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# How Faith Communities Facilitate Conversations Around End-of-Life Concerns

Interviews show the benefits of training and engagement on advance care planning

## Overview

Advance care planning is a process that allows an individual to discuss and document his or her preferences and values regarding medical care in the case of a serious or life-limiting disease. This medical and legal process seeks to ensure that patients receive the care they want in the setting of their choice. It may also reduce stress on family members and avoid conflict among them. Ideally, such advance care planning conversations would take place well before the end of life. According to one study, some 70 percent of people over the age of 60 who were in an inpatient setting and had to make a decision about treatment during the last week of life were physically unable to communicate their wishes to family or clinicians.<sup>1</sup> Yet research indicates that only about 1 in 3 Americans has completed any advance care plan for the end of life.<sup>2</sup>

Advance care planning typically includes a patient-initiated advance directive, which names a health care agent—an individual designated in a legal document to make a health care decision for the individual granting the power—and describes the type of care a person would want. Effective planning requires individuals to engage in potentially difficult conversations with loved ones and ensure that legal documents are available to relevant caregivers. It can also include physicians' medical orders, such as a Do Not Resuscitate (DNR) order or Physician Orders for Life-Sustaining Treatment (POLST).

The rate at which members of racial and ethnic communities engage in advance care planning varies. For example, African-Americans are less likely to have advance care plans than non-Hispanic whites, which may reflect a historic mistrust of the health care system, less knowledge of and access to services, and spiritual beliefs (for instance, that God controls and determines the time of death). One patient in a 2016 qualitative study of African-American hospice patients and their caregivers told researchers, “I didn’t feel comfortable just going along with the doctor’s advice. I mean she obviously was the one telling me how sick I was, but I couldn’t see myself in hospice until I talked to a person at my church about it.”<sup>3</sup>

This perspective supports a key finding of the examples presented in this report: Faith communities can complement health care systems as sources of information and support as people consider health care decisions in life-threatening situations. These experiences were selected from a geographically and theologically diverse group of religious communities from across the United States: a Jewish community in New York City; a group of six predominantly African-American churches in Los Angeles; a mosque in Atlanta; a United Methodist Church in Rochester, Minnesota; the Catholic Archdiocese of Los Angeles; and a nondenominational church in Fraser, Michigan. The final example discusses the work of hospital chaplains who serve people of faith and play an important role in ministering to the increasing number of patients unaffiliated with any religious organization but who nevertheless have spiritual concerns, including questions about advance care planning, as they experience serious illness.

The following examples are the product of telephone interviews with faith leaders, congregants, chaplains, and others during the fall of 2016 and early 2017. These illustrations are not representative of the full spectrum of religious thought about, or activity around, advance care planning within these communities or American society. Instead, they were selected because they offer a number of instructive stories about the ways in which people of faith are already engaged in conversations about serious illness care.

This document also includes a brief description of the advance care planning tools used in these communities and mentioned here frequently, a glossary, and the websites of organizations involved in advance care planning.

Across the examples discussed here, four themes emerged:

- **Faith communities are a natural, appropriate venue for advance care planning.** Many faith leaders shared stories of congregants’ relief and gratitude at the opportunity to confront difficult questions within the context of their community. Numerous interviewees called advance care planning “a gift” or “a blessing” for their families that would save them from the pain of making uninformed medical decisions when confronted by a crisis.
- **For people of faith, advance care planning can be simultaneously a theological, medical, and legal process.** For example, Catholic ethics distinguishes between medical care that is “ordinary,” which the dying patient must receive, and “extraordinary,” which the patient can refuse. A particular medical treatment, such as the use of a ventilator, can be either ordinary or extraordinary, depending on the circumstances. The Rabbinical Council of America recommends that Orthodox Jews present all end-of-life issues and questions to an authority on Jewish law, preferably before the issues become urgent. Attempts to engage people of faith in advance care planning should consider relevant theological teachings and include faith leaders, chaplains, or religious scholars as complementary resources for medical decision-making.
- **Some faith communities make a theological distinction between actions taken to hasten death (such as suicide or euthanasia) and the decision to forgo or withdraw life-sustaining treatment when death is inevitable.** Many faith communities believe that life is a gift from God and that only God can determine the time of death. At the same time, many also believe it is morally acceptable to forgo or withdraw life-sustaining

medical treatment when there is little likelihood of survival. This distinction was notable in some traditions' statements, though tremendous nuance and complexity are contained within. It is often a challenge for family members to interpret these statements in the context of an individual patient's health situation.

- **Many faith communities are open to a variety of tools for advance care planning, including trainings, workshops, sermons, book discussion groups, film screenings, forums, and even board games.** These tools can be grounded in a particular theology or be universally applicable. The source of information about advance care planning matters to people of faith and should be a key consideration in developing resources. While some faith communities welcome outside experts, others prefer that information come from trusted community leaders.

These experiences demonstrate that, for people of faith, preparing for death can be not only a gift they provide to their family, but also a way to express their faith in God's plan; it can be an expression of religious gratitude for life and the anticipation of a better world. The people portrayed here do not express a conflict between trusting in God and documenting their medical choices. For them, advance care planning can be an enactment of that very trust, and a way to embrace their faith to the end of their lives. These examples are intended to provide thought leaders in religious communities and the health system with examples they might use to enact similar collaborative models in their own communities.



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## How We Can Make the End of Life Personal Again

By Ira Byock, M.D.

Before the 20th century, sickness and dying in the United States took place amid one's family, friends, and immediate community. Doctors did what they could but generally played minor roles. Things changed abruptly in the late 1930s and early 1940s with the advent of new antibiotics like penicillin. Suddenly, people began surviving conditions such as pneumonia, kidney infections, and ruptured appendices. World War II accelerated advances in anesthesia, surgery, and lifesaving treatments of sepsis and trauma. The lesson that my generation, the baby boomers, took away from the advances in medicine was that progressively ill people needed progressively more intensive treatments.

From the symptoms that lead to a diagnosis through the eventual, inevitable decline of health and function, illness and dying remain fundamentally personal. Throughout history, when people's lives have been threatened—dissolving any pretense of invincibility—they have turned to their community, and often their community's faith leaders, for support. Today's churches, synagogues, mosques, temples, and meeting houses remain places of comfort and caring, safe and supportive environments for discernment and discussion about the guidance our spiritual traditions can offer to those facing life's most difficult passages. Faith leaders and communities may be uniquely suited to convene conversations concerning matters of mortality.

In our contemporary world, there are special advantages to convening conversations about advance care planning within a religious or spiritual community. From a cultural perspective, doing so liberates illness, caregiving, dying, and grieving from the exclusive confines of medical experts. More tangibly, sessions such as those described in this report provide practical information that can guide people in making good use of lifesaving treatments consistent with their own wishes, with direction from their faith's tenets and teachings.

Doctors and other health care professionals bring to the discussion their expertise in diagnostics and therapeutics. Patients, and when appropriate their families and faith leaders, bring their individual values. Together, clinicians and the people they serve can determine the best course of treatment at any point in time.

And for faith communities, coming together to support one another in exploring and planning for these most profound problems of human life can enhance a sense of meaning and purpose. In fact, while advance care planning is a good place to start, faith communities can play broader, vitally important roles in supporting people through illness, caregiving, dying, and grieving.

Those of us who are drawn together by common beliefs, prayers, and practices can ensure that as age or infirmity takes its inevitable toll, members of our community are not forgotten. Faith communities can accompany people who are vulnerable on a journey that they have not chosen. We can make certain that they are not abandoned and that their most basic physical needs are met, by keeping them safe, warm, dry, and as comfortable as possible. We can bear witness to their suffering, as well as their continued dignity and worth. We can celebrate their accomplishments and honor their contributions.

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Conversations around end-of-life matters are evidence of a significant cultural trend: the reclaiming of illness and dying from the realm of medicine and returning it to the sovereignty of personal experience. By rebalancing the proper role of health care in service to families and communities, we can ensure that each person receives the best care possible. People of faith can support one another not only in living fully but also in dying well.

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## What Matters

### Caring Conversations About End of Life—Advance Care Planning in a Jewish Community | New York City

What Matters: Caring Conversations About End of Life was established in 2015 to bring the Respecting Choices model of advance care planning facilitation to this Jewish community.<sup>4</sup> “We found that when people are thinking about or dealing with serious illness, they are curious about what their Judaism says,” according to Sally Kaplan, program director of What Matters. “Sometimes they are fearful to bring it up. This is letting people know that Judaism does have points of view, but it’s very inclusive.”<sup>5</sup>

Approximately 4.2 million people in the United States identify their religion as Jewish.<sup>6</sup> What Matters aims to develop resources that speak to people no matter where they are on the spectrum of Jewish observance. To that end, the program created a document, “Understanding Advance Care Planning as a Jewish Process,” which highlights particular Jewish values: that life is sacred; that the tradition of “sacred dialogue” can be applied to

health care decisions; and that the Jewish tradition of an ethical will can be a model for end-of-life discussions.<sup>7</sup> This resource also provides links to Jewish perspectives on advance directives from the governing bodies of the three major denominations in the community: the Rabbinical Council of America (Orthodox), the Rabbinical Assembly (Conservative), and the Union for Reform Judaism.

What Matters also partnered with the Center for Pastoral Education at the Jewish Theological Seminary to create Sage Voices, a set of videos of rabbis and religious leaders discussing end-of-life medical decisions such as artificial nutrition and hydration, life support, and DNR orders.<sup>8</sup> The Jewish Theological Seminary is one of the main centers of rabbinic training in the country.

What Matters is a collaboration among agencies in New York City, including The New Jewish Home, a nonprofit that provides care for elders; the Center for Pastoral Education; and the JCC Manhattan, a Jewish community center on the Upper West Side. According to the JCC Association, there are 350 Jewish community centers and camps across the U.S.<sup>9</sup> Plaza Jewish Community Chapel, a nonprofit, community-owned Jewish funeral home, provided the initial funding for What Matters. In the second year, the UJA-Federation of New York, which is the fundraising and social services arm of the local Jewish community, offered additional funding.

In the first year, 34 people from What Matters trained to be certified facilitators by completing the Respecting Choices “First Steps” online learning modules and an additional online module on Jewish values developed by the Jewish Theological Seminary.<sup>10</sup> The new facilitators also completed a one-day in-person training. The first five pilot sites included three congregations (a Reform, a nonaffiliated, and a Modern Orthodox synagogue) as well as The New Jewish Home and JCC Manhattan. Each site has a team of What Matters facilitators to help members with advance care planning conversations.

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“ Advance care planning is not something that people normally think of, even those of us who have always been a member of a synagogue. We would think of the birth, the burial, the marriage. Yes, that’s when I turn to my synagogue. But not this. This is new ground. This is a new idea.”

Howard Sharfstein

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To date, facilitators at the first five sites have had more than 175 individual conversations, sometimes including family members or the health care agent. For many people, these conversations are the start of a thoughtful planning process that encourages them to speak with their physician, rabbi, lawyer, or family members about their wishes long before a crisis arises. “Our goal is to achieve a culture change in the Jewish community,” said Kaplan. “We consider it a major shift when we see people become open to talking and learning about advance care planning, reflecting on their options, meeting with their clergy to explore Jewish values, and starting conversations with their loved ones.”<sup>11</sup>

Howard Sharfstein is a What Matters certified facilitator at Central Synagogue, a Reform congregation in midtown Manhattan. Until recently, he had never talked about his own end-of-life wishes, despite being a trusts and estates lawyer and a two-time cancer survivor.<sup>12</sup> Now he understands the gift these conversations can be. “Advance care planning is not something that people normally think of, even those of us who have always been a member of a synagogue. We would think of the birth, the burial, the marriage. Yes, that’s when I turn to my

synagogue. But not this. This is new ground. This is a new idea," said Sharfstein. "But when people start to think about it and reflect upon it, they realize it's a gift. It's a gift to themselves, and a gift to their families."<sup>13</sup>

Sharfstein and others work to make What Matters part of the fabric of this community of 2,300 families by keeping members informed at services, through web resources, and by word of mouth. Sharfstein has spoken with congregants himself after services. "They have just had an hour and a half of prayer and reflection," he said. "I ask, 'Have you reflected on this?'"<sup>14</sup>

Sarah Robinson is a social worker at the Shira Ruskay Center at The Jewish Board and one of five facilitators at Lincoln Square Synagogue, a Modern Orthodox community of 700 families where her husband is the rabbi.<sup>15</sup> The facilitators introduced What Matters to the congregation by connecting it to that week's Torah portion about the death of the patriarch Jacob, who blessed and prepared his sons for his death. The response was immediate: Congregants at each of the three services told facilitators they would like to have a conversation. "It's an amazing opportunity to give your members a voice," Robinson said. "It is a way to be respectful of them and make them the center of congregational life."

The second year of What Matters began in September 2016 and includes four new pilot sites: DOROT (a nonprofit that provides services to the elderly; its acronym is the Hebrew word for "generations") and three new synagogues (Modern Orthodox, Conservative, and Reconstructionist). They have certified 32 new facilitators and 10 instructors, who are able to train new facilitators.<sup>16</sup>



## **Closing the Gap About Crossing Over**

### Addressing the Disparity in Advance Care Planning Among Elderly African-Americans | Los Angeles

This pilot program provides training for African-American pastors and lay leaders. It was designed by Dr. Maisha Robinson, assistant professor of neurology and chair of palliative medicine at Mayo Clinic in Jacksonville, Florida. She grew up in Memphis, Tennessee, the daughter of African Methodist Episcopal Church pastors, and became a scholar in the Robert Wood Johnson Foundation Clinical Scholars Program at the University of California, Los Angeles. There, she developed the program as a way to combine her interests in advance care planning, faith, and neurology.<sup>17</sup>

Robinson found a key partner in Dr. Gwendolyn Phillips Coates, a bishop elected by the Dominion Assembly of Christian Churches, who had worked with underserved communities for Providence Hospice of Seattle. She worked largely through the African-American church, social events, and outreach opportunities.<sup>18</sup> Coates uses

Christian theology to support her advocacy for advance care planning. “My model is Jesus, who was constantly telling his disciples, ‘I’ve got to leave. I’ve got to die. So let me help you get ready for my death,’” she said.<sup>19</sup> Coates points out that everyone that God healed in the Bible is dead today as she urges people of faith to document their end-of-life wishes, no matter what they are, as a way to “give peace to your family.”<sup>20</sup>

Research shows that some African-Americans lack familiarity with advance care planning, are less likely to have advance care plans than non-Hispanic whites, and mistrust the health care system.<sup>21</sup> They may place greater emphasis on communal decision-making in serious illness and on individual religious beliefs and practices that may appear to be at odds with end-of-life planning.<sup>22</sup> These include the Christian belief that God allows everything that happens, both disease and miracles, and that end-of-life planning “may interfere with God’s plan.”<sup>23</sup>

With these concerns in mind, Robinson and Coates developed a multistage pilot intervention to train pastors and lay leaders in six predominantly African-American Christian churches in Los Angeles.<sup>24</sup> To address mistrust of the health care system, they focused their training on helping clergy members become knowledgeable and conversant about advance care planning and invited participants to bring family members and friends to discuss concerns about communal decision-making. Robinson and Coates were confident that pastors and church leaders could, on their own, address religious questions in their own communities.<sup>25</sup>



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Dr. Gwendolyn Phillips Coates

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The Rev. Joyce Reece Kitchen, the pastor at Emmanuel-Henry McNeal Turner African Methodist Episcopal Church, was looking for an advance care planning tool when she learned about the pilot program. “Our faith doesn’t stop at the door of the hospital. Our faith is an integral part of our decisions and everything we do, and it should be included in end-of-life concerns,” she said. “Especially at the end of life, people don’t call the doctor. They call the pastor.”<sup>26</sup>

In the program’s first phase, Robinson and Coates met with community leaders, clergy, and church members and leaders to discuss barriers to advance care planning and to determine the training components that they would find the most useful. Then they offered a four-hour training to pastors and lay leaders with a curriculum that included an overview of advance care planning, the Five Wishes advance directive document, the role of a health care proxy, and cultural and religious beliefs that affect perceptions of advance care planning.<sup>27</sup>

In the next phase, Robinson and Coates invited pastors and lay leaders to a two-hour training on Five Wishes at the Alliance for Living and Dying Well in Santa Barbara, California. After the session, the pastors and lay leaders created individual presentations for their congregations and reviewed them with Robinson and Coates, who paid presentation participants for their time and surveyed them before and after the presentation. The data they collected is being analyzed for publication, and they hope to offer the intervention on a larger scale.

Reece Kitchen has given the presentation she developed with Robinson and Coates to her congregation four times and is scheduled to offer it to another congregation where her son is the pastor. She has also set a date to share it with a large group of her own family members. “I’m trying to make sure as many people as possible have the information,” she said.<sup>28</sup>



## **Two Decades of Advance Care Planning at Christ United Methodist Church**

Rochester, Minnesota

For nearly 20 years, the Rev. Nancy Wheeler Handlon, parish nurse Patricia Hrabe, and others have offered education to parishioners of Christ United Methodist Church about end-of-life choices and planning. Wheeler Handlon, a former hospice chaplain and bereavement coordinator, was appointed the minister for congregational care at the church in Rochester, Minnesota, in 1998.<sup>29</sup> She believes the foundation for congregational care is based on Jesus' ministry of love and compassion for all of God's children.<sup>30</sup> "Each person is sacred and holy because God breathes into them the breath of life, and God will be with them when they take their last breath," she said.<sup>31</sup>

As a parish nurse for 18 years, Hrabe feels that she was able to offer congregants nearing the end of life and their families a valuable connection to their faith.<sup>32</sup> Parish nurses are registered nurses who provide health care resources in congregational settings and serve as health counselors and educators.<sup>33</sup> Along with another parish nurse, Ann

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“ I have come to see that persons who work on these issues are able to live life more fully. The other side of this is that I have seen many people not deal with these issues until their life is nearly over, burdened through much of life with unresolved grief and pain.”

—the Rev. Nancy Wheeler Handlon

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Loth, Hrabe taught classes on advance directives and a series called Life's Journey, which included discussion on spiritual needs, hospice care, funeral planning, grief, and legal planning.<sup>34</sup>

Several years ago, Wheeler Handlon and Hrabe presented Living Fully, Dying Well, a curriculum developed by the late Methodist Bishop Rueben Job that covers topics related to advance care planning and what Job called the “theology of aging.” Each chapter has an accompanying section on a DVD and begins with a teaching point, a section of Scripture, and educational content.<sup>35</sup>

The United Methodist Church (UMC) is a Protestant denomination with more than 7 million lay members in the United States.<sup>36</sup> Key documents from the denomination include “Faithful Care for Dying Persons” in the Social Principles of the UMC, which urges all persons to discuss their wishes with family, physicians, and pastoral counselors, create an advance directive, and use hospice care at the end of life. The UMC rejects euthanasia and affirms God’s “love and purpose for all persons, regardless of health.”<sup>37</sup> According to The Book of Resolutions of The United Methodist Church, there is no requirement to use life-sustaining treatments “when the burdens they impose outweigh the benefits they offer, or when the use of medical technology only extends the process of dying.”<sup>38</sup>

Christ United Methodist Church is a progressive church of 800 to 1,000 members and a member of the Reconciling Ministries Network, which seeks to welcome all people to full participation in the United Methodist Church.<sup>39</sup> It is heavily influenced by the proximity of Mayo Clinic, a major integrated health system that has 30,000 employees in the area and draws the majority of the 3 million annual visitors to Rochester.

In September 2015, Hrabe and congregant Kathy Estry attended a public event with surgeon and author Dr. Atul Gawande sponsored by the Minnesota Network of Hospice and Palliative Care.<sup>40</sup> Inspired by the event, Hrabe and Estry searched for resources in the Rochester medical community and connected with Honoring Choices Minnesota, an advance care planning initiative based on the Respecting Choices model. Honoring Choices Minnesota shared resources, including a sample advance directive; it also provided a representative who could participate in a church forum. Hrabe and Estry then offered follow-up sessions using additional advance care planning tools: a game designed to help start conversations around end-of-life preferences called My Gift of Grace; a screening of a “Frontline” series episode, “Being Mortal”; The Conversation Project Starter Kit; and Honoring Choices’ advance directives.<sup>41</sup>

Wheeler Handlon believes that faith communities should offer education about end-of-life issues regularly, help alleviate the fear of death, and be available when people feel ready to talk. “As a pastor and chaplain working with persons at the end of their lives for 30 some years, I have come to see that persons who work on these issues are able to live life more fully. The other side of this is that I have seen many people not deal with these issues until their life is nearly over, burdened through much of life with unresolved grief and pain. So many of our older ones were never told they could grieve the death of a baby, the death of a brother who never came back from the war, the pain of growing up with a parent’s alcoholism, and other situations. It is a matter of becoming aware of what is most precious to us in life, coming to peace with those who matter most to us, and having a close relationship with God that enables us to live life in all its richness,” she said.<sup>42</sup>



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## Islamic Last Will and Testament Workshop Al-Farooq Masjid Atlanta

For the past several years, Al-Farooq Masjid, the largest mosque in Atlanta, has offered programs on completing an Islamic will. The Quran recommends that Muslims create a will, a practice that was emphasized by the Prophet Muhammad.<sup>43</sup> The Islamic will provides for the distribution of assets according to Islamic law. It also allows Muslims to request a Muslim burial, name a health care agent, and request that end-of-life medical decisions be made according to Islamic law.<sup>44</sup>

Although mosques do not have formal membership, approximately 1,000 people gather for prayer on Fridays at Al-Farooq Masjid. Dr. Y. Khalid Siddiq, the former mosque director who now serves as the director of outreach programs and education, is a physician who moved to the United States from Pakistan more than 40 years ago.<sup>45</sup> "Mosques should focus on and emphasize the practical application of Islamic faith and its practices in the everyday life as a Muslim. Things which Muslims take for granted when they live in a Muslim country," Siddiq said.<sup>46</sup> He believes all mosques should hold programs on basic Islamic teachings around end-of-life concerns.

For the past several years, Al-Farooq Masjid of Atlanta has held programs on Islamic wills, each of which was attended by about 150 people.<sup>47</sup>

According to Siddiq, Muslim families typically use a collective approach to medical decision-making, coming to a decision together rather than vesting the decision in one person. In addition, Muslim culture and tradition assume that individuals will seek treatment as it is needed. For these reasons, completing a health care proxy form can be a relatively less important part of the program on Islamic wills.<sup>48</sup>

At the same time, the majority of American Muslims (63 percent<sup>49</sup>) are immigrants to the United States and often lack a broad family structure of support locally. So Siddiq frequently recommends that community members name a health care proxy, even though it is not a major part of advance care planning in Muslim communities outside the U.S.



As Muslims, our theology is to be very conscious of the fact that we're going to pass away one day and to act accordingly, to try to be as good as we can all our lives."

Edward Mitchell

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Euthanasia or suicide is strictly forbidden in Islam.<sup>50</sup> Muslims should seek treatment in life-threatening situations, but pursuit of treatment is discouraged when knowledgeable experts agree that the side effects will outweigh the benefits or that the treatment will be futile.<sup>51</sup> The code of ethics of the Islamic Medical Association of North America (IMANA), an association of Muslim physicians, states that when a team of physicians has determined that death is inevitable, the patient "should be allowed to die without unnecessary procedures. ... If the patient is on mechanical support, this can be withdrawn." IMANA provides a sample Islamic Living Will and Advance Directive and recommends that health care providers encourage Muslims to complete it.<sup>52</sup>

Recently, Edward Mitchell, the executive director of the Georgia chapter of the Council on American-Islamic Relations (CAIR-Georgia) and the Al-Farooq Masjid jointly offered an interactive workshop on Islamic wills and inheritance law, Muslim burial practices, and the role of the health care proxy. Participants in the workshop received a copy of an Islamic Last Will and Testament that they could complete during the event.<sup>53</sup>

An attorney, Mitchell developed this workshop at the request of his father, who saw members of the African-American Muslim convert community going through the dying process without an Islamic will. Mitchell received a positive response to his initial presentation at the Islamic Community Center of Atlanta and has since made the workshop one of CAIR-Georgia's regular offerings, presenting it at about a dozen of the 81 mosques in and around Atlanta.<sup>54</sup>

Mitchell believes that Muslims, like many other Americans, postpone end-of-life planning because of their busy schedules but that they are not resistant to the subject. "As Muslims, our theology is to be very conscious of the fact that we're going to pass away one day and to act accordingly, to try to be as good as we can all our lives," he said.<sup>55</sup> He is encouraged by the number of invitations he receives to present the workshop. "We've had experiences with Muslims who pass away without anything written down, and it creates chaos if the family has a disagreement about what to do. And so I think that is a problem within our community and part of the reason we do the seminar is to address that problem."<sup>56</sup>



## **Leaving a Legacy of Love: New Life Ambassadors for Christ Christian Church**

Fraser, Michigan

Minister Philesha Gough is a spiritual care ministry leader at New Life Ambassadors for Christ Christian Church in Fraser, Michigan, and a health minister trained by the Henry Ford Macomb Faith Community Nursing Network (FCNN). She points to research and Scripture indicating that good health requires the care of body, mind, and spirit. “You’re holding issues internally and not finding an avenue to release them,” she said. “They could cause health problems, such as high blood pressure or heart issues caused by stress.”<sup>57</sup> The guiding Scripture of her health ministry is 3 John 1:2. “Beloved, I pray that you prosper in all things and be in health, just as your soul prospers.”<sup>58</sup>

Gough brings this perspective to her work as a certified “First Steps” facilitator for Respecting Choices, an advance care planning system, and to the Leaving a Legacy of Love series of seminars she has presented. So far, she has shared this series with four congregations.

New Life Ambassadors for Christ Christian Church is a predominantly African-American nondenominational church of about 100 to 125 members. Gough became a health minister in 2008 after completing more than 35 hours of training from the FCNN. More than 35 congregations in Macomb County belong to this network of parish nurses and health ministers, whose purpose is “to develop whole person (spirit, body, mind, and relationships) health ministries that enhance well-being and relieve suffering among congregational members” and the communities in which they are located.<sup>59</sup>

The Rev. Ameldia Brown is the director of the FCNN and the associate pastor at New Life. As a Christian pastor, her support for advance care planning is based on her belief that Jesus has taken the “sting” out of death and that, after death, the spirit will be in a better place and in the joyful presence of the Lord. “Advance care planning can help individuals to realize, discuss, and embrace these truths in a way that increases their experiences of the love of God,” she said.<sup>60</sup>

When the FCNN started in 1994, parish nurses and health ministers told Brown they needed advance care planning resources. “It kept coming back to end of life, to death and dying, and how angry parishioners were at the pastors and leadership for not doing enough around end-of-life decision-making,” she said.<sup>61</sup> Brown became a certified facilitator through Respecting Choices and then made their facilitator training available to the FCNN. More than 40 of the 53 parish nurses and health ministers have completed the training. The goal of the FCNN is for 80 percent of the parish nurses and health ministers to maintain this credential.

After Gough completed her “First Steps” facilitator training, she and a team of community leaders presented a three-part “Lunch and Learn” series, called Leaving a Legacy of Love. This series was developed by Brown and community members, including a mortician and an insurance agent. Leaving a Legacy of Love is a modified version of a presentation given to Respecting Choices class facilitators for free use.



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the Rev. Ameldia Brown

The first session, led by Brown, focused on having conversations about end-of-life decisions, including selecting a patient advocate, completing a living will, and using Five Wishes.<sup>62</sup> In the second session, an insurance agent discussed financial planning. The third was led by a funeral director who discussed planning for funeral expenses.

The sessions have had a significant impact. One participant, who served as a caregiver for a dying family member, decided to make advance funeral arrangements for a loved one who died soon thereafter. She reported that it alleviated her stress because she had gone through the sessions, said Gough.<sup>63</sup>

Gough is also a licensed minister who presides at and coordinates funerals for her church. In many African-American Christian churches, a funeral is also called a homegoing. “If we know this person has lived a godly life, and they have given their life over to God as a servant to the Lord, they are going home to have eternal life with the Lord,” she said. Although she knows from personal experience that death causes grief and bereavement, it can also be a time of joy. “I think about my mother and others who have passed away in the Lord. I know that I will see them again. And that’s why it’s a joyful occasion when someone passes on in the Lord.”<sup>64</sup>



## Care and Prepare

### Finding Loving Care at the End of Life—Archdiocese of Los Angeles | Los Angeles

In 2015, as California lawmakers and voters discussed state legislation that would eventually legalize physician-assisted suicide, the Roman Catholic Archdiocese of Los Angeles discovered that its members needed more information about the Catholic ethics of end-of-life care. “We could sense that they understood that there was a teaching, but the majority hadn’t heard it or didn’t understand,” said Kathleen Buckley Domingo, associate director of the Office of Life, Justice, and Peace at the Archdiocese of Los Angeles.<sup>65</sup>

Catholic teaching on this subject includes *The Gospel of Life* by Pope John Paul II and two statements by the United States Conference of Catholic Bishops: “To Live Each Day With Dignity: A Statement on Physician-Assisted Suicide” and “The Ethical and Religious Directives (ERDs) for Catholic Health Care Services.”<sup>66</sup> The ERDs expressly forbid euthanasia and distinguish between “ordinary or proportionate” means of preserving life, and “extraordinary or disproportionate” means. Individuals are required to preserve life using proportionate means,

which, in the judgment of the patient, “offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community.”<sup>67</sup> Persons may forgo disproportionate means.

The Archdiocese of Los Angeles is the largest in the country, serving nearly 5 million individuals. Mass is offered in more than 40 languages across 287 parishes.<sup>68</sup> Latinos, the largest ethnic group in the archdiocese, are represented in every parish.<sup>69</sup> Archbishop José H. Gomez, the highest-ranking Hispanic bishop in the United States, leads the archdiocese. He has written that “there is no precise dividing line” for categorizing a method as proportionate or disproportionate means, but his writing offers some reflection and teachings on how to distinguish between the two.<sup>70</sup>

The archdiocese reached out to Dr. Ira Byock, founder and chief medical officer of the Institute for Human Caring of Providence Health & Services in Torrance, California.<sup>71</sup> Byock describes himself as a Jewish, liberal, progressive palliative care physician who has long opposed physician-assisted suicide.<sup>72</sup> When the aid-in-dying law was enacted in California in June 2016, the archdiocese and the Institute for Human Caring developed a training called Care and Prepare: Finding Loving Care at the End of Life, which is offered to any parish that requests it. So far, 30 trainings have taken place.<sup>73</sup>



Once you realize dying is personal, people of faith can support each other in these very difficult, but normal, times in human life.”

Dr. Ira Byock

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At the workshop, leaders from the archdiocese discuss the new law and offer an overview of Catholic moral theology. Representatives from the institute discuss ways to find good medical care and the process of writing an advance directive. The workshop concludes with shared stories, questions, and discussion.<sup>74</sup> The response to the workshops has been extremely positive. Patricia Osman, a former nurse and retired social worker, organized the workshop at St. Paul the Apostle Catholic Church in October 2016. “Most of us dread the dying process,” she said. “I think that this workshop added some grace to the process.”<sup>75</sup>

The partnership between the Institute for Human Caring and the archdiocese has been transformative for the archdiocese and for Catholics in the community. In October 2016, Byock spoke to a gathering of 700 priests and the archbishop about advance care planning and the importance of access to quality hospice and palliative care. Some people will choose to legally hasten their death as this is the world we now live in, Byock said. The responsibility—in both health care and in faith communities—is to provide the best care possible and ensure that people feel wanted, worthy, and dignified through the very end of life.<sup>76</sup> During the 45 minutes of questions that followed, Byock was struck by the stories shared by the priests. “They sounded like sons, brothers, and members of families more than anything else,” he said.<sup>77</sup> This tenderness is central to Byock’s message of whole-person care. “The fundamental nature of serious illness is not medical. It includes medical problems, but illness experience is intensely personal,” he said.<sup>78</sup> “Once you realize dying is personal, people of faith can support each other in these very difficult, but normal, times in human life.”<sup>79</sup>



Brad Wilson/Getty Images

## Hospital Chaplains

Bend, Oregon | Winston-Salem, North Carolina | Boston | Clinton and West Bloomfield, Michigan

Chaplains can help people from a variety of faith traditions with advance care planning in hospitals, nursing homes, and other health care facilities. Chaplains must assess the spiritual needs of patients and families, create treatment plans, and provide spiritual care to patients. They may collaborate with members of the patient's medical team, as well as outside clergy.<sup>80</sup> The Joint Commission, the largest health care accrediting body in the U.S., requires spiritual assessments to be available to patients in a hospital.<sup>81</sup> About two-thirds of hospitals in the U.S. have chaplains.<sup>82</sup>

Health care chaplains must also be able to serve the growing population of people who do not identify with a religious group. In the United States, more than 20 percent of the population reports no religious affiliation.<sup>83</sup> So chaplains can be a critical source of spiritual care for that segment of the population that identifies as "none of the above" but nevertheless encounters questions of meaning and the need for support when a crisis happens.

Hospital chaplains may be certified by a number of different organizations. Those who are board-certified by the Association of Professional Chaplains, for example, complete four units of clinical pastoral education and 2,000 hours of work experience, demonstrate Professional Chaplain Competencies, and have a letter of endorsement or support from a recognized spiritual or faith group.<sup>84</sup> Competencies for chaplains who receive additional certification in hospice and palliative care include the ability to “incorporate a working knowledge of the ethical and legal issues, including advance care planning, inherent in hospice/palliative care.”<sup>85</sup>

Chaplains use a variety of tools for advance care planning. Many learn these skills through clinical pastoral education programs; some chaplains complete formal training in facilitating advance care planning conversations. They may also help patients learn about advance care planning using tools such as Five Wishes and The Conversation Project Starter Kit.

Chaplain Katrina Scott is the oncology chaplain and palliative care liaison at Massachusetts General Hospital (MGH) in Boston. She offered a monthly workshop at the MGH Cancer Center on advance care planning for eight years. Scott relies on her Respecting Choices “First Steps” training and believes that the job of the chaplain is to “hold and support the family, to help them see the picture that’s ahead.”<sup>86</sup> Because of their training in nonjudgmental listening, Scott believes that chaplains can take the time to draw out their patient’s deepest concerns. “You don’t always know what people are praying for,” she said. “One of my goals as a chaplain is to always ask a question I don’t know the answer to.”<sup>87</sup>



You don’t always know what people are praying for. One of my goals as a chaplain is to always ask a question I don’t know the answer to.”

Chaplain Katrina Scott

In some settings, chaplains are seen as the vehicle for advance care planning. The Rev. Dr. Bobby Baker is the director of Faith and Community Partnerships at Methodist Le Bonheur Healthcare (MLH) in Memphis, Tennessee.<sup>88</sup> He also supervises the chaplains throughout this hospital system. When a patient is admitted to the hospital and wants to discuss advance care planning, he or she is referred directly to chaplains.<sup>89</sup> The chaplains became responsible for advance care planning as a response to the frequent number of end-of-life issues that were coming before the System Ethics Committee and because of the ability of chaplains to provide coverage to all four of the hospitals in the system. All chaplains are trained to use Five Wishes to help patients discuss and document their wishes for end-of-life care.<sup>90</sup>

Baker also directs the Congregational Health Network (CHN), a collaborative partnership between the MLH and 500 local congregations.<sup>91</sup> The CHN connects congregational volunteers and specially trained navigators, who are employed by the MLH, to help patients receive health care support in and out of the hospital. The CHN also uses Five Wishes as the primary tool for advance care planning.

Hospital chaplains also routinely provide support and education to medical staff and employees in health systems. The Rev. F. Keith Stirewalt is the chaplain for clinical engagement for Wake Forest Baptist Medical Center in Winston-Salem, North Carolina. His goal is to normalize conversations about death and dying within the medical setting and beyond. He feels that all employees should know the basics of advance care planning and complete their own documentation. According to Stirewalt, all people have a “theology of health” that shapes the way they understand their physical health and the world. For this reason, medical caregivers should create opportunities for patients to share their beliefs and faith life. “The failure to understand the spirituality of health is a failure to understand our patients,” he said.<sup>92</sup>

Hospital chaplains can also be an advance care planning resource for local clergy. St. Charles Health System in Bend, Oregon, is the only West Coast rural designated health system to be a sponsor of The Conversation Project. The Rev. Scott Johnson, the palliative care chaplain at St. Charles, hosted an interfaith luncheon for local clergy in September 2015 that was attended by a diverse group of more than 60 people representing 25 faith communities. Johnson prepared attendees to use The Conversation Project Starter Kit in a workshop for adults. He also presented a theological framework and posed rhetorical questions to help participants reflect on advance care planning.<sup>93</sup> One of the attendees was Alan Burke, a recently released bishop of the Church of Jesus Christ of Latter-day Saints who is now the supervisor of clinical support for Outpatient Behavioral Health and Spiritual Care at St. Charles. He continues to use these resources with members of his local Mormon community and extended family.<sup>94</sup>

Some chaplains have an even broader vision for advance care planning. The Rev. James Kraft is the director of advance care planning and collaborative care, and supervisor to chaplains in Michigan at Henry Ford West Bloomfield Hospital and at Henry Ford Macomb Hospital in Clinton.<sup>95</sup> Kraft is certified by Respecting Choices to facilitate conversations and train instructors. He believes that chaplains and community clergy can provide stronger support if they maintain regular contact as patients move in and out of the hospital. His vision includes a network of faith communities around each hospital and a “spiritual care discharge plan” for all patients. “My goal is to change the way we do health care from diagnosis to death,” said Kraft. “I see advance care planning as the thread that goes through every aspect of the person’s journey.”<sup>96</sup>

## Appendix A: Advance Care Planning Tools Mentioned in This Report

### The Conversation Project Starter Kit

<http://theconversationproject.org/starter-kits/>

Started in 2010 and “dedicated to helping people talk about their wishes for end-of-life care,” The Conversation Project works in collaboration with the Institute for Healthcare Improvement, a not-for-profit organization focused on health and health care improvement. The Conversation Project’s vision is for a grassroots public media campaign to help make it easier to have conversations about dying and “to encourage people to talk now and as often as necessary so that their wishes are known when the time comes.”<sup>97</sup> The Conversation Project Starter Kit is a free tool, available online in nine languages, designed to help people talk openly about their wishes for end-of-life care.<sup>98</sup>

- “How to Choose a Health Care Proxy & How to Be a Health Care Proxy”
- “Conversation Starter Kit for Families and Loved Ones of People With Alzheimer’s Disease or Other Forms of Dementia”
- “How To Talk To Your Doctor”
- Pediatric Starter Kit: Having the Conversation With Your Seriously Ill Child.<sup>99</sup>

The Conversation Project website also offers a robust Community Resource Center that has specialized resources for faith communities, including sermons, planning tools, and instructions for participating an annual event called “Conversation Sabbath.”<sup>100</sup>

### Five Wishes

<https://agingwithdignity.org>

Five Wishes is an advance directive document created by Aging with Dignity, a nonprofit organization whose mission is to “safeguard the human dignity of people as they age or face serious illness.”<sup>101</sup> Individuals can use the Five Wishes document to select a health care agent and describe their “wishes” for medical treatment, level of comfort, and how they want to be treated at the end of life. They can also record “what I want my loved ones to know” about topics such as forgiveness, love, and reconciliation between family members, and plans for funeral services.<sup>102</sup>

Five Wishes is available in 28 languages and meets the legal standard for an advance directive in 42 states and the District of Columbia.<sup>103</sup> It is available online or in print for a fee.

### Respecting Choices

<http://www.gundersenhealth.org/respecting-choices/>

Respecting Choices is an advance care planning system that includes all stages of planning and “embeds these planning processes into the routine of healthcare and the norm for the people in the community.”<sup>104</sup> The Respecting Choices system includes continuous quality improvement of three elements: competency training for health care professionals and those in an advance care planning facilitator role; engagement of patients and the community; and the design of effective systems to implement advance care planning.<sup>105</sup>

These examples frequently mention the Respecting Choices advance care planning facilitator role. A number of individuals in faith communities mentioned in this report are certified as Respecting Choices “First Steps”

facilitators, trained to assist adults with foundational advance care planning conversations.<sup>106</sup> Facilitators can receive certification at national courses or through implementation of a Respecting Choices Advance Care Planning program within their own organization.<sup>107</sup>

In addition to “First Steps” facilitator training, Respecting Choices offers facilitator certification in disease-specific planning (“Next Steps”) and planning for people who are frail or living in facilities for long-term care (“Last Steps”). They also offer Instructor Certification, which allows an organization to provide ongoing facilitator training.<sup>108</sup> There are fees associated with these tools and trainings.

## Honoring Choices

<http://www.honoringchoices.org/tools-resources/resources>

Honoring Choices Minnesota is an initiative of the Twin Cities Medical Society that encourages families and communities to have discussions regarding end-of-life care choices. It is “based on the training, principles and overall methodology of Respecting Choices.”<sup>109</sup>

There is a national network of states that are developing similar advance care planning programs that include not only Minnesota but also Alaska, Florida, Hawaii, Idaho, Massachusetts, Napa Valley (California), North Dakota, Pacific Northwest (Oregon and Washington), Virginia, and Wisconsin.<sup>110</sup>

## Appendix B: Glossary

**Advance care planning.** The whole process of discussion, choice, and clarification of a patient's medical values and goals that can start at any time and be revisited periodically, but becomes more focused as health status changes. Ideally, these conversations 1) occur with a person's health care proxy and physician, along with other members of the clinical team; 2) are recorded and updated as needed; and 3) allow for flexible decision-making in the context of the patient's current medical situation.

**Advance directive.** A broad term encompassing several types of patient-initiated documents, especially living wills and durable power of attorney or proxy statements. People complete these forms at any time, in any state of health that allows them to do so.

**Agent.** An individual designated in a legal document, known as a power of attorney for health care, to make a health care decision for the individual granting the power; also referred to in some statutes as durable power of attorney for health care, attorney in fact, proxy, or health care representative. A health care agent may also be called a health care proxy.

**Capacity to make a health care decision.** An individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision. The term is frequently used interchangeably with competency, but it is not the same. Competency (or incompetency) is often distinguished as a legal status imposed by a court, although most states have dropped the term in favor of "legal incapacity."

**Cardiopulmonary resuscitation (CPR).** A group of treatments used when a person's heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It entails pressing on the chest to cause blood to circulate, applying electrical shocks to re-establish the heart's rhythm, and may or may not consist of mouth-to-mouth breathing, or other method of ventilation.

**Do not resuscitate (DNR) order.** A physician's order written in a patient's medical record indicating that health care providers should not attempt CPR in the event of cardiac or respiratory arrest. In some regions, this order may be transferable between medical venues. Also called a No CPR order, a DNAR (do not attempt resuscitation) order, and an AND (allow natural death) order.

**Durable power of attorney for health care.** A type of advance directive that identifies the person who should make medical decisions for a person no longer able to do so.

**End-of-life care.** Health care, including acute care and long-term care, provided to individuals who are very ill, have a prognosis that is likely to worsen, and are expected to die from their illness.

**Hospice.** A service delivery system that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition. It also supports family members coping with the complex consequences of illness, disability, and aging as death nears.

**Life-sustaining treatment.** Medical procedures that replace or support an essential bodily function. Life-sustaining treatments include CPR, mechanical ventilation, artificial nutrition and hydration, dialysis, and certain other treatments.

**Living will.** A type of advance directive. Living wills are written (or video) statements about the kinds of medical

care a person would want (and not want) under certain specific conditions if he or she becomes unable to express those wishes.

**Palliative care.** The comprehensive care and management of the physical, psychological, emotional, and spiritual needs of patients of all ages (and their families) with chronic, debilitating, or life-threatening illness.

**POLST.** Physician Orders for Life-Sustaining Treatment are created with and signed by a health professional, usually a physician, for someone who is seriously ill. Because they are actual doctor's orders, they are more likely to be followed by other health professionals, including emergency personnel. In specific states, the abbreviations used vary slightly and include POST, MOST, MOLST, and others.

**Proxy.** Substitute decision-maker.

**Surrogate.** A person who, by default, becomes the substitute decision-maker for an individual who has no appointed agent.

Citations for all entries in the glossary are available at <http://www.pewtrusts.org/en/research-and-analysis/fact-sheets/2015/05/pew-glossary-improving-end-of-life-care>.

## Appendix C: Organizations and Resources for Advance Care Planning Mentioned in This Report

Association of Professional Chaplains

<http://www.professionalchaplains.org>

Congregational Health Network

<http://www.methodisthealth.org/about-us/faith-and-health/congregational-health-network/>

Henry Ford Macomb Faith Community Nursing Network

<https://www.henryford.com/locations/macomb/patients/spiritual-support>

Institute for Human Caring

<http://www.providence.org/institute-for-human-caring/>

Islamic Medical Association of North America

<https://imana.org>

Living Fully, Dying Well by Rueben Job

<https://www.cokesbury.com/forms/ProductDetail.aspx?pid=444199>

My Gift of Grace/Hello

<http://www.mygiftofgrace.com>

My Gift of Grace is a card game developed by Common Practice, in which a group of players answer questions about living and dying well.<sup>111</sup> In 2017, My Gift of Grace was renamed Hello.

Sage Voices

<http://www.jtsa.edu/sage-voices>

What Matters: Caring Conversations About End of Life

<http://www.jccmanhattan.org/jewish-living/advanced-care-planning/>

### Resources of Major Religious Groups

Religious Groups' Views on End-of-Life Issues

Pew Research Center, Nov. 21, 2013

<http://www.pewforum.org/2013/11/21/religious-groups-views-on-end-of-life-issues/> Voices from 16 religious group address end-of-life questions such as euthanasia and physician-assisted suicide.

National Association of Evangelicals: "Resolution: Allowing Natural Death"

<https://www.nae.net/allowing-natural-death/>

Rabbinical Council of America (Orthodox): "Halachic Guidelines to Assist Patients and Their Families in Making 'End-of-Life' Medical Decisions"

<http://www.rabbis.org/pdfs/hcpi.pdf>

Rabbinical Assembly (Conservative): “Jewish Medical Directives for Health Care”

[http://www.rabbinicalassembly.org/sites/default/files/public/halakhah/teshuvot/19861990/mackler\\_care.pdf](http://www.rabbinicalassembly.org/sites/default/files/public/halakhah/teshuvot/19861990/mackler_care.pdf)

Union for Reform Judaism: “Health Care Decisions on Dying”

<http://www.urj.org/what-we-believe/resolutions/health-care-decisions-dying>

United Methodist Church: “Social Principles: The Nurturing Community”

<http://www.umc.org/what-we-believe/the-nurturing-community>

United States Conference of Catholic Bishops: “Ethical and Religious Directives for Catholic Health Care Services”

<http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>

## Endnotes

- 1 Maria J. Silveira, Scott Y.H. Kim, and Kenneth M. Langa, "Advance Directives and Outcomes of Surrogate Decision Making Before Death," *New England Journal of Medicine* 362, no. 13 (2010): 1211-18, <https://dx.doi.org/10.1056/NEJMsa0907901>.
- 2 Kuldeep N. Yadav et al., "Approximately One in Three US Adults Completes Any Type of Advance Directive for End-Of-Life Care," *Health Affairs* 36, no. 7 (2017): 1244-51, <http://dx.doi.org/10.1377/hlthaff.2017.0175>.
- 3 Patrick J. Dillon and Amber Basu, "Toward Eliminating Hospice Enrollment Disparities Among African Americans: A Qualitative Study," *Journal of Health Care for the Poor and Underserved* 27, no. 1 (2016): 229, <https://dx.doi.org/10.1353/hpu.2016.0014>.
- 4 Sally Kaplan, Samantha Kessler, and Mindy Schachtman, pers. comm., Oct. 6, 2016.
- 5 Ibid.
- 6 Pew Research Center, "Calculate the Size of the U.S. Jewish Population," accessed Feb. 21, 2017, <http://www.pewforum.org/2013/10/01/jewish-population-calculator/>. An additional 1.2 million people self-identify as "Jews of no religion."
- 7 JCC Manhattan, "Understanding Advance Care Planning as a Jewish Process," accessed Feb. 3, 2017, <http://jccmanhattan.org/attach/WhatMattersAdvanceCareJewishProcessFINAL.pdf>.
- 8 The Jewish Theological Seminary, "Sage Voices," accessed Feb. 3, 2017, <http://www.jtsa.edu/sage-voices>.
- 9 JCC Association of North America, "Discover the JCC Difference," accessed March 11, 2017, <http://www.discoverjcc.com/main/discover-the-jcc-difference/>.
- 10 Sally Kaplan, Samantha Kessler, and Mindy Schachtman, pers. comm., Oct. 6, 2016.
- 11 Sally Kaplan, email message to Jennifer L. Hollis, March 8, 2017.
- 12 Howard Sharfstein and Samantha Kessler, pers. comm., Nov. 30, 2016.
- 13 Ibid.
- 14 Ibid.
- 15 Sarah Robinson, pers. comm., Jan. 27, 2017.
- 16 Sally Kaplan and Samantha Kessler, pers. comm., Jan. 26, 2017.
- 17 Maisha Robinson, "Helping African Americans of Faith Embrace End-of-Life Discussions," *Journal of Palliative Medicine* 19, no. 2 (2016): 235, <https://doi.org/10.1089/jpm.2015.0321>; Maisha Robinson, pers. comm., Nov. 9, 2016.
- 18 Dr. Gwendolyn Phillips Coates, email message to Jennifer L. Hollis, Jan. 24, 2017.
- 19 Dr. Gwendolyn Philips Coates, pers. comm., Oct. 21, 2016.
- 20 Ibid.
- 21 Camille P. Wicher and Mary Ann Meeker, "What Influences African American End-of-Life Preferences?" *Journal of Health Care for the Poor and Underserved* 23, no. 1 (2012): 28 and 52, <https://www.researchgate.net/publication/225072873>; Kimberly S. Johnson, Katja I. Elbert-Avila, and James A. Tulsky, "The Influence of Spiritual Beliefs and Practices on the Treatment Preferences of African Americans: A Review of the Literature," *Journal of the American Geriatrics Society* 53, no. 4 (2005): 711-19, <http://dx.doi.org/10.1111/j.1532-5415.2005.53224.x>.
- 22 Dr. Maisha Robinson, pers. comm., Nov. 9, 2016.
- 23 Dr. Maisha Robinson, email message to Jennifer L. Hollis, Jan. 23, 2017.
- 24 The churches in this project are Holman United Methodist Church, Emmanuel-Henry McNeal Turner African Methodist Episcopal Church, Price Chapel African Methodist Episcopal Church, First African Methodist Episcopal Church, People's Independent Church of Christ, and God Answers Prayer Ministries.
- 25 Dr. Maisha Robinson, pers. comm., Nov. 9, 2016.
- 26 The Rev. Joyce Reece Kitchen, pers. comm., Nov. 22, 2016.
- 27 Dr. Maisha Robinson, pers. comm., Nov. 9, 2016.
- 28 The Rev. Joyce Reece Kitchen, pers. comm., Feb. 6, 2017.
- 29 The Rev. Nancy Wheeler Handlon, pers. comm., Jan. 17, 2017.
- 30 The Rev. Nancy Wheeler Handlon, email message to Jennifer L. Hollis, Feb. 2, 2017.
- 31 The Rev. Nancy Wheeler Handlon, pers. comm., Jan. 17, 2017.
- 32 Patricia Hrabe, email message to Jennifer L. Hollis, Jan. 26, 2017.

- 33 United Methodist Church, "Glossary: Parish Nurse." accessed Feb. 8, 2017, <http://www.umc.org/what-we-believe/glossary-parish-nurse>.
- 34 Patricia Hrabe, email message to Jennifer L. Hollis, Jan. 26, 2017.
- 35 Nancy Wheeler Handlon, email message to Jennifer L. Hollis, Feb. 21, 2017.
- 36 United Methodist Church, "United Methodists at-a-Glance," accessed Jan. 10, 2017, <http://www.umc.org/news-and-media/united-methodists-at-a-glance>.
- 37 United Methodist Church, "Social Principles: The Nurturing Community," accessed Jan. 10, 2017, <http://www.umc.org/what-we-believe/the-nurturing-community#care-dying>.
- 38 United Methodist Church, "Book of Resolutions: Faithful Care for Persons Suffering and Dying," accessed Jan. 10, 2017, <http://www.umc.org/what-we-believe/faithful-care-for-persons-suffering-and-dying>.
- 39 Christ United Methodist Church, "Our Theology and Mission," accessed Feb. 3, 2017, <http://www.cumethodist.com/our-theology-and-mission/>; Patricia Hrabe and Kathy Estry, pers. comm., Dec. 16, 2016; Kathy Estry, email message to Jennifer L. Hollis, Jan. 25, 2017.
- 40 Minnesota Network of Hospice and Palliative Care, "Speaking of Being Mortal," accessed Feb. 21, 2017, <http://www.mnhpc.org/event/speaking-of-being-mortal/>.
- 41 Patricia Hrabe and Kathy Estry, pers. comm., Dec. 16, 2016; Kathy Estry, email message to Jennifer L. Hollis, Jan. 25, 2017.
- 42 The Rev. Nancy Wheeler Handlon, email message to Jennifer L. Hollis, March 13, 2017.
- 43 Dr. Y. Khalid Siddiq, email message to Jennifer L. Hollis, May 11, 2017.
- 44 Al-Farooq Masjid of Atlanta, "Download of Islamic Last Will and Testament," accessed March 10, 2017, <http://alfarooqmasjid.org/will/>.
- 45 Dr. Y. Khalid Siddiq, pers. comm., Jan. 14, 2017.
- 46 Dr. Y. Khalid Siddiq, email message to Jennifer L. Hollis, Jan. 31, 2017.
- 47 Dr. Y. Khalid Siddiq, pers. comm., Jan. 14, 2017.
- 48 Dr. Y. Khalid Siddiq, email message to Jennifer L. Hollis, March 11, 2017.
- 49 Pew Research Center, "Muslim Americans: No Signs of Growth in Alienation or Support for Extremism," accessed Feb. 7, 2017, <http://www.people-press.org/2011/08/30/muslim-americans-no-signs-of-growth-in-alienation-or-support-for-extremism/>.
- 50 Dr. Y. Khalid Siddiq, email message to Jennifer L. Hollis, May 11, 2017.
- 51 Saleem Saiyad, "Do Not Resuscitate: A Case Study From the Islamic Viewpoint," *Journal of the Islamic Medical Association of North America* 41, no. 3 (2009): 112, <http://dx.doi.org/10.5915/41-3-4477>.
- 52 Shahid Athar et al., "Medical Ethics From Islamic Perspective," *Journal of the Islamic Medical Association of North America* 36, no. 1 (2005): 14-15, <https://imana.org/medical-ethics-from-an-islamic-perspective/>.
- 53 Edward Mitchell, pers. comm., Dec. 2, 2016.
- 54 Edward Mitchell, pers. comm., Jan. 27, 2017.
- 55 Ibid.
- 56 Edward Mitchell, pers. comm., Dec. 2, 2016.
- 57 Minister Philesha Gough, pers. comm., March 22, 2017.
- 58 Minister Philesha Gough, pers. comm., Feb. 1, 2017.
- 59 Henry Ford Health System, "Henry Ford Macomb Faith Community Nursing Network," accessed Feb. 3, 2017, <https://www.henryford.com/locations/macomb/patients/spiritual-support>; The Rev. Ameldia Brown, email message to Jennifer L. Hollis, Feb. 6, 2017.
- 60 The Rev. Ameldia Brown, email message to Jennifer L. Hollis, Feb. 6, 2017.
- 61 The Rev. Ameldia Brown, pers. comm., Nov. 2, 2016.
- 62 Minister Philesha Gough, pers. comm., Feb. 1, 2017.
- 63 Minister Philesha Gough, pers. comm., Nov. 30, 2016.
- 64 Minister Philesha Gough, pers. comm., March 22, 2017.
- 65 Kathleen Buckley Domingo, pers. comm., Nov. 2, 2016.
- 66 Vatican, "Evangelium Vitae," accessed Jan. 31, 2017, [http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf\\_jp-ii\\_enc\\_25031995\\_evangelium-vitae.html](http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae.html); United States Conference of Catholic Bishops, "To Live Each Day With Dignity," accessed Jan. 31, 2017, <http://www.usccb.org/issues-and-action/human-life-and-dignity/assisted-suicide/to-live-each-day/upload/to-live-each-day->

- with-dignity-hyperlinked.pdf; United States Conference of Catholic Bishops, "Ethical and Religious Directives for Catholic Health Care Services (Fifth Edition)," accessed Jan. 31, 2017, <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>.
- 67 United States Conference of Catholic Bishops, "Ethical and Religious Directives for Catholic Health Care Services (Fifth Edition)," accessed Feb. 7, 2017, <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>.
- 68 Archdiocese of Los Angeles, "ADLA Newsroom," accessed Jan. 31, 2017, <http://media.la-archdiocese.org/overview/>.
- 69 Kathleen Buckley Domingo, pers. comm., Nov. 2, 2017.
- 70 Archbishop José H. Gomez, *A Will to Live: Clear Answers on End of Life Issues*, (Charlotte, North Carolina: Basilica Press, 2006): 35-39.
- 71 Providence Institute for Human Caring, "Ira Byock," accessed Feb. 8, 2017, <http://www.providence.org/institute-for-human-caring/about-us/dr-ira-byock>.
- 72 Dr. Ira Byock, pers. comm., Dec. 7, 2016.
- 73 Phone interview with Kathleen Buckley Domingo, Nov. 2, 2017.
- 74 Ibid.
- 75 Patricia Osman, pers. comm., Nov. 14, 2016.
- 76 Angelus, "Time to Change the Conversation," accessed Oct. 19, 2016, <http://www.angelusnews.com/articles/time-to-change-the-conversation>.
- 77 Dr. Ira Byock, pers. comm., Dec. 7, 2016.
- 78 Ibid.
- 79 Ibid.
- 80 Committee on Approaching Death, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (Washington, D.C.: the National Academies Press, 2014): 246.
- 81 David R. Hodge et al., "Older Adults' Spiritual Needs in Health Care Settings: A Qualitative Meta-Synthesis," *Research on Aging* 34, no. 2 (2011): 131-132, <http://journals.sagepub.com/doi/10.1177/0164027511411308>.
- 82 *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (Washington, D.C.: the National Academies Press, 2014): 246. Pew Research Center, "Religious Landscape Study," accessed Feb. 21, 2017, <http://www.pewforum.org/religious-landscape-study/>.
- 83 Pew Research Center, "Religious Landscape Study," accessed Feb. 21, 2017, <http://www.pewforum.org/religious-landscape-study/>.
- 84 Board of Chaplaincy Certification Inc., "Certification Frequently Asked Questions," accessed Jan. 19, 2017, <http://bcciprofessionalchaplains.org/content.asp?pl=25&sl=26&contentid=26>.
- 85 Board of Chaplaincy Certification Inc., "Competencies of the Certified Hospice & Palliative Care Chaplain," accessed Feb. 8, 2017, <http://bcciprofessionalchaplains.org/content.asp?pl=45&sl=42&contentid=49>.
- 86 Katrina Scott, pers. comm., Oct. 13, 2016.
- 87 Ibid.
- 88 The Rev. Dr. Bobby Baker, pers. comm., Dec. 21, 2016.
- 89 Ibid.
- 90 The Rev. Dr. Bobby Baker, pers. comm., Jan. 31, 2017.
- 91 Methodist Health, "Congregational Health Network," accessed Feb. 4, 2017, <http://www.methodisthealth.org/about-us/faith-and-health/congregational-health-network/>.
- 92 The Rev. F. Keith Stirewalt, pers. comm., Nov. 8, 2016.
- 93 The Rev. Scott Johnson, email message to Jennifer L. Hollis, Jan. 30, 2016.
- 94 Bishop Alan Burke, pers. comm., Dec. 22, 2016.
- 95 Kraft works with Ameldia Brown of the New Life Ambassadors for Christ Christian Church.
- 96 The Rev. James Kraft, pers. comm., Nov. 21, 2016.
- 97 The Conversation Project, "Our Purpose," accessed Feb. 19, 2017, <http://theconversationproject.org/about/>.

- 98 The Conversation Project, "Starter Kits," accessed May 12, 2017, <http://theconversationproject.org/starter-kits/>.
- 99 Ibid.
- 100 The Conversation Project, "Community Resource Center," accessed Feb. 19, 2017, <http://theconversationproject.org/resources/>.
- 101 Aging with Dignity, "History and Mission," accessed Feb. 21, 2017, <https://agingwithdignity.org/about-us/history-and-mission>.
- 102 Aging with Dignity, "Sample Document," accessed Feb. 22, 2017, <https://agingwithdignity.org/docs/default-source/default-document-library/product-samples/fwsample.pdf?sfvrsn=2>.
- 103 Aging with Dignity, "Five Wishes," accessed Feb. 21, 2017, <https://agingwithdignity.org/five-wishes/about-five-wishes>.
- 104 Gundersen Health, "Respecting Choices Frequently Asked Questions," accessed Feb. 7, 2017, <http://www.gundersenhealth.org/respecting-choices/faqs/>.
- 105 Ibid.
- 106 Gundersen Health, "Learn How to Become Certified," accessed Feb. 20, 2017, <http://www.gundersenhealth.org/respecting-choices/certification/>.
- 107 Ibid.
- 108 Ibid.
- 109 Honoring Choices, "The Honoring Choices Story," accessed May 12, 2017, <http://www.honoringchoices.org/tools-resources/about/history>.
- 110 Honoring Choices, "National Network," accessed Feb. 19, 2017, <http://www.honoringchoices.org/tools-resources/about/partners/other-states>.
- 111 My Gift of Grace, "About the Game," accessed Feb. 7, 2017, <http://www.mygiftofgrace.com>.

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