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2023 GUIDEBOOK

# SUPPORTING DIVERSE FAMILY CAREGIVERS: A GUIDE FOR PATIENT ADVOCACY GROUPS



WITH SUPPORT FROM



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## ACKNOWLEDGMENTS

The National Alliance for Caregiving presents *Supporting Diverse Family Caregivers: A Guide for Patient Advocacy Groups*, made possible with support from AstraZeneca. NAC would like to thank everyone who played a role in the creation of this guide, including the below:

### National Alliance for Caregiving

#### Leadership

Jason Resendez, President and CEO

Patrice Heinz, Chief Operating Officer

#### Project Lead & Author

Lauren Tokarewich, MLIS, Senior Manager, Special Projects

#### Additional NAC Contributors

Fawn Cothran, PhD, RN, GCNS-BC, FGSA, Hunt Research Director

Michael Reese Wittke, MPA, Vice President, Policy & Advocacy

Sarah Callahan, Advocacy Fellow

Lauren Rachel St. Pierre, former director, Innovation Services

#### Advisory Committee

Hoda Badr, PhD, Professor, Department of Medicine Leader, Cancer Prevention and Population Sciences Program, Baylor College of Medicine and Dan L. Duncan Comprehensive Cancer Center

Rachel Cannady, Strategic Director of Cancer Caregiver Support, American Cancer Society

Nichole Fisher, RN, BSN, Supervisor, Clinical Research, Willamette Valley Cancer Institute and Research Center

Eboni Green, PhD, RN, President and CEO, Caregiver Support Services

Lauren Pongan, National Director, Diverse Elders Coalition

Martha Abshire Saylor, PhD, RN, Assistant Professor, Johns Hopkins School of Nursing

Venus Wong, PhD, BCBA, CPO, Eviset

#### Expert Committee of Patient Advocacy Organizations

Harold Abrams, Project Manager, National LGBT Cancer Network

Susan Ash-Lee, Senior Vice President, Clinical Programs and Application, Cancer Support Community

Nikkya Hargrove, Vice President, Operations & Programs, Harboring Hearts

Jennifer C. King, PhD, Chief Scientific Officer, G02 for Lung Cancer

Bellinda King-Kallimanis, Director of Patient-Focused Research, LUNGeVity

Lauren Rosenthal, MPH, Director, National Lung Cancer Roundtable at American Cancer Society

Katie Schoeppner, MSW, LISCW, Director, Patient Services, Be The Match

Sherrill Wayland, MSW, Director of Special Initiatives, SAGE

Chris Zavadowski, Caregiver Ambassador, Lymphoma Research Foundation

## FOREWORD

Dear Caregiving Advocates and Partners:

I've spent my career working to build power for historically marginalized communities. From narrowing achievement gaps for Latino students to championing the inclusion of people of color in Alzheimer's research, one thing has been crystal clear: adequately supporting family caregivers is critical to building equity. This is a personal issue for me.

I grew up watching my mom balance a full-time job while raising three kids and taking care of my grandmother who faced multiple health challenges – a dynamic all too familiar in Latino households. It was tough work that she performed out of love and out of necessity. It was work that was made harder by the inequities she faced along the way as a Latina sandwich caregiver.

These experiences shape my perspectives on caregiving, the care injustices that too many among us face – especially women of color – and the power of collaboration to create opportunity.

That's why since taking over the helm of the National Alliance for Caregiving in 2022, I have committed our organization to create health, wealth and equity for all family caregivers. After all, while caregiving impacts us all, it doesn't impact us all equally. Health and economic equity need to be front and center.

NAC's research, the oral histories we developed for this Guide, and the eye-opening fact sheets contributed by our partner the Diverse Elders Coalition tell us that minoritized caregivers often face serious inequities in the healthcare system as they care for their loved ones. Those experiences have consequences. They can result in health stresses, financial pressures and emotional anxieties for the caregiver and often lead to poorer outcomes for their loved ones receiving care.

Patient advocacy groups can be a powerful asset in the fight to ensure diverse caregivers are heard, supported, and treated with respect and dignity in the health care system. This Guide offers a pathway to do just that. We invite you to explore its contents, learn about the lived experiences of diverse caregivers, and follow the tips they have offered. We hope you will take these learnings and create best practices to reach and serve the diverse caregivers in your communities.

Thank you for your partnership as we travel this journey to create health, wealth and equity for all family caregivers.

In partnership,



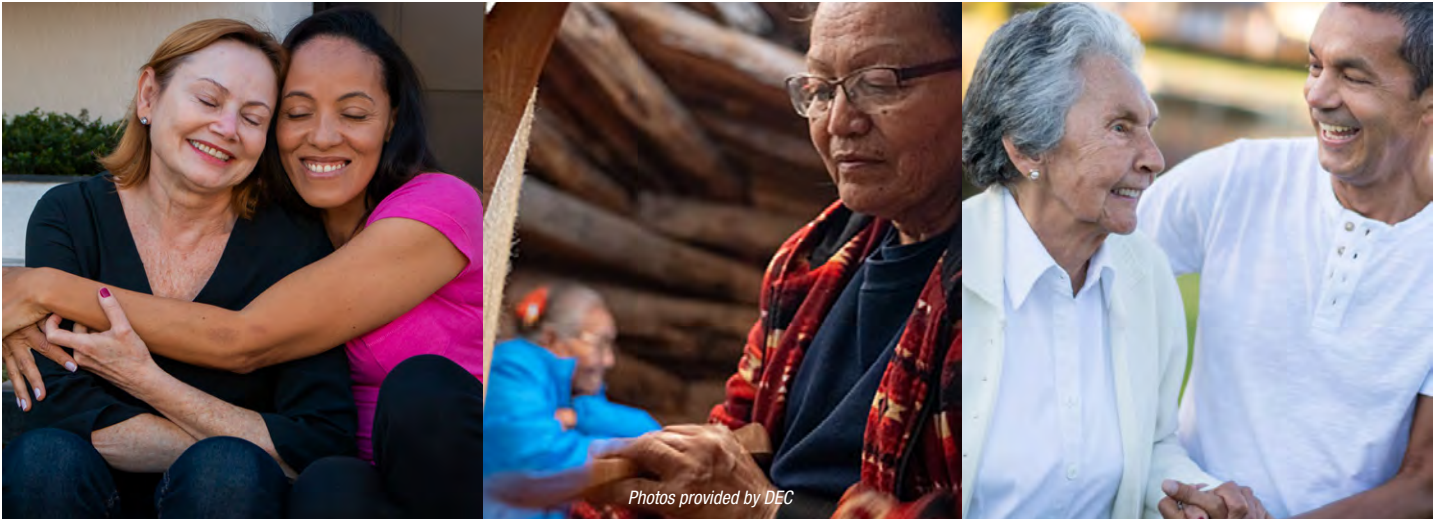
Jason Resendez  
President and CEO

***“With the growing number of diverse caregivers and the disproportionate health disparities faced by families in underserved communities, now is the time to deliver supportive, inclusive resources that drive health equity. AstraZeneca is proud to support patient advocacy groups providing culturally relevant resources that have the power to advance equitable care and transform patient outcomes. We are immensely thankful to NAC for bringing awareness to this critical topic and collaborating with caregivers and patient advocacy groups to publish this guide.”***

– ***Christie Bloomquist***  
***Vice President of US Corporate Affairs & Government Affairs, AstraZeneca***  
***President, AstraZeneca Foundation***

## INTRODUCTION

There are over 53 million family caregivers in the United States, and of these 53 million caregivers, 17% identify as Hispanic/Latino, 14% identify as African American, 8% identify as LGBTQ+ and 5% identify as Asian American or Pacific Islander.<sup>1</sup> One out of every four American Indian and Alaska Native adults identify themselves as a family caregiver.<sup>2</sup> This number continues to grow each year, and soon, the aggregate number of family caregivers from diverse communities will outnumber non-Hispanic white, non-LGBTQ+ caregivers.



Photos provided by DEC

Racial and ethnic minority populations face continuous health disparities, including disproportionate levels of chronic disease like lung cancer, heart disease, blood cancer and lupus. Caregivers who are from a diverse racial or ethnic community or who identify as a diverse sexual orientation or gender identity often face inequities in the healthcare system. These caregivers' different cultural backgrounds and identities often shape concepts of their role that influence their expectations, assumptions, and their needs throughout their caregiving journey, yet these needs are often going unanswered or misunderstood.

Diverse family caregivers require culturally responsive resources, supports and services in order to promote health equity and to meet their needs in an inclusive way. Equally important, it is necessary that these culturally responsive resources reach family caregivers, and are made available to them *where they exist*.

Patient advocacy groups are in a unique position to assist not just the patients their organization has been formed for, but those who are caring for the patient. The National Alliance for Caregiving conducted research and interviews with diverse family caregivers not only to determine what culturally responsive resources and supports caregivers would like to receive, but to know whether they were finding patient advocacy groups as a source of support. Patient advocacy groups were also interviewed in order to determine how they currently interact with diverse family caregivers, and what they would like to know in order to increase family caregivers' awareness of them.

The culmination of that research has resulted in this guide, *Supporting Diverse Family Caregivers: A Guide for Patient Advocacy Groups*. This guide has been created to assist patient advocacy groups in reaching diverse family caregivers and providing culturally responsive resources and supports to them. Most of the information found in this guide is from diverse family caregivers themselves; the aim is that patient advocacy groups will keep these findings in mind as they continue to shape their outreach, their resources, and their interactions with diverse family caregivers.

While this guide is meant for patient advocacy groups, others in the healthcare system, such as providers, would benefit from the information as well. It is difficult to navigate the healthcare system, even more so when the system does not account for differences in culture and identity. Culture and identity influence our thoughts, feelings and actions, and they are impossible to separate from the family caregiver experience. Culture and identity should be acknowledged, included, and responded to on every level of help that a family caregiver receives.

<sup>1</sup>The National Alliance for Caregiving. (2020, December). *Caregiving in a diverse America: Beginning to understand the systemic challenges facing family caregivers*. The National Alliance for Caregiving. [https://www.caregiving.org/wp-content/uploads/2021/11/NAC\\_AmgenDiverseCaregiversReport\\_FinalDigital-111821.pdf](https://www.caregiving.org/wp-content/uploads/2021/11/NAC_AmgenDiverseCaregiversReport_FinalDigital-111821.pdf).

<sup>2</sup>Division of Population Health. (19 April, 2019). *Caregiving among American Indian/Alaska Native adults*. Centers for Disease Control and Prevention. <https://www.cdc.gov/aging/data/infographic/2017/american-indian-adults-caregiving.html>.

# WHAT PROVIDERS SHOULD KNOW: FACTSHEETS ABOUT DIVERSE FAMILY CAREGIVERS

## THE DIVERSE ELDERLY COALITION

The following factsheets were created by the Diverse Elders Coalition for their toolkit for healthcare providers, [Caring for Those Who Care](#). DEC has graciously granted permission for the factsheets to be used in this guide so that patient advocacy groups can also benefit from their knowledge.

The Hispanic/Latino caregivers factsheet is available in Spanish, while the Southeast Asian American caregivers factsheet is available in Khmer, Mien and Vietnamese. These translated factsheets can be found in the Appendix of this guide.



## CARING FOR THOSE WHO CARE

Resources for Providers: Meeting the Needs of Diverse Family Caregivers

# What Providers Should Know About African American and Black Family Caregivers



**There is no uniform ethnicity, culture, language, and/or experience among those who identify as African American/Black.**

(Kusow, 2014)

◆ **There are distinctions within “African American” and between “African American” and “Black” that have cultural and linguistic significance.**

- A US-born person with African descent is considered African American
- A majority of African immigrants identify with their respective ethnicities of origin
- Afro-Cubans, Afro-Caribbeans, Afro-Brazilians, Afro-Haitians, and Afro-Latino people may or may not identify with the term “African American”

## HEALTH DISPARITIES

- ◆ **African American and Black people have a greater risk for heart disease, stroke, high blood pressure, Alzheimer’s/dementia, and diabetes.**
- ◆ **African American and Black caregivers are more likely to provide care for someone who has a long-term/chronic physical condition (NAC, AARP, 2015).**
- ◆ **Amidst health and socioeconomic disparities, African American/Black families remain resilient.**
  - Higher rates of grandparent caregivers (Tang et al., 2015)
  - Complex family structures
  - Multiple caregivers
  - **Familism:** defined as a social structure where the needs of the family are more important and take precedence over the needs of any family members

## CULTURAL COMMITMENT TO CARE

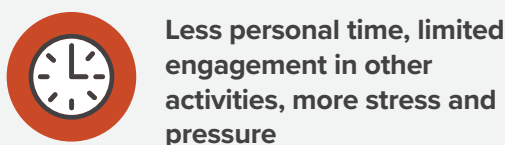
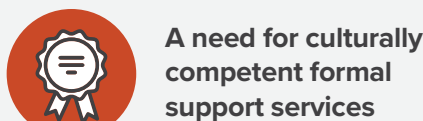
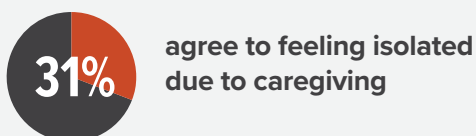
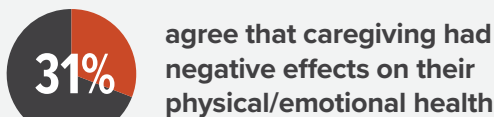
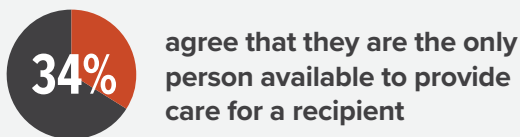
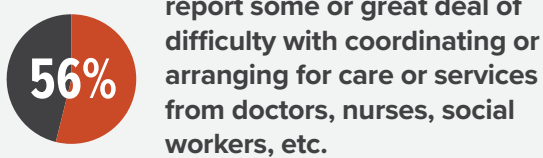
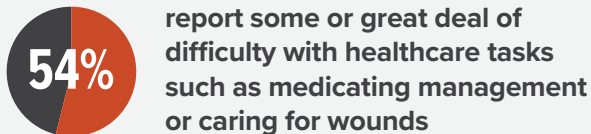
- ◆ **African American/Black caregivers reported that “caring for ill or disabled family members was seen as a responsibility (Scharlach et al., 2006).**
  - Fulfilled cultural norms
  - Maintained cultural continuity
  - Strengthened family ties
- ◆ **On average, African American/Black caregivers agree that cultural obligation is a reason they provide care. However, this can lead to challenges.**
  - African American/Black caregivers were more likely to be women, younger, and “sandwiched” between caring for more than one person (NAC, AARP, 2015)
  - Grandparent caregivers are disproportionately women, younger, less educated, and living in poverty, representing a highly vulnerable population (Minkler et al., 2005)
  - More likely to utilize informal support networks, such as religious organizations

## CARING FOR THOSE WHO CARE

### What Providers Should Know About African American and Black Family Caregivers



#### IN OUR SURVEY OF AFRICAN AMERICAN AND BLACK FAMILY CAREGIVERS:



#### HOW CAN PROVIDERS BETTER SUPPORT AFRICAN AMERICAN AND BLACK FAMILY CAREGIVERS?

- **Recruit, promote, and support a diverse interdisciplinary workforce that understands/represents the culture of the community**
  - Allows for easier communication between hospital case managers and home liaisons
  - More opportunities to identify caregivers and to deliver effective caregiving training
- **Development of culturally and linguistically competent in-office materials to deliver information such as medication management and caregiving training**
  - Ensure that materials are written at a 5th grade reading level or lower
  - Include pictures that reflect African American older adults and families
- **Identify and include relevant family members in person-centered care planning**
  - Revise Patient Demographic Forms and/or Adult History forms to identify whether a patient is providing care for a friend or family member
  - Expand your organization's definition of "family" to include friends, neighbors, and others outside of the traditional family structure
- **Utilize traditional modes of contact/outreach in identification and promoting supportive services, education, and training (AARP, 2018; Navaie, 2011)**
  - In-person meetings
  - Telephone
  - Print material (delivered by mail)
  - Newsletter



**DIVERSE  
ELDERS  
COALITION**

## CARING FOR THOSE WHO CARE

Resources for Providers: Meeting the Needs of Diverse Family Caregivers

# What Providers Should Know About American Indian and Alaska Native Family Caregivers

There are **574** federally recognized American Indian/Alaska Native tribes. Each tribe has their own nation within a larger nation, regardless of national and state borders.

- **Tribal/Self Governance is essential to American Indian/Alaska Native culture. Tribal governments are responsible for a broad array of services, including:**
  - Education
  - Law Enforcement
  - Judicial Systems
  - Healthcare
- **Family is the center unit of American Indian/Alaska Native culture. Taking care of the family is part of traditional values, and Elders are highly regarded among family structures and in society (Scharlach et al., 2006; p. 139-140).**

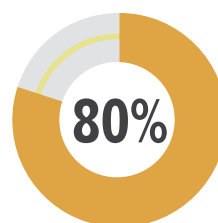


## HEALTH DISPARITIES

- **Diseases of the heart, cancer, and diabetes are leading causes of death for American Indian/Alaska Natives.**
  - AI/AN are 2x as likely than whites to have diabetes (CDC, 2017)
  - Diabetes is a strong risk factor for heart disease—the leading cause of death
  - Common types of cancer include prostate, breast, lung, colon, and kidney
- **Rural tribal communities are geographically isolated from care services and resources.**
  - Exacerbates health disparities
  - Lack of caregiver training

## CULTURAL COMMITMENT TO CARE

- **Many American Indians and Alaska Natives express a distrust of the majority culture and government due to a history of poverty, displacement, and discrimination. As a result, caregivers are more reluctant to use formal supportive services (Scharlach et al., 2006).**
- **American Indians and Alaska Natives often feel a strong cultural commitment to caring and a reliance on family and tribe for support.**
  - Healthcare services provided by tribal health providers
  - Community Health Representatives through Indian Health Services
  - Local tribal community-based organizations
- **On average, AI/AN caregivers agree that cultural obligation is a reason they provide care.**



OF AMERICAN INDIAN/ALASKA NATIVE CAREGIVERS AGREED OR STRONGLY AGREED THAT CULTURAL COMMITMENT TO CAREGIVING WAS A REASON THAT THEY PROVIDED CARE TO A LOVED ONE.



## CARING FOR THOSE WHO CARE

### What Providers Should Know About American Indian and Alaska Native Family Caregivers



#### IN OUR SURVEY OF AMERICAN INDIAN AND ALASKA NATIVE FAMILY CAREGIVERS:



#### HOW CAN PROVIDERS BETTER SUPPORT AMERICAN INDIAN AND ALASKA NATIVE FAMILY CAREGIVERS?

- **To provide for American Indian/Alaska Native caregivers it is necessary to be aware of their roots in social, historical, cultural, economic, and environmental issues**

  - Strengthen tribal and community-based organizations to increase capacity of programming
  - “Shared” dedication rather than reinvent the wheel
- **Build relationships with tribal communities in your region. This can include developing 1:1 relationships with tribal leaders, elders, Community Health Representative, and tribal members.**
- **Develop culturally and linguistically competent in-office material for training, information on caregiving, disease information, and intervention outreach**

  - Avoid words such as “caregiver burden”
  - 6th grade reading level or lower
  - Use images with representation of American Indians/Alaska Natives
- **Consult with local tribal leaders, elders, local institutions in local tribal communities in disseminating print material and to develop or increase capacity programming**

  - Increased visibility of print material to reduce stigma, provide disease information, and caregiver training/information
  - Tribal leaders, elders are the centerpoint of tribal communities



DIVERSE  
ELDERS  
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## CARING FOR THOSE WHO CARE

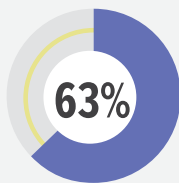
Resources for Providers: Meeting the Needs of Diverse Family Caregivers

## What Providers Should Know About Chinese and Korean American Family Caregivers

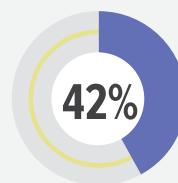


The umbrella group “Asian American and Pacific Islander” or AAPI consists of more than 50 different ethnicities with over 100 languages spoken.

- Chinese are the largest Asian American ethnic group aged 55 and older (NAPCA, 2013).



OF THE CHINESE POPULATION ARE FOREIGN BORN (PEW, 2015)



OF THE FOREIGN-BORN POPULATION IS AGED 50 AND OLDER

### HEALTH DISPARITIES

- Historically, AAPI communities have faced significant barriers to accessing affordable health insurance and quality health services, and these barriers have contributed to health disparities.
  - Asian American, Native Hawaiian, and other Pacific Islander communities are likely to lack health insurance coverage
  - Health conditions that are common in the AAPI community—like diabetes, obesity, cancer, HIV/AIDS and mental illness—often go undiagnosed and untreated. (WHIAAPI)

### CULTURAL COMMITMENT TO CARE

- On average, Chinese American caregivers agree that cultural obligation is a reason they provide care for their relative or friend.
- AAPI caregivers are more likely to adopt or be influenced by expectations related to the concept of filial piety (virtue of respect, care, obedience).
- Chinese and Korean American family caregivers reported that caring for ill or disabled family members (Scharlach et al., 2006):
  - Fulfilled cultural norms
  - Maintained cultural continuity
  - Strengthened family ties

### HOW CAN PROVIDERS BETTER SUPPORT CHINESE AND KOREAN AMERICAN FAMILY CAREGIVERS?

- Utilize culturally competent, trained Medical Interpreters when speaking to AAPI family caregivers
  - Limited English proficient patients were 27% more likely to be readmitted (Diamond et al., 2017)
- Assess for difficulty with cultural tasks in caregiver & patient screening
  - Caregivers who reported high difficulty with cultural tasks had poorer health outcomes
  - Edit caregiver burden screening tools to collect information about caregiving responsibilities

## CARING FOR THOSE WHO CARE

### What Providers Should Know About Chinese and Korean American Family Caregivers



#### IN OUR SURVEY OF CHINESE AND KOREAN AMERICAN FAMILY CAREGIVERS:

**16%** report some or a great deal of difficulty assisting with cultural tasks, such as:

- Overcoming language barriers when talking with healthcare or service providers
- Translating health-related information into main language
- Legal issues related to immigration or naturalization procedures

**51%** report some or a great deal of difficulty with healthcare tasks such as medication management and caring for wounds

**42%** report some or great deal of difficulty with coordinating or arranging for care or services from doctors, nurses, social workers, etc.

**36%** of Korean American caregivers agreed or strongly agreed that caregiving had negative effects on their emotional health

**Caregivers who report more difficulties performing cultural tasks:**

- Have higher levels of four types of caregiver strain and depression
- Provided lower ratings of the quality of healthcare provided to their care recipients
- Report feeling less satisfied with support from family members or friends

#### HOW CAN PROVIDERS BETTER SUPPORT CHINESE AND KOREAN AMERICAN FAMILY CAREGIVERS?

*continued*

- **Develop translated in-office materials for disease knowledge, treatments, and training**
  - In-language materials help mitigate the limited opportunities to speak to providers due to time constraints
  - In-office materials are seen by AAPI older adults as the most impactful in providing health-related information (AARP, 2018)
- **Provide culturally competent referrals and resources**
  - Dissemination of culturally competent in-office material for training and information
  - Affordable and in-language referrals
- **Develop in-language caregiver support groups**
  - Resolve social and linguistic isolation
  - Provide support network for older adult LEP caregivers
- **Develop in-language caregiver education/training workshops**
  - Advertisements and materials that reflect AAPI older adults and caregivers
  - Ensure that materials are translated both linguistically and culturally

**FOREIGN-BORN CAREGIVERS IN THE US ARE OLDER, HAVE LOWER EDUCATIONAL DEGREES, LOWER INCOME, AND ASSIST MORE WITH CULTURE-RELATED TASKS, LIKE TRANSLATING HEALTHCARE INFORMATION FROM ENGLISH.**



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## CARING FOR THOSE WHO CARE

Resources for Providers: Meeting the Needs of Diverse Family Caregivers

## What Providers Should Know About Southeast Asian American Family Caregivers



**Southeast Asian American (SEAA) is a political and racial identity for a subgroup of Asian Americans who were primarily resettled in the United States as refugees in the 1970s. The label includes:**

### Cham

A MUSLIM MINORITY GROUP

### Khmer

### Khmer Loeu

OR HIGHLAND KHMER

### Hmong

### Iu Mien

OR MIEN

### Khmu

### Lao

OR LAO LOUM/LOWLAND LAO

### Taidam

### Khmer Kampuchea Krom

OR ETHNIC KHMER

### Montagnards

OR HIGHLANDERS OF SEVERAL DIFFERENT ETHNIC GROUPS

### Vietnamese

\* CERTAIN ETHNIC CHINESE ALSO HAVE HERITAGE IN CAMBODIA, LAOS, AND VIETNAM.

## HEALTH DISPARITIES

- **Limited English proficiency rates for Southeast Asian American communities are between 40–50%. For elders, those numbers can jump as high as 90%.**
- **SEAA are affected by the traumas of war and resettlement, low socioeconomic status, and recent mass deportations.**
  - Inadequate access to mental health services
  - Adult children removed from family caregiving structure
  - Promotes distrust of any formal services
- **Poverty rates in all SEAA ethnic groups are above the national average (11.3%).**
  - Hmong 27.4%
  - Cambodian 18.2%
  - Vietnamese 13%
  - Laotian 12.2%

## CULTURAL COMMITMENT TO CARE

- **Family and Respect are two pillars of the Vietnamese traditional values.**
- **Vietnamese caregivers reported that caring for ill or disabled family members (Scharlach et al., 2006):**
  - Fulfilled cultural norms
  - Maintained cultural continuity
  - Strengthened family ties
- **On average, SEAA caregivers agree that cultural obligation is a reason they provide care for their relative or friend.**

**ABOUT 1.1 MILLION SOUTHEAST ASIANS WERE RESETTLED DURING THE VIETNAM WAR AND CAMBODIAN GENOCIDE. INADEQUATE RESETTLEMENT SUPPORT UPON ARRIVAL LED TO MANY BARRIERS FOR SEAA, AMONG THEM HIGH RATES OF LIMITED ENGLISH PROFICIENCY.**

## CARING FOR THOSE WHO CARE

### What Providers Should Know About Southeast Asian American Family Caregivers



#### IN OUR SURVEY OF SOUTHEAST ASIAN AMERICAN FAMILY CAREGIVERS:



agree that they are the only person available to provide care to their care recipients



report some or a great deal of difficulty assisting with cultural tasks, such as translating health information into their native language



report that their healthcare providers did not know about the care they provided to their loved one(s)



One quarter of those surveyed agree that caregiving had negative effects on their physical/emotional health

- Less personal time, limited engagement in other activities, more stress and pressure
- **22.7%** agreed to feeling isolated due to caregiving
- **14.3%** reported feeling more symptoms of depression sometimes or often

#### HOW CAN PROVIDERS BETTER SUPPORT SOUTHEAST ASIAN AMERICAN FAMILY CAREGIVERS?

- **Utilize culturally competent, trained Medical Interpreters when speaking to Southeast Asian American family caregivers**
- **Assess for difficulty with cultural tasks in caregiver & patient screening**
  - Caregivers who reported high difficulty with cultural tasks had more poor health outcomes than patients who reported low difficulty
- **Develop translated culturally competent in-office materials for disease knowledge, treatments, outreach and training**
  - Reduction of stigma surrounding diseases
  - Lower readmission rates
  - Higher caregiver satisfaction
- **Create partnerships and provide funding/support to community-based organizations that provide services to SEAA communities**
- **Disaggregate data that is collected on intake forms and in healthcare settings**
  - Better understanding of challenges and resiliencies unique to SEAA communities
- **Provide culturally competent referrals and resources to resolve high difficulty with cultural tasks**
- **Development of in-language caregiver support groups**
  - Nearly half of SEAA caregivers indicate being the only person available to provide care
  - Improve mental health and reduce isolation
  - Creation of safe place to share concerns and learn from others
  - Better caregiver outcomes



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## CARING FOR THOSE WHO CARE

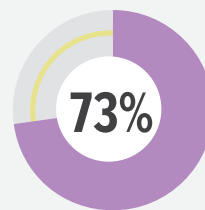
Resources for Providers: Meeting the Needs of Diverse Family Caregivers

## What Providers Should Know About Hispanic and Latino Family Caregivers

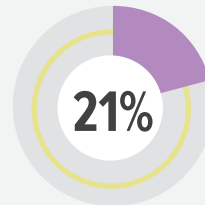
The Hispanic/Latino community is the largest ethnic minority group in the US, comprising 18.1% of the total US population.

(Census, 2018)

- **Culture and language have a big impact on access to care and supports.**
  - More likely to rely on family and less likely to seek outside sources (Flores et al, 2009)
  - Spanish-speaking Hispanic/Latino family caregivers report feeling unprepared resulting in isolation and separation from social life (AARP)
- **There is really no good word for “caregiver” in Spanish. The word “cuidador” is sometimes used, but it does not resonate with many Hispanic and Latino people (NHCOA).**



**73%**  
OF US HISPANIC/LATINO HOUSEHOLDS SPEAK SPANISH AT HOME (PEW, 2017)



**21%**  
1 IN 5 OLDER AMERICANS WILL BE HISPANIC/LATINO BY 2060 (ACL, 2017)

### CULTURAL COMMITMENT TO CARE

- **Familism: a central Latino cultural value. It involves dedication, commitment, and loyalty to family. Regularly spending time with one’s immediate and extended family is part of familism. It also involves seeking the family’s advice for important decisions.**
- **Hispanic/Latino families tend to adopt or be impacted by the value of familism (McClearly et al, 2013).**
  - 27% of Hispanics/Latinos living in the US live in multigenerational family households
  - Caregiving is described as “something that just needed to be done—not merely the ‘correct’ thing to do”

### HEALTH DISPARITIES

- **Barriers to service utilization**
  - Lack of culturally and linguistically appropriate materials and services
  - Even when providers speak Spanish, they don’t understand how culture affects care
- **Disproportionately affected by Alzheimer’s and related dementias, diabetes, and poor mental health**
  - Hispanic/Latino caregivers are more likely to be affected by caregiver strain and depression
  - Recent political climate has promoted fear among the Hispanic/Latino population
    - Exacerbates distrust in institutional entities
    - Promotes stress and worsens health outcomes



## CARING FOR THOSE WHO CARE

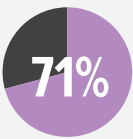
### What Providers Should Know About Hispanic and Latino Family Caregivers



#### IN OUR SURVEY OF HISPANIC/ LATINO FAMILY CAREGIVERS:



report some or great deal of difficulty with personal care tasks and healthcare tasks such as medication management, wound care



report some or great deal of difficulty with arranging for care or services from doctors, nurses, social workers, or other professionals



report some or great deal of difficulty with cultural tasks, such as:

- Overcoming language barriers when talking with healthcare or service providers
- Translating health-related information into main language
- Legal issues related to immigration or naturalization procedures



**The lack of informal and formal support increases strain for caregivers**

- **50.9%** agree that they are the only person to help care recipients
- **30.3%** report agreed to feeling more isolated due to caregiving
- **31.3%** agreed that caregiving had negative effects on their physical/emotional health
- **16.3%** reported feeling more symptoms of depression sometimes or often

#### HOW CAN PROVIDERS BETTER SUPPORT HISPANIC AND LATINO FAMILY CAREGIVERS?

- **Recruit, promote, and support a diverse workforce that understands/represents the culture of the community**
  - Cultural representation among providers is important for Hispanic/Latino caregivers and older adults (Terlizzi et al., 2019)
  - Easier communication, improved patient and caregiver outcomes
- **Utilize culturally competent, trained Medical Interpreters when speaking to Hispanic/Latino family caregivers and older adults**
- **Assess for difficulty with cultural tasks in caregiver & patient screening**
  - Caregivers who reported high difficulty with cultural tasks had more poor health outcomes than patients who reported low difficulty
- **Partner with community-based organizations to provide culturally competent referrals and resources**
- **Develop translated culturally competent in-office material to provide information and training**
- **Utilize community leaders to recruit and deliver comprehensive, innovative programming amongst Hispanic/Latino older adults and caregivers**
  - Opportunity to provide information around different disease stigma
- **Development of in-language caregiver support groups**
  - May lead to improved caregiver outcomes
  - Opportunity to provide caregiver training workshops



**DIVERSE  
ELDERS  
COALITION**

## CARING FOR THOSE WHO CARE

Resources for Providers: Meeting the Needs of Diverse Family Caregivers

## What Providers Should Know About Lesbian, Gay, Bisexual, Transgender and Queer/Questioning (LGBTQ+) Family Caregivers



**Lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) family caregivers have challenges and resiliencies unique to their identities.**

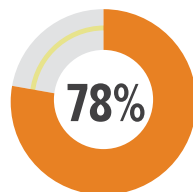
- **Being gay was a mental illness until the 1980s. Marriage equality just happened in 2015. Older adults have had not an experience of tolerance—theirs has been an experience of survival.**
- **Family of Choice:** many LGBTQ+ people become estranged from their biological families because of their LGBTQ+ identities, and instead create “families of choice” from friends, peers, and neighbors. In many cases, these are the people providing care for LGBTQ+ community members, who are less likely to be married, less likely to have children, and more likely to live alone.

### CULTURAL COMMITMENT TO CARE

- **Many people who identify as LGBTQ+ rely on families of choice to provide care.**
  - Four times less likely to have children and twice as likely to be single
  - Family of choice not frequently recognized by formal services
- **LGBTQ+ adults become caregivers at a much higher rate than general caregiving population (AARP & National Alliance for Caregiving, 2015).**
  - LGBTQ+ caregivers make up around 9% of the caregiving population
  - This number could be higher, as some people may be afraid to come out due to discrimination

### HEALTH DISPARITIES

- **Caregivers who identify as a gender and/or sexual minority report being discriminated by healthcare providers and bureaucratic health systems (Fredriksen-Golden, Jen, Bryan, & Goldsen, 2016).**
  - Hesitance about reaching out to services and seeking guidance with care
  - Rely more heavily on support from family, friends, and neighbors
- **Transgender people experience widespread discrimination in health care, employment, and housing (Bradford et al., 2013).**
- **Because of a history of discrimination and barriers in health care as mentioned (family of choice), LGBTQ+ caregivers and recipients may not get the information, education, training, and other resources necessary to provide high quality and sustainable care.**



**78% OF LGBTQ+ OLDER ADULTS GO BACK IN THE CLOSET UPON ENTERING A NURSING HOME OR ASSISTED LIVING FACILITY.**



## CARING FOR THOSE WHO CARE

### What Providers Should Know About LGBTQ+ Family Caregivers




#### IN OUR SURVEY OF LGBTQ+ FAMILY CAREGIVERS:

**43%** report some or great deal of difficulty with healthcare tasks such as medication management or caring for wounds


**63%** report some or great deal of difficulty coordinating or arranging for care services from doctors, nurses, social workers, etc.

**37%** More than a quarter agree to feeling isolated due to caregiving

- Less personal time, limited engagement in other activities, more stress and pressure
- Higher incidence of isolation than other groups

 **LGBTQ+ caregivers are more likely to report feeling they are the only person available to provide care than other diverse groups**

- 45% agree that they are the only person available to provide care
- Other family members may make unfair assumptions that the LGBTQ+ person “has no partner or kids” and thus has the time to care for an older adult

 **LGBTQ+ caregivers are less likely to seek help because they are afraid of discrimination**

#### HOW CAN PROVIDERS BETTER SUPPORT LGBTQ+ FAMILY CAREGIVERS?

- **Collect information on gender identity and sexual orientation to better understand the needs your patients and caregivers**
  - Edit demographic intake tools to collect information about sexual orientation and gender identity
  - Reflect the words people use to describe their identities and relationships
- **Provide culturally competent referrals and resources**
- **Develop and leverage partnerships with CBOs to refer caregivers to LGBTQ+-friendly training and support groups**
- **Create welcoming, supportive, and safe environments for LGBTQ+ caregivers and older adults**
  - Utilization of posters, signs, rainbow flag on front door to welcome LGBTQ+ adults, but only after a training and policy audit to ensure that services are welcoming
  - Eliminate fear of judgment, discrimination, and rejection
  - Provide ongoing LGBTQ+ competency training to staff
  - Develop culturally competent advertisements, brochures, pamphlets that reflect LGBTQ+ constituents
- **Develop programs to engage LGBTQ+ older adults and/or caregivers**
- **Ensure that your organization’s nondiscrimination policy includes sexual orientation and gender identity, and any use of the word of “family” makes it clear that chosen families also count**



**DIVERSE  
ELDERS  
COALITION**

# RESEARCH WITH DIVERSE FAMILY CAREGIVERS

NATIONAL ALLIANCE  
FOR CAREGIVING



## INTRODUCTION TO THE RESEARCH

In the spring of 2022, the National Alliance for Caregiving engaged Limelight Insights by Shugoll to conduct a series of qualitative, one-on-one, in-depth interviews with diverse caregivers. Diverse caregivers were defined as having racial/ethnic diversity, diversity in sexual orientation or gender identity and gender diversity.

NAC's primary goal of this research was to gather feedback from caregivers on the challenges they face when identifying, accessing and understanding resources available to them as caregivers part of a culturally diverse group. It was also meant to determine what supports and services could improve diverse caregivers' experiences, and how patient advocacy groups could support these diverse caregivers.

## METHODOLOGY

This study focused on the caregivers of patients with lung cancer, blood cancer, lupus or heart disease. Though the study made an effort to engage American Indian/Alaska Native caregivers, unfortunately they are not represented in these results.



**NAC's primary goal of this research was to gather feedback from caregivers on the challenges they face when identifying, accessing and understanding resources available to them as caregivers part of a culturally diverse group.**

### Caregivers Interviewed (total n=29)

Caregivers	Total (n=29)
Black caregivers	7
Hispanic caregivers	7
Asian American and Pacific Islander caregivers	7
LGBTQ+ caregivers	8

Limelight Shugoll also spoke to 9 male caregivers among this group total of 29 caregivers, which represents diversity in the caregiving world as most family caregivers are female.



## INFOGRAPHIC

The following infographic details important findings from these interviews on diverse caregivers, including how their culture affects the way they care, the challenges they face as diverse caregivers, their experience accessing and understanding caregiver resources, the resources needed to answer challenges faced by diverse caregivers and the role of patient advocacy groups in their lives.



### Cultural traditions and values were found to have a significant impact on the caregiving journey

- Caregiving is seen as a responsibility and a duty
- Caregivers are traditionally female and grew up seeing family taking care of one another, so caregiving is “natural”
- Most diverse caregivers would never put their elders in a senior home
- Some diverse caregivers and patients are very private about illness
- Most diverse caregivers do not want to burden others with their own needs



### In general, race, ethnicity and sexual orientation were not found to have a significant impact on the caregiving experience, although there were isolated incidents of bias

Examples of bias or stigma include:

- Assumptions that the caregiver does not understand English
- Being provided “bare minimum” information as if they will not understand anything more
- Young caregivers not being taken seriously
- Male caregivers not being taken seriously
- Disabled caregivers not being taken seriously



### Resources can mostly be found on the internet and are easily accessible, however it is difficult and overwhelming to find them

- It can be hard to find the “good” resources and dig through everything available
- Caregivers feel as if they’re on their own with only the internet available to them
- Feel all the resources are mostly for those caring for elders



## INFOGRAPHIC CONTINUED



### Preferred format for caregiver resources:

- Chat forums or boards with other caregivers
- Interactive resources where an answer can be found quickly
- Apps and downloadable materials
- Print outs caregivers can take with them after leaving a provider
- Podcasts or videos with helpful information
- Short, to the point, easily digestible information



### Cultural Sensitivity of Caregiver Resources

- Caregivers would like to see resources with images of people who look like them
- Most resources are general and don't consider culture
- It would be helpful if culture was acknowledged up front with in-person resources so expectations can be met



### Resources caregivers would like to see:

- A comprehensive app for caregivers
- Real time advice from a healthcare professional
- Resources in languages other than English or translation services
- Health care education, advice, tips and tricks
- Respite for the caregiver



### Patient advocacy groups are not a go-to for caregivers, who are not aware they exist or that they are available to them

- Caregivers are overwhelmed and do not have time to reach out to patient advocacy groups
- Privacy concerns may stop caregivers from reaching out to groups
- Caregivers would like to learn about patient advocacy groups through trusted medical professionals



### Patient advocacy groups can better serve diverse family caregivers by:

- Increasing their awareness and familiarity with diverse communities
- Increasing their cultural sensitivity
- Providing basic information on health care and education
- Emphasizing diversity, equity and inclusion
- Creating resources and education specifically designed to support caregivers
- Connecting them with other caregivers
- Providing large communities of support
- Being easily accessible and open to help

# WHAT CAREGIVERS SAY





## REACHING DIVERSE FAMILY CAREGIVERS

### HOW

#### Short, simple, to the point messages

Caregivers don't often have a lot of time to look for information outside of their caregiving duties along with their own normal activities of daily living. When they do have time to sit down to search for supports, services and information, they can often become overwhelmed with the results and sorting out the information that will actually be helpful to them. By advertising with short, simple, to the point messaging, patient advocacy groups can get caregivers' attention and convey that they will be able to assist them and provide them with what they need.

#### Emphasize that there are supports and services for the caregiver, and define what a caregiver is

We know that sometimes caregivers do not identify themselves as a caregiver, and that this lack of identification as a caregiver can vary across cultures. By defining what patient advocacy groups consider to be "caregivers," caregivers will be able to identify and know right away that there are resources available to them. It is also important to be aware that the term "caregiver" may not be used in a certain culture or even preferred by an individual. The term "care partner" has become more popular; using language inclusive to everyone is important in regards to respecting their identity and providing them help.

In both our one-on-one focus group sessions and in our oral histories, the majority of caregivers did not realize that patient advocacy groups were there for them as well, not just for the patient. One caregiver expressed the surprise she felt when she contacted a patient advocacy group for her wife and happened to learn that they held a support group specifically for caregivers. Others said that knowing there were caregiving resources in a place that is also meant to help the patient made them feel less guilty about exploring and utilizing their support options.

#### Be genuine in equity and inclusion

Caregivers in one-on-one focus group sessions asked that cultural sensitivity within patient advocacy groups themselves be increased. They suggested sharing stories and images of caregivers from different cultures, hiring representatives from different racial/ethnic/cultural backgrounds for caregivers to connect with, coordinating support groups for different racial/ethnic/cultural groups and becoming more educated on cultural needs.

**"I want to understand what they do. How they support patients and caregivers. How do I access them? I want to know the protocol around communicating with them. And how many patients do you have in your advocacy group? Are there five patients or 500? I would not want to waste my time on a group that had just five people."**

– Female, Asian American caregiver

**"Educate people that anybody can be a caregiver - it's not only a job for a certain group of people or gender."**

– Male, Hispanic/Latino caregiver

A male LGBTQ+ caregiver who participated in the oral histories we conducted stressed that patient advocacy groups being genuine in wanting to learn about and help caregivers was more important than having someone who was LGBTQ+ to speak with. He said, “I don’t think it has to be a gay person. It could just be a straight person who really gets it through their own history or their own family, or can just get the equivalences between their own history and what it might be for a gay person. It’s the quality of the person rather than what their actual orientation is.”

### **Work together with healthcare providers**

A majority of the caregivers we spoke to said the easiest as well as the most trusted place to receive information on patient advocacy groups was through their provider, hospital, or treatment center. Suggestions ranged from providing written pamphlets that the caregiver could look at later, to having doctors suggest patient advocacy groups specific to a patients’ condition, to installing a patient advocacy group liaison who could meet with caregivers and patients who were a part of the condition population they served.

### **Be active in making caregivers aware that patient advocacy groups exist**

Oftentimes the time and energy it takes for caregivers to seek out supports and resources that meet their needs is not worth it in the long run when they are so focused on the needs of the patient and getting everything they must do in a day completed. One caregiver (female, Asian American) said, “I don’t have time to chase down whether I can get somebody to pay for the cab that I need to take her [her mother] somewhere. By the time I figure that out, I’ll just take her somewhere.” Being clear, direct, and prominent about the supports and services available means caregivers will not have to spend time searching for them, and the supports will be more likely to be utilized and answer caregiver needs.

### **Provide resources in languages other than English, along with translation services**

More than 60 million Americans speak a language other than English, with the number growing yearly.<sup>1</sup> Caregivers of different races, ethnicities and cultural backgrounds should be able to find the information they need in the language they prefer to speak. If a patient advocacy group has resources, services and supports in other languages available, or has a translator who will be able to translate these resources, they need to make this clear to caregivers.

### **Use images of all different ethnicities, races, and family dynamics so more people can see themselves represented**

Several caregivers stated that in order to help them feel included and connected to patient advocacy groups, they would like to see resources, supports and services being run by people who look like them or promoted with images of people like them who are being served by the group. This would help them feel understood as a caregiver of their own racial, ethnic or cultural background.

There can also be a sense of mistrust among diverse caregivers and the healthcare system, and employing those of different racial, ethnic and cultural backgrounds would help to start building trust among patients, their caregivers, and patient advocacy groups. One caregiver (female, Black/ LGBTQ+) explained, “it’s not a whole lot of us that are these doctors, that are over these groups, these advocacy groups. That are in places where we can see them as employees, as members of the healthcare community. Where we can see people, because when we see people that look like us, doing what we do, then we trust that.”



<sup>1</sup>Dietrich, S. & Hernandez, E. (2022, August). Language used in the United States: 2019. U.S. Census Bureau. <https://www.census.gov/content/dam/Census/library/publications/2022/acs/acs-50.pdf>.



## WHEN

The ideal time to reach out to a caregiver will differ widely, because every caregiver handles stress, organization of time and duties, and the way in which they digest information differently. However, it doesn't hurt to make it known the resources that are available to them whenever possible.

### At time of diagnosis

When first learning about the condition of the person they'll be caring for, it can be helpful for caregivers to be given information and resources they can turn to in order to learn more about and digest the diagnosis. This information can also be helpful in preparing the caregiver for their role and letting them know what to expect.

Though many caregivers said they may be too overwhelmed to read any information given to them at the time of diagnosis, these same caregivers stated that if they had been given printed information or pamphlets to take home, they would read them eventually and then could have connected to patient advocacy groups when they were ready or when they needed them.

Some caregivers also said that meeting with someone from a patient advocacy group at the time of diagnosis, or knowing that a patient advocacy group for the condition they were caring for was out there, would have been helpful to them in simply knowing they were not alone.

### During a doctor's appointment

When caring for someone else, a lot of a caregiver's time is spent in doctor's offices, hospitals and at treatment centers. Rather than having to search for information on patient advocacy groups, caregivers would prefer that these groups meet them where they will naturally be over the course of the day. Patient advocacy groups should supply information and resources to healthcare centers so caregivers can find them without having to search for them.

### When a caregiver is searching for information

When caregivers do find the time to look for resources and supports, the easiest and most accessible way to do this is through the internet. Caregivers found that the most credible resources were ones from places that had brand recognition, where the information was kept up to date with guides and videos, that were positively reviewed by users and the Better Business Bureau, and that came up early in their search results. Working to build credible, easy to access supports, services and information will mean that a caregiver is more likely to connect with and utilize the help of a patient advocacy group.

### Throughout the pathway of their care journey

Due to the fact that all caregivers have different experiences, journeys and feelings relating to providing care, it can be important to meet the caregiver on their pathway of care. Caregivers at different stages of their experience require different information and supports. A caregiver who has been providing care to someone for three years does not necessarily need education and information on the condition they're caring for, but may need information on clinical trials or where to find respite. Ensuring that there is support available for every part of the caregiving journey, and that this support is offered when needed, will put patient advocacy groups on caregivers' radars.

**“I don't think it's in a geographic place. I think it's at a certain point in the pathway of your experience. So I would have experienced them, and probably accepted what they had to offer, if they showed up through the phase of care we were at - like through my palliative care provider. Like integrated some way in the pathway of care.”**

– Female, Asian American caregiver

**“What I think should happen is really do advertisements more to specific people who are actually searching for this stuff. Get data on when people go online, saying, ‘What to expect as a caregiver.’ Maybe get their email so you can target them so they know you understand what they're going through.”**

– Female, Asian American caregiver

## WHERE

### Through a trusted medical professional

An overwhelming amount of caregivers we spoke to asked that patient advocacy groups be recommended to them through a trusted medical professional, or at a medical center. Putting information about patient advocacy groups in hospitals or working with doctors to ensure they give information about these groups to their patients, makes patient advocacy groups easily accessible and puts them at the top of the caregiver's mind when they're trying to find help.

Because medical professionals are viewed as knowledgeable and are already there as a source of information and support for the caregiver and patient, being directed to a patient advocacy group by them lends the group a level of credibility. Caregivers can trust that the group will be there for them with resources and support, rather than having to spend time determining whether the group is credible or can help them.



### “Where the caregiver is”

Some caregivers expressed interest in patient advocacy groups advertising their purpose and what they can do for caregivers in places where diverse caregivers congregate as they live their daily lives, such as at church, the grocery store, or on the TV channels they watch and the radio stations they listen to.

When asked, one caregiver (Female, Black) said the best way to get her notice was through, “a billboard, television commercial or social media ad – everybody is on social media. You can go into churches, go into restaurants. The best time to catch an African American person is on a Sunday, because they go to church and they go out to eat, or to a park to relax.”

Another caregiver pointed out that they were directed to patient advocacy groups by people involved in the same condition community as them. Patient advocacy groups may attract more caregivers by simply engaging caregivers in their own condition or population community, either through word-of-mouth or targeted advertisements.

### Social media and online

Targeted social media messaging can also ensure that caregivers will find patient advocacy groups without having to search too hard for them. Social media advertisements are where short, simple, to-the-point messages come into play, with the ads making it clear that they have information and supports for caregivers.

### Available app or texting service

Caregivers also said they would be interested in a simple app or texting service. The majority of caregivers preferred to have someone real to talk to in a quick and to-the-point way. Being able to message a healthcare professional or someone else providing support with a question and getting a quick response would be helpful. They also expressed the desire to have the bulk of the information they're looking for located in one place, rather than having to search through several resources or websites to find the answer. An app or texting service could be a step towards creating this one-stop shop.

**“I think it has to come from the healthcare providers. They need to provide pamphlets and tell us that these groups are available. The nurses need to talk about it. The doctors need to say it. Because when they tell you, they are in a place where you trust them more than anyone else, so you tend to go and pick up those pamphlets and look into it.”**

– Male, Asian American caregiver

## RESOURCES AND SUPPORTS CAREGIVERS WANT TO SEE FROM PATIENT ADVOCACY GROUPS

### Caregiver specific support groups

One in five caregivers feel alone<sup>2</sup> and even if they don't, it's important to them to have someone to speak with who can relate to their experience. Some caregivers find this connection and support in caregiver specific focus groups, which can be provided by patient advocacy groups. Support groups can be a safe space where caregivers can talk about what they've been going through with others who understand them and who won't judge them, and can help with feelings of stress, depression, and guilt.



Some of the caregivers we spoke to expressed further interest in caregiver support groups that were specific to a racial, ethnic or cultural background, or were specifically for LGBTQ+ members. In this way, caregivers could talk not only about the connections in their caregiving experience, but their connections as a caregiver of a specific culture or identity which has its own nuanced feelings or expectations that can only be understood by someone from the same culture.

It is also important to have support groups in different languages. One Latina caregiver we spoke to talked about how she does not personally know any other Latino caregivers who are caring for someone with lung cancer, and she feels isolated by the experience, especially since she finds that there is stigma attached to lung cancer in her community. Speaking with someone in her language with a similar cultural background about the lung cancer caregiving experience would help her feel less alone.

### Real time connection with a healthcare professional or someone with information

Caregivers do not have the ability to spend hours of their time and energy searching for information, and if they do not get the answer they need when they first go looking for it or ask for it, they are often unable to follow up. Setting up a quick form of communication where a caregiver can speak directly with healthcare staff or someone knowledgeable about the information they need allows them to get a quick answer.

Sometimes having the ability to speak with someone directly face-to-face, rather than virtually or over the phone, is preferable. Healthcare professionals speak to a lot of patients and have a lot to do, and sometimes their responses can be hurried, distracted, or not as in depth as a caregiver may need. The same thing can occur at patient advocacy groups with staff who may not have dedicated time to answer questions on the phone, or who may not know an answer and are unable to follow up and search for one when the caregiver is not physically with them. One caregiver (Female, Black) told us that, "people tend to be very mean and rude over the phone, but when you're looking someone in the face and they can see that you're exhausted, they tend to want to help you. Even if they don't know the answer, they can at least partially find something out for me."

**Some of the caregivers we spoke to expressed further interest in caregiver support groups that were specific to a racial, ethnic or cultural background, or were specifically for LGBTQ+ members.**

<sup>2</sup>The National Alliance for Caregiving & AARP. (2020, May). *Caregiving in the U.S. 2020*. The National Alliance for Caregiving. <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>.

## Resources tailored to cultural needs

Largely, diverse caregivers agree that it would be extremely helpful to them to be provided resources and supports that are tailored to the needs of their culture. While in some instances this benefit may just be an added bonus, such as being able to talk to someone of the same age, race, ethnicity and culture who is experiencing caring for the same condition, in many cases it is the bare minimum of what should be available to save the caregiver time and energy in fighting for something they shouldn't have to ask for.

For example, many cultures have religions, diets, customs relating to death and illness, and holidays that need to be taken into account for both the patient and caregivers' sake. When a caregiver is spending their time doing everything needed to provide care, they don't want to also have to inform, and in some cases fight for, the right to get their care recipient proper meals, or to have a spiritual advisor who is knowledgeable about their religion.

It is important to ask caregivers what they identify as – what their culture is, the religion they practice, the language they speak – and then to become educated on that identity. This will allow patient advocacy groups to provide caregivers with culturally responsive resources and supports without the caregiver having to constantly teach others about their culture or to explain why a resource isn't helpful to them, and then expend energy on getting a helpful resource or service.

## A one-stop place for the caregiver

When caregivers look for information, most of the time they are looking for articles on how to care for their recipient, or how to navigate the healthcare system. It is not often they are looking for resources to help themselves, and many caregivers can even feel guilt over considering their own well-being. Since patient advocacy groups are a resource caregivers may use to find information to help their care recipient, it would be helpful for these groups to also have a page, or “corner” of their website dedicated to caregiving.

While this page should hold the information caregivers are looking for in order to help their recipient, it can also hold information on how the caregiver can care for themselves, and provide support groups and respite resources for the caregiver. We were told, “when I'm trying to find the Cancer Association, heart, lung or whatever association, they could have resources there for me as the caregiver there on the same page. I think it would make me feel less guilty, to be honest. It would feel like I'm doing it for them, and then all of a sudden, I am also finding something for myself. My intention was for them, but somehow I am getting good stuff out of it, too,” (Male, LGBTQ+ caregiver).

## Financial assistance

Caregiving can cause increased costs in health care as well as additional necessities that are often not thought of like transportation, hotel stays or home modifications. The cost of caregiving can be the reason for financial inequities, and are an increased burden on socioeconomic status. There are both federal and state programs that provide caregivers reimbursement or financial support under certain circumstances. By making themselves familiar with these programs, patient advocacy groups can inform caregivers of these available benefits and answer basic questions about them to improve the caregiving experience.

Caregivers may also be deterred from looking for services that may help themselves, such as mental health or respite services, in part due to financial complications. Programs exist that can financially support the caregiver in their need to care for their own mental well-being, but they must be aware of them in order to take advantage of them.

**“Everyone was dancing around, instead of asking you straight, ‘Culturally, what do you want?’ There was hesitation to ask and there was a hesitation to tell. We didn't ask, we didn't tell.”**

– Male, LGBTQ+ caregiver



**Caregivers need easy to skim resources that allow them to get the answer they need quickly, in a way that they can easily understand.**

### **Educational resources on how to interact with the healthcare system**

Navigating the healthcare system can be hard even for those who are familiar with it, and for many caregivers, they have been thrust into a role that they had not prepared for, with no background knowledge or experience on how to constantly interact with doctors and insurance. All caregivers find themselves becoming an advocate at some point, and for diverse caregivers, they may run into even more instances where they have to advocate for their own cultural rights or the rights of the patient in a system that is systemically biased towards them.

Patient advocacy groups can create both resources and supports to help guide a caregiver through the healthcare system, letting them know when and how to fight for something, or if there is an easier path to getting what they need. It is also helpful for caregivers to know that someone is in their corner and backing them. Even through difficulty with the system, knowing that a patient advocacy group is there to support them every step of the way can help caregivers feel less alone and helpless in their journey.

### **Easy to read/understand/translate resources**

As has been stated previously, caregivers do not have a lot of time to look for information. Sometimes, they find the resource they need to answer a question they have, but the answer is hidden in a block of text or behind complicated medical jargon. Caregivers need easy to skim resources that allow them to get the answer they need quickly, in a way that they can easily understand.

Creating easy to follow resources in simple terms also makes it much easier for caregivers to translate the information into the language they need to in order to explain something to their recipient or a family member. Clear cut, direct and simplified information saves the caregiver time, energy, and puts less of a burden on them and their care experience in the long run.



**Patient advocacy groups can create both resources and supports to help guide a caregiver through the healthcare system, letting them know when and how to fight for something, or if there is an easier path to getting what they need.**

# ADVOCATING FOR THE CAREGIVER



# ADVOCATING FOR FAMILY CAREGIVERS FROM DIVERSE POPULATIONS: IDEAS FOR THE PATIENT ADVOCACY COMMUNITY

## BACKGROUND

Caregiving can often be an intense, complex, and stressful undertaking. It can also be a very sensitive and personal journey. As an example—the challenges, hurdles, and joys of the caregiving experience can vary depending on cultural and familial norms.

Caregivers who identify as racial or ethnic minorities, LGBTQ+, live in rural areas, and others often face increased systemic barriers. Being a family caregiver is typically a long-term endeavor and there is a whole of society need for an increased focus and commitment to improving comprehensive and culturally responsive support and recognition for unique caregiver populations.

Fortunately—for the first time ever—we now have a [national strategy](#) to support family caregivers. Ensuring that the strategy is implemented in a way that is equitable and inclusive will be critical. The information below provides a few examples of how the patient advocacy community can work to improve the lives of family caregivers from diverse populations.

## A SNAPSHOT FROM THE DATA

- African American caregivers report experiencing 2.4 financial impacts as a result of providing care—more than either non-Hispanic white or Asian American caregivers.<sup>1</sup>
- More Asian American caregivers find their role highly emotionally stressful; more so than either African American or Hispanic/Latino caregivers.<sup>2</sup>
- Hispanic/Latino caregivers are more often in a high intensity care situation than non-Hispanic white and Asian American caregivers and half are the sole unpaid caregiver for their recipient.<sup>3</sup>
- LGBTQ+ caregivers report that their role is moderately-to-highly emotionally stressful. Most feel they had no choice in taking on their caregiver role and more often report feeling alone. LGBTQ+ caregivers more often report being in fair or poor health than non-LGBTQ+ caregivers.<sup>4</sup>
- Caregivers of rural-living recipients more often report high levels of financial strain and have experienced a greater number of financial impacts as a result of caregiving. Caregivers of rural-living recipients more often have difficulty taking care of their own health and less often report having health insurance.<sup>5</sup>

## Core Challenges to Address Across Caregiver Populations

*\*Outlined in the 2022 National Strategy to Support Family Caregivers<sup>6</sup>*

- Increased awareness of family caregiving
- Increased emphasis on integrating the caregiver into processes and systems from which they have been traditionally excluded
- Increased access to services and supports to assist family caregivers
- Increased financial and workplace protections for caregivers
- Better and more consistent research and data collection



**Caregivers who identify as racial or ethnic minorities, LGBTQ+, live in rural areas, and others often face increased systemic barriers.**

<sup>1</sup>National Alliance for Caregiving and AARP. (2020, May). The “typical” African American caregiver. *The National Alliance for Caregiving*. [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).

<sup>2</sup>National Alliance for Caregiving and AARP. (2020, May). The “typical” Asian caregiver. *The National Alliance for Caregiving*. [https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316\\_CGProfile\\_Asian\\_508.pdf](https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_CGProfile_Asian_508.pdf).

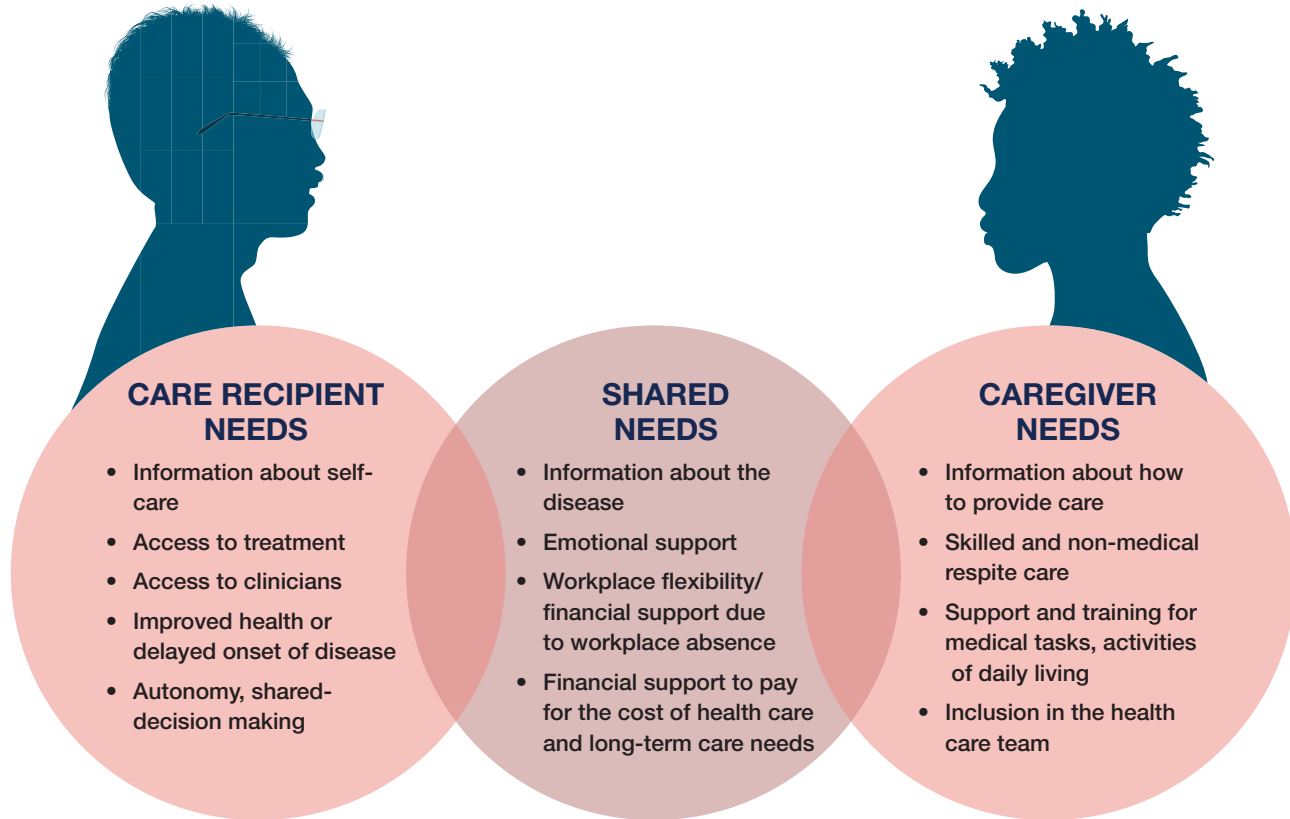
<sup>3</sup>National Alliance for Caregiving and AARP. (2020, May). The “typical” Hispanic caregiver. *The National Alliance for Caregiving*. [https://www.caregiving.org/wp-content/uploads/2020/05/AARP1316\\_CGProfile\\_Hispanic\\_May7v8.pdf](https://www.caregiving.org/wp-content/uploads/2020/05/AARP1316_CGProfile_Hispanic_May7v8.pdf).

<sup>4</sup>National Alliance for Caregiving and AARP. (2020, May). The “typical” LGBTQ caregiver. *The National Alliance for Caregiving*. [https://www.caregiving.org/wp-content/uploads/2020/05/AARP1316\\_CGProfile\\_LGBTQ\\_May7v8.pdf](https://www.caregiving.org/wp-content/uploads/2020/05/AARP1316_CGProfile_LGBTQ_May7v8.pdf).

<sup>5</sup>National Alliance for Caregiving and AARP. (2020, May). The “typical” caregiver of a care recipient living in a rural area. *The National Alliance for Caregiving*. [https://www.caregiving.org/wp-content/uploads/2020/05/AARP1316\\_CGProfile\\_Rural\\_May7v8.pdf](https://www.caregiving.org/wp-content/uploads/2020/05/AARP1316_CGProfile_Rural_May7v8.pdf).

<sup>6</sup>RAISE Family Caregiving Advisory Council. (2021, September 28). *Recognize, assist, include, support & engage (RAISE) family caregiver’s act: Initial report to congress*. Administration for Community Living. <https://acl.gov/RAISE/report>.

While care recipients and their caregivers have their own individual needs, there are times when these needs can intersect. Patient advocacy groups can advocate for caregivers by calling for policy or helping to create programs that address any of the needs below:



### Examples of Approaches to Improve Equity Among Family Caregivers

Improve access to research for family caregivers and their care partners and better integrate family caregivers into research design and medical product development.

Develop more inclusive language in literature, programs, resources, etc. that recognizes and invites participation from caregivers from diverse, racial/ethnic, and other groups.

Include and invest into more resources to overcome language and cultural barriers and prioritize providing translated resources, culturally tailored services (i.e., culturally responsive dietary accommodations), and information.

Financial support resources for diverse caregivers should focus on preparing care for the future, future finances, and financial education.

Public-private partnerships should focus on community-based organizations (CBOs) working with diverse caregivers to increase diverse caregiver participation in research.

Ensure that the eligibility criteria for programs and services designed for caregivers offer an inclusive definition of “family”—to include siblings, aunts, uncles, cousins, nieces, nephews, grandparents, grandchildren, and domestic partners.

Recognize and increase access to caregiver programs, resources, services, and support networks that are designed to go beyond traditional notions of the family structure and are inclusive of the LGBTQ+ community.

Facilitate better access to programs, services, and resources to caregivers in rural areas and where access to technology is less readily available or counter-productive to the needs of the caregiver or person receiving care.

Ensure workplace protections for family caregivers that prohibits discrimination or retaliation against an applicant based on caregiving responsibilities or an employee because of family caregiver responsibilities.

Collect disaggregated data on diverse family caregiver populations and address the lack of segmentation and intersectionality in family caregiver research.

Support reforms and new programs in mental and behavioral health to support family caregivers who are facing mental health challenges and for those that are caregivers to individuals with mental health or substance abuse challenges.



## A CAREGIVER'S BILL OF RIGHTS

From Jo Horne, author of *Caregiving: Helping an Aging Loved One*

### FAMILY CAREGIVERS HAVE THE RIGHT . . .

- To take care of themselves. This is not an act of selfishness. It will give them the capacity to take better care of the person they care for.
- To seek help from others even though the person they care for may object. Caregivers can recognize the limits of their own endurance and strength.
- To maintain facets in their life that do not include the person they care for, just as they would if he or she were healthy. Caregivers know that they do everything that they reasonably can for the person they care for, and they have the right to do some things for themselves.
- To get angry, be depressed, and express other difficult feelings occasionally.
- To reject any attempt by the person they care for (either conscious or unconscious) to manipulate them through guilt, anger, or depression.
- To receive consideration, affection, forgiveness, and acceptance for what they do for the person they care for as long as they offer these qualities in return.
- To take pride in what they are accomplishing and to applaud the courage it has sometimes taken to meet the needs of the person they care for.
- To protect in their individuality and their right to make a life for their self that will sustain them in the time when the person they care for no longer needs their full-time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.

# EMPOWERING THE CAREGIVER



## PROVIDING CULTURALLY RESPONSIVE SUPPORTS TO CAREGIVERS

There are over 53 million family caregivers in the United States caring for a family member, friend or neighbor.<sup>1</sup> These unpaid family caregivers are the backbone of our healthcare system, yet they often aren't afforded a recognized position within that system. Because of this, family caregivers often find themselves having to fight for the things they, or their care recipient, may need in order to receive proper care and support.

Family caregivers from diverse backgrounds, such as a race, ethnicity, sexual orientation or gender identity, or culture that are considered a “minority” in the United States may have an even harder time receiving care or support that meets their cultural needs. The system in place was not built to be culturally responsive, and there may be implicit systemic bias at work that is challenging to overcome. This in turn causes a mistrust of the healthcare system, leaving diverse caregivers with nowhere to turn for the support they need.

Due to their close work with patients and their relationship with the healthcare system, patient advocacy groups are in a position to speak directly to diverse family caregivers in order to determine their needs, and to point them in the direction of supports and resources that would be most beneficial to them. Some of these supports and resources may even be available from the patient advocacy group itself. However, the first step is to identify the challenges faced by the family caregiver so that these challenges can be responded to, all in a way that is responsive to their culture and identity.

It is not the responsibility of anyone to educate others on their culture or identity, and it's just as important not to assume another person's culture or identity. However, there are some simple questions that can be asked by patient advocacy groups so they are aware of the information they need to find and provide to a specific caregiver. The following questions are an example of what a patient advocacy group can ask a caregiver in order to provide them information tailored to their individual cultural background and situation. It is important to explain that the questions are being asked to get the caregiver the best information possible, and that they do not have to answer any question that they don't want to.

- What race or ethnicity do you identify as?
- What religion do you practice?
- Do you identify as a member of the LGBTQ+ community?
- What language do you prefer to receive your information in?
- What challenges are you facing as a caregiver?
- What help or support do you need?
- Would you be interested in speaking to others who share your experience?

Once these questions have been answered, patient advocacy groups can assist diverse family caregivers in accessing services, supports and resources that are culturally responsive. For example, if an Indian caregiver of Hindu faith explained that they were having trouble getting their mother food she could eat from a delivery service, patient advocacy groups could assist with providing recommendations to programs that had options that catered to the caregiver's mother's dietary needs.

**The first step is to identify the challenges faced by the family caregiver so that these challenges can be responded to, all in a way that is responsive to their culture and identity.**



**Understanding the identity of the caregiver, as well as understanding the challenges they face, is the first step in determining what supports they can be connected with in order to ease the burden of their caregiver role.**

<sup>1</sup>The National Alliance for Caregiving & AARP. (2020, May). *Caregiving in the US 2020*. The National Alliance for Caregiving. <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>.



## ASSISTING THE CAREGIVER IN CARING FOR THEMSELVES

Family caregivers can have a hard time caring for themselves when they're caring for other people. Twenty-one percent of caregivers reported that their health is only fair or poor in 2020, and 23% agreed that they had difficulty caring for their own health.<sup>2</sup> When helping someone with a health condition, it can be difficult for caregivers to find the time to put aside for themselves, or to think about their own self-care. Caregivers neglecting their own health and well-being can lead to stress, depression and burnout, so it's important to encourage them to recognize when they themselves need support and where to get it.

Due to differences in cultures, it can be possible that a diverse caregiver may have a harder time admitting that they need help for themselves. In some cultures, the illness of a family member can be a very private thing, and in many cases, children are naturally expected to take care of their parents and may feel like they cannot speak up about their own struggles. There are also disparities in the healthcare system that mean those from racial or ethnic minority groups are far less likely to receive mental health care if they do ask for it.<sup>3</sup>

Patient advocacy groups can help empower diverse family caregivers to recognize, speak up, and receive support for their own self-care by:

### Helping eradicate guilt

One the first barriers a caregiver may need to surpass in admitting they need help is the guilt that can be associated with it. Many caregivers feel that when they are caring for someone who is in poor health, the focus should not be on themselves. The mindset may be that they just need to work through their own challenges and to push forward for the good of their care recipient. Unfortunately, this guilt can prevent a caregiver from looking for help and poses a greater risk to their own mental well-being.

Patient advocacy groups can help normalize a family caregiver asking for help in a variety of ways. They can center the caregiver in discussions within their own organization, allowing a space where it feels natural for a caregiver to voice their needs. They can emphasize the importance of self-care, and provide examples of everyday self-care, such as taking a walk or taking an hour to read each day, or by providing recommendations to vetted respite programs. They can also simply ask

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<sup>3</sup>American Psychiatric Association. (2017). *Mental health disparities: Diverse populations*. American Psychiatric Association. <https://www.psychiatry.org/File%20Library/Psychiatrists/Cultural-Competency/Mental-Health-Disparities/Mental-Health-Facts-for-Diverse-Populations.pdf>.

the caregiver how they are feeling, and help guide them towards supports and services so that the caregiver is aware they are available and can access them in their own time.

One way to determine how a caregiver is feeling is by providing them with a health self-assessment, which the National Alliance for Caregiving has available in English [here](#) and in Spanish [here](#). Allowing caregivers space to think about themselves and how they're feeling outside the needs of their care recipient may help ease some of their guilt, and may open the door to them looking for help in the future.

### **Reminding caregivers that their own well-being is important for them to continue providing care**

Caregivers can become so wrapped up in providing care to someone else that they sometimes forget that if they become ill themselves, they can no longer be a successful caregiver. It takes a lot of energy and strength to do not just everyday tasks like preparing food and cleaning, but to also attend doctor's appointments and administer medication. If a caregiver is having trouble sleeping, is consistently stressed or has a difficult time getting out of bed in the morning, then they will also have a harder time providing care to their care recipient.

Care relationships are ultimately partnerships, where both the caregiver and the care recipient depend on one another to maintain their own health and well-being. By acknowledging these partnerships and treating them as such, patient advocacy groups can help remind caregivers that their role is not only to care for another person, but to care for themselves as well, so that the partnership remains strong.

### **Not assuming ability or privilege**

When presented with a problem, it can be easy to say "all you have to do is this," because we often base solutions on our own knowledge and experience. It is important to keep in mind that not all caregivers have the same knowledge, experience, privilege or background. An "easy" or "obvious" solution may not be so to a caregiver, and therefore should never be treated as such.

There can be multiple reasons a caregiver has not looked for or followed up on supports and services for their own self-care or mental well-being. A lack of insurance or financial support, language barriers, lack of proper accommodations for disabilities or a lack of diversity among providers can all be reasons why a caregiver may not have pursued therapy, respite services or caregiver friendly activities and programs.

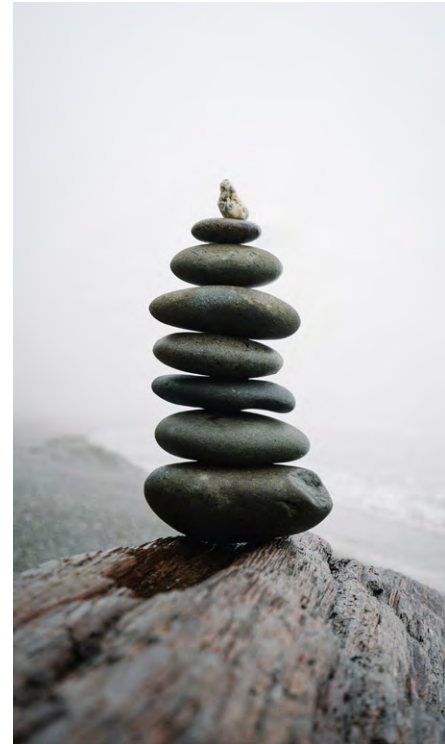
Instead of assuming what may be helpful to a caregiver, patient advocacy groups should ask questions about what they're looking for, what information they can provide them, and what support they need in order to advance their well-being.

### **Ensuring materials are culturally responsive**

Any information, supports or services that are provided to a family caregiver should be culturally responsive. Having a varied range of materials on self-care and mental well-being that address different backgrounds and cultures will not only normalize the idea of the caregiver taking care of themselves, it will be more of a guarantee that the caregiver will be able to relate to the information. This in turn may lead to them beginning to look for support for themselves and even potentially finding support that has their culture and identity in mind.

All patient advocacy groups should be aware of or have their own materials that are culturally responsive to a caregiver's needs. If a patient advocacy group is unequipped to provide culturally responsive information, they should reach out to another group or organization that may be able to fill in the gaps in order to provide the caregiver with the best support possible.

There are also several resources patient advocacy groups can use to start developing their own culturally responsive resources. The Anxiety and Depression Association of America has multiple



**Instead of assuming what may be helpful to a caregiver, patient advocacy groups should ask questions about what they're looking for, what information they can provide them, and what support they need in order to advance their well-being.**

fact sheets on how cultural differences can affect mental health in different populations, including their own resources, located [here](#). The Centers for Disease Control and Prevention have also created a [Behavioral Health Implementation Guide for the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care](#). Both of these resources are a good place to start in developing culturally responsive information tailored to the condition population a patient advocacy group interacts with.

### Verifying and promoting free or low-cost mental health services and respite programs

Patient advocacy groups should make an effort to be familiar with federal or national programs that offer free or low-cost mental health services, or that offer respite to family caregivers. If a group is local, they should be aware of local services as well; all patient advocacy groups should be able to connect caregivers to those who can get them information on services local to them if needed.

By bringing financially viable services directly to caregivers, it becomes easier for the caregiver to focus on and begin utilizing programs for their own self-care. Eliminating the amount of time and effort it takes a caregiver to seek out help for themselves will assist them in feeling less guilt about taking attention away from their care recipient, and having information at the ready on how programs can be afforded makes the choice of whether or not to use these programs an easier one.

### Helping them navigate the mental healthcare system

Those from an underrepresented racial or ethnic background are less likely to receive mental health services than non-Hispanic white people. In 2015, 48% of white patients received mental health services while among Black and Hispanic/Latino patients, only 31% received mental health services, with the number being even lower among Asian American patients at 22%.<sup>4</sup> There are many reasons those from diverse populations have a harder time receiving care, including lack of insurance or inadequate support for mental health services in safety net settings, or a lack of diversity among health providers, or even culturally competent providers or those who speak the correct language.

Navigating the healthcare system to find affordable care that is also culturally responsive can be more trouble than it's worth for caregivers who are spending the majority of their time caring for someone else's health needs, which is where patient advocacy groups can lend support. By assisting the caregiver in finding a mental health service that will work for them and by helping them navigate the system in order to qualify for or afford the program they want to utilize, these groups can help caregivers get the mental health support they need and teach them some things on how to navigate the system for future needs.



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<sup>5</sup>Centers for Disease Control and Prevention. (28 June, 2021). *About mental health*. Centers for Disease Control and Prevention. <https://www.cdc.gov/mentalhealth/learn/index.htm>.

## HELPING REDUCE STIGMA SURROUNDING MENTAL HEALTH

Mental illness is extremely common in the United States. More than 50% of the population will be diagnosed with a mental illness or disorder at some point in their life, and one in five adults experience a mental illness in any given year.<sup>5</sup> Family caregivers, who face increased strain and anxiety in their daily lives, are more at risk of experiencing mental stress and possible illness. Yet despite how common mental illnesses can be, there is still a great amount of stigma surrounding the diagnosis and treatment of a mental illness.

Stigma can cause feelings of shame and isolation, and can ultimately prevent someone from seeking treatment to assist with their mental well-being. Mental illness stigma has been found to be higher among ethnic minorities, and the consequences of this stigma can be even worse on these populations that also face social adversities such as poverty and systemic discrimination.<sup>6</sup> Because of this, it is critically important to help diverse family caregivers to recognize and overcome this barrier.

### Education

Education about mental health, mental illnesses, and general feelings of stress and anxiety and what can be done to address them are extremely important. Education on these topics tells caregivers what to look for, normalizes the possibility that they may experience these things and prepares them for the future. Simply understanding facts on mental health and emotional well-being can help caregivers internally battle any stigma that may be attached.

The National Alliance on Mental Illness (NAMI) provides some great educational resources on mental health as it relates to different cultural backgrounds, located [here](#). Mental Health America (MHA) held a discussion in 2020 on how culture and race can impact identifying and treating mental health conditions, which can be found [here](#).

### Connect caregivers to someone from their own culture who they can speak to about mental health

Whether it's by helping caregivers find a provider, a therapist, a support group, or even someone within the organization, patient advocacy groups should do their best to connect caregivers to someone from their own culture whom they can speak to about mental health challenges. Having someone to relate to who acknowledges that their feelings and mental health concerns are valid helps reduce the stigma surrounding mental health.

Someone from a similar background will know how to speak about mental health in a way that makes sense to the caregiver and that does not feel patronizing or shameful. They will have an understanding of the challenges the caregiver faces and the specific ways in which mental health stigma may affect them, and they'll be able to speak to these challenges and offer viable solutions.

### Help caregivers with how to speak to family and friends

One of the biggest reasons someone may avoid seeking out help for themselves is over fear and shame of what their family and friends may think. This can be especially challenging as a family caregiver, when so much of life is tied up in caring for someone else and filling a specific role within the family unit. Patient advocacy groups can help ease this fear by providing caregivers with



**Education about mental health, mental illnesses, and general feelings of stress and anxiety and what can be done to address them are extremely important.**

<sup>5</sup>Eylem, O., de Wit, L., van Straten, A. et al. (2020). Stigma for common mental disorders in racial minorities and majorities a systematic review and meta-analysis. *BMC Public Health* 20(879). Doi: 10.1186/s12889-020-08964-3.

tools on how to speak with family and friends about their mental health and what they may be doing to maintain their own well-being.

Supporting caregivers in how to handle these conversations will ease their anxiety and stress over what their loved ones may be thinking. It also helps reduce stigma, not only for the caregiver, who will be learning how to speak with others about their mental health needs, but for the family and friends who will be gaining education from somebody who is close to them and has firsthand experience.

### **Be open about mental health awareness**

From the get-go, patient advocacy groups need to be open about mental health awareness on their website, in their programs, and within their own organization. Recognizing the mental health needs of both patients and caregivers up front helps reduce stigma by normalizing them as a natural possible part of the family caregiver experience and makes it easier for a caregiver to accept and seek out help should they ever need to.

Patient advocacy groups should do the work to use non-stigmatized language when discussing mental health. The Centers for Disease Control and Prevention have both [Preferred Terms for Select Population Groups & Communities](#) and [Health Equity Guiding Principles for Inclusive Communication](#) available as resources.

It's also imperative that patient advocacy groups speak out publicly against stigma at every opportunity available. The ultimate goal is to minimize mental health stigma as much as possible in the public space and within all of the diverse populations in America; this can be achieved if those with a platform are willing to speak against it.

### **Talk to them about medication and therapy**

A lot of stigma around mental illness can surround taking medication used to control symptoms such as lack of sleep, anxiety or depression. Sometimes there can be shame surrounding having to take a pill, because it can be seen as there being “something wrong” that needs to be “fixed.”

It is extremely important to speak with caregivers about medication, therapy, and other treatments related to mental illness. Patient advocacy groups can help caregivers understand that the need to take medication to sleep or to speak with a professional about their struggles does not make a caregiver “less than” or mean that they are unable to handle their caregiving responsibilities. Groups can reinforce with caregivers the value in recognizing they need support in order to continue caring for themselves and their care recipient, and that they are taking steps in the right direction.

Patient advocacy groups are in a strong position to speak positively about seeking professional treatment for caregivers' mental health, and helping caregivers understand that there is no shame in taking medication or seeing a therapist. They can offer educational materials surrounding treatment, speak to caregivers about their feelings on it, and connect them with those who can speak about medication from a firsthand experience so they can form their own opinions outside of a stigmatized mindset.

**Recognizing the mental health needs of both patients and caregivers up front helps reduce stigma by normalizing them as a natural possible part of the family caregiver experience, and makes it easier for a caregiver to accept and seek out help should they ever need to.**





## RESOURCES

Below is a helpful list of resources for patient advocacy groups who would like to understand more about diverse family caregivers in America, as well as how to reach out to them and provide them with culturally responsive material. Helpful resources patient advocacy groups can provide to caregivers themselves or to providers who are also working to support diverse family caregivers are also included.

### For Patient Advocacy Groups

[Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers](#)

The National Alliance for Caregiving

[The Diverse Elders Coalition](#)

[Family Caregiving in Diverse Communities: Addressing the Needs of Diverse Family Caregivers for Older Adults](#)

Diverse Elders Coalition

[Growing Your Capacity to Engage Diverse Communities](#)

Family Voices

[Lessons on Reaching and Engaging With Diverse Audiences](#)

Fleischman Hillard

[Stigma: CAMH Mental Health and Addiction 101 Series](#)

The Centre for Addiction and Mental Health

[Working with Culturally Diverse Families](#)

PACER Center

### For Caregivers

[American Cancer Society](#)

[Be The Match](#)

[Cancer Support Community](#)

[Caregiver Action Network](#)

[Caregiver TLC](#)

[Eldercare Locator](#)

[Financial Steps for Caregivers: What You Need to Know About Protecting Your Money and Retirement](#)

WISER

[GO2 for Lung Cancer](#)

[Harboring Hearts](#)

[Lungevity](#)

[Lupus Foundation of America](#)

[National LGBT Cancer Network](#)

[Partnering with Your Healthcare Provider](#)

The Washington State Department of Social Health and Services' Dementia Action Collaborative (DAC) & the Dementia and Palliative Education and Network (DPEN)

[SAGE](#)

### For Providers

[Caring for the Caregiver: Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team](#)

The National Alliance for Caregiving

[Caring for Those Who Care](#)

The Diverse Elders Coalition

[Reimagining Clinical Trial Recruitment Through a Family-Centered Lens: Caregiver Recommendations for Enhancing Clinical Trial Participation Diversity](#)

The National Alliance for Caregiving

# STORIES FROM THE HEART: A COLLECTION OF ORAL HISTORIES WITH DIVERSE FAMILY CAREGIVERS

These oral histories were conducted in the fall of 2022 in order to gather the perspectives and stories of diverse family caregivers in America. This group of diverse caregivers spoke on the how their own culture impacted the way they provided care, the challenges they may have faced as caregivers due to their culture not being addressed, the culturally responsive resources and supports they would like to see for caregivers and how patient advocacy groups can reach them with supports and resources that are helpful to them and their caregiving experience. Along with written vignettes, these oral histories were turned into short video vignettes, which can all be viewed [here](#).



## Claire

*Claire's husband was diagnosed with idiopathic cardiomyopathy several years ago, leading to the eventual need for a heart transplant, which he has now received. Claire did not become his care partner immediately upon diagnosis because he was still very fit and active, but eventually, his health began to decline enough to need a transplant, and this is when Claire started caring more for him.*

*Claire and her husband are Jewish, and a large part of their culture is a connection with their community. Claire's husband received his transplant during the pandemic, so friends and family were not able to visit and bring food as they usually would have done, but they did arrange chairs outside so they could have safe, socially distanced visits.*

*While caring for her husband while he received his transplant, Claire did encounter some challenges. During the Sabbath, she does not drive, so she could not travel back and forth from the hospital each day. Usually, a Sabbath room would be provided, but it was not available during the pandemic. Claire befriended another Jewish caregiver and they found a place to spend the Sabbath together. Claire and her husband also keep Kosher, and while her husband was supplied Kosher meals by the hospital, Claire was not, so she was often unable to sit and eat with him because she had to go out to get her own food.*

*Claire was never connected with a patient advocacy group and never went looking for one. When you are struggling to stay afloat and make it through every day, you often don't have time to search out help. She thinks social workers should be able to connect care partners to groups that can help.*

*Now that Claire is retired, she wants to ensure that she can be there for others who are going through the same experience she did. She has started attending support groups and wants to connect with other transplant care partners. If patient advocacy groups hosted informal care partner meetings they would be beneficial and allow connections to be made. She also thinks something like a national call line, where care partners could call in to ask questions, or just have someone to talk to, is a very needed resource.*

## Gwendolyn

*Gwendolyn's wife has lupus and other related diagnoses, and Gwendolyn has been caring for her for the past ten years. Neither Gwendolyn nor her wife have received many resources or much information on the disease, and Gwendolyn herself is rarely recognized as the care partner or given information specific to her role.*

*Unfortunately doctors have been dismissive of the symptoms Gwendolyn's wife has experienced before, claiming they are "typical" for an African American woman. Gwendolyn has had to constantly advocate to make sure her wife gets the care she needs, and that the information they need has been given to them, but after a while, it becomes tiring to constantly chase down responses. Much of the time, Gwendolyn's wife grins and bears the pain, and Gwendolyn helps her through it.*

*Dealing with a diagnosis such as lupus can be isolating, and Gwendolyn would appreciate having more information about the disease and connecting with others experiencing it. Currently, she learns what she needs by attending doctor's appointments; she has never been connected to a patient advocacy group. However after learning about them, she thinks patient advocacy groups could be helpful in following up with caregivers, providing more research and information on certain diseases and how they affect the Black and Brown community, and providing supports and resources on self-care for care partners. If patient advocacy groups were to put information about what they offered in healthcare settings, she believes they would be easier to find.*

*There can be a level of distrust between the Black and Brown community and the healthcare system, and Gwendolyn believes that above all else needs to be worked on. Those from the community who already work in healthcare need to be given a voice and leadership positions to begin to make change, and the system itself needs to be educated and demonstrate growth in how they understand and interact with Black and Brown people.*

## Harold

*Harold was a primary caregiver for his mother, who was diagnosed with chronic adult leukemia. His mother's care consisted of an extensive support system including Harold's boyfriend, sister, father and a series of home health aides. Significantly, Harold had additional support from members of his parents' church community, which he considers to be reflective of his Black culture. Even after his mother moved across the country to be closer to her family, church members would fly out to visit her often, sent food and provided other resources regularly.*

*During a doctor's appointment trying to secure pain medication for his mother, the provider made Harold feel uncomfortable and judged. Through recommendations from his sister who works in healthcare he was able to find an alternate provider who was welcoming to both him and his mother and importantly provided needed medical attention.*

*Despite being Black and queer, Harold felt he had most of the resources needed as a caregiver. He wasn't aware of patient advocacy groups who assist caregivers but admits this resource could have been helpful. As far as discovering what patient advocacy groups are, he believes simple, to-the-point targeted messaging to BIPOC and LGBTQ+ communities on social media is important, including examples of what services patient advocacy groups provide, associated costs and where to find them.*

## Hernan

*Hernan is a support person for a friend with chronic obstructive pulmonary disease whom he met through his job as a social worker at the Queens Center for Gay Seniors. Hernan does not consider himself a caregiver for his friend but acts more as an individual in a group of people who help provide care.*

*Hernan's friend does not have a spouse or biological family members, so he has built his own found family through others connected to the center, which is how Hernan got to know him. It is not a "typical" caregiver/recipient relationship, but Hernan has experience as a social worker that he is happy to lend to his friend as a part of his team.*

*Caring for friends can be a large part of the LGBTQ+ culture. As a social worker, Hernan is used to taking care of others, and was ready to take care of family members when needed. Although caring for his friend snuck up on him and wasn't expected, Hernan is glad to help. Hernan mentioned that another unfortunate part of both aging and providing care can mean that LGBTQ+ individuals end up concealing their identity, which can cause challenges, though Hernan's friend has not experienced this and is secure in his identity.*

*In order to reach more LGBTQ+ caregivers, Hernan stresses the importance of training, sensitivity and genuine inclusivity. He doesn't believe that those providing resources need to be a part of the LGBTQ+ community, but they need to have an understanding of the culture and experience and have to be genuine in their inclusivity, and not just providing lip service. There is a generational divide in the LGBTQ+ community, and many caregivers and patients may not be out with their identity, so it is important that resources, supports and services are sensitive and take all of these factors into account.*

## Maggie

*Maggie has been a caregiver for both her husband and her son, both of whom had blood cancer. While her husband was diagnosed with non-Hodgkin's lymphoma in 2014, her son was diagnosed with acute myeloid leukemia in 2019 and ended up needing a bone marrow transplant.*

*Maggie is Chinese, but was born and raised in the Philippines. When her son was sick and in the hospital, she stayed with him 24/7, often sleeping in his hospital room. At the time, she didn't realize this wasn't common, or may be cultural, but it's what she remembers doing for her parents when they were sick. Food and faith are also a large part of her culture that affected her*

*caregiving. Friends and family would bring comfortable, familiar food to Maggie and her son, which helped support them, and Maggie was able to walk to church and attend mass in order to have some spiritual nourishment.*

*Many of the nurses who cared for Maggie's son in the hospital were Filipino and understood exactly how Maggie was feeling as a mother. They would support her by urging her to get rest, giving her a place to store her food, and reassuring her. Connecting with those with a shared cultural background was very helpful to Maggie. She also found support in other caregivers in the hospital, or patients who had also been diagnosed with blood cancer and survived, although she never found a formal support group.*

*It wasn't until her son was more stable that Maggie found a patient advocacy group through the internet. She reached out to them because she feels it's important to help other caregivers going through what she went through. She has signed up for a peer-to-peer network and hopes she can lend support to other caregivers, which she feels is important to do and will help her own caregiving journey.*

*Maggie believes patient advocacy groups should connect with hospitals in some way to make caregivers more aware of them. To be culturally responsive, they should have translators available and make sure they are sensitive to the needs of working caregivers or caregivers with children. Above all else, she believes patient advocacy groups should be sensitive to the mental well-being of caregivers, and do their best to help remove the stigma some cultures can feel about admitting that they need help.*

## Martha

*Martha is the care partner to her wife, who was diagnosed in late 2016 with stage 4 metastatic lung adenocarcinoma. At the initial diagnosis, the resources provided to Martha by the medical team as a care partner were minimal. Martha, who is a licensed clinical social worker specializing in end of life care, was especially struck by the fact that a meeting with the cancer center social worker wasn't offered to her as an opportunity to discuss community resources such as support groups, referrals for assistance, or counseling. Martha and her wife had three children under the age of 18 years old at home and were just given a dire terminal prognosis. More could have been offered to them.*

*Living in New York, Martha and her wife haven't experienced problems getting culturally responsive support or resources as a same sex couple. Martha did note that there have been a few times that healthcare individuals would assume they were sisters or good friends instead of a married couple but that it never impacted the care they received. In a time of high stress and worry over navigating an already complicated healthcare system, having to explain what her relationship was added another layer of burden to the experience. Martha is hopeful that as we are progressing forward those things will change and become easier for same sex couples. Another thing Martha noted was that despite being heavily involved in lung cancer communities, there have been few same sex couples she and her wife have met, which raises some questions as to where LGBTQ+ caregivers and patients are receiving support and resources.*

*As a therapist, Martha was able to connect with patient advocacy groups via her own networks and through social media private groups for specific caregivers. Without her having this prior background, it may have been more challenging for Martha to navigate these opportunities.*

*Ultimately, caregivers need to be met at medical institutions and centers. If the staff at these institutions don't have resources or specific support available, patient advocacy groups should have a role there to ensure caregivers are getting the information they need and are seeking.*

*Though connecting with other lung cancer caregivers or even LGBTQ+ caregivers would be helpful, Martha doesn't feel like she needs people to identify the same way as she does or to even have the same experience as her for her to feel supported. It didn't have much significance to Martha if there was a fellow lung cancer caregiver who was part of a same sex couple but more that the person is a caregiver in general. Martha and her wife have become dedicated advocates in their communities through this experience. What's most important to them is that those facing health hardships in the future find better support from the time of diagnosis. Martha feels we have a responsibility to take care of each other and make the way a little easier as much as we can.*

## Myra

*Myra is a care partner to her husband, who was diagnosed with lung cancer about a year ago. She and her husband are a team, so Myra never questioned that she would be the one helping with his care. She's also never considered the term "caregiver" to apply to her, since she and her husband are working together.*

*Myra's identity as a Latina is very important to her, as is her husband's as a Latino. Her husband prefers to speak in Spanish, and the language barrier can be a challenge for them because her husband is unable to receive care in Spanish. It is important for Myra to accompany her husband to his appointments so she can translate, but even then, information in a different language is a lot to process for both of them. Sometimes, Myra's husband does not ask a question because he is not sure he has all the information, or Myra has a hard time acting as the in-between communicator when she is missing information.*

*Both Myra and her husband have been unable to find patient or care partner support groups for lung cancer that are in Spanish. This can make them both feel isolated and lonely. Connecting with someone not just based on diagnosis, but on language, culture, and identity, are very valuable. Myra also says that she has not been able to readily find resources in Spanish, because there is no easy place to look for them.*

*Myra is involved with a patient advocacy group she found through an internet search, and she takes advantage of their care partner support groups, though she thinks these groups should be more diverse. There needs to be more awareness around patient advocacy groups in general. Myra talks about how, in the Latina community, it can be difficult to talk about emotions because you just want to get through the situation. She also talks about how there is very little awareness of lung cancer in her community, and that a negative stigma is attached to it because people believe it is a disease that happens to you based on your choices and is not just something that happens. Patient advocacy groups need to make it clear they are a safe space to discuss these things.*

*Ultimately, Myra just wants patient advocacy groups to connect both her and her husband with survivors of lung cancer who speak their language and share a cultural background with them. Speaking with others with these built-in connections creates trust and comfortability and can help patients and care partners deal with the emotions of a diagnosis and with how to move forward.*

## Nia

*Nia has been a caregiver for her husband since 2019. Her husband has been diagnosed with heart failure, hypertension, diabetes, kidney failure, high cholesterol, and is blind. Nia was engaged when her husband's health began failing, so she married him with the understanding that she would be moving into a caregiving role.*

*Nia's husband has been in and out of the hospital constantly since 2020, sometimes in critical condition. The care that both Nia and her husband have received has not always been great. Nia has had to be a constant advocate for her husband's needs as a blind man, and she has had to constantly chase people down to make something right, sometimes receiving little or no response in return. Once, she had to involve the National Federation of the Blind in order to ensure that she was able to stay with her husband and that he would receive equitable care.*

*Faith is extremely important to Nia's culture as an African American, and her faith has helped her and her husband continue to fight and demand equitable care. They have managed to survive based on the support of friends and the church, because she does not qualify for any of the caregiver support programs she has been able to find. Nia has been unable to work while providing care, but they still make too much money to get the support they need. She has also sometimes experienced receiving less support or quality care than others around her and thinks this may have been different if she had more money or wasn't Black.*

*Nia has been in constant survivor mode for the past several years, and has been unable to search for patient advocacy groups or to return calls when all she's provided with is a phone number. When she has been able to get in touch with people, she's*

*been directed somewhere else. Due to her caregiving responsibilities, Nia is unable to keep following up when she is redirected somewhere else and needs an answer to her needs with the first person she contacts.*

*Nia believes patient advocacy groups should have a liaison at the hospital to reach caregivers or provide their materials to them so they can be read later. As for the content of the material, she asks that patient advocacy groups educate themselves on the African American community, and on the concept of white privilege versus Black reality. Nia also hopes groups will educate themselves on disabilities like blindness and deafness, and to not assume needs or abilities based on these disabilities.*

## Paurvi

*Paurvi was a caregiver for both her mother and her father. While her father had Alzheimer's, her mom had many conditions, including lung disease that turned into lung cancer, which originated from cervical cancer.*

*Paurvi's parents immigrated from India, and being Indian and practicing the Hindu faith are still a very large part of Paurvi's culture and identity, and definitely affected the way she provided care and experienced bereavement and loss. As the only child, second generation immigrant and a "working" daughter, Paurvi expected to care for her parents just as they cared for her. She also has a profound belief in extended family as a support system to help care, though because most of her family was still in India, she did not get to experience this support in the way that her parents talked about it.*

*Many times, Paurvi found herself having to educate the healthcare system on how to provide culturally responsive resources and support to her and her mom. While in the hospital, and during home care, it was clear that ethnic diversity had yet to be taken into account in patient care and family support. For example, there were no meal options that met her mom's cultural dietary needs, and spiritual support was provided by a chaplain who was unfamiliar with the Hindu faith. Though Paurvi has a background in healthcare and knew where to push for things, it took a lot of energy to ensure her and her mother's cultural needs were met. Looking back on her support of her father, she also found limited understanding of dementia in the Indian immigrant community, and also limited understanding of Indian culture and religion in memory care and the health system.*

*Paurvi wasn't able to find any resources or groups that were specific to Indian caregivers. She found that patient advocacy groups were too siloed, and she was unable to find the time and energy to chase them down. In order for these groups to be accessible to caregivers, Paurvi believes they need to explain exactly how they can address and support what caregivers need, and to make it clear that they will do more than provide a "to do" list, rather, they would actually do the work and help with the needs caregivers express. She also believes that groups and the healthcare system can integrate DEI into engaging with caregivers, clarifying how a family, the person needing care, and the specific caregiver identifies in culture, faith, and ethnicity. To be helpful, this would inform customizing resources, supports and services based on that identity, rather than forcing a caregiver to continuously explain and fight for their cultural needs.*

## Pierre

*Pierre is caring for his wife, who was diagnosed with advanced stage non-small cell lung cancer. This diagnosis came as a shock because Pierre's wife has no known risk factors for lung cancer. Because Pierre was a physician and had his wife's permission to speak with her doctors about her results, he was informed of the lung tumor first and was the one to break the news to her.*

*Pierre finds balancing his role as a former physician and caregiver challenging. While he immediately realized how it felt to be a caregiver upon his wife's diagnosis, he also had the background knowledge to access resources, information, and when and how to push for things when advocating for his wife's care. However, he is always mindful of remaining her caregiver and not slipping into a situation where he is acting as her physician.*

*It was difficult for his wife to find resources on lung cancer because there is a lot more attention paid to other types of cancer.*

*Pierre's wife had to do a lot of work to find a community she could connect with, and the information was not provided by her medical team. Pierre acknowledges that without advocating for themselves, caregivers would not receive much information and support, and that there needs to be resources out there that better address the needs of caregivers.*

*In order to reach caregivers, Pierre thinks it would be helpful for patient advocacy groups to be recommended by medical teams at the time of diagnosis. Since there can be a lot of overwhelming information at that time, he thinks it would be especially helpful if connections to patient advocacy groups were included in an information packet, and if someone on the medical team had made clear to him what he was about to face as a caregiver and where he could go for resources and support.*

*All caregivers have different experiences and needs, with little time on their hands. By connecting with caregivers and asking what their specific needs are and providing support for those needs, patient advocacy groups can save the caregiver time and energy and make it more likely that they receive the help they need.*

## Terrence

*Terrence was a co-caregiver with his sister for his mother, who had heart disease. When she ended up needing triple-bypass surgery, Terrence moved back to Omaha to help take care of her while she was out of work and needed some help. He was a younger caregiver at this time, and it was his first experience caring for someone like this.*

*Terrence considers a part of his own cultural identity as an African American to be taking care of your own, especially your elders. To him, it was unthinkable to put his mother in a nursing home, and he and his sister were passionate about caring for her in a home environment. However, he was not provided with many resources to do so. Everything he learned about heart disease he learned as he went by looking up information himself or speaking to healthcare professionals in his family. No one on his mom's healthcare team talked to him about being a caregiver.*

*While Terrence was also unaware of patient advocacy groups while caring for his mom, he thinks they're a valuable resource. He did not go looking for them, and they were not connected with him, but he believes that timing and approach are everything. If a person you've built trust with is presenting you with patient advocacy groups to turn to for help, he believes they would be better received. Someone acting as a liaison at the hospital, like the discharge coordinator or social worker who already works with the family caregiver, would be the ideal person.*

*Terrence never needed to relate to the resources he was reading in order to get the information he needed from them, but he sees the value in connecting with these resources through a racial, ethnic or cultural background. Diseases more prevalent in the African American community for example, should depict African American people on resources relating to them, and be sensitive to that culture.*

*Overall, patient advocacy groups should be receiving more support from the healthcare system to ensure they are able to reach caregivers. Currently, these groups tend to focus on one condition, but Terrence points out that if a patient has one condition, they're likely to get another. Bringing these groups under one umbrella in some way would also be helpful in reaching both the patient and the caregiver.*



# APPENDIX



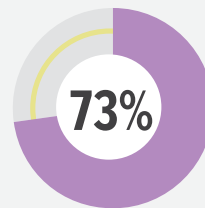
COALICIÓN DE ADULTOS MAYORES DIVERSOS (DIVERSE ELDERERS COALITION)  
Cuidando a los que cuidan: satisfacer las necesidades de los cuidadores familiares

## Cuidadores familiares hispanos/latinos

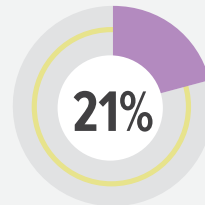
La comunidad hispana es el grupo étnico minoritario más grande de los Estados Unidos, comprendiendo el 18.1% de la población total de los Estados Unidos.

(Censo, 2018)

- **La cultura y el idioma tienen un gran impacto en el acceso a la atención y apoyos.**
  - Es más probable que confíen en la familia y menos probable que busquen recursos externos (Flores et al, 2009)
  - Los cuidadores familiares hispanos/latinos de habla hispana informan que se sienten poco preparados, lo que resulta en el aislamiento y la separación de la vida social (AARP)
- **Realmente no hay una buena palabra para “cuidador en español”. La palabra “cuidador” se utiliza a veces, pero no resuena con muchos hispanos y latinos. (NHCOA)**



EL 73% DE LOS HOGARES HISPANOS DE ESTADOS UNIDOS HABLAN ESPAÑOL EN CASA (PEW, 2017)



1 DE CADA 5 ESTADOUNIDENSES ADULTOS MAYORES SERÁ HISPANO/LATINO PARA 2060 (ACL, 2017)

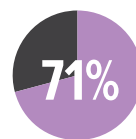
### COMPROMISO CULTURAL CON EL CUIDADO

- **El familismo: un valor cultural central de los latinos. Implica dedicación, compromiso y lealtad a la familia. Pasar regularmente tiempo con la familia inmediata y extendida es parte del familismo. También implica buscar el consejo de la familia para las decisiones importantes.**
- **Las familias hispanas tienden a adoptar o ser impactadas por el valor del familismo. (McClearly, 2013)**
  - El 27% de los hispanos/latinos que viven en los Estados Unidos viven en hogares familiares multigeneracionales.
  - El cuidado se describe como “algo que simplemente hay que hacer”, y no como lo “correcto” que hay que hacer”

### EN NUESTRA ENCUESTA A LOS CUIDADORES FAMILIARES HISPANOS:



informa que tiene alguna o mucha dificultad con las tareas de cuidado personal y de atención médica, como el manejo de los medicamentos y el cuidado de las heridas



informa que tiene alguna o mucha dificultad para coordinar la atención o los servicios de médicos, enfermeras, trabajadores sociales u otros profesionales



afirma tener alguna o mucha dificultad con las tareas culturales, como, por ejemplo hablar con los proveedores de atención de servicios





## ¿CÓMO PUEDEN LOS PROVEEDORES APOYAR MEJOR A LOS CUIDADORES FAMILIARES HISPANOS?

- **Reclutar, promover y apoyar una fuerza laboral diversa que entienda/represente la cultura de la comunidad**
  - La representación cultural entre los proveedores es importante para los cuidadores hispanos/latinos y los adultos mayores (Terlizzi et al., 2019)
  - Comunicación más fácil, mejores resultados para el paciente y el cuidador
- **Utilizar intérpretes médicos capacitados y culturalmente competentes al hablar con los cuidadores familiares hispanos/latinos y los adultos mayores**
- **Evaluar la dificultad de las tareas culturales en la selección del cuidador y del paciente**
  - Los cuidadores que informaron de una alta dificultad con las tareas culturales tuvieron más resultados de salud deficientes que los pacientes que informaron de una baja dificultad
- **Asociarse con organizaciones comunitarias para proporcionar referencias y recursos culturalmente competentes**
- **Desarrollar material traducido y culturalmente competente en la oficina para proporcionar información y formación**
- **Utilizar a los líderes de la comunidad para reclutar y ofrecer una programación integral e innovadora entre los adultos mayores hispanos/latinos y sus cuidadores**
  - El conocimiento del entorno como indicador de la utilización de servicios formales (Starrett, 1990)
  - Oportunidad de proporcionar información sobre el estigma de las diferentes enfermedades.
- **Desarrollo de grupos de apoyo para cuidadores en su idioma**
  - Puede llevar a mejorar los resultados de los cuidadores
  - Oportunidad de ofrecer talleres de formación para cuidadores

**CUIDANDO A LOS QUE CUIDAN**

Recursos para proveedores: satisfacer las necesidades de los cuidadores familiares

## ¿Reciben los cuidadores familiares diversos la ayuda que necesitan?

Muchas actividades diferentes pueden ser consideradas como cuidado. En una encuesta realizada en 2019 a cuidadores familiares de comunidades de color, comunidades de indios americanos/nativos de Alaska y comunidades LGBT, la Coalición de Adultos Mayores Diversos descubrió que los cuidadores realizaban una amplia gama de tareas para amigos y familiares adultos mayores, entre las que se incluyen:

**TAREAS**

- Tareas de cuidado personal como bañarse y vestirse
- Tareas domésticas diarias o diligencias como las tareas del hogar, la lavandería o la compra
- Tareas de atención sanitaria en el hogar, como la toma de medicamentos y el cuidado de las heridas
- Coordinar o gestionar los cuidados o servicios de los médicos, etc.
- Hacer frente emocionalmente a los problemas de salud o las discapacidades
- Obtener información sobre los problemas de salud o las discapacidades
- Encontrar un lugar en el que puedan vivir para recibir los servicios de atención o cuidados que necesiten
- Inscribirse en Medicare, Medicaid y otros seguros
- Conseguir que los servicios sean pagados por Medicare, Medicaid, etc.
- Cuestiones jurídicas, como la elaboración de un testamento, un poder notarial o una tutela, o la redacción de instrucciones anticipadas.
- Cuestiones financieras relacionadas con la salud, como la planificación del patrimonio, la gestión de los bienes, la propiedad o las cuentas bancarias
- Cuestiones jurídicas relacionadas con los procedimientos de inmigración o naturalización
- Traducción de información relacionada a la salud a su lengua materna

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# អ្នកយើងដទៃជនជាតិអាមេរិក កាំងអាស៊ីអាមេរិក

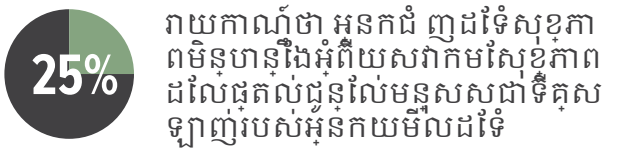
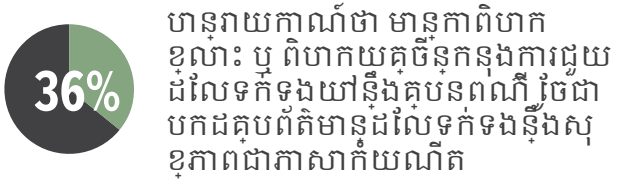
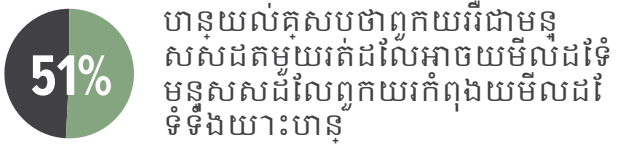


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ម នុថាណាត់	ប្រក៏ជនជាតិយដុសងៗយទៀត		

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យ៉ាកនុងស្ថិតិននគរសារអ្នកយើងដទៃ ជនជាតិអាស៊ីអាមេរិកយើង ហានុយអាមេរិក



ភាពខុសគ្នានន្តសុខភាពរបស់ជនជាតិ និងមួយៗ

- សហមនុស្សជនជាតិអាស៊ីអាមេរិកកាំងដលៃមានកម្រិតភាសាអង់យរលសទប រឺមាន 40-55%។ សំរាប់មនុស្សសម្រាប់ ចិននុការយយ៉ាះអាចយកនុយ ឡើងរហូតដលៃ 90%
- សហមនុស្សជនជាតិអាស៊ីអាមេរិកកាំង រឺ ហានុទទួលរងនូវការប៉ះពាល់ពីសង្គម និង ការផ្តល់សេវាទំលើយ៉ាងបន្ត មានស្ថានភាពយសវៃ ប្រកិចចទប និង ការនិរយទសយ៉ាគុបយទសវិញយៃគុចិន៖
  - មិនមានយសភាមសុខភាពផ្តល់ចិត្តគុបគុគានុ
  - កម្មារយពញ្ញវៃយគុត្រូវហានុកែយចញ្ញកនុងការដទៃពីគុសារ
  - បយងកិនុការមិនទុកចិត្តយលីយសភាមយៃផ្តសងៗ
- កម្រិតនន្តភាពគុក៏គុកយ៉ាកនុងសហមនុស្សជនជាតិ អាស៊ីអាមេរិកកាំង រឺខុសជាងកម្រិតនន្តភាពគុក៏គុកទទឹងសកលយ៉ាក (11.3%)
  - មួង (27.4%)
  - កមពុជា (18.2%)
  - យៀតណាម (13%)
  - ឡាវ (12.2%)

សហជំនុំផងដែរជួយមន្ត្រីសហគ្រប់ជាតិសាសន៍  
យកចិត្តទុកដាក់នឹងមន្ត្រីសសដលៃយយឹងហារមភ ផ្តល់ការងារលំអុនកយមីលដទៃ  
គ្រប់ជាតិសាសន៍



# យតីអុនកផ្តាត់ផ្តាងររដតយធវីចៃយមតចយមីបីគាំ គុទគ្រូសារអុនកយមីលដទៃជនុជាតិអាស៊ីអាយរនយ័យ ផ្តសងៗ?យគុបីគុហាស់ចំយណៈងៃអុំពីរបបធម៌ ហារីក ហាត់ដំ ញបកដគុបដជនកសុខភាព យាយពលដលៃនិាយ ជាមួយគ្រូសារអុនកយមីលដទៃជនុជាតិអាស៊ីអាយរនយ័យ

- យគុបីគុហាស់ចំយណៈងៃអុំពីរបបធម៌  
ហារីកហាត់ដំ ញបកដគុបដជនកសុខភាព  
យាយពលដលៃនិាយជាមួយគ្រូសារអុនក  
យមីលដទៃជនុជាតិអាស៊ីអាយរនយ័យ
- ផ្តល់ជំនួយដលៃទក់ទងនឹងកិចចការ  
ពិហាកៗដលៃទក់ទងនឹងរបបធម៌  
សំរាប់អុនកយមីលដទៃ និង ការពិនិតយ  
អុនកជំងឺ
  - អុនកយមីលដលៃទក់ទងនឹងរបបធម៌ពិហាកៗ និង  
មិនមានសុខភាពលម ជាងអុនកយមីលដ  
ដលៃទក់ទងនឹងរបបធម៌
- អុភិវឌ្ឍន៍សមាភារៈយាកនុងការិ  
យល័យ ដលៃមានុសមតាភាពជួយការ  
របកដគុបយាយនឹងរបបធម៌ដលៃទក់ទង  
នឹងចំយណៈងៃជនុជំងឺ ការពហាល  
ការផ្តសពវជ្ជាយ និង ការបណ្តុះ  
បណ្តាល
  - កាត់បន្ថយការមាក់រយយាយជុំវិញជំងឺយផ្តសង  
ៗ
  - កាត់បន្ថយការចូលមន្ទីរយពទយ
  - បយងកីនុការយពញចិតតខុតយាយលំអុនក  
ដទៃ
- បយងកីនុការសហការណ៍ និង ផ្តល់ការ  
ឧបតាមភ ការគាំគុទយ អុងការមូលជាប  
នុសហារមន្ត្រី យមីបីផ្តល់យសវាកមដលៃ  
អុនកយមីលដទៃជនុជាតិអាស៊ីអាយរនយ័យ
- ទិនុន្ត្រយដលៃទក់ទងហានុពីការបំប  
កយចញពីដបបបទទទូលចូល ននុ យស  
យវាកមសុខភាព
  - យល់ដៃអុំពីទុកលំហក និង ភាពអុត់ធ្ងន់យ  
កនុងសហារមន្ត្រីជនុជាតិអាស៊ីអាយរនយ័យ
- ផ្តល់ការបញ្ជូនបនុតដលៃសមរមយ  
និងធនុធានុរបបធម៌យមីបីយដោះគុសា  
យកិចចការដលៃទក់ទងយាយនឹងរបបធម៌
- បយងកីតគុកុមគាំគុទ នូវភាសាយមីកំយ  
ណិតសំរាប់អុនកយមីលដទៃ
  - ជិតពាក់កណ្តាលននុអុនកយមីលដទៃជនុជាតិ  
អាស៊ីអាយរនយ័យ ហានុយអាយដៃពាកុយរីជា  
មនុសសដតមានកំរត់ដលៃអាចផ្តល់ការយ  
មីលដទៃហានុ
  - យធវីយអាយសុខភាពផ្តល់ចិតតគុបយសរយ  
ឡើង និង កាត់បន្ថយភាពងយកា
  - បយងកីតបដនុលងដលៃមានុសុភាពយមី  
បីយអាយពាកុយហានុដចករដលៃកភាពគុព្យ  
ហារមណ៍ និង យៀនុពីអុនកនៃទ
  - ផ្តល់យណៈងៃគុសាយលៃអលំអុនក  
យមីលដទៃ

យកចិត្តទុកដាក់នឹងមនុស្សដដែលយើងហាមមក  
ធនធានសំរាប់អ្នកយមីលដទៃមនុស្សចាស់ ផ្តល់គំរូការងារលំអ្នកយមីលដទៃ  
គ្រប់ជាតិសាសន៍

# យតីអ្នកយមីលដទៃ គ្រប់ជាតិសាសន៍ ហានិច្ចទទួលជំនួយគ្រប់គ្នានដលៃពួកយរ គុត្តរការដៃប្រយទ?



សុកមមភាពជាយគុចិនគុបយទេ ដលៃអាចរាប់បញ្ចូល  
កន្លងការយមីលដទៃ។ យាកន្លងសុចិត្តិគនគុភាសារបស់អ្នក  
កយមីលដមៃមសុហាមន៍នានា រួចជាជនជាតិអាយមរិកកាំង  
ឥណ្ឌា ជនជាតិយមៃអាឡាសុសា និងពួកយទេទីបីយ  
កន្លងឆ្នំ 2019 The Diverse Elders Coalition ហានិយអាយរ  
ងថា អ្នកយមីលដទៃអ្នកហានិច្ចទទួលកិចចការជាយគុចិន  
ពីមនុស្សចាស់ដលៃពួកយរយមីលដនៃនិង សុមាជិកគុភាសារ  
របស់មនុស្សចាស់ដលៃពួកយរយមីលដយែនោះ រួមមាន

### កិចចការ

- ការងារផ្តល់ខុលានរួចជា ការងតុទឹក និង ការយសុល្យកពាក់
- ការងារផ្តោះគុបចាំគរៃ រួចជា យហាកសុអតុសុយល្យកបំពាក់ ឬ យទិញឥវ៉ាន
- កិចចការកន្លងការដទៃសុខុភាពយផ្តោះ រួចជា យលបថានំ និង ការពាហលរមូស
- យធីការទំនាក់ទំនង ឬ យធីការយរៀបចំ សំរាប់ការយមីលដ ឬ យសុរកមមកពីគុរយពទយ
- ការបារៈពាល់លំអរមមណ៍យាយពលដលៃយដោះគុសាយជាមួយ បញ្ញហាសុខុភាពរបស់មនុស្សចាស់ដលៃពួកយរយមីលដ ឬ បញ្ញហាពិការ
- ការទទួលយកពីគុមាន អុំពីបញ្ញហាសុខុភាពយផ្តសងៗ ឬ បញ្ញហាពិការ
- រកកដនលងដលៃពួកយអាចរស់យាហាន យមៃបីទទួលជំនួយ ឬ យសុរកមមដទៃយផ្តសងៗ
- បារៈយមៃបីទទួលយកធានារាប់រងដផុនកសុខុភាពសំរាប់មនុស្សចាស់ អ្នកមានគុហាក់ចំនូលតិច និង ធានារាប់រងយផ្តសងៗយទៀត
- ទទួលយកយសុរកមមធានារាប់រងដផុនកសុខុភាពសំរាប់មនុស្សចាស់ អ្នកមានគុហាក់ចំនូលតិច
- បញ្ញហាដលៃទក់ទងនឹងចាប់រួចជា យធីបណុឌតមរគុក គុត្តរការជំនួយពីយមធារិ និង ទទួលការដណនាំ
- បញ្ញហាដលៃទក់ទងនឹងហិរញ្ញញវតុថុនិងសុខុភាព រួចជា ការយធីដផុនការអុចលនគុទពយ ដបងដចកគុទពយសុមបតុតិ ធូលី និង រណនីធានារ
- បញ្ញហាដលៃទក់ទងនឹងចាប់អុយនាគុបយរសុនំ និង និគិរិធិកន្លងការចូលសុញហាតិ
- ការបកដគុបជាភាសារកំយណ៍តុអុំពីពីគុមានដលៃទក់ទងនឹងសុខុភាព
- យកចិត្តទុកដាក់នឹងមនុស្សដលៃយើងហាមមក
- ធនធានសំរាប់អ្នកយមីលដទៃមនុស្សចាស់ ផ្តល់គំរូការងារលំអ្នកយមីលដទៃគ្រប់ជាតិសាសន៍

MV DONGH YIETC NYUNGC NYEI TENGX MIENH GOX MIENH NYEI CEIX LIEPC JIEZ DAAIH NYEI DORNGX (DIVERSE ELDERERS COALITION)  
Tengx Goux Mbuo Nyei Liuc Leiz Ziux Goux Mienh Nyei Mienh: Lorz tengx duqv zuqv nyei jauv bun mv fih hnaangv ziux goux hmuangv doic nyei mienh

# Southeast Asian Meiv Guoqv Gox Hmuangv Doic Nyei Mienh



Mv norm waac, Southeast Asian nyei Meiv Guoqv Mienh naaic yiem guoqc jaa wuov coutv daaih. Mv joux waac naaic gorngv muonc mbuox yietc zungv, sei yiem wuov hyaangx 1970, mv fingx mienh naaic biaux deic bung daaih yiem Meiv Guoqv nyei ndortv naanc mienh. SE Asian nyei Meiv Guoqv Mienh liemh jienv naaiv:

**Cham**

**Khmer**

**Khmer Loeu**  
or Highland Khmer

**Hmong**

**Iu Mien**  
or Mein

**Khmu Lao**  
or Highland Lao

**Taidam**

**Khmer Kampuchea Krom**  
or Ethnic Khmer

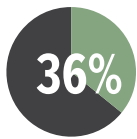
**Montagnards**  
or Highlanders of several different ethnic groups, Vietnamese

\*Deix baav janx-kaevq nyei mienh fingx mv' baac maaih kev yiem mv deix deic bung—Cambodia, Laos, caux Vietnam.

## YIEM ZAAH MAANGC DAAIH NYEI FIENX, LIUC LEIX ZIUX GOUX MIENH NYEI SE ASIAN MEIV GUOQV MIENH MBUOX NYEI WAAC:



zaah liux nyei mienh gorngv sei naic kungx ninh mbuo fangc-mbienc, maaih ziangh hoc mbenc duqv cuotv tengx bun ninh mbuo nyei hmuangv-doic hnaangv



zaah liux nyei mienh gorngv camv deix zoqc deix tengx goux mienh guei-jei leic-nyeic gong-bouh naic aqc nyei, hnaangv faan sin-tiv nyei fienc bieqc ninh mbuo nyei dauh daangh waac



zaah liux nyei mienh gorngv ninh mbuo dorh hmuangv-doic nyei jauv naic ndie-sai mv hiuv

## SIN TIV MV' FIH HNAANGX NYEI JAUV

- Haih gorngv meiv guoqv waac mbienc wuov deix yiem mbuo nyei SE Asian Meiv Guoqv mienh nyei laangx naic maaih 40-50% hnaangv. Yiem mienh gox mienh wuov guaanh, mv haih gorngv meiv guov waac naaic haih ndongc 90% hlaang.
- Mv deix sic naic guen zuqc SEAA nyei mienh; deic bung fanv, biaux deic bung, kouv ga'naanc, caux zunc cuotv guoqv nyei sic. Weic laix zuqc mv deix jauv, mbuo SEAA cingx daaih—
  - Mv maaih gaux liuc leix nyei dorngx daaih tengx m'ngorngv-famv nyei sic
  - Zorqv cuotv buangv ziepc betv hyaangx faux maengx hnyaangx-jeiv nyei domh mienh yiem goux hmuangv doic nyei dorngx
  - Jaa mv bungx hnyouv nyei sic yiem gan leiz nyei liuc leiz dorngx
- Cuotv daaih nyei fienc gorngv taux ga'naanh nyei jauv yiem yietc zungv SEAA fingx nyei mienh naic gauh hlaang yietc norm Meiv Guoqv deic bung nyei mbu'ndongx wuonc (11.3%)
  - Janx-baac-miuh Hmong (27.4%)
  - Janx-Ka'menx Cambodian (18.2%)
  - Janx -Vietnam Vietnamese (13%)
  - Janx-Lauv Laotian (12.2%)



**MV DONGH YIETC NYUNGC NYEI TENGX MIENH GOX MIENH NYEI CEIX LIEPC JIEZ DAAIH NYEI DORNGX (DIVERSE ELDER'S COALITION)**  
**Tengx Goux Mbuo Nyei Liuc Leiz Ziux Goux Mienh Nyei Mienh: Lorz tengx duqv zuqc nyei jauv bun mv fih hngangv ziux goux hmuangv doic nyei mienh**



## **MBUO HNAANGV HAIX NOR HAIH GAUH TENGX LONGX DEIX MBUO SE ASIAN MEIV GUOQV MIENH NYEI LIUC LEIX ZIUX GOUX HMUANGV-DOIC NYEI MIENH?**

- **Sei gorngv, mbuo caux jienv SE Asian nyei Meiv Guoqv ziux goux mienh wuic waac nor, mbuo longc faan waac gong-mienh hiuv duqv caux haaih longc mbuo nyei SE Asian leiz-fingx wuov deix. Mv deix gongh mienh oix zuqc njaux jiez caux yaac hoqc jiez, aengx maaih sou wuov deix.**
- **Gorngv taux gongh bou, zaah naaic baengc mienh nyei ziangh hoc wuov, aqv zuqc lorz maangc gaax haqv deix dorngx maaih aqc nyei jauv bun ninh mbuo**
  - Goux mienh nyei gong-meinh gorngv maaih kov nyei jauv yiem gong-bou longc nitv mbuo nyei SE Asian nyei leiz-fingx wuov deix wuov, naaic gauh maaih zeqc naanc nyei jauv cuotv bun ninh mbuo. Beiv taux baengc mienh nor, baengc mienh gauh maaih zoqc deix zeqc naanc jauv cuotv bun ninh mbuo
- **Mbenc cuotv faan daaih nyei sou longc jienv mbuo nyei SE Asian nyei leiz-fingx daaih tengx njaux mienh, yaac bun ninh mbuo hoqc baengc nyei jauv**
  - Zoqc njiec deix gamh nziex baengc nyei jauv
  - Baengc mienh gauh zoqc deix da' nqaang ndie-sai dorngx
  - Liuc leix ziux gox gongh-mienh nyei mienh gauh hnyouv nqaai camv
- **Mv Dongh Yietc Nyungc Nyei Tengx Mienh Gox Mienh Nyei Ceix Liepc Jiez Daaih Nyei Dorngx (Diverse Elders Coalition)**
- **Tengx Goux Mbuo Nyei Liuc Leiz Ziux Goux Mienh Nyei Mienh: Mbuo Hnaangv haav nor tengx duqv zuqc mv fi'hnaangv nyei goux hmuangv doic mienh?**
  - Caux tengx mienh nyei ceix liepc jiez daaih nyei dorngx benx doic, tengx bun yaac caux lorz gouv cuotv nyei nyaanh bun SEAA fingx mienh
- **Yiem ndie-biauv nyei dorngx, mbuo fiev daih nyei nzaangc yiem longc jienv nyei sou-gorn wuov, mbuo aav zuqc bun nqoi, maiv dungz zorpc zuqc dieh nyungc fingx. Weic laix zuqc:**
  - Gauh bieqc hnyouv aqc nyei dorngx nduqc hngangv bun SEAA nyei juangc laangx mienh
- **Lorz tengx nyei dorngx caux gong-mienh wuov baan hoqc longc mbuo nyei SE Asian nyei leiz-fingx bieqc ninh mbuo liuc leiz nyei gong daaih tengx zuix goux nyei gong mienh**
- **Mbenc cuotv norm liuc leiz ziux goux gong-mienh nyei tengx doic guanv, yiem gorngv mbuo gaanv nyei buonv-waac. Longx nyei jauv cuotv bun mv deix gong-mienh liemh naaiv—**
  - Yiem SEAA liuc leix ziux gox nyei gong-mienh wuov, maaih yietc buonc nyei gong-mienh zoux daaih bun hiuv, naic kungx ninh mbuo gaanv tengx goux hnaangv
  - Zoux faux longx, tengx hnyouv/m'ngorngv-faamv nyei jauv caux tengx zoqc njiec deix ndoqc nyei jauv
  - Zoux cuotv norm dorngx daaih bun mienh gapv zunv doic, lomh nzoih tanx waac caux hoqc aengx njaux doic
  - Liuc leix ziux goux gong-mienh zoux gong longx jienv mingh, maaih baengh orn hnyouv daaih tengx ninh mbuo nyei duqv zipv nyei mienh

**TENGX GOUX LIUC LEIZ ZIUX GOUX NYEI GONG-MIENH NYEI FIENX**

Mbuox Nyei Fienx: Bun Duqv Zuqc Tengx Nyei Jauv Bun Maiv Dongh Yietc Nyungc,  
Mv Fih Hnangv Nyei Goux Hmuangv Doic Ziux Goux Mienh

## Mbuo Nyei Maiv Dongh Yietc Nyungc, Mv Fih Hnangv Nyei Ziux Goux Hmuangv Doic Nyei Gong-Mienh Longc Duqv Zuqc Mbuo Bun Daaih Caux Tengx Nyei Jauv Nyei?

Maaih camv-nyungc gong-bou mbuo haih corngh zingh caux hnamv fih hnangv ziux goux mienh nyei gong. Yiem 2019 nyei zaah mangc daih goux hmuangv doic mienh nyei fiensex yiem mv guanh mienh - Meiv Guoqv Indian/Yiem Alaska cuotv daih nyei buonv-deic, caux LGBT mienh, Maiv Dongh Yietc Nyungc Goux Mienh Gox Mienh Nyei Ceix Liepc Jiez Daaih Nyei Dorngx (Diverse Elders Coalition) buatc liuc leiz ziux goux nyei gongh mienh tengx nyei jauv naic gengh jangv nyei. Mv deix gong-bou liem jienv naaiv—

### GONG-BOU MBUOX-DAAN

- Goux buonv-sin nyei gong-bou, hnaangv nzaux sin caux zuqv lui hox
- Biauv zong hnoi-hnoi nyei gong, hnaangv fioux biauv, nzoux lui hox, fai mingh poc maix ga'naaiv
- Yiem biauv goux buonv-sin nyei gong, hnaangv nyanc ndie caux goux ga'naaiv-mun nzuih
- Mbenc cuotv liuc leix fai goux nyei jauv yiem ndie-saai wuov
- Mbuo longc ga'nqix daaih goux mbuo ganh nyei zeic naanc fai waic nyei jauv
- Lorz fiensex mbuox taux ninh mbuo nyei zeqc naanc fai buonv-sin waaic nyei jauv
- Lorz yiem nyei dorngx maaih janx haaih tengx goux caux liuc leiz mbenc
- Medicaid, fai dieh norm beu sengh nyei dorngx
- Medicare caux Medicaid hungh jaa tengx bun nyanh mbuo duqv zipv daaih nyei liuc leiz mbenc
- Horpc doz-leiz nyei sic, hnangv zoux cuotv norm goux jaa-dingh nyei daan, lorz zoux ziouv gunv sic nyei mienh, zoux cuotv norm jaa-ndaangc daan daaih mbuox tong hmuangv doic caux ndie-saai hnangv haix nor goux mbuo yiem kouv nyei ziangh hoc
- Zinh nyanh nyei sic yaac fih hnangv goux mienh nyei sic; mbenc jaa-dingh jaa-dorngx nyei jauv, fai goux nyaanh laamx daan
- Horpc doz-leiz nyei jauv yaac fih hnangv yiem nyeic guoqv biaux daaih nyei sic fai yienc fingx nyei jauv
- Faan sin tiv fiensex bieqc gaanh nyei dauh daangh waac

- Tengx faux mbuox yiem Medicare,

## DIVERSE ELDERERS COALITION

Quan Tâm Những Người Chăm Sóc: Đáp Ứng Nhu Cầu của những Người Chăm Sóc Thân Nhân trong Những Gia Đình Đa Dạng

## Người Chăm Sóc Thân Nhân trong Gia Đình Mỹ gốc Đông Nam Á

Người Mỹ gốc Đông Nam Á (SEAA) là một nhóm nhỏ trong số Người Mỹ gốc Á với nét đặc thù về bản sắc chính trị, chủ yếu là người tị nạn tái định cư ở Hoa Kỳ vào thập niên 1970. Những nhóm này bao gồm:

**ChămPa**

**Khơ Me**

**Khơ Me Lơ**

hoặc Khmer miền Cao

**Hmong**

**Ưu Miên**

hoặc Miên

**Khmu Lao**

**Khơ Mú Lào**

hoặc Lào Lùm / Lào miền Xuôi

**Taidam**

**Khmer Kampuchea Krom**

hoặc Khmer Nam Bộ

**người Thượng Montagnards**

hoặc người Tây Nguyên thuộc một số dân tộc thiểu số khác ở Việt Nam

\* Một số sắc tộc người Hoa cũng có sắc thái Campuchia, Lào và Việt Nam.



### QUA CUỘC KHẢO SÁT CỦA CHÚNG TÔI VỀ NHỮNG NGƯỜI CHĂM SÓC THÂN NHÂN TRONG GIA ĐÌNH NGƯỜI MỸ GỐC ĐÔNG NAM Á:

51%

đồng ý rằng họ là người duy nhất có thể chăm sóc cho những người cần chăm sóc

36%

cho biết đã gặp phải nhiều khó khăn khi giúp đỡ thân nhân trong một số công việc mang tính văn hóa, chẳng hạn như thông dịch những thông tin về sức khỏe sang ngôn ngữ của họ

25%

cho biết rằng các nhà cung cấp dịch vụ y tế không biết rằng họ đang phải chăm sóc cho (những) người thân yêu của họ

### SỰ BẤT CÂN XỨNG VỀ Y TẾ

- Tỷ lệ trình độ Anh ngữ hạn chế trong cộng đồng người Mỹ gốc Đông Nam Á chiếm từ 40-50%. Đối với người lớn tuổi, con số này có thể lên tới 90%
- Người Mỹ gốc Đông Nam Á bị tác động tâm lý do chiến tranh và quá trình tái định cư, tình trạng kinh tế xã hội thấp và những vụ trục xuất hàng loạt gần đây
  - Không được tiếp cận đầy đủ các dịch vụ sức khỏe tâm thần
  - Con cái trưởng thành không được sự chăm sóc của gia đình
  - Mất lòng tin vào các dịch vụ chính quy
- Tỷ lệ đói nghèo trong các nhóm sắc tộc người Mỹ gốc Đông Nam Á đều cao hơn so với mức trung bình của cả nước (11,3%)
  - Hmong (27,4%)
  - Campuchia (18,2%)
  - Việt Nam (13%)
  - Lào (12,2%)

**DIVERSE ELDERNS COALITION**

Quan Tâm Những Người Chăm Sóc: Đáp Ứng Nhu Cầu của những Người Chăm Sóc Thân Nhân trong Những Gia Đình Đa Dạng



## NHÀ CUNG CẤP DỊCH VỤ LÀM THẾ NÀO ĐỂ HỖ TRỢ TỐT HƠN CHO NHỮNG NGƯỜI CHĂM SÓC THÂN NHÂN TRONG GIA ĐÌNH NGƯỜI MỸ GỐC ĐÔNG NAM Á?

- ◆ **Khi tiếp xúc với người chăm sóc thân nhân trong gia đình người Mỹ gốc Đông Nam Á, cần phải có Thông Dịch Viên chuyên về Y Khoa am hiểu về văn hóa và được huấn luyện đầy đủ**
- ◆ **Đánh giá mức độ khó khăn trong những công việc mang tính văn hóa qua những lần khảo sát bệnh nhân & người chăm sóc**

  - Những người chăm sóc làm những công việc mang tính văn hóa có mức độ khó khăn cao mang tới kết quả sức khỏe kém hơn so với những bệnh nhân có mức độ khó khăn thấp
- ◆ **Phác thảo và phiên dịch những tài liệu phù hợp với văn hóa về bệnh tật, phương pháp chữa trị, huấn luyện và tiếp cận**

  - Giảm bớt những quan niệm sai lầm về căn bệnh
  - Giảm tỷ lệ tái phát của căn bệnh
  - Tăng mức độ hài lòng của người chăm sóc
- ◆ **Tạo quan hệ đối tác và tài trợ hoặc hỗ trợ cho các tổ chức cộng đồng cung cấp dịch vụ cho cộng đồng SEAA**
- ◆ **Phân tách những dữ liệu được thu thập được từ các đơn nhận khách và từ các cơ sở chăm sóc sức khỏe**

  - Hiểu rõ hơn về những thách thức và khả năng phục hồi của cộng đồng SEAA
- ◆ **Giới thiệu và cung cấp nguồn hỗ trợ phù hợp với văn hóa để giải quyết khó khăn trong những việc làm mang tính văn hóa**
- ◆ **Thành lập nhiều nhóm hỗ trợ cho người chăm sóc bằng ngôn ngữ của họ**

  - Gần một nửa số người chăm sóc SEAA cho biết rằng chỉ có họ là có thể chăm sóc
  - Để cải thiện sức khỏe tinh thần và giảm sự cô lập
  - Để có một nơi lành mạnh nhằm chia sẻ lo lắng và học hỏi lẫn nhau
  - Để việc chăm sóc có hiệu quả hơn

**QUAN TÂM NHỮNG NGƯỜI CHĂM SÓC**

Tài Nguyên dành cho Nhà Cung Cấp Dịch Vụ: Đáp Ứng Nhu Cầu của những Người Chăm Sóc Thân Nhân trong Những Gia Đình Đa Dạng

## Những Người Chăm Sóc Thân Nhân trong các Cộng Đồng Đa Dạng Có Nhận Được Sự Trợ Giúp Mà Họ Cần Không?

Có nhiều thứ việc được xem là công việc chăm sóc. Trong một cuộc khảo sát năm 2019 về những người chăm sóc cho thân nhân trong giới cộng đồng người da màu, cộng đồng người Mỹ Da Đỏ, Thổ Dân Alaska và trong giới LGBT (đồng tính luyến ái, song tính luyến ái, chuyển giới), Liên Minh Người Cao Niên Đa Dạng nhận thấy rằng những người chăm sóc phải làm nhiều thứ việc cho bạn bè và người thân lớn tuổi, bao gồm:

### CÔNG VIỆC

- Những việc chăm sóc cá nhân như tắm rửa và thay quần áo
- Những việc lặt vặt hàng ngày ở nhà như nội trợ, giặt giũ hoặc mua sắm
- Những việc chăm lo sức khỏe tại nhà như cho uống thuốc và chăm sóc vết thương
- Phối hợp hoặc sắp xếp cho những lần đi bác sĩ và dịch vụ y tế, v.v.
- Đối phó về mặt tâm lý với những vấn đề sức khỏe hoặc bệnh tình của họ
- Tìm kiếm thông tin về những vấn đề sức khỏe hoặc bệnh tình của họ
- Tìm một nơi sinh sống mà họ có thể nhận được những dịch vụ y tế hoặc nhu cầu cần thiết
- Ghi danh xin trợ cấp y tế Medicare, Medicaid, những loại bảo hiểm khác
- Tìm đến những dịch vụ y tế được chi trả bởi Medicare, Medicaid, v.v.
- Những vấn đề pháp lý như lập di chúc, di chúc sống, làm giấy ủy quyền hoặc quyền giám hộ
- Những vấn đề tài chính liên quan đến sức khỏe như lập kế hoạch kế thừa tài sản, quản lý tài sản, hoặc trưng mục ngân hàng
- Các vấn đề pháp lý liên quan đến thủ tục di trú và nhập tịch
- Thông dịch những giấy tờ liên quan đến sức khỏe sang ngôn ngữ của họ



THE NATIONAL ALLIANCE FOR CAREGIVING WOULD  
LIKE TO THANK ALL OF THE PATIENT ADVOCACY  
GROUPS WHO GAVE THEIR SUPPORT AND EXPERTISE TO  
THE COMPLETION OF THIS GUIDE.



#### About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on building health, wealth, and equity for family caregivers through research, innovation, and advocacy. We envision a society that values, supports, and empowers family caregivers to thrive at home, work, and life. Learn more at [www.caregiving.org](http://www.caregiving.org).

National Alliance for Caregiving  
1730 Rhode Island Avenue NW  
Suite 812  
Washington, DC 20036

202.918.1013 phone  
202.918.1014 fax  
info@caregiving.org

caregiving.org