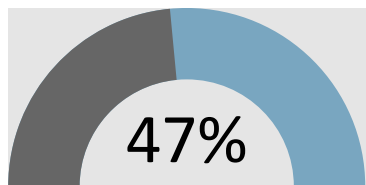
**57% of Black family caregivers experience significant caregiving and financial strain.**



**31% of Black caregivers take on more debt while caregiving.**



**66% of Black caregivers have a job outside of caregiving.**



**Nearly half of Black Caregivers have a household income under \$50,000.**

For more information on caregiver finances, including how to be **proactive, plan, manage**, and search for **financial assistance**, explore the guides, videos, and resource directory available at [caregivinghaven.org](https://caregivinghaven.org).

Source: AARP, National Alliance for Caregiving, American Society on Aging Generations, Family Caregiver Alliance



## Self-Care

Black caregivers often face heightened **emotional and psychological challenges** due to the combined pressures of caregiving and systemic racism. You may be more likely to experience higher levels of **stress, anxiety, and depression** compared to other caregiver groups (Diverse Elders Coalition, 2021).

Self-care is critically important to caregivers' physical and mental wellbeing. Approximately 30 percent of Black caregivers experience **increased isolation and greater physical and mental stress** due to their caregiving duties (Dozan et al., 2021). Prioritize self-care so you can sustain the demanding role of caregiving and mitigate the negative health impacts of chronic stress.



***31% of Black caregivers agree that caregiving had negative effects on their physical and emotional health***

Diverse Elders Coalition

**Self-Care QUICK CHECK:** In the last week have you...

**Slept enough?**

**Engaged in a hobby?**

**Practiced mindfulness?**

**Talked to someone about your feelings?**

**Exercised?**

**Spent time with friends?**



## Getting Help

Being a caregiver can quickly feel overwhelming. It is easy to become burnt out by overcommitting and neglecting other areas of your life. Seeking help is necessary. The Senior Alliance Caregiving Haven website has listings of local resources and expert advice. Visit [www.caregivinghaven.org](http://www.caregivinghaven.org).

### Grow Your Network

Building a support network as a caregiver can start with small steps. Contact local community centers, churches, faith communities, or healthcare providers for information on **support groups**. Joining **online forums** and **social media groups** focused on caregiving can also help you connect with others.

Support groups and social networks offer safe spaces to **share experiences, challenges, and successes** with others who understand what it is like to be a caregiver. Participation in support groups can **reduce your feelings of isolation and stress while providing practical solutions** for common caregiving issues.



**34% of Black Caregivers state  
that they are the only  
person available to provide  
care for their loved one.**

Diverse Elders Coalition

Accessing community resources for help with caregiving tasks and support is necessary to manage the demands of caregiving. Community-based organizations, local government agencies, and non-profits offer helpful services, including **respite care, legal aid, and educational workshops**. In some instances, financial assistance may be available for caregivers.

Attend **local caregiver events** to meet people who understand your situation. Ask friends, family, or neighbors for help. Gradually, these connections will grow into a strong support network.

## Lean On Your Community

**Family and community** are integral to caregiving. In the Black Community, **caregiving responsibilities are often shared** among family members, including extended family and close friends, often called "**fictive kin**" (Taylor et. al, 2022).

The importance of family and community in caregiving are seen in cultural values such as collectivism, mutual aid, and respect for elders (Johnson & Carter, 2020, & Diller, 2015). These values **strengthen family bonds** and encourage communities to come together to provide care. This approach to caregiving provides a strong support system that helps **distribute emotional and physical burdens**. Remember, it is okay to ask for help - leaning on extended networks gives the support you need to balance your responsibilities.

## Lean On Your Faith

Faith, spirituality, and religion provide many caregivers a **framework for understanding and coping** with the challenges of caregiving they face by offering comfort in times of stress and uncertainty. Religious communities can serve as support networks by offering **spiritual guidance and practical assistance** through programs and services. Prayer, meditation, and participation in religious services can be uplifting and peaceful. Spiritual practices can help caregivers maintain their mental and emotional well-being. Faith-based teachings often emphasize the importance of compassion, service, and perseverance, which are **values that resonate with the caregiving experience**.

### Caregiver Story

*My 80-year-old mother has diabetes and early-stage dementia. It's a balancing act each day to manage her pills, check her blood sugar, and deal with her memory lapses. She recently forgot who I was. It absolutely broke my heart. I was able to stay patient and find ways to connect with her thanks to tips from other caregivers.*

*Support that I've gotten through a caregiver group and my church have been my life line. I don't know how I'd get through this without them. A couple of the caregivers in the group shared ways to connect with a loved one when they don't recognize you. This is what helped me get through the moment when my mother didn't recognize me as her daughter. Despite the hard times, the moments when I connect with my mother make it all worthwhile.*

**Alma, caregiver to her mother**

# Resources

To find more programs and services for older adults and caregivers in your area, visit the online resource directory at [caregivinghaven.org](https://caregivinghaven.org).

## Area Agencies on Aging Association of Michigan

Area Agencies on Aging (AAAs) support older adults and their caregivers in living with independence and dignity. Michigan is home to 16 AAAs. Visit the Area Agencies on Aging Association of Michigan website to find your local AAA.

**Phone: 517-886-1029**

**Website: <https://4ami.org>**

## Elder Abuse, Neglect, and Exploitation

Guidance on recognizing, documenting, and reporting suspected elder abuse.

**Phone: 855-444-3911**

**Website: <https://www.michigan.gov/ag/initiatives/elder-abuse>**

## Elder Law and Advocacy Center (ELAC)

Assists older adults and caregivers with legal issues related to housing, benefits, estate planning, guardianship, abuse or exploitation.

**Phone: 313-937-8291**

**Website: <https://nlsmichigan.org/elder-law/>**

## Healthier Black Elders Center (HBEC)

Free health education workshops, healthcare professional training, older adult research participation opportunities.

**Phone: 313-664-2600**

## Lichtenberg Older Adult Nest Egg

Older Adult Nest Egg offers tools and resources to help older adults and caregivers make sound financial decisions, protecting them from financial exploitation and supporting their well-being.

**Website: <https://www.olderadultnestegg.com>**

# Resources

To find more programs and services for older adults and caregivers in your area, visit the online resource directory at [caregivinghaven.org](https://caregivinghaven.org).

## Michigan 211

Community resource database, local support connections, health services, basic needs assistance, emergency resources, social service referrals.

**Phone: 2-1-1 | 844-875-9211 (24/7 line)**

**Website: <https://mi211.org>**

## NAACP Detroit Branch

Advocacy in civil rights, criminal justice, economic empowerment, legal rights, public policy, and health.

**Phone: 313-871-2087**

**Website: <https://www.detroitnaacp.org>**

## National Caucus and Center on Black Aging

Advocacy, employment, health and wellness, and affordable housing services for minority older adults.

**Phone: 202-637-8400**

**Website: <https://ncba-aging.org>**

## Turner African American Services Council (TAASC)

Opportunities that improve access to wellness, health education, and healthcare for underserved and diverse older adults.

**Phone: 734-998-7409**

**Website: <https://medicine.umich.edu/dept/geriatrics-center/community-programs/turner-senior-resource-center/turner-african-american-services-council-taasc>**

## U.S. Department of Health and Human Services Office for Civil Rights

File a civil rights, conscience, religious freedom, or health information privacy complaint.

**Phone: 800-368-1019 | TDD 800-537-7697**

**Website: <https://www.hhs.gov/ocr/index.html>**



# Acknowledgements

This guide would not have been possible without the support of others. We extend our deepest gratitude to:



Dr. Cathy B. Scott, PhD, MSW, FGSA, has been with the University of Tennessee at Chattanooga's Social Work program since 2010 and now serves as the BSW program director. With over 20 years of experience, her most rewarding work is in gerontological social work. She is known for mentoring future social workers, collaborating with community organizations, and supporting older adults and their families.



Healthier Black Elders Center Community Advisory Board  
Members: Josephine Redd, Brenda Evans, Henry Swift, and JoAnn Smith

## References

- AARP. (2021). *Family caregivers face significant financial strain, spend on average \$7,242 each year*. Retrieved from [<https://press.aarp.org/2021-6-29-AARP-Research-Shows-Family-Caregivers-Face-Significant-Financial-Strain,-Spend-on-Average-7,242-Each-Year>]
- Alexander, K., Oliver, S., Bennett, S. G., Henry, J., Hepburn, K., Clevenger, C., & Epps, F. (2022). *"Falling between the cracks": Experiences of Black dementia caregivers navigating U.S. health systems*. *Journal of the American Geriatrics Society*, 70(2), 592–600. <https://doi.org/10.1111/jgs.17636>
- American Psychological Association. (2016). *The impact of discrimination*. American Psychological Association.  
<https://www.apa.org/news/press/releases/stress/2015/impact>
- Caregiver statistics: Demographics*. Family Caregiver Alliance (2016)  
<https://www.caregiver.org/resource/caregiver-statistics-demographics/>
- Caregiving in a diverse America*. National Alliance for Caregiving. (2021).  
[https://www.caregiving.org/wp-content/uploads/2022/02/NAC\\_AmgenDiverseCaregiversReport\\_FinalDigital-020622-1.pdf](https://www.caregiving.org/wp-content/uploads/2022/02/NAC_AmgenDiverseCaregiversReport_FinalDigital-020622-1.pdf)
- Caregiving in the U.S. 2020: A Focused Look at Family Caregivers of Adults Age 50+* (2020).  
<https://www.aarp.org/content/dam/aarp/ppi/2021/05/caregiving-in-the-united-states-50-plus.doi.10.26419-2Fppi.00103.022.pdf>
- Diller, J. V. (2019). *Cultural diversity: A Primer for the Human Services*. Cengage.
- Dozan, S., Biggar, A., Ewald, C. A. and B., Huisingh-Scheetz, M., & Harrison, J. (2021, October 20). *Care, blackness, and generational values*. American Society on Aging Generations.  
<https://generations.asaging.org/care-blackness-and-generational-values>
- Diverse Elders Coalition. (2021). *Caring for those who care*. Diverse Elders Coalition.  
<https://www.diverseelders.org/wp-content/uploads/2021/03/DEC-Toolkit-Final-R2.pdf>
- Ellis KR, Hecht HK, Young TL, Oh S, Thomas S, Hoggard LS, et al. *Chronic Disease Among African American Families: A Systematic Scoping Review*. *Prev Chronic Dis* 2020;17:190431. DOI: <http://dx.doi.org/10.5888/pcd17.190431>.

## References

- Johnson, V. E., & Carter, R. T. (2020). *Black Cultural Strengths and Psychosocial Well-Being: An Empirical Analysis With Black American Adults*. *Journal of Black Psychology*, 46(1), 55-89. <https://doi.org/10.1177/0095798419889752>
- Musa, D., Schulz, R., Harris, R., Silverman, M., & Thomas, S. B. (2009). *Trust in the health care system and the use of preventive health services by older black and white adults*. *American journal of public health*, 99(7), 1293–1299. <https://doi.org/10.2105/AJPH.2007.123927>
- National Alliance for Caregiving & AARP (2020). *Caregiving in the U.S. 2020: African American caregiver profile*. Retrieved from [[https://www.caregiving.org/wp-content/uploads/2020/05/AARP1316\\_CGProfile\\_AfricanAmerican\\_May7v8.pdf](https://www.caregiving.org/wp-content/uploads/2020/05/AARP1316_CGProfile_AfricanAmerican_May7v8.pdf)]
- Reinhard, S., Caldera, S., Houser, A., & Choula, R. (2023). *Valuing the Invaluable: 2023 Update*. AARP. <https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-the-invaluable-2023-update.doi.10.26419-2Fppi.00082.006.pdf>
- Taylor, R. J., Chatters, L. M., Cross, C. J., & Mouzon, D. M. (2022). *Fictive Kin Networks among African Americans, Black Caribbeans, and Non-Latino Whites*. *Journal of family issues*, 43(1), 20–46. <https://doi.org/10.1177/0192513x21993188>
- Unson, C., Njoku, A., Bernard, S., & Agbalenyo, M. (2023). *Racial and Ethnic Disparities in Chronic Stress among Male Caregivers*. *International journal of environmental research and public health*, 20(12), 6188. <https://doi.org/10.3390/ijerph20126188>