



2023 GUIDEBOOK

SUPPORTING DIVERSE FAMILY CAREGIVERS: A GUIDE FOR PATIENT ADVOCACY GROUPS

KEY TAKEAWAYS

ABOUT THIS GUIDE

The National Alliance for Caregiving conducted structured interviews with professionals from patient advocacy groups and diverse family caregivers caring for someone who had been diagnosed with heart disease, blood cancer, lung cancer or lupus, conditions that are known to disproportionately affect diverse communities. We wanted to better understand how culture and identity affects the way caregivers provide care, access culturally responsive supports and resources, and how caregivers engage with patient advocacy groups.

FIVE MAIN FINDINGS EMERGED FROM THIS RESEARCH:

1

Culture significantly impacts the way caregivers provide care

2

Diverse family caregivers can experience bias and stigma in the healthcare system based on their cultural background or identity

3

Diverse family caregivers find it difficult and overwhelming to identify useful resources, especially those that are culturally responsive

4

Diverse family caregivers were either unaware of patient advocacy groups or did not know patient advocacy groups could be utilized for their own needs separate from the patient

5

Diverse family caregivers would prefer to be connected to patient advocacy groups through a trusted medical professional at the time most relevant to their care journey

With the guidance of a panel of disease representative patient advocacy organizations, these findings shaped the content of this guide and supported the need for sections detailing the research findings, articulating what diverse caregivers say about their experiences, and offering tips for both advocating for and empowering diverse caregivers. What Providers Should Know: Factsheets About Diverse Family Caregivers, was contributed by the Diverse Elders Coalition and offers supporting evidence documenting the unique needs of diverse caregivers.

Key takeaways pulled from these sections offer an outline for what patient advocacy groups should know about diverse family caregivers, how they can better reach them, and what they can do to provide culturally responsive supports, resources and information.

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ADVOCATING FOR THE CAREGIVER



Patient advocacy groups can be a powerful voice in advocating for diverse family caregivers in the United States by calling for policy that will improve their experiences and by internally building structures and supports directed towards diverse family caregivers. Some suggestions to improve equity among family caregivers:

- Improve access to research on family caregivers and their care partners and better integrate family caregivers into research design
- Develop more inclusive language in literature and programs
- Offer an inclusive definition of the word “family” in programs and resources that are provided
- Address the lack of segmentation and intersectionality in family caregiver research
- Recognize and increase access to caregiver programs, resources and supports that are designed to go beyond traditional notions of family structure and are inclusive of the LGBTQ+ community
- Support reforms and new programs in mental and behavioral health to support family caregivers

EMPOWERING THE CAREGIVER



Our research found that the first step in providing culturally responsive supports and resources to caregivers was to determine their needs, both culturally and as a caregiver. Patient advocacy groups are in a position to speak personally with the caregiver to determine what the caregiver’s cultural needs are, the challenges they are facing in the caregiving journey and any other information they would like to share in order to receive culturally responsive materials. Some questions to ask caregivers (when the caregiver is agreeable) include:

- 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?



Patient advocacy groups are also in a position to assist caregivers in caring for themselves by supporting them through their care journey. Patient advocacy groups can provide assistance to help caregivers:

- Eradicate guilt
- Remind them that their own well-being is important for them to continue providing care
- Ensure materials are culturally responsive
- Find free or low-cost mental health services and respite programs
- Navigate the mental healthcare system

Sometimes caregiving can cause stress, anxiety or depression, leading to a decrease in mental well-being. Asking for and receiving help for mental illness can be tough for a caregiver. Patient advocacy groups can help reduce this stigma through:

- Offering education
- Connecting caregivers to trusted sources, including healthcare professionals, from their own culture who they can speak to about mental health
- Helping caregivers navigate conversations with family and friends about their mental health
- Promote awareness of mental health
- Talking to them about medication and therapy

Scan to read the full guide, explore the DEC Factsheets, and learn about the lived experiences of diverse caregivers:

