



African American

OUTREACH GUIDE

Caring Connections

In collaboration with
 **DUKE INSTITUTE ON
CARE AT THE END OF LIFE**

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I. Overview

“Hospice offers the best hope not to be alone, to be with family, to have pain controlled, and to be connected to your faith and beliefs.

We are as entitled and deserving as anyone else to have these hopes fulfilled.”

— RICHARD PAYNE, MD
PROFESSOR OF MEDICINE AND DIVINITY
ESTHER COLLIFLOWER DIRECTOR
DUKE INSTITUTE ON CARE AT THE END OF LIFE
DURHAM, NC

Harlem Renaissance author, poet and playwright, Langston Hughes (1902-1967) once said, *“There is no color line in death.”* Mr. Hughes understood that however we reach the end of life, our mortality is universal; there is no color line in death and there should not be one in life either.

With that thought in mind, it is interesting to note that while the African American population accounts for over 12% of the overall U.S. population, fewer than 10% of those entering hospice programs across the country are African American. Conversely, the white/Caucasian population comprises 80.1% of the U.S. population (U.S. Census estimate for 2006)¹ and accounts for more than 80% of hospice admissions.²

Within Medicare decedents ages 65 and older, the disparity is even more pronounced. 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).³ 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.” The researchers theorize “that racial disparities in hospice utilization decrease in areas where hospice utilization is more common” and that “one promising strategy to help reduce white/African American disparity in hospice use appears to be to increase access to hospice care for all eligible individuals”.⁴

Given the inequalities described above, the purpose of this Guide is to provide outreach strategies and resources for providers and coalitions to better support African Americans with end-of-life issues.

¹<http://quickfacts.census.gov/qfd/states/00000.html>

²NHPCO Facts and Figures, 2007. www.nhpco.org

³Connor 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.

⁴Connor 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.

The Guide specifically provides you with a review of significant end-of-life issues relevant to African American communities, and detailed strategies and tools gathered from hospice programs and experts. The “Resources” section offers many suggestions for continuing your research and outreach efforts. We encourage you to focus on taking time to get to know your community and fostering meaningful relationships, growing together as you reach out. In addition, the Caring Connections team has a wealth of materials that can assist you with virtually all aspects of your outreach, located at www.caringinfo.org/community.

We hope that this Guide will help highlight the importance of improving outreach and access efforts with African Americans in your community, as well as provide practical tools so that ultimately patients and their families will be better served in a culturally competent way, honoring and respecting their traditions.

A. DEMOGRAPHICS

There are over 300 million Americans living in the U.S. today, 39 million of whom are African American (just over 12 percent of the total population). One out of every four African Americans lives in New York, Florida or Georgia, with the largest concentration in the South (55 percent). The highest proportions are in the District of Columbia (57 percent) and Mississippi (37 percent), and the lowest are in Montana, Idaho and Vermont (less than one percent each). 52 percent of all African Americans live within metropolitan areas, with only 13 percent in nonmetropolitan areas.⁵

Most African Americans are high school graduates, and one in six has a college degree. Median income is about \$32,000, one in four live below the poverty level, and about nine percent are unemployed (double the national average). African Americans are less likely to be married than non-Hispanic whites, and a larger proportion of their households are maintained by women. African Americans are more likely to live with and care for grandchildren.

B. HISTORY

Many African Americans remember the days of segregation, Jim Crow laws and violence towards their people. And 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. For example, while emancipation from slavery was achieved in 1865, many African American families are only three generations removed from slavery. And as recently as 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. In addition, 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.⁷ So when African Americans do seek care for their health, particularly at the end-of-life, it is little wonder that many worry that hospice is just another way to hasten death.

⁵U.S. Census Bureau. (2004). The American Community – Blacks. www.census.gov/prod/2007pubs/acs-04.pdf.

⁶U.S. Census Bureau. (2004). The American Community – Blacks. www.census.gov/prod/2007pubs/acs-04.pdf.

⁷Bogart, 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.

“Black people still don’t believe in the political process, because the process has never served us. We’ve been betrayed by the political process, betrayed by the medical process, betrayed by each and every process in America, and it’s all based on racism. That distrust affects our entire personality in a great many ways.”

— AFRICAN AMERICAN FOCUS GROUP MEMBER,
NEW YORK, NEW YORK, 2005
(SEE FOCUS GROUP REPORT IN SECTION II)

C. HEALTHCARE DISPARITIES

Population-specific differences in the presence of disease, health outcomes and access to healthcare are all part of the healthcare disparities conversation. A 2002 Institute of Medicine (IOM) study found that “a consistent body of research demonstrates significant variation in the rates of medical procedures by race, even when insurance status, income, age, and severity of conditions are comparable. Research further 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.”⁹ This comprehensive report entitled, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, basically reveals that African Americans are dying from treatable and preventable illnesses with more frequency than other ethnic groups.

“Among African Americans, non-acceptance of advance directives appears to be part of a much broader pattern of values regarding quality of life, as well as a historical legacy of segregation. [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.”⁸

For example, African Americans are more likely to develop cardiovascular disease and HIV/AIDS, and are twice as likely to die from diabetes. Cancer incidence rates are ten percent higher overall, with a 25 percent greater chance of dying from it than whites. African Americans have higher infant mortality rates, and are more likely to live with a cognitive disability. Seven million African Americans do not have health insurance, and life expectancy is nearly ten years less than for whites.¹⁰

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.¹¹

⁸Searight, 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.

⁹Institute 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.

¹⁰Centers for Disease Control. (2008). National Center for Health Statistics: Health of Black or African American Population. Retrieved from www.cdc.gov/nchs/fastats/black_health.htm.

¹¹Institute of Medicine. (2005). Addressing Racial and Ethnic Health Care Disparities. Retrieved from www.iom.edu/Object.File/Master/33/249/BROCHURE_disparities.pdf.

While the reasons for these disparities are numerous and frequently directly correlated to lower socioeconomic status, African Americans do not seek healthcare as often, and when they do, it is often with a physician they may see only once. The healthcare system in America and its many services have made incredible strides over the years, yet much work is to be done with regard to differences in quality of care and treatment options based on ethnic background.

D. 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. The highest percentages live in New York, Massachusetts, Minnesota and Florida, and nearly all were born in Africa or Latin America.¹²

Recent immigrants may present with advanced disease that has gone untreated, either because of lack of care or a preference for alternative (and potentially less effective) treatments. Others may have undergone extreme trauma as part of their immigration experience or in their home countries, including illegal flight, genocide and extreme poverty. 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. Be sensitive to the special customs of these groups, particularly with regard to traditional medicine.

“I have seen more young people who are immigrants diagnosed with advanced cancer. It’s not that unusual for those from a foreign country to present with illness that is further along. And when the patient is young, they’re often hesitant to call back home to tell their parents how very sick they are. I have to encourage and facilitate those calls. What’s wonderful, though, is that these are often tight communities that provide a network of support. In many cases groups of strangers from the same country immigrated together in search of employment, so their “community” came with them, and it is built on a shared place of origin, culture and tradition.”

— Lyla Correoso, MD,
Attending Physician with the Visiting Nurse Service of New York, NY

¹²U.S. Census Bureau. (2007). The American Community Blacks. Retrieved from www.census.gov/prod/2007pubs/acs-04.pdf.

E. RELIGION

Historically, African American slaves in the U.S. were denied religious freedom, and racial segregation led to the development of separate, organized religious denominations. 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.¹³

Further, a profile of African American religious participation reveals that 70 percent attend religious services at least a few times a month, and 80 percent pray nearly every day. 27 percent read religious books and 21 percent watch or listen to religious programming on television or radio daily. Overall, 80 percent consider themselves to be either very or fairly religious.¹⁴

In African American faith communities, members seek out everything from spiritual guidance, to relationship counsel, to adult vocational education programs. Each African American religious tradition takes great pride in its ability to hold together its congregation even in the gravest of times. 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 remains the backbone of African American communities.

Note that because of the popularity of Christianity among African Americans, 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.

“[Healthcare] decisions and actions taken are often based on religious traditions, such as fasting, prayer, seeking God (specifically God’s will) and even asking a doctor to pray with or for the patient and family.”

— STACIE PINDERHUGHES, MD,
CHIEF, DIVISION OF HOSPICE AND PALLIATIVE MEDICINE,
NORTH GENERAL HOSPITAL, NEW YORK, NY

¹³Religion Newswriters Foundation. (2007). A Guide to African Americans and Religion. Retrieved from www.religionlink.org/tip_070108.php#stats.

¹⁴Mamiya, L. (2006). *Pulpit & Pew: Research on Pastoral Leadership*. Section II: Profiles and Studies of African American Laity. Durham, N.C.: Duke Divinity School. p. 24.

Section II. 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. Men and women were interviewed separately. Group participants discussed their general feelings and issues regarding end-of-life thinking, talking and planning. Participants were then asked to read and react to topics such as advance care planning, end-of-life caregiving and hospice. Key findings are below.

A. DEATH, DYING AND ADVANCE CARE PLANNING

Group participants were divided on their comfort level on the topic of death and dying – some seemed at ease, while others felt that it was culturally taboo to even discuss it. Older participants indicated that they talk about it more as they themselves are aging. Generally, there is a conflict between wanting to be informed medically, but being culturally bound to privacy and wanting to turn to and rely on faith first and foremost.

Most participants were unaware of the true meaning of advance care planning, using it interchangeably with end-of-life care, which they connected with life insurance and funeral planning. Many misinterpreted the materials they were given, and thought that advance care planning referred to an agency or organization where all advance directives are stored. Hospice staff, therefore, should emphasize the role of the family, and that it is possible to name the person who would make decisions on a patient's behalf. There was significant distrust that even if preferences are specified in writing, that the medical professional in charge would not honor them.

“What I sense that you're leading at is, a person fills out a document and then you get this document notarized or something and this goes to some agency and then when the person is ill then the hospital had the responsibility to contact this agency and see if this person has a document ready and the document says or the person says, ‘This person wants to be kept alive by all means possible,’ then the doctors are going to be bound by that document. I don't think it's going to happen like that.”

— AFRICAN AMERICAN FOCUS GROUP MEMBER COMMENTING ON ADVANCE DIRECTIVES

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 few weeks to be given a chance at recovery. While most feel that advance care planning is a wise idea, concerns were expressed; some even stated that the very idea of writing your wishes down was quite strange, especially “pre-crisis.”

“It interests me now. There was a time when I used to kind of shy away from that, because... there's just something about it that you just don't want to talk about. You don't want to hear about it. But as you get older, it comes to the forefront of your mind and so it's like you want to go and find out things about it.”

— AFRICAN AMERICAN FOCUS GROUP MEMBER COMMENTING ON DEATH

B. CAREGIVING

The African American family structure is usually tightly-knit, extended, matriarchal, and includes many close friends who are considered kin. While families are more dispersed today, it is still expected that family members will find a way to care for loved ones in their own homes. This choice is always preferred to someone coming ‘from the outside.’ Therefore, caregiving provides the strongest foundation on which to begin a discussion of end-of-life issues. 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.

“I think we talk about mostly caring for each other or our loved one at the end, during the end of their life on earth other than just their dying. Blacks seem to be concerned with taking care of their people.”

— AFRICAN-AMERICAN FOCUS GROUP MEMBER

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.” Yet 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. Some were still doubtful even after reading NHPCO handouts explaining the Hospice Medicare Benefit.

Section III. Strategies for Reaching Out to African American Communities

There are many ways to conduct outreach that meets the needs of your organization and your community. By showing yourself as a true partner who wants to give, you engender goodwill and open the doors to all members of your community. 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

Before implementing any strategies in your outreach, it is important to critically assess your existing resources, survey your community, formulate a plan and gather support. This foundational analysis is critical to any outreach effort, no matter which community you are targeting. 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.** As you begin, your first step should be an assessment of your existing financial and personnel 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?

Visit the Caring Connections Web site at www.caringinfo.org/community for resources that can get you started. For instance, "The Golden Rules of Outreach" outlines essential elements of outreach, and "Community Assessment Guide" helps you evaluate the specific end-of-life needs in your community.

Additionally, do you already have a staff person who is designated as outreach coordinator? Can you afford to hire new staff? Perhaps you have someone who is already engaged in community outreach, but his/her work is focused on a different ethnic population. Conceivably, this person might be able to take on additional duties, or assume a new role. (We will explore this point in more detail in "Find the Right Fit" section of this Guide.)

- **Survey your community.** Gather local demographics as well as your own organization's current trends. Learn what African Americans in your community already know (or don't know) about hospice and palliative care. Some may be well aware but choose other options, while others may be misinformed and not understand the true benefits.

The focus group findings summarized previously in this Guide offer some insight, and you might consider conducting your own one-on-one informational interviews or organizing small focus groups to gather data specific to your community. Or, hold a town hall meeting to open a wider dialogue.

The structured conversations in this type of gathering provide opportunities for community members to share their concerns, needs and questions about end-of-life care and services. See Caring Connections “Convening Town Hall Meetings” at <http://www.caringinfo.org/Community/Outreach-StrategiesAndTools.htm> for details.

With the knowledge gained during these groups and/or meetings, you will have targeted, detailed and intimate information that gives you the most personal perspective on how African Americans in your own community truly think and feel about end-of-life care. Your staff will be better educated and your ability to serve the community will be infinitely greater.

- **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 entire organization should be engaged and share the same vision of inclusiveness and growth. The key element is forming a planning team, which should include staff as well as a wide range of community members. These individuals will ensure that a core working group is in place to support the hard work of your primary outreach liaison, and provide reassurance that he/she is part of a larger team working together to build lasting links between your hospice (or coalition) and African American community members. (More suggestions for team planning and building will be discussed in the “Build Partnerships” section of this Guide).
- **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 (see the “Consider Marketing” section of this Guide). Tap into existing networks, particularly the African American hospice outreach programs operating across the country that are highlighted in this guide.

Lyla Correoso, MD has found that there is a great lack of understanding among both the African American as well as the general population regarding end-of-life care options and treatment. She describes some specific examples:

- Encountering many caregivers who simply quit their jobs to take care of a parent, spouse or other loved one, not knowing about the Family and Medical Leave Act (FMLA).
- Little to no understanding of the concept of palliative care. Hospice home care statistics for the organization revealed there were 5,000 patients who could benefit from the palliative care model but were not getting referred accordingly. So it is not only the patients themselves who are un-informed, but many healthcare professionals, as well.
- A suspicion of hospice even among nurses, who in some cases also had very little understanding of advance directives (a particular problem in the state of New York because patients are required to have healthcare proxies). In response to this, a special hospice teaching program was initiated designed specifically for nurses. And to help those nurses who were struggling to find the right words with their patients, the organization developed a card with talking points for use when interacting with patients and families.

- **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, as they are all part of the team. 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.”

An excellent resource is 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 barriers to quality care for African Americans with serious illness and strategies to improve their care. For more information about APPEAL, visit www.iceol.duke.edu.

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. It is a big job, and hopefully one made more manageable by the support of your entire planning team. In addition, consider the diversity of the team itself. While it is not absolutely necessary and will not guarantee success, if your staff reflects the community you are seeking to serve, your ability to connect may be enhanced.

- **Select a messenger.** As introduced in the “Get Organized” section of this Guide, if you do not already have a point person, perhaps one can be hired, or another position can be adapted to fulfill the role. Alternatively, you might find a current hospice volunteer or another community member who would be willing to take on these responsibilities in a volunteer capacity. If you can make this happen, we suggest that you clarify how this person will serve as an official representative of your hospice and speak on your behalf.

In filling this position, there are some important skills the person must possess. Personality matters more than anything else. *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?* In many

settings at which African Americans will be present, it is expected that a prayer will begin and end a meeting, so he/she must be both comfortable in prayerful environments, as well as saying prayers him/herself. *Is he/she able to engage with diverse groups of people? What level of commitment does he/she bring? Can he/she be patient and commit for the long term? Does he/she have a willingness to work after hours and to attend a variety of functions across town?* Finding the right fit for that individual who will share your primary message with the community is of the utmost importance, so try to make your match carefully and appropriately.

- **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. For the specific purpose of outreach to African Americans, many hospice programs expressed that it can help if some members of the team look like the patients they serve. 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. As mentioned in the “Get Organized” section of this Guide, be sure to provide diversity training for all of your staff, especially for those engaged in direct patient and family contact.

“I don’t think necessarily you have to be an African American to provide good care to African Americans, but if you’re not, you really need to be aware of the culture and some of the issues in that culture, and really look at how you feel about dealing with people from that culture,”

— AFRICAN AMERICAN NURSE ¹⁵

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. Simply meet the community where it is. Try to do more listening than talking in your growing relationships. Yet 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. We suggest that you leave behind any preconceived ideas and stereotypes and don’t make assumptions.

- **Address what hospice is and is not.** Be sure to focus on the “mis-facts,” and don’t assume that everyone is accurately informed. 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. Clearly, awareness among caregivers is a key to building true understanding.

¹⁵ From an interview for the Institute of Medicine’s “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care” report, 2002.

So wherever you are, whenever given the opportunity, explain hospice benefits clearly. The ability to pay should not be a deterrent for anyone, and particularly African Americans who are more often uninsured. Explain the Hospice Medicare Benefit, and how re-certification works, if needed. Patients and families, and even some healthcare providers themselves, are often unacquainted with the benefits available should the patient live past six months; they are also sometimes unaware that some patients “graduate” from hospice.

- **Support the caregiver.** Recognize and respect the strong history and tradition in African American communities of “taking care of our own.” African Americans have done so for centuries, and so effective outreach activities should not include a “we’ll come in and do it for you ... because we can do it better” message. Offer to support current caregivers, explaining how the interdisciplinary team will care for the family, as well as the patient’s physical, emotional and spiritual needs. 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, you must be patient throughout this process. Be prepared to make multiple visits, with many family members present, sometimes even with the pastor involved (see the “Embrace the Faith Community” section of this Guide), acting as a family liaison. This won’t be a one-time conversation, and you may not get buy-in the first time. 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.** As healthcare professionals, 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. Sometimes it’s best to listen. Many patients and families want someone to take the time to hear about their life’s journey.

Cassandra Cotton, CNA, CHPNA, of Nathan Adelson Hospice shares this perspective on the need to educate families about pain and suffering. “Education is a huge component – for patients, families and faith leaders. No one should die in pain. Alleviation of pain does not mean that prayers and hope for healing are discontinued. Pain and suffering are not necessary for atonement of life’s indiscretions. Yet my own mother viewed her suffering as necessary for past sins. She died believing that if she had had just a little more faith she would have been healed.”

Gloria Ramsey, RN, JD, a nationally recognized expert in bioethics, nursing education, and health disparities, as well as a professor with the Uniformed Services University of the Health Sciences in Bethesda, Maryland, shares the following observations about the need to respect privacy and how differently African Americans deal with crisis. “What’s of concern, from a deeply rooted cultural belief, is that African Americans are very private about diagnoses. The whole notion of people coming to the house, driving the vehicle with the hospice logo on it – these are difficult things for African Americans to accept. The concept of it being ‘my business, and I don’t want people in my business’ can be a struggle, as well, because in an effort to keep people out of ‘my business,’ families are keeping out the very people who could be of great help.”

You and your team members may need to adjust your approach. Currently, your preferred style for initial consults might be to say, “Here’s what *hospice* can do for you.” Instead, begin the conversation with, “What can we do for *you*?” A frequent comment made by African Americans under hospice care is that they would actually like to be asked what they think, what they know and how you can help. A common statement is “*If only we had been asked.*” So ask the questions and go from there. Eventually, the time will come to share the benefits and support that the hospice team will be able to provide.

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. Your words and messages are critical as you strive to be heard.

- **Be genuine.** This is a simple, yet profoundly important element in your outreach. Be sincere and transparent. Connect deeply, and seek to genuinely empathize with the range of end-of-life issues your African American community is facing. 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 buy into. Anything less is disingenuous and will be quickly dismissed as staged efforts to gather people in without true substance.
- **Use the right words.** Try to use simplified terminology. Palliative sedation, end-of-life care, DNRs, advance care directives, opioids, artificial hydration and nutrition – while these are all used frequently in hospice settings, for someone unfamiliar with the healthcare system and facing crisis, these terms can be very confusing and even frightening. Consider focusing on the term “comfort care,” especially in the beginning.

When simplifying your language, however, be careful to not do so in a patronizing manner. Many healthcare professionals, who use medical jargon in everyday speech, should be reminded that using less technical language is a basic courtesy to patients and families who are just learning how to navigate the system.

In addition, be sure to recognize the connected role of faith and medicine when having conversations with the African American community (see the “Embrace the Faith Community” section of this Guide.) Steer clear of scientific and medical absolutes as much as possible, and if you’re comfortable, include references to faith when you engage African Americans in dialogue.

- **Rely on word of mouth.** Your commitment, your passion and your high standards of care will speak for themselves, and your personal relationships will inspire confidence. 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. Rely on the good that you do being shared verbally within the various community systems that exist. While this shouldn't preclude some targeted marketing as discussed in the "Get Organized" and "Think About Marketing" sections of this Guide, it is a frequent method of information sharing within the African American community, and one that can be relied on.
- **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.

Dr. Bernice Catherine Harper, MSW, MSc.PH, LLD, one of the original leaders of the African American hospice movement, a former Medical Care Advisor to the Department of Health and Human Services (HHS), founding president of the Foundation for Hospices in Sub-Saharan Africa (FHSSA), and a former Board member of the National Hospice and Palliative Care Organization (NHPCO), emphasizes the importance of recognizing the role that "Dr. Jesus" plays for African American Christians facing serious illness. "Among African Americans, there are those who will be suspicious of anyone who purports to have medical answers that are best left to 'Dr. Jesus.' Be careful with any comments that begin with, 'The doctor said ...' or 'The experts all say ...' These statements of medical absolutes will not go over well. Instead, consider saying, 'While only God can really know when it's your mother's time, the best medical information tells us that ...' or 'We really can't know for sure, but with God's will and what medical science tells us ...' This manner of explanation is presented in a culturally appropriate manner and takes in the role of faith, and will be 'heard' best."

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. It's one thing to struggle with physical pain, but altogether another to be so overwhelmed by medical expenses that there simply isn't enough money to buy groceries for the family. Ensure that your staff is aware of the community resources available to help with a wide range of issues, some completely removed from the patient's physical needs, and be certain that they share this information in detail with patients and families. Above all, an environment should be created in which a patient or family member feels comfortable enough to bring these kinds of problems to anyone on the team.
- **Recognize disparities and remember history.** In this Guide's overview and focus group summaries, a very brief review is provided of African Americans views and experiences with regard to healthcare and death and dying. Additional 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. This attitude is driven both by the patients, who prefer the treatments for longer than is necessary or beneficial, and by the doctors, who want to "do right" by their African American brothers and sisters. Be mindful of the realities of treatment differences, healthcare disparities and basic historical experiences.

Stacie Pinderhughes, MD, of North General Hospital, New York, NY, 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?'"

Lyla Correoso, MD explains, "Sometimes death is not the biggest factor. Sometimes staff has to focus on concrete services, such as paying for the electric bill and securing guardianship of children and/or parents before they can deal with issues of death and dying. Many homes are in need of additional support prior to the onset of illness, that is, there was dysfunction before, so there is no reason to expect that these problems will go away when tragedy strikes."

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 – brochures, newsletters, annual reports, and training manuals – anything that the public will see – 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.

Consider revising/re-thinking *all* of your collateral, including everything from the display boards you set up at area events to welcome packets for patients and families. Some hospices include coupons from local restaurants and hand-made quilts –anything that makes a personal connection and expresses warmth and concern. If you don't have the resources or time to create or re-create your own marketing materials, Caring Connections offers a variety of brochures that you might consider utilizing.

- **Work within your systems.** If your hospice is part of a wider healthcare system in which all public relations and marketing are managed by a separate department, communicate well before any advertising is submitted. Don't let anything go out until many eyes have viewed it, especially your own, checking for accuracy of language and appropriateness of images. Since you are the one delivering the message, be sure that the actual materials are ones that are suitable and present the right ideas to draw in the African American community.

Sally Sharpe, RN, with Pike's Peak Hospice & Palliative Care in Colorado Springs, CO, serves as palliative liaison for communications and marketing. Revising existing collateral was a key part of her outreach strategy. "We formed a coalition to help look at our existing materials. We found that most only included images of white people, which wasn't an accurate representation of our community at all, and they missed an opportunity to target and address the specific fears and needs of the African American community. So we created a new brochure and video that includes images of African Americans, Hispanics, Asians and Caucasians. Basically, the pictures in the outreach materials have to look like your community, and having a specific handout just for the population you're targeting is critical. It should also include the right buzz words, which, in this case, are: relief of suffering, comfort, family and faith, and overall, less of a focus on death and more on 'transition.'"

G. BUILD PARTNERSHIPS

The foundation of all outreach is relationships, built over time on deep trust and understanding. Seek them out in both obvious and obscure areas. Commit to fostering meaningful, life-long partnerships with a wide variety of African American groups in your community. Nurture them and continually re-examine them to be sure they are thriving and mutually beneficial. 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 vibrant, mutually beneficial, long-term engagement.

- **Engage the entire community.** As discussed in the “Get Organized” section of this Guide, it is imperative to gather support. 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 local faith leaders, healthcare professionals, business leaders, academics and students to be a part of the team that will guide your outreach. 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 your population. Gather this information by simply asking anyone in a position to know, scouring local media, noting community events, surfing the Internet and checking your local Yellow Pages. When you have a fairly comprehensive list, and have done the necessary research to learn about their priorities and interest, start reaching out. (Suggestions for how to do this may be found in the next two sections, “Embrace the Faith Community” and “Participate in and Host Community Events.”)

Stacie Pinderhughes, MD, offers the following suggestion for connecting with area businesses, specifically local restaurants. “Food is very important in African American culture. It is life. It is nurturing. So building a relationship with Sylvia’s, a well-known restaurant in our area, has been vital. Sylvia’s agreed to provide meals to hospice patients and their families once a week. Having a restaurateur of this caliber come in with food that is familiar, is key. Offering families the opportunity for table fellowship is important. Theologically it is very Eucharistic, and this brings great peace to all who are with us.”

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, showing your commitment and passion for their cause. Contact their leadership first, and ask whether they have any topics they would like you to address at one of their upcoming meetings (see the "Participate In and Host Community Events" section of this Guide.) If they don't have something in mind, offer your own presentation ideas, and set aside a singular agenda of promoting your own hospice. Instead, use these opportunities to get to know the members themselves and to learn about their needs. Promoting your program and welcoming new consumers will come in time.

Cheryl Gilkes, a professor of sociology and African-American studies states: "Throughout history, black churches have shielded African Americans from the harmful effects of personal and structural racism and their worship services have also functioned as a therapeutic community where people can sing with joy and exuberance or cry out in pain among those who care and understand."¹⁶

Caring Connections offers a Faith Community Outreach Guide that can serve as a supplement to this section. 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.caringinfo.org/Community, then click on "Faith Outreach" to download the Guide for free.

¹⁶Gilkes, C.T. (1980). The Black Church as a therapeutic community: Suggested area for research into the black religious experience. Journal of the Inter-denominational Theological Center, 8, 29-44.

- **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. (See the “Embrace the Faith Community” section of this Guide.) By pooling resources on projects and events, the benefits can be enormous.
- **Involve and engage young people.** Young adults, teenagers, even ‘tweens’ 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, providing diversity through ethnicity and age! Young people will be eager to help spread the word about you and what you do, especially if they’re engaged in a project that excites them. So don’t leave this pool of potential participants out when seeking opportunities for partnership-building.

Gloria Ramsey, RN, JD, relates, “You want to go into a place where you’re building upon existing and already established relationships and infrastructure. You can’t build that capacity and do the work, too. There needs to be great give and take between both parties. After you’ve made your assessment (because you need to know your baseline), let them assess if they want to work with you, too. Build on the knowledge you gather about community, culture and church — all these must go together.”

H. EMBRACE THE FAITH COMMUNITY

Within African American communities, faith can carry more weight than medicine. As discussed in the “Religion” section of this Guide, many African Americans are deeply connected to their faith community and will turn there for support before seeking help from other agencies. The church serves as the bedrock of spiritual activity, a center of social engagement, an indispensable source of information on all topics and a critical foundation of support in times of crisis.

- **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. And since the place of worship is often the primary source of information on a wide range of subjects, it offers one of the best ways to reach the widest audience in a safe, trusted environment.

“If I can’t have cure in my body, at least let me have healing in my soul.”

— BISHOP SIMON GORDON,
TRIEDSTONE FULL GOSPEL BAPTIST CHURCH,
CHICAGO, ILLINOIS

- **Find your “In.”** Begin by identifying the person who handles health-related issues. This might be a lay leader, member of the Diaconate (deacon or deaconess), parish nurse, the head of the congregational care ministry or a social worker who serves as bereavement coordinator. He/she can be your conduit to the pastor (unless you are able to meet with the pastor from the outset). 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. Come early and stay late for personal introductions and to distribute materials 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.

Research shows that there are more than 1,700 church-sponsored outreach programs providing for the spiritual and physical well-being of African Americans. These programs cover basic needs such as food, clothing and shelter; financial aid and counseling for personal problems; health-related concerns such as HIV/AIDS and substance abuse; and recreation and fellowship for youth and families.¹⁷ So within this spectrum of faith-based support, be aware that you may be competing with many requests from other groups and simply emphasize that hospice can also be a part of those conversations.

- **The Pastor’s role is a critical one.** Not all clergy and faith leaders have the skills to advise families on end-of-life decisions. Be aware that many families will keep their pastor intimately involved in discussions and decisions about their care. Some families will even ask their pastor to be present for at least the initial meeting with hospice admissions staff. Welcome his/her presence and encourage the family to keep that relationship strong.

Generally, pastors emphasize the duality of spirituality and proper medical care, and when serious illness is involved, it is important that he/she understands the wide range of hospice services, and how they can support his/her congregants. Be aware that some families see the pastor’s job as praying for healing, first and foremost. While the pastor him/herself will acknowledge that he/she cannot work miracles, the mere suggestion of hospice might be of concern to a family who will perceive it as a pastor turning away from faith and more towards medicine.

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.

Sally Sharpe, RN, involves pastors as intimately as possible in all familial interactions, particularly in the very beginning. “We ask pastors to be present when the initial meeting takes place with a family, or at a minimum, to call in from their offices while we’re meeting with the family. The best strategy is to try to make sure that the pastor is actually there in the home. We have developed a great relationship with our African American community and church. If the pastor is pro-hospice, it makes the process much easier, and infuses it with trust and security.”

¹⁷Billingsley, A. (1999). *Mighty like a river: The Black Church and social reform*. New York: Oxford University Press.

- **Celebrate life and living, and the role of faith and hope!** Explain that hospice is not about giving up and ending life prematurely, but instead about celebrating life and making the time remaining as meaningful as possible. Hospice's focus is appropriately on life and living, with the ever-present acknowledgment of the role that faith plays. 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. Hope is always a part of hospice.

Dr. Bernice Catherine Harper, MSW, MSc.PH, LLD, shares this perspective on the need to recognize death and dying and views on hospice within African American communities: "Be aware that African Americans, like most of us, are not into death and dying; they are into life and living! As a general rule, they see death as going home, and going away from a world of discrimination and hardship. So they can't get too excited about hospice. To them, hospice is a white middle class movement, and not one they view as personally applicable. So we need to help them understand it and be aware of it and present it to people of color in the appropriate cultural context. Be prepared to address the underlying concerns of the patient and family who will respond with, 'Where have you been my whole life? When I needed clothes? Or food? Now you come when I'm dying. But I'm going home. I don't need this now.' We need to break those barriers to healthcare and hospice for African Americans."

Check out Caring Connections' *It's About How You LIVE* campaign toolkit and NHPCO's 2008-09 Outreach Guide which uses the theme of Hope, Dignity, Love...It must be hospice. Both resources contain a collection of ideas, suggestions and materials to help you with your outreach efforts.

The Duke Institute on Care at the End of Life, and the Duke Divinity Office of Black Church Studies developed the Proctor Covenant Statement on End-of-Life Care. The covenant serves as an initial pledge signed by faith leaders from across the country to support initiatives to improve end-of-life care in the black church. The Proctor Covenant statement is available to view and download in the Appendix of the Guide and can be used as a theological statement on quality care at the end of life and a defining statement, standard and guide for African American clergy. For more information, visit www.iceol.duke.edu.

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, or ones that target issues of interest to the African American community. Organize events and invite everyone to participate. These can be held in conjunction with existing events or independently. Either way, find the appropriate focus and work collectively to plan successful gatherings that energize and inform and bring your diverse groups together.

As with many other elements of your outreach, the key is to take your time and do your research before rushing into things. 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.

- **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 (see the “Build Partnerships” section of this Guide). 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. In conjunction with your coalition or planning team, select a prominent community figure to host the event.

- **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.** Don’t waste your new partner’s time or yours by trying to guess which topics will be of most interest. Ask your contacts which issues are important to them. Combine this with the data from your community surveys. (See the “Get Organized” section of this Guide.) You can serve as a clearinghouse organizer for a variety of topics, all with specified relevance to that community group. Hospice, advance care planning, caring for the caregiver, and how to pay for healthcare may be topics to offer depending on your initial assessment.

- **Team up.** Don't try to do it alone! As mentioned in the "Build Partnerships" section of this guide, 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.

Families affected by homicide or gang violence are a natural outreach for hospice since staff members are experts at loss. Bereavement support to families experiencing loss bridges a gap and shows hospice as an inclusive caring group of experts who seek to help all those who are facing death and dying. However, when referring to what might be perceived as a stigmatizing topic for African American communities, be sure to avoid the suggestion that the issues are solely African American problems; homicide, gang violence and crime are universal societal concerns.

- **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. And, if appropriate, bring your table-top displays and handout materials.

Examples of events include:

- ❖ Black History Month
- ❖ Martin Luther King, Jr. Day
- ❖ Kwanzaa (usually celebrated by younger families in addition to Christmas)
- ❖ Juneteenth celebration (www.juneteenth.com)
- ❖ Women's and men's group meetings and conferences
- ❖ Fashion shows
- ❖ School productions
- ❖ and more ...!

Toula Wootan, Director of Community Relations for Community Hospice of Northeast Florida in Jacksonville, turned her outreach into a special initiative on community relations, targeting everyone who might be in need. She says, "It's all about relationship-building, and the overall goal should be one of community building. You must be patient and take time to build trust, particularly around healthcare. You need to show that you care about the health and welfare of the community. Show your sincerity by taking things a step further. For instance, we've partnered with one of our city hospitals for indigent care. We reach out by providing preventative care to local churches. In addition, we have the largest murder rate in the state of Florida. So to address a broad community concern, we launched an initiative called 'Operation Safe Street.' We involved many community groups, particularly African American churches. The focus was on gun control. We're experts in loss and bereavement, but can offer our support in ways other than hospice. We try to show that we care about the community, holistically. Our message is that we're here to care for you, and we're concerned about the same issues that you're facing."

See the Appendix section of the Guide to download PowerPoint templates for Hospice and Advance Care Planning presentations that you can adapt for your community education needs.

“You should always ask to participate in health fairs or other community events, such as Juneteenth celebrations. These events are a part of the community, and you should absolutely be there to help support the event and the occasion itself. Some will be invitation-based, so your goal, as part of relationship-building, is to be the one invited. If you’ve built the right kind of relationship, one that is focused on more than death and dying, they’ll see you as a resource and want to include you. So if you’ve been the first to reach out and trust has been built, you will be seen as a true partner.”

— SALLY SHARPE, RN
PIKE’S PEAK HOSPICE & PALLIATIVE CARE
COLORADO SPRINGS, CO

J. CONNECT WITH AFRICAN AMERICAN MEDIA

The opportunities to get your message out are plentiful and 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.** While you may have already done a good amount of market research on your community, as described in the “Get Organized” section of this Guide, 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. This may give you some insight into what’s being advertised – by whom and to whom.

However, because many people not of African descent rely too heavily on the media for research into the African American community, 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. A good comparison is the representation of Italian-Americans in literature and film, where an almost fantasy version is concocted with its emphasis on mafia ties. The best way to research real African Americans is to go into their communities and participate in their everyday activities.

- **Make contact.** As you have with all other groups or individuals, make formal and sincere introductions. Explain your intent. But 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. As with all of the strategies, a personal relationship will take you much further than throwing collateral at a media representative and expecting it to lead to a prominent feature.

- **Get your advertisements and articles printed.** Buy advertising space and submit articles - and don't necessarily propose something that solely features your hospice, at first. Instead, help celebrate a traditional African American holiday (see the "Participate in and Host Events" section of this Guide). 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 – and make sure that it is appropriate to the African American community, 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!

Sharon Latson, Senior Director of Access Initiatives, VITAS Innovative Hospice Care® of Chicagoland, suggests that it's wise to link up with ethnic-specific media, but to be subtle in your advertising with them. "Historically, African American businesses weren't able to advertise or be employed by some local media, so they created their own. This has built a rich pool of African American media specialists who know how to reach their audience. While our objective is to get VITAS' name out, we try to do it in a way that is not just about hospice. We submit ads that convey a message of 'When you may need us the most.' This way, we create a presence and an awareness of VITAS in the community in an understated way."

As all of these strategies suggest, one of the most important things that your organization must do when working with any cultural community for the first time is to build trust. Gaining the trust of a community takes time. Developing trust must be your main goal when seeking new partnerships and relationships. In our goal-oriented society, it is all too easy to focus on project goals rather than relationships. However, meaningful relationships are the best path to long term accomplishments. This is the best guarantee to successfully build partnerships and implement outreach activities with the African-American community.

For more information and resources on outreach to diverse communities, visit www.caringinfo.org/community, and click on 'Diversity Outreach'.

IV. Model Outreach Programs and Initiatives

A. BRIDGING THE HEALTHCARE GAP: A TOUCH OF GRACE HOSPICE, INC., CHICAGO, ILLINOIS

After working in the hospice field for many years, Dr. Jennifer Moore knew she wanted to help decrease healthcare disparities among minorities, and specifically, increase the use of hospice services among African Americans.

Her solution? Founding and directing her own hospice, one that would focus on serving African Americans in the inner city. With a mission of bridging the healthcare gap among minorities and improving the overall quality of care to the local population, A Touch of Grace Hospice, Inc. focuses on the highest standards of care and cultural sensitivity, and provides extensive and ongoing diversity education and training for its staff, serving a census that is comprised of 97% minorities.

Moore understood what the barriers were from the outset – primarily distrust and misunderstanding. She found that increasing minorities' use of hospice must begin with healthcare provider education, and how hospice itself is presented. She advises professionals to stay away from typical “med-speak” and to present information in a culturally appropriate manner. The role of faith must be emphasized, not in a sense of giving false hope, but relating to their fears, and acknowledging the need to pray for hope and healing.

Another large obstacle is re-informing the community on what hospice truly is, and dispelling myths, especially those pervasive among African American communities. So education is a key component – in all of her outreach, with individual patients and families, as well as staff. Moore has found that once the community is well informed, residents become more receptive to the hospice dialogue. And the fact that her staff mirrors the community it is serving (94% are African American) is a particularly beneficial aspect.

Moore's key outreach strategies include the following:

- ❖ Create and make available culturally sensitive material
- ❖ Acknowledge the faith of the community
- ❖ Address what hospice is not
- ❖ Strive to have healthcare staff that looks like the community you're serving
- ❖ Meet with people one-on-one and be genuine
- ❖ Rely on word of mouth
- ❖ Consider more than end-of-life needs, because for some families, you have to start there before you can even talk about hospice

B. CONNECTING THROUGH FAITH: NATHAN ADELSON HOSPICE, LAS VEGAS, NEVADA

It's personal for Cassandra Cotton, CNA, CHPNA, Community Relations and Outreach Coordinator at Nathan Adelson Hospice. After making a career switch to hospice after her own mother became ill, Cotton found fewer African Americans being served, and set out to change that. So she turned to her faith community, and with the support of her supervisor and pastor, established *The Caring Touch Ministry* at her church, one of the largest congregations in the state. The ministry's goals are to support those who have been diagnosed with a life-limiting illness or are experiencing a debilitating disease, and to provide ongoing education about hospice services and continue the dialogue on end-of-life issues with the wider community.

Cotton says, "The education process begins with identifying the role of both the faith community and hospice. For centuries, faith communities have been the epicenter of caring. Hospice providers must find ways to educate faith communities and engage faith leaders in end-of-life care conversations. The congregation must have an informed, trained leader who has an understanding of the range of hospice services and how these services are delivered."

Cotton's first steps with *The Caring Touch Ministry* were to create a task force that helped spread the word throughout the congregation, and conducting a survey of the congregation to learn what they knew about hospice. She found great misunderstanding about hospice and a reluctance to discuss death and dying. So her strategies focused on hospice education, and training a core team of congregants to serve as members of the hospice ministry. Members now serve as hospice educators, spiritual caregivers and important referral sources.

Her next and ongoing initiative was setting up a workshop as part of a wider church health fair, entitled, "Getting Your House in Order." The focus was on advance care planning, presented in a scripture-based way so that the message of "preparing for your home-going" was one the community would hear. She emphasized the importance of building partnerships for the event, and linked with other churches, local Social Security and Medicare offices, the Nevada Center for Ethics and Policy, elder-law attorneys and notaries, nurses and hospice aides, volunteers, and funeral directors. She made sure that other community partners, such as local eateries and entertainers, would provide in-kind donations, and make the event fun and interactive. "Getting Your House in Order" events provide ongoing education and are well received by the entire community. And *The Caring Touch Ministry* serves as a solid link between its congregation and Nathan Adelson Hospice.

C. EMPHASIZING COMMUNITY-BUILDING: PIKE'S PEAK HOSPICE & PALLIATIVE CARE, COLORADO SPRINGS, COLORADO

In 2001, One Voice At a Time (OVAT) was begun as an initiative by Pike's Peak Hospice and Palliative Care (PPHPC) to address the under-utilization of hospice services by African Americans in Colorado Springs/El Paso County. Led by Sally Sharpe, a nurse who serves as palliative liaison and director of communications and marketing, OVAT quickly turned into a community-building endeavor as well. Recognized locally and state-wide for its innovative ideas, OVAT has received multiple awards, including the Outstanding Achievement Award from the Colorado Hospice Organization in 2003, and the Urban League Community Outreach Award in 2004.

The OVAT advisory committee was formed with the intention of not simply informing the community of what PPHPC does, but also listening to what the community's needs were. OVAT staff focused on spreading that message. Within a year of its inception, OVAT had reached out to other prominent organizations in the African American community such as the Black Leadership Forum, NAACP and the Urban League. From the initial support a coalition was created, including staff, ministers of local congregations, prominent African American leaders and a wide range of community members simply interested in supporting the cause. Recent events include healthcare conferences and fairs, Urban League Elder gatherings, and an NAACP-sponsored Freedom Fund. And as a part of bereavement outreach, an OVAT committee member suggested "Barber Shop Gatherings," which has turned into a popular way to support local African American men in one of their most comfortable settings.

In 2003, OVAT released new brochures and a video geared directly towards end-of-life care for African Americans and other minorities. PPHPC credits its success to building strong relationships, initiating community gatherings and always making face-to-face contact (as opposed to direct mailings). While promoting OVAT events, it also sought to build the initiative beyond hospice. OVAT has become a community-building and enriching program, and together with the strong ties built with both the African American and other minority communities, continues to spread the message of hospice and palliative care.

D. FOCUSING ON CHILDREN:

HOSPICE AND PALLIATIVE CARE OF GREENSBORO, GREENSBORO, NORTH CAROLINA

Kids Path, a unique children's hospice program developed by Hospice and Palliative Care of Greensboro, is the most diverse program of all those offered by the organization, serving well over fifty percent minorities in both North and South Carolina and West Virginia. Housed in its own facility, it cares for children ages 3 – 18 who are living with serious, progressive medical conditions. In addition, it provides support for children and youth experiencing the grief associated with the illness or death of a loved one.

The goal of Kids Path is to enhance the quality of life for children and those who share their lives while regaining a sense of normalcy. Ursula Robinson, Vice President of Clinical Services, explains that “the program is unique in that it targets all sick children, not only those with a six-month prognosis and eligible for Medicare, but situations where the doctor does not believe they will reach adulthood. It is palliative care in the truest sense.” Currently serving 40 children, it also reaches out to grieving children whose parents are in hospice. Kids Path is the only vendor allowed in the Guilford County school system.

While the demographics of the area show a majority of Caucasian residents, Hospice and Palliative Care of Greensboro and Kids Path serves a very high percentage of African Americans in the community, more than the average hospice. Robinson works with families and the wider community, emphasizing education. “For those who are eligible for hospice benefits and services, it is their right to receive them. We find that far too many don't utilize hospice simply because they don't understand what is available and what they are entitled to.” For African American families with terminally ill children, Kids Path serves a community need that offers quality care to minorities, while building trust, faith, hope and understanding.

V. Resources for African American Outreach

A. PROFESSIONAL ORGANIZATIONS

- **Bureau of Labor Statistics (BLS)**, www.bls.gov/news.release/empsit.nr0.htm, is the principal fact-finding agency for the federal government in the field of labor economics and statistics. The BLS is an independent national statistical agency that collects, processes, analyzes and disseminates essential statistical data to the U.S. public, Congress, other federal agencies, state and local governments, and the business and labor sectors.
- **Caring Connections**, www.caringinfo.org, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. Caring Connections provides free resources and information that address end-of-life issues such as advance care planning, serious illness, caregiving, grief and more.
- **Duke Institute on Care at the End of Life**, www.iceol.duke.edu, is a catalyst for growth and transformation, a global resource to improve care for those at life's end. The mission of the Institute is to create and promote the growth of knowledge and to encourage the application of that knowledge in caring for the whole person at life's end.
- **Institute of Medicine of the National Academies (IOM)**, www.iom.edu/?id=33252, provides a vital service by working outside the framework of government to ensure scientifically informed analysis and independent guidance. The IOM's mission is to serve as adviser to the nation to improve health. It provides unbiased, evidence-based and authoritative information and advice concerning health and science policy to policy-makers, professionals, leaders in every sector of society and the public at large.
- **National Center for Cultural Competence (NCCC)**, www11.georgetown.edu/research/gucchd/nccc, provides national leadership and contributes to the body of knowledge on cultural and linguistic competency within systems and organizations. Major emphasis is placed on translating evidence into policy and practice for programs and personnel concerned with health and mental healthcare delivery, administration, education and advocacy.
- **National Center for Health Statistics (NCHS)**, www.cdc.gov/nchs/fastats/black_health.htm, is the nation's principal health statistics agency and operates as a part of the Centers for Disease Control and Prevention. The NCHS compiles statistical information to guide actions and policies to improve the health of US citizens. It serves as an excellent public resource for health information and a critical element of public health and health policy.

- **National Hospice and Palliative Care Organization (NHPCO)**, www.nhpco.org, is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end-of-life and their families.
- **Office of Minority Health (OMH)**, www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=51, seeks to improve and protect the health of racial and ethnic minority populations through the development of health policies and programs that will eliminate health disparities. It advises the federal government on public health program activities affecting American Indians and Alaska Natives, Asian Americans, Blacks/African Americans, Hispanics/Latinos, Native Hawaiians and other Pacific Islanders.
- **Robert Wood Johnson Foundation**, www.rwjf.org/reports/grr/046134.htm, seeks to improve the health and healthcare of all Americans. Its efforts focus on improving both the health of everyone in America and their healthcare – how it's delivered, how it's paid for, and how well it does for patients and their families.
- **U.S. Census Bureau**, www.census.gov/prod/2007pubs/acs-04.pdf, serves as the leading source of quality data about the nation's people and economy. This link is to a 2004 report that present a portrait of the African American population in the U.S. It provides a wide range of information on demographic, social, economic and housing characteristics of the population.

B. EDUCATIONAL TOOLS

- **APPEAL (A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End) Training, Duke Institute on Care at the End of Life**, www.iceol.duke.edu/events/2008appealtraining.html, is designed for healthcare professionals working with African American patients and families facing serious illness in hospitals, hospices, outpatient clinics, nursing homes and office-based settings and covers a wide range of issues pertinent to end-of-life care, from cultural issues to healthcare disparities. Participants include physicians, nurses, social workers, medical chaplains and other clergy, psychologists, counselors, hospice and hospital administrators, pharmacists and family caregivers.
- **Key Topics on End-of-Life Care for African Americans**, Duke Institute on Care at the End of Life, www.iceol.duke.edu/resources/lastmiles/index.html. Topics covered in this on-line book range from the impact of health disparities on end of life decision-making to spiritual aspects of care at life's end, to sociological and cultural perspectives on death and dying and finally, even to health policy considerations. The information is provided for individuals and organizations interested in increasing their understanding of African American perspectives on end-of-life care that influence important questions such as access to hospice and palliative care, and the quality of care delivered in those settings.

C. WEB SITES

- **African Americans.com**, www.africanamericans.com/Demographics.htm, has over 750 web pages on the African American community. The site covers many topics, including black history, the civil rights movement, slavery, African American art, and black gospel music. It also includes profiles of famous African American historical leaders such as Martin Luther King Jr., Muhammad Ali, Frederick Douglass, as well as current black celebrities, like Tiger Woods, Michael Jordan, Serena Williams, and more.
- **Black Demographics.com**, www.blackdemographics.com, provides interesting facts and statistics about the African American population nationwide.

D. LITERATURE

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VI. Acknowledgements

Author:

Juliette Marchioli

National Hospice and Palliative Care Organization
Alexandria, VA

Contributors:

Lyla Correoso, MD

Visiting Nurse Service of New York
New York, NY

Cassandra Cotton, CNA, CHPNA

Nathan Adelson Hospice
Las Vegas, NV

Bernice Catherine Harper, MSW, MSc.PH, LLD

Former Medical Care Advisor, HHS
Founding President, FHSSA
Former Board Member, NHPCO
Rockville, MD

Sharon R. Latson, BA

VITAS Innovative Hospice Care® of Chicagoland
Chicago, IL

Jennifer Moore, PhD

A Touch of Grace Hospice, Inc.
Chicago, IL

Stacie Pinderhughes, MD

North General Hospital
New York, NY

Gloria Ramsey, JD, RN

Uniformed Services University of the Health Sciences
Bethesda, MD

Ursula Robinson, MSW, LCSW

Hospice and Palliative Care of Greensboro
Greensboro, NC

Sally Sharpe, RN

Pike's Peak Hospice & Palliative Care
Colorado Springs, CO

Toula Wootan, MSH

Community Hospice of Northeast Florida
Jacksonville, FL

NHPCO Staff:

Melanie Abijaoude

Philip Banks

Kathy Brandt, MS

Helen Ennis

Gwynn Sullivan, RN, MSN

Emil Zuberbueller, BS

Duke Institute on Care at the End of Life:

Tracey A. Adams, M Div

Richard Payne, MD

Jeanne Twohig, MPA

VII. Appendix

Click on links below to view and download the documents. All documents may be accessed at

www.caringinfo.org/community

then clicking on “Diversity Outreach”.

[Proctor Covenant Statement on End-of-Life Care \(pdf\)](#)

[Advance Directives and End-of-Life Decisions \(ppt\)](#)

[Understanding Hospice, Palliative Care and End-of-Life Issues \(ppt\)](#)