





NHPCO's Caring Connections program created The African American Outreach Guide to provide resources and strategies to assist hospices and coalitions in their outreach efforts to African Americans. This abbreviated version of the larger Guide provides you with a review of significant end-of-life issues relevant to African American communities to help you begin your outreach efforts today. A list of resources for continuing your outreach efforts is also included.

1. Background And History

Researchers have found that in the last year of life, black decedents were less likely to use hospice than white decedents (22% vs. 29%, respectively).¹ Hospice utilization has also been shown to be "lower among African-Americans than among white decedents, across all age groups," "across all causes of death except Alzheimer's disease" and "in 31 of 40 states."²

Many African Americans remember the days of segregation, Jim Crowe laws and violence towards their people. Many African Americans are deeply distrustful of the government and the healthcare system, a distrust that is rooted in both historical and present day experiences.

- Emancipation from slavery was achieved in 1865; many African American families are only three generations removed from slavery.
- 40 years ago, African American men with syphilis were purposely left untreated and studied to determine the long-term effects of the disease; many died in excruciating pain, all unnecessarily.

"... [Do Not Resuscitate] DNR orders may be viewed as a way of limiting expensive healthcare or as cutting costs by ceasing care prematurely. Historically, this perspective may stem from a long history of distrust of the white-dominated healthcare system."

¹Connor, SR, Elwert F, Spence C, Christakis NA. Geographic variation in hospice use in the United States in 2002. J Pain Symptom Manage. 2007 Sep; 34(3):277-85.

²Connor SR, Elwert F, Spence C, Christakis NA. Racial disparity in hospice use in the United States in 2002. Palliat Med. 2008 Apr; 22(3):205-13.

³ Searight, H.R., Gafford, J. (2005, February 1). Cultural diversity at the end of life: Issues and guidelines for family physicians. American Family Physician, 71(3), 515-522.



A. Healthcare Disparities

- A survey of African Americans conducted from 2002-2003, reported in the Journal of Acquired Immune Deficiency Syndrome, found that nearly half of the respondents believe that the U.S. government created HIV/AIDS, in part, as a plot to exterminate blacks.⁴
- Research indicates that U.S. racial and ethnic minorities are less likely to receive even routine medical procedures and experience a lower quality of health services."⁵
- Peer-reviewed medical journals cite countless examples of African American patients experiencing discrimination, from the refusal to administer appropriate medications (most notably opiates), to inferior care.
- The IOM report specifically found that African Americans are less likely than whites to receive kidney
 dialysis or transplants, undergo coronary bypass surgery or receive state-of-the-art HIV/AIDS treatments.⁶

B. African American Origins

For purposes of this Guide, we have limited our focus to US-born African Americans (unless otherwise specified). However, it is important to be aware that eight percent of the total black population is foreign-born, and most came to the U.S. after 1990.⁷ Take the time to learn where the family is originally from and ask about specific healthcare traditions that are important to them; then integrate these treatments into the plan of care.

C. Religion

While African Americans practice a number of religions, Protestant Christianity remains the most popular with a nearly 76 percent following, the majority of Baptist and Methodist tradition. Seven percent identify themselves as "Other", six and a half percent are Catholic, less than one percent are Jewish and about ten percent do not identify with any religious group.⁸

A profile of African American religious participation reveals:

- ♦ 70 percent attend religious services at least a few times a month.
- 80 percent pray nearly every day.
- ♦ 80 percent consider themselves to be either very or fairly religious. 9

In African American faith communities, members seek out everything from spiritual guidance, to relationship counsel, to adult vocational education programs. From native Africans initial embracing of Western religions while retaining elements of their own native traditions, the evolution of the Black church into today's modern religious practice remain the backbone of African American communities.

Note that Christian themes and spirituality predominate throughout this Guide, and many of the strategies tie into a Christian faith base. However, we recognize that not all African Americans are involved with a church, nor are all Christian.

⁴Bogart, L.M., Thorburn, S. (2005). Are HIV/AIDS conspiracy beliefs a barrier to HIV prevention among African Americans? Journal of Acquired Immune Deficiency Syndrome, 39(2), 213-218.

⁵ Institute of Medicine. (2002). Report Brief: What Health Care Providers Need to Know about Racial and Ethnic Disparities in Healthcare. Retrieved from www.iom.edu/Object.File/Master/4/175/Disparitieshcproviders8pgFINAL.pdf.

⁶ Institute of Medicine.(2005). Addressing Racial and Ethnic Health Care Disparities. Retrieved from www.iom.edu/Object.File/Master/33/249/BROCHURE disparities.pdf.

⁷ U.S.Census Bureau.(2007). The American Community0Blacks. Retrieved from www.census.gov/prod/2007pubs/acs-04.pdf.

 $^{^8}$ Religion Newswriters Foundation.(2007). A Guide to African Americans and Religion. Retrieved from www.religionlink.org/tip 070108.php#stats.

⁹ Mamiya,L.(2006).Pulpit&Pew:Research on Pastoral Leadership. SectionII:Profiles and Studies of African American Laity. Durham, N.C.: Duke Divinity School. P.24.



11. Caring Connections African American Focus Group Findings

In May 2006, NHPCO's Caring Connections conducted two African American end-of-life focus groups in St. Louis, Missouri. Group participants discussed their general feelings and issues regarding end-of-life thinking, talking and planning. Key findings are below.

A. Death, Dying and Advance Care Planning

- Some seemed at ease with the topic of death and dying, while others felt that it was culturally taboo to even discuss it.
- Generally, there is a conflict between wanting to be informed medically, but being culturally bound to privacy and wanting to rely on faith first and foremost.
- Most participants used the term advance care planning interchangeably with end-of-life care, which they
 connected with life insurance and funeral planning.
- Many thought that advance care planning referred to an agency or organization where all advance directives are stored.
- There was significant distrust that even if preferences are specified in writing, that the medical professional in charge would not honor them.
- Many said they would not want to be kept alive on life support indefinitely because of a fear of being a burden on their loved ones, but would want a chance at recovery.

B. Caregiving

The African American family structure is usually tightly-knit, extended, matriarchal, and includes many close friends who are considered kin. Participants repeatedly stated, "We take care of our own." It is important to stress that hospice supports caregivers; it does not replace family members or preclude them from playing a central caregiving and decision-making role.

C. Understanding of Hospice

- About half of the participants had heard of hospice care, although there was much confusion over what hospice really is.
- Some recognize that hospice is for when "they run out of things to do medically; they can't do anything to cure you."
- Many think of it as a place someone is "sent away to" when their family has "abandoned" them, and equate
 it to nursing homes.
- Because nursing facilities are viewed so negatively, it is important to emphasize that hospice care is most often provided in a person's own home.
- The most frequent concern was the financial aspect, and an inability to believe that Medicaid, Medicare and most private insurance companies cover hospice expenses.

III. Strategies For Reaching Out To African American Communities

The most successful outreach programs have been patient, and have taken time to simply observe and listen. We suggest that you be very creative and pursue opportunities that you wouldn't ordinarily consider. Above all, remember the deeply rooted historical issues for most African Americans, and be sensitive to these in your interactions.

A. Get Organized

It is important to critically assess your existing resources, survey your community, formulate a plan, and gather support. While it is always noble to want to expand and diversify your clientele, you must be prepared to serve them adequately, should your outreach be successful!

Evaluate resources.

- Will the overall financial health of your organization be able to support the special requests and additional expenses that will arise as you conduct your outreach and your census increases?
- Additionally, do you already have a staff person who is designated as outreach coordinator?
 Can you afford to hire new staff?

Survey your community.

- Gather local demographics as well as your own organization's current trends.
- Learn what African Americans in your community already know about hospice and palliative care.

Gather support and form a planning team.

- Be certain that your senior leadership and all levels of staff are on board with your outreach plans.
- The key element is forming a planning team, which should include staff as well as a wide range of community members. The team will provide support and reassurance to build lasting links between your hospice and African American community members.

Develop a plan.

- ♦ As you gather your data and support, decide where you want to start.
- Discuss short and long-term goals and expectations.
- Develop a plan of action, one that is linked to any existing marketing strategies for hospice access in your service area.
- ◆ Tap into existing networks, particularly the African American hospice outreach programs operating across the country that are highlighted in this guide.

Train your team.

- Make sure your hospice incorporates diversity training into your staff orientation or ongoing in-service education.
- ◆ Train all of your staff, including administrative and clinical personnel.
- Emphasize the following end-of-life care issues specific to African American communities: healthcare history, healthcare disparities, spiritual aspects of care, and sociological and cultural perspectives on death and dying.



Cassandra Cotton, CNA, CHPNA, of Nathan Adelson Hospice, shares the following story that illustrates the need for staff to be culturally sensitive.

"You need to start by asking, 'What's in your basin?' This refers to the contents of the personal care kits that patients in her program receive upon admission. Many people don't know that fine-tooth combs are difficult to use and can be damaging to African American hair. And so if you present a welcome packet with items that are not suitable for them, it gives the impression that the organization doesn't really know or care about patients. It also misses an opportunity for deeper understanding and connection. Give your staff the right tools to care for patients, and make sure they know how to use them correctly."

B. Find the Right Fit

As you begin your outreach to African American communities, your planning team must be led by the right messenger. This messenger is the one who serves as the primary point of contact and organizer for all African American outreach activities.

Select a messenger.

If you do not already have a point person, perhaps one can be hired, or another position can be adapted to fulfill the role. You might find a current hospice volunteer or another community member who would be willing to volunteer.

- ◆ Is this person open-minded and creative?
- ◆ Is he/she the type of person who can develop and maintain relationships?
- Is he/she comfortable with public speaking?
- What about offering prayers?
- Is he/she able to engage with diverse groups of people?
- What level of commitment does he/she bring?
- ◆ Does he/she have a willingness to work after hours and to attend a variety of functions across town?

If you can, hire diversely.

Making staff diversity a priority is simply smart and forward thinking - it enriches your organization and ensures that you remain vibrant and growing. So if your staff is not already diverse, consider targeted recruitment to build a team that more accurately mirrors the wide range of people represented in your community.

C. Educate, Support and Listen to Your Community

Informing, caring for and genuinely hearing the needs of the African American community are essential elements in your outreach, and enrich the opportunity for positive community-building. Be sure to focus on education, show your support for the family systems that are already in place caring for loved ones, take your time, ask questions, and listen to the answers.



Address what hospice is and is not.

- ♦ Learn what misconceptions are prevalent, and address the common misunderstandings.
- One of the biggest barriers to hospice use among African American communities is that they
 associate hospice with a "place" as opposed to a concept, and that "place" is where they go to die,
 so it's definitely not a "place" they want to go.
- There is also the view that suffering is part of hospice because traditional medicine is no longer allowed, or that pain is actually encouraged based on faith beliefs.
- ♦ Whenever given the opportunity, explain hospice benefits clearly.

Support the caregiver.

- Recognize and respect the strong history and tradition in African American communities of "taking care of our own."
- Offer to support current caregivers, explaining how the interdisciplinary team will care for the family.
- Explain different options for care, from home-based to inpatient facilities.

Take your time and be patient.

- Because many African Americans are suspicious of hospice and the entire healthcare system, and prefer to keep their illness to themselves be patient throughout this process.
- Be prepared to make multiple visits, with many family members present, sometimes even with the pastor involved, acting as a family liaison.
- You must be willing to go through many rounds with the family so they know you're committed and that you truly have their best interests at heart.

Listen to their story.

You have an incredible wealth of information - both from your clinical training as well as your professional experiences, and the natural inclination is to want to share all of it. Yet many African American families are not going to be interested in hearing from you just yet - they would rather be heard themselves, first. Begin the conversation with, "What can we do for you?"

D. Find Your Voice and Let Your Message Be Heard

Whenever and with whomever you engage, do so consistently, with a clear voice that sends the same message every time - we care, and are here to support you in all of your needs. Be mindful of the actual language used in personal conversations, and if appropriate, integrate faith-based language as you are comfortable.

Be genuine.

This is a simple, yet profoundly important element in your outreach. Be sincere and transparent. You and your colleagues must be willing to devote time and energy to making lasting changes that support your outreach. With your staff embracing this intention, it is one that your community will eventually accept as well.

Use the right words.

Palliative sedation, end-of-life care, DNRs, advance care directives, opioids, artificial hydration and nutrition - for someone unfamiliar with the healthcare system and facing crisis, these terms can be very confusing. Consider focusing on the term "comfort care," especially in the beginning. When simplifying

African American

your language, be careful to not do so in a patronizing manner. Steer clear of scientific and medical absolutes.

Rely on word of mouth.

Your commitment, your passion and your high standards of care will speak for themselves. Within African American communities, personal testimony and word of mouth are among the most meaningful ways to share trusted information and get your message out.

Remember that it's not just business.

Regardless of how your planning team is structured or who is in charge, it is critical to operate within more of a social work frame, and less from the bottom-line business perspective. While building the numbers will be vital as you seek to maintain support and justify your outreach efforts, it is not the only thing that matters.

E. Look and Think Beyond Hospice

There must be a commitment to more than simply introducing African Americans within your community to hospice. It's more than numbers and larger than your organization. It is about social justice and ending healthcare disparities, and helping African Americans recognize that hospice truly helps the living. As you reach out, simply consider the big picture.

Consider more than the illness.

Sometimes a patient's illness is just one part of a bigger, highly complex family system. Ensure that your staff is aware of the community resources available to help with a wide range of issues.

Recognize disparities and remember history.

Research reflects that many African American doctors themselves treat their own patients differently, too, and are often inclined to treat disease more aggressively, and turn to hospice later, rather than sooner. Be mindful of the realities of treatment differences, healthcare disparities and basic historical experiences.

Stacie Pinderhughes, MD, reminds us that,

"Blacks and Latinos don't want to 'embrace your dying.' So in communities of color the discussion can't be about the dying, it has to be about the living. Initiatives must answer the question, 'How does this palliative care help my living?'"

F. Consider Marketing

Marketing is just one aspect of outreach and community engagement along with education, public/community relations, and sales. If you don't get your message out, who will? Remember that there are many misconceptions about hospice within the African American community. This is an opportunity to dispel those myths and spread the word about what hospice is, and is not.

Revise existing collateral or create new materials.

Collaborate with your communications team, and be sure that all of your public relations and marketing materials offer an accurate representation of your demographics and a thorough understanding of the



population you seek to serve. Images that African Americans will connect with include extended family gathered around the bedside of a loved one, families sitting together and holding hands, and a faith leader praying over a patient with family present.

G. Build Partnerships

The foundation of all outreach is relationships, built over time on deep trust and understanding. This section lists a number of ways and a wide range of organizations that you can turn to, to get your community-building underway and your partnerships established for mutually beneficial, long-term engagement.

Engage the entire community.

Your planning team can be comprised of staff and volunteers (with all interdisciplinary team members represented), as well as a wide range of African American community leaders. Don't leave anyone out. Invite members to attend meetings, and encourage them to consider committing to meeting regularly to provide guidance, suggestions, focus, and oversight.

Learn about African American organizations.

There are numerous groups, committees, organizations, and coalitions within your community geared specifically towards African American interests and needs. Some are nation-wide, and others are based right in your own community and serve the needs of those in your area.

Some of these groups include:

- Professional organizations, such as the National Medical Association (www.nmanet.org), National Black Nurses Association (www.nbna.org), and the National Association of Black Social Workers (www.nabsw.org)
- ◆ Local chapters of the NAACP (www.naacp.org), National Urban League (www.nul.org) and National Black Chamber of Commerce (www.nationalbcc.org)
- Multi-cultural centers, both within the community and on college campuses
- Health-related organizations, such as HIV/AIDS, child/maternal health, diabetes, heart disease, and others
- Sororities and fraternities on college campuses, and their related alumni groups and members through the National Pan-Hellenic Council (a coalition of the nine largest historically African American Greek-letter fraternities and sororities with over 1.5 million members).
- Men's organizations, like 100 Black Men of America (www.100blackmen.org) and the Masons (www.freemasonry.org)
- Women's organizations, including the National Council of Negro Women (www.ncnw.org) and Sisterhood Agenda (www.sisterhoodagenda.com)

Join them.

While you may be asked to attend a specific group meeting as a result of the relationships you build, also be proactive and join them. Contact their leadership first and ask whether they have any topics they would like you to address at one of their upcoming meetings. If they don't have something in mind, offer your own presentation ideas, and set aside a singular agenda of promoting your own hospice. Use these opportunities to get to know the members themselves and to learn about their needs.



Link up.

Hospice can be linked to so many causes in your community, presenting perfect partnerships for collaboration. An example is the Balm in Gilead programs, which focus primarily on African American HIV/AIDS awareness and cervical cancer (ISIS Project). Often, their events will be co-sponsored by local churches. By pooling resources on projects and events, the benefits can be enormous.

Involve and engage young people.

Young adults and teenagers, have the energy and enthusiasm of youth, and an excitement and passion about causes that can invigorate families, schools, and communities. Many are often seeking to fulfill community service hours, either through their school or their church, and will eagerly take on a variety of tasks within your hospice.

H. Embrace the Faith Community

Faith is "It."

Studies suggest that African Americans are willing to participate in health education programs such as smoking cessation, blood pressure, and cancer screenings when they are held at their churches, mosques, and synagogues.

Find your "In."

Begin by identifying the person who handles health-related issues. Set up a time to meet and find out the needs of the congregation. If appropriate at the first meeting, offer to host an advance directive or a hospice session. If the church holds its own health fairs, ask to set up an exhibit. Consider attending services regularly, if appropriate. Become a presence in the church. In time, congregants will know you as the hospice contact, and may start coming to you with their needs.

The Pastor's role is a critical one.

Be aware that many families will keep their pastor intimately involved in discussions and decisions about their care. Welcome his/her presence and encourage the family to keep that relationship strong. Pastors often find themselves negotiating the delicate balance between continuing to pray for hope and healing, but also encouraging the supportive network and resources of hospice.

Celebrate life and living, and the role of faith and hope!

Explain that hospice is not about giving up but instead about celebrating life and making the time remaining as meaningful as possible. Because faith and healthcare are inextricably linked within African American communities, your team will be unsuccessful if you avoid spirituality and talk only about medicine. But do emphasize that accepting hospice does not mean the patient must give up faith and hope for healing.

I. Participate In and Host Community Events

To help make hospice a household word in your community, participate in local community events, especially ones organized by and for African Americans. Organize events and invite everyone to participate. These can be held in conjunction with existing events or independently.



Come to my house!

Look for opportunities to invite folks to "your house." Welcome all potential partners and interested parties to an inaugural event to initiate your outreach. Community or prayer breakfasts are often very successful and can be incorporated into a workday. Ask one of the attending faith leaders to offer a blessing before the meal, thereby acknowledging the integral role that spirituality plays from the very beginning.

Think very creatively about opportunities to gather. For instance, an event scheduled around the birthdays of Charles Drew (the father of the modern blood bank) or Daniel Hale Williams (the physician who performed the first successful open heart surgery) is an excellent way to honor the contributions of prominent African Americans, built around a creative celebration that also focuses on wider healthcare/hospice topics.

Can I come to your house?

As your relationships grow, invitations to "go to them" may come. If you sense reticence, spend more time getting to know one another, and in time, as trust is established, the call may happen. If appropriate, bring copies of your collateral materials to distribute.

Make your message relevant.

Ask your contacts which issues are important to them. Combine this with the data from your community surveys. You can serve as a clearinghouse organizer for a variety of topics, all with specified relevance to that community group.

Team up.

Don't try to do it alone. There are many other organizations with whom you can partner and host joint events. Hospice can play a role with health prevention groups focusing on HIV/AIDS, diabetes, and cancer, or offering bereavement support to families of accident, suicide, or homicide/gang-related victims.

Go everywhere, attend everything.

There is rarely a lack of African American-focused community events to attend. Go to as many as you can, and invite staff members with you, particularly if it's to a high profile event, such as a gala or an awards banquet. Include a diverse representation of staff disciplines and ethnicity.

Examples of events include:

- Black History Month
- Martin Luther King, Jr. Day
- Kwanzaa (usually celebrated by younger families in addition to Christmas)
- Juneteenth celebrations
- Women's and men's group meetings and conferences
- Church concerts
- School productions

J. Connect With African American Media

Consider the media outreach as an extension of your outreach plan. Research your local media, and determine which are targeted to African Americans. There are often daily, weekly or monthly periodicals, published by and for the African American community, as well as radio and television stations (both secular and religious) geared specifically to the same.



Research media outlets.

Do some specific digging to gather all of the information you can on your local media, learning which demographics they target. Turn on your radio and television and tune into their stations. Listen to the advertisements and make lists of popular topics and personalities. Be appropriately cautious of the information you come across. Many African Americans will tell you that their community is much different than even the black media portrays them.

Make contact.

Make formal and sincere introductions. Explain your intent. Before asking about advertising or articles, get to know key staff members - reporters, publishers, DJs. Invite them to join your advisory group, or come to a specific event.

Get your advertisements and articles printed.

Buy advertising space and submit articles rather than propose something that solely features your hospice. Instead, help celebrate a traditional African American holiday. While "Hospice X honors Topic Y" is getting your name out, it's being done in a more subtle and gracious manner. In time, you might present a specific ad or article on your hospice or coalition featuring images and language that are relevant and fitting.

Find your own spokesperson.

There may be an African American celebrity, local or national (e.g., music industry representative, civic leader, local business owner) who would be interested in becoming another voice for hospice. If a high-profile personality lives in your own community, or someone you know has a personal contact that could be promising ... pursue it!

IV. Resources

- NHPCO's African American Outreach Guide available at www.nhpco.org/access.
- ◆ The Duke Institute on Care at the End of Life's APPEAL (A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End) training. Designed specifically for healthcare providers working with African Americans facing serious illness, the curriculum (accredited CEU's) includes a wide range of topics: spirituality, cultural beliefs, values and traditions of African Americans that may influence end-of-life care, the impact of racial disparities throughout the healthcare continuum and their relevance to the experience of African Americans at life's end, and barriers to quality care for African Americans with serious illness and strategies to improve their care. More details can be found at www.divinity.duke.edu.
- ◆ Excellent tools and resources are available at www.caringinfo.org/event_planning_toolkit, where you will find checklists for planning your event, sample flyers and posters, even how to publicize your event. While most event planning strategies can be effective regardless of your audience, some will be more successful depending on the specific community you are trying to reach. The following essential elements are geared specifically for participating in and hosting events for African American audiences.
- ◆ NHPCO's Caring Connections offers a Faith Community Outreach Guide that can serve as a supplement to the Embracing Faith section of this guide. It provides a very comprehensive review of why reaching out to faith communities is so important and detailed strategies for how to do so. Visit www.nhpco.org/access to download the Guide for free.