

# 安寧療護



Chinese-American

OUTREACH GUIDE

*Caring*  *Connections*  
a program of the  
National Hospice and Palliative Care Organization



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## I. Chinese-Americans: An Overview of Key Facts and Cultural Beliefs

Many people may wonder why Caring Connections has written an outreach guide specifically for the Chinese-American community. Why specifically for the Chinese community, and not for all Asians in the United States?

The Asian-American community is incredibly diverse. The Chinese community is the largest Asian ethnic group in the US, yet it represents only 25% of all Asian Americans. Other groups in the Asian community include: Japanese, Koreans, Vietnamese, Thai, Laotians, Hmong and Cambodians; as well as those from South Asian countries such as India, Pakistan, Bangladesh and Sri Lanka. Given this diversity, we chose to first focus on the Chinese community since it represents the largest. Caring Connections is seeking funding to develop Outreach Guides specific to other Asian communities.

There are some similarities between Chinese culture and the cultures of Japan, Korea, Vietnam and Cambodia. This is mainly due to the fact that over many centuries, China has had a great influence in Asia. Therefore you may find that some cultural issues discussed in this guide are relevant to other communities. However, we want to emphasize the importance of listening to and learning about the unique aspects of the communities you are partnering with and to be careful not to make generalizations or assumptions.

This section features key cultural facts and beliefs about Chinese-Americans and includes specific information about:

- ◆ *Demographics*
- ◆ *History*
- ◆ *Socio-economics*
- ◆ *Language*
- ◆ *Healthcare Practices*
- ◆ *End-of-Life Care Cultural Beliefs and Attitudes*
- ◆ *Religion*

## A. Demographics

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The majority of Chinese-Americans are from one of two nations: either from the mainland of China (People's Republic of China) or Taiwan (Republic of China), an island nation only 75 miles from the Chinese mainland. People from both countries share a similar racial, ethnic and religious background. However, there are important language and cultural differences that will be discussed later in this section.

In 2004 there were more than 3.3 million Chinese people living in the US, an increase of over half a million people since the 2000 census. Chinese-Americans make up 1.2% of the total US population, and they are the largest Asian ethnic group, comprising almost 25% of all Asian Americans. Despite their low birthrates, Chinese-American households tend to be larger due to the common practice of multiple generations and extended family living together.<sup>1</sup>

## B. History

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Chinese people have been immigrating to the United States since the late 1800s. In some communities, especially in California and Hawaii, many Chinese-Americans immigrated generations ago and, thus their decedents retain few cultural elements from their heritage. However, in recent years, there has been an increase in immigration. According to a special report from the U.S. Census in 2000, 70% of Chinese-Americans are foreign born.<sup>2</sup> Therefore their traditional culture may still be very important and prevalent in their current lives.

The largest Chinese populations in the United States are concentrated in the major metropolitan areas of: New York City, San Francisco, Los Angeles, Houston, Seattle, Chicago, Philadelphia and Portland. Chinese-Americans also make up almost 10% of the Hawaiian population.<sup>3</sup>

## C. Socio-economics

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The Chinese-American population is very economically diverse. While their median income is higher than the national median income, there are slightly more Chinese-Americans in poverty than the national average. Some of these differences can be explained by where people are originally from. On the mainland of China even highly educated people may have had little exposure to the English language. Therefore, professionals from the mainland who immigrate to the US may have a more difficult transition and find themselves able to only obtain low skilled jobs. Those from Taiwan who immigrate to the US have usually had more opportunity to learn English and be exposed to American culture, and therefore more easily transition to a professional career in the US.<sup>4</sup> Those from Hong Kong, which is located on mainland China but was a British colony until 2000, are also generally more likely to speak English and be familiar with the American lifestyle than others from the mainland.

<sup>1</sup> US Census Bureau. (2005). *Selected Population Profile in the United States* (Chinese alone or in any combination): 2005 American Community Survey. Washington, DC: Author. Available at [www.census.gov](http://www.census.gov).

<sup>2</sup> US Census Bureau. (2004, December). *We the People: Asians in the United States*. Census 2000 Special Reports. Washington DC: Author. Available at [www.census.gov](http://www.census.gov).

<sup>3</sup> US Census Bureau. (2005) Various city population profiles. Available at [www.census.gov](http://www.census.gov).

<sup>4</sup> Fitzgerald, H.E., Lester, B.M., Zuckerman, B.S. (1999) *Children of Color: Research, Health, and Policy Issues*. New York: Garland Publishing.

## D. Language

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A large majority of people from mainland China and Taiwan speak Mandarin Chinese, the official language of both countries. Cantonese, a common spoken dialect of Chinese, is as different from Mandarin as French is from Spanish, and most Chinese people only speak one or the other. However, Cantonese and Mandarin share a common written language so Chinese characters are understandable by all. Cantonese is spoken mainly by people who have immigrated from the Guangdong province, where Hong Kong is located. California and Hawaii have many residents who speak Cantonese.

There are important differences between written Chinese in mainland China and in Taiwan. Since the 1950s, mainland China has used “simplified” characters, a way of writing characters with less detail. Taiwan uses only traditional complex characters.

*(Please note: The materials associated with this outreach guide use traditional characters since most printed media for Chinese communities in North America use traditional characters.)*

## E. Healthcare Practices

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Traditional Chinese Medicine (TCM) is the most common form of healthcare among first generation immigrants, which is a majority of the Chinese-American population.<sup>7</sup> Developed over thousands of years, TCM is mainly guided by a holistic concept of health that emphasizes achieving balance and harmony throughout bodily systems. Qi or Ch’i is a term that the Chinese use to describe the “life force.” TCM aims to restore the balance of qi or ch’i, using various methods, some of which are described below.<sup>6</sup> Examples of TCM, described in detail below, include the use of herbal medicine, acupuncture and other modalities.

Recent immigrants most likely to be knowledgeable about and comfortable with TCM, but many may be in low wage jobs without health insurance. Socioeconomics plays a role in healthcare practices. Most recent immigrants, who are more likely to be familiar with TCM are also more likely to have a lower wage job without health insurance. Recent immigrants who are United States citizens may not know about Medicare or Medicaid or how to access benefits. TCM services are often much more affordable for the uninsured than traditional healthcare. Therefore, TCM can seem to be the best option for recent immigrants.

### Common Practices of Traditional Chinese Medicine:

It is important to understand the basic methods of TCM because some Chinese-Americans may treat a condition with TCM before seeking the care of a doctor:<sup>7</sup>

- ◆ **Herbs** - The most important and most common method of TCM is herbal therapy. Sometimes patients use herbs to treat the side effects of modern medicine, especially cancer patients receiving chemotherapy. Some herbs are easily used as home remedies while others are prepared by herbalists in the community.<sup>6,7</sup>
- ◆ **Acupuncture** - This well-known technique of inserting and manipulating needles into specific points on the body seeks to restore health and well-being, or Qi/Ch'i. Acupuncture is the most common 'professional' practice of TCM in the US, since many states require a license to practice.<sup>7</sup>
- ◆ **Coining and Pinching** - This is a special massage technique that is used to draw out fever and illness. While not as widespread as the use of herbs and acupuncture, this is a practice that may be interpreted as abusive since it can leave bruises or marks on the skin.
- ◆ **"Hot" and "Cold" food** - Another important aspect of TCM is the belief that diet can play a direct role in illnesses – specifically the hot and cold theory of food and disease. This belief is based on keeping qi/ch'i in balance through the integration of nutrition and medicine. If qi/ch'i is out of balance then pain, discomfort or bleeding can result. Carefully monitoring the amount of "hot" and "cold" food eaten is essential to keeping balance. However, "hot" and "cold" does not refer to the actual temperature of the food, but the type of energy that it provides. Many fruits and vegetables are considered "cold" while meat is considered "hot". Sometimes food served in healthcare settings such as hospitals or hospice facilities can conflict with Chinese beliefs about food.<sup>6,8</sup>

To learn more about Traditional Chinese Medicine, go to the Chinese-American Medicine Society's Web site, [www.camsociety.org](http://www.camsociety.org) (under 'Health Issues').

### Blending TCM and Modern Medicine:

Both TCM and modern medicine are practiced in mainland China and Taiwan, and most Chinese-Americans are comfortable following both medical belief systems. However, certain areas of healthcare are seen as better suited for modern medicine, such as emergency care and identifiable illnesses such as cancer, stroke, surgery and diabetes. Some chronic illnesses, such as arthritis or digestive issues, may be largely treated with TCM.

Many Chinese people will use TCM first to treat a symptom or illness before seeing a doctor. Because TCM emphasizes that each part of the body is interrelated with others, it should be expected that many Chinese-Americans will integrate elements of TCM into the care they receive, including end-of-life care. People may design their own therapy, for example changing their diet, often seeking assistance from practitioners, who may or may not be licensed. Some patients and families may be reluctant to disclose their use of TCM, fearing American clinicians will disapprove.<sup>6,7</sup>

<sup>5</sup> Bowman, K.W., Singer, P.A. (2001). *Chinese Seniors' Perspectives on End of Life Decisions*. Social Science & Medicine, 53(4): 455-464.

<sup>6</sup> Salimbene, S. (2005). *Providing culturally-sensitive healthcare to patients of Asian Origin*. In *What Language Does Your Patient Hurt In? A Practical Guide to Culturally Competent Patient Care* (2<sup>nd</sup> ed.). Amherst, MA: Diversity Resources, Inc.

<sup>7</sup> Wang, C. (1996) *Traditional Chinese Medicine in Chinese-American Communities*. New York: Chinese-American Medical Society. Available at [www.camsociety.org](http://www.camsociety.org).

<sup>8</sup> Center for East Asian Studies, University of Kansas. (2003). *Chinese Nutrition and Cuisine*. Available at [www.kas.ku.edu](http://www.kas.ku.edu).

### Doctor as Authority Figure:

In the Chinese culture, doctors are seen as very trustworthy and often, doctors' opinions are considered the most important. Doctors are perceived as highly intelligent, principled, moral and possessing special knowledge. Elders may feel comfortable deferring to doctors even over the opinions of their children. Therefore, identifying a healthcare proxy could be seen as unimportant to some Chinese elders. Consensus among family members is valued, and the opinion of the doctor can impact and guide end-of-life discussions, while the opinion of a healthcare proxy, or 'sole advocate,' may be seen as a barrier to the decision-making process.<sup>5, 6</sup>

### Respect for Elders:

Filial Piety "Hsiao": This is a concept that comes from Confucian philosophy. Children feel they have a duty to assist parents and other family members in protecting their health, safety and general well being, in order to help elders reach an advanced age.<sup>5</sup>

### Harmony and Saving Face:

Emotional harmony is a major component of the Eastern attitude towards living. Discussing death may be perceived as a topic that will interfere with inner harmony.<sup>5</sup>

### Fatalism:

Many life events in Chinese culture are considered unpredictable and uncontrollable. While people may feel they have some ability to shape the future, the ultimate outcome, such as having a serious illness or experiencing a loss, is often viewed as pre-determined by destiny.<sup>5</sup>

## ***F. End-of-Life Care Cultural Beliefs and Attitudes***

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Fatalism is a well-documented part of Chinese culture. One study has shown that some Chinese elders may have a high degree of fatalism about the end of life and feel that advance care planning cannot help change the future.<sup>9</sup> However, in some rural Chinese communities, elders often plan for death and some may even hold pre-death celebrations.<sup>9</sup>

Family plays an important role in the end-of-life decision-making process. Personal autonomy is not highly valued in Chinese culture, and therefore choosing a single healthcare advocate or proxy may be uncomfortable for some Chinese-Americans.<sup>9</sup>

One study showed that Chinese elders feel that their children may advocate for aggressive treatment out of a sense of filial duty. If children do not advocate for aggressive treatment, they can be negatively viewed as not looking out for their parents' best interests.<sup>5</sup>

End-of-life care is not widely known or taught in the Chinese medical profession, and therefore for people from mainland China, the concepts of end-of-life care may be new to them or unfamiliar.<sup>10</sup> While talking about death may be 'taboo' within the Chinese culture, there is no evidence that disclosing bad news does harm to Chinese patients. Also, Traditional Chinese Medicine texts do not ask doctors to avoid talking about death.<sup>9</sup>

## G. Religion

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There are two major religions in mainland China and Taiwan, Taoism and Buddhism. Christianity is more widespread in Taiwan than in mainland China, however in Taiwan there are approximately one million Christians (or roughly 5% of the population).<sup>11</sup> Confucianism, which is an important moral philosophy that emphasizes ethical behavior, is often mistakenly viewed as a religion. Yet, the teachings of Confucius have greatly influenced beliefs about the appropriate way to live one's life, and death and dying.

In mainland China, religion has not been freely practiced for many years due to government policies, though Confucian philosophy has remained widely taught.<sup>12</sup> Therefore, those from the mainland who have immigrated to the US may be estranged from religion when they immigrate to the US, yet have strong Confucian beliefs. Others may have embraced Protestant Christianity or Catholicism upon coming to the US and this may be an important part of their personal identity. At least one-third of Chinese-Americans, especially younger generations, are Christians. This may lead to diverse religious views within families about the death and dying.<sup>13</sup>

While talking about death may be a taboo subject in Chinese culture, there is not a well documented 'fear of death' among Chinese.<sup>9</sup> Buddhism, Taoism, and Confucianism all perceive death in a positive and open minded light. Their attitudes towards death are summarized below:

- ◆ **Buddhist:** 'belief in new life after death'- Death is part of the process of the wheel of rebirth. Death is a way to enlightenment
- ◆ **Taoist:** 'life and death unified' - Life and death are natural processes. One becomes part of nature upon death, and does not need to grieve when facing death.
- ◆ **Confucian:** 'Willing to die to preserve virtue' - One should not be afraid of death. If a non-virtuous act is needed to preserve life, a person would rather die.<sup>9</sup>

<sup>5</sup> Bowman, K.W., Singer, P.A. (2001). *Chinese Seniors' Perspectives on End of Life Decisions*. *Social Science & Medicine*, 53(4): 455-464.

<sup>6</sup> Salimbene, S. (2005). *Providing culturally-sensitive healthcare to patients of Asian Origin*. In *What Language Does Your Patient Hurt In? A Practical Guide to Culturally Competent Patient Care* (2<sup>nd</sup> ed.). Amherst, MA: Diversity Resources, Inc.

<sup>7</sup> Wang, C. (1996) *Traditional Chinese Medicine in Chinese-American Communities*. New York: Chinese-American Medical Society. Available at [www.camsociety.org](http://www.camsociety.org).

<sup>8</sup> Center for East Asian Studies, University of Kansas. (2003). *Chinese Nutrition and Cuisine*. Available at [www.kas.ku.edu](http://www.kas.ku.edu).

<sup>9</sup> Cy, T., Chong, A., Sy F. (2003) *Breaking Bad News: A Chinese Perspective*. *Palliative Medicine*, 17:339-343.

<sup>10</sup> Wang, X.S., Li, J.D., Reyes-Gibby, C.C., Guo, H., Liu, S.J., Cleeland, C. (2004) *End-of-Life Care in Urban Areas of China: A Survey of 60 Oncology Clinicians*. *Journal of Pain and Symptom Management*, 27(2), 125-131.

<sup>11</sup> Taiwan Government Information Office. (2004). *A Brief Introduction to Taiwan: Religion*. Available at [www.gio.gov.tw/taiwan-Web\\_site/5-gp/brief/info04\\_19.html](http://www.gio.gov.tw/taiwan-Web_site/5-gp/brief/info04_19.html).

<sup>12</sup> *China (includes Hong Kong and Macau): International Religious Freedom Report 2002*. Available at [www.state.gov/g/drl/rls/irf/2002/13870.htm](http://www.state.gov/g/drl/rls/irf/2002/13870.htm).

<sup>13</sup> Carnes, T. and Fenggang, Y. (2004). *Asian American Religions: Making and Remaking of Borders and Boundaries*. New York: New York University Press.

## II. Chinese-American Focus Group Summaries

This section includes summaries of two different consumer focus group initiatives with Chinese-Americans from Caring Connections and the California Coalition for Compassionate Care. The following summaries offer valuable information to better understand Chinese-Americans' attitudes and beliefs about end-of-life care.

### A. *Caring Connections: Chinese Focus Group Summary (May 2006)*

In May 2006, Lake Research Partners (LRP) conducted four focus groups with Chinese-Americans for Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO). These focus groups were part of a broader study aimed at informing NHPCO's outreach and communication efforts to diverse racial and ethnic communities. Since the goal of community outreach is to engage people in end-of-life discussions before they are faced with a crisis, the focus groups were conducted with middle-aged Chinese-Americans who had not lost a loved-one in the past two years and had never had a life-threatening illness or injury. Two groups were conducted in Mandarin in Los Angeles, one in Mandarin in Houston, and one in English in Houston.

The following are key findings from the focus groups:

#### Advance Care Planning

While there was diversity in the degree to which participants were comfortable talking about death, there was agreement that talking about death, especially with elders, is taboo and disrespectful. Many participants say they have not talked with their loved ones about their end-of-life wishes. Some would prefer to leave the decision to their family. Most say that they would not want to be kept alive on life support, primarily because they do not want to burden their loved ones. Some participants felt that advance care planning is something they would do only after being diagnosed with an illness, not "before the crisis."

#### End-of-Life Caregiving

Dying peacefully is important to Chinese people. As one participant stated, "We Chinese say, we don't expect to have a good life, but we'd rather have a good death. It's a good fortune to have a good death."

Participants were divided about withholding life support from a loved one. Because of the importance of filial duty and respect, some said it was difficult to remove a parent from life support. "My husband originally was reluctant to give permission to the removal of life support for fear that people would accuse him of not fulfilling filial duties [important obligation to take care of one's parents]. But when he saw his mother was in great pain, he at last said OK... She left peacefully." More generally, participants' comments suggested that there are very different attitudes and practices around withholding care in Taiwan and mainland China.

## Hospice

Hospice is a novel concept to most respondents. Some were confused about the specific services provided, some thought hospice was nursing home care. The Buddhist Compassion Relief Tzu Chi Foundation in Taiwan is very popular and influential in Taiwan, and Taiwanese were more likely to be familiar with hospice. Some did not realize there was hospice in America, and only knew Tzu Chi in Taiwan.

The central tenets of hospice resonated with respondents. However, some did not know that Medicare, Medicaid and most private insurance covers hospice.

## Other Results

Eastern religious beliefs are still relevant, Chinese-Americans think about illness and death in holistic terms, especially in terms of heat and cold. Chinese Christians tended to use their religion as a basis for viewing end-of-life issues.

Respect for doctors is very important, and because of this, doctors may have a very significant role to play in end-of-life care decisions. Women seemed especially likely to defer to doctors when making end-of-life decisions.

## ***B. California Coalition for Compassionate Care 2002-03 Needs Assessment***

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In 2002 and 2003, the California Coalition for Compassionate Care (CCCC) conducted focus groups to assess the end-of-life care educational needs of Chinese-Americans in several California communities to better inform its outreach to Chinese-Americans.

The goals of the focus groups were to understand the advance care planning (ACP) messages that resonate with Chinese-Americans, identify the most successful tools and strategies for communicating these messages and discuss ways to ensure that Chinese-Americans individuals, families, health professionals, and organizations have ready access to culturally appropriate ACP educational tools.

Eight focus groups were conducted in Mandarin and Cantonese, with 82 Chinese-American consumers from several California communities. Participants were predominantly female and most were between the ages of 40-80; there was a near even split between mainland Chinese and Taiwanese. Additionally, interviews were conducted with eight physicians in several California communities. All physicians were bi- or multi-lingual, speaking English as well as Cantonese, Mandarin and/or Taiwanese.

**The following are key findings from the consumer focus groups and physician interviews:**

### Consumer Focus Groups

- ◆ Chinese-Americans in California are still very hesitant to talk about death and end-of-life related decisions. Most consider the topic taboo or are uncomfortable discussing it. Despite this reservation, participants were interested in learning how to talk about these issues more directly.
- ◆ Participants reported poor communication with their healthcare providers, in many cases because of language differences and some cases due to a provider's lack of cultural sensitivity.
- ◆ Most participants lacked information on end-of-life issues, *e.g., hospice, palliative care, pain management, the dying process and advance directives.*
- ◆ Many participants said they would have made different decisions if they had had more complete information at the time of the loved one's death. Many thought their choices were essentially to insist on aggressive care or do nothing. Participants interpreted the option of hospice, if suggested by a doctor, as doing nothing.
- ◆ Participants had little or no knowledge of advance directives, but indicated their interest in completing one if they could get assistance.

## Physician Interviews

- ◆ Physicians said one barrier to good end-of-life care is that many Chinese-Americans still believe that talking about death will result in an earlier death.
- ◆ Most Chinese families insist on aggressive treatment and prefer to go to the hospital to die. Physicians reported that Chinese-Americans, don't want to die in their home, due to a belief it brings bad luck and makes it difficult to sell the house to another Chinese family. Also, families are uncomfortable having strangers in the house caring for them, particularly if the caregivers don't speak Chinese.
- ◆ Physicians would appreciate end-of-life materials in Chinese.

For more information about the California Coalition for Compassionate Care, visit [www.finalchoices.org](http://www.finalchoices.org).

### III. Building Partnerships in the Chinese-American Community *Featuring HomeReach Hospice of OhioHealth*

This section offers specific tips for building partnerships with Chinese-Americans in your community. HomeReach Hospice of OhioHealth is featured throughout this section as a model for hospices and end-of-life coalitions seeking to develop these relationships.

In this section you will find the following tips with an accompanying practical example from HomeReach Hospice on how to:

- ◆ Assess Your Community Demographics
- ◆ Recruit a Community Liaison
- ◆ Gather Feedback
- ◆ Engage Community Stakeholders
- ◆ Integrate Cultural Competency Into Your Organization
- ◆ Use Culturally-Appropriate Language
- ◆ Build Trust

#### A. Assess Your Community Demographics

Before you begin your outreach to the Chinese-American community, take time to determine exactly who you are trying to reach by assessing the diversity of your community. **The following is a sample of some of the data that would be helpful to gather:**

- ◆ Are there more people with a Taiwanese background or more people whose roots are in mainland China?
- ◆ What are the different dialects that people in your community speak?
- ◆ Are most residents recent immigrants or American-born?
- ◆ What is the average age, education level and economic status of the Chinese-American population?

*HomeReach Hospice of OhioHealth received a grant in 2005 from the Aetna Foundation to improve access to and educate the Chinese-American community of Columbus, Ohio about end-of-life care; the Link, Learn, and Support End of Life project was established. The project is geared towards the Mandarin-speaking population as well as other underserved immigrant populations.*

*There are approximately 15,000 Chinese-Americans spread out over the sprawling Columbus area. The Chinese community is largely middle-class, educated immigrants from Taiwan, and many elders live with children and grandchildren. In recent years, the Asian community has represented only about 1% of HomeReach Hospice patients and families. The lack of a central neighborhood where people congregate presented a challenge to determine how best to reach the community.*

## **B. Recruit a Community Liaison**

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One component of successful outreach includes the involvement of a bilingual, bicultural person who is well connected to the local Chinese-American community. Consider the skills needed to achieve your goals as well as the credibility the person brings to your agency or coalition. Ideally the person should be able to work with a diverse group of people, rather than only on traditional qualifications, such as education level. It is important to assess his/her credibility with and access to the people you are trying to reach.

*Because the Chinese-American community in Columbus is very spread out it was somewhat difficult for HomeReach Hospice to initially identify influential community leadership to establish a collaborative working relationship. It decided to partner with a local service provider, Asian American Community Services (AACS).*

*HomeReach Hospice project coordinator Betty Tom-Denzer, MA, LPC works closely with designated AACS liaison Valerie Huang, MA, a program manager. Valerie is originally from Taiwan and has ties to the Buddhist and Christian communities. She has a thorough understanding of both Western and Eastern end-of-life care issues and at the beginning of the project, she became a certified Respecting Choices™ facilitator. (For more information about Respecting Choices™, visit [www.gundluth.org/eolprograms](http://www.gundluth.org/eolprograms).)*

## **C. Gather Feedback**

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Seek input from the local Chinese-American community before you begin any outreach initiative. One way to begin is to survey or interview Chinese-American families who have received hospice services and learn about their experiences. In order to successfully provide services, it is essential for the members of the Chinese-American community to describe their experiences with hospice and voice their desires for and concerns about end-of-life care. The degree to which individual Chinese-Americans are receptive to discussing end-of-life issues often depends on whether or not they were born in the US, how many years they have been in the US if they are immigrants, and how much they identify with their Chinese background.

In addition, ask members of the community about current projects, initiatives or priorities. For instance, if there is a major initiative related to (end-of-life topic) you may want to wait before introducing your initiative or find a way to dovetail your work with current activities. Actively listen to their concerns and develop a mutually realistic action plan that reflects their values.

*AACS community liaison Valerie Huang surveyed 52 members of the Chinese community, the majority of who were under age 50. She discovered a growing awareness of end-of-life issues among younger Chinese-Americans and a need for more education.*

*The experience of administering the survey revealed many Chinese-Americans in Columbus didn't want to discuss hospice, and many, especially those over age 50, were unreceptive to the survey. As a result, the two best avenues for engaging people seemed to be adult children taking care of elderly parents, and religious communities.*

*Local religious leaders from the Chinese-American community were brought together to discuss the goals of the end-of-life care outreach, and also to become educated about the availability of hospice services.*

*In addition to the survey, Betty Tom-Denzer interviewed family members of patients who died to determine how satisfied they were with the care from HomeReach Hospice and to see what could be improved upon or done differently. In Betty's experience, Chinese-Americans and other Asian families have not been as likely to complete surveys after a loved one dies. She feels that face-to-face interviews may encourage families to share their feelings about the hospice experience. In particular, Betty hopes that her background as a Chinese-American woman, a bereavement counselor, and the daughter of parents who have benefited from the hospice care will help families to be open about their hospice experiences. In the past, informal conversations Betty has had with families have revealed that the respect patients and families have for the authority of healthcare providers may be a barrier to openly discussing concerns or questions about care.*

#### **D. Engage Community Stakeholders**

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Create formal relationships with key community stakeholders to help build bridges with the Chinese-American community and strengthen your outreach potential. Do your homework to learn who is influential in the community and then meet with potential members to explain what you are trying to accomplish.

Individuals who may be influential in the Chinese-American community include clergy, social service providers, cultural centers, interpreters, local Chinese-American businesses, and in some communities, there may be a significant concentration of Chinese-Americans at the local university. Other stakeholders include health and human service organizations, and the political community (local town and county representatives).

*In addition to forming a relationship with Asian-American Community Services, HomeReach Hospice has created relationships with Buddhist and Christian faith communities, the Department of Aging, the local health department, a local Asian health clinic, and Meals on Wheels. They have also worked with an informal network of Chinese-American professionals from several local universities and the Organization of Chinese-Americans (Columbus Chapter) who are active in their community. Efforts were also made to build a relationship with the Chinese-American Coalition for Compassionate Care (CACCC) to benefit from their focus on outreach and education to the Chinese-American community on end-of-life issues.*

## E. Integrate Cultural Competency Into Your Organization

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Increasing awareness of and education to the community are often the first steps for outreach to a new population your organization would like to serve. It is equally as important to review your organization as a whole to assess whether anything should be changed internally to better serve the community you are targeting. **Some questions to ask include:**

- ◆ Are staff members comfortable with addressing end-of-life concerns that might arise in the course of service which are particular to this population?
- ◆ Are you confident your staff will be able to serve this community with respect and cultural sensitivity?
- ◆ Is your organization able to link Chinese-Americans to other services in your community that might be of help to them?
- ◆ Will our current communication and other systems be able to address language barriers, new faith backgrounds, and work with patients who may have different approaches to patient autonomy and end-of-life decision making?

Incorporating cultural competency goals into the strategic plan of your organization or coalition can also ensure long-term commitment and funding adequately supports those goals.

*A further objective of the Link, Learn, and Support End of Life Project for HomeReach Hospice was to increase access of Chinese-Americans and other immigrant patients and families they serve. It has been important to educate HomeReach Hospice staff to prepare to serve these communities in larger numbers. Operational systems were identified where HomeReach Hospice could improve, such as addressing cultural differences, use of interpreters during care, and appropriate translation of informational materials and forms. Focus groups were held with staff and an internal action plan was developed. One success has been that an acupuncture consultant who was invited to educate staff about this practice is now available for home visits if requested by a family or patient.*

*Another systems issue has been trying to identify patterns in the referrals that HomeReach Hospice receives for patients and families in the Asian community as well as the other communities. The organization is seeing a pattern that many patients and families from underserved backgrounds are often admitted only if they have a medical crisis resulting in a hospitalization and/or an emergency room visit. These families have generally not responded to advertising nor sought hospice services on their own. Because of these circumstances, Betty Tom-Denzer has worked with the admissions department and AACCS in collaboration with other community project partners to help determine additional patterns and a process that might enable HomeReach Hospice to better serve these communities.*

*Additionally, a monthly facilitated “case debriefing” session for staff is held to enable staff to share their experiences with complex, diverse family and patient need situations in order to learn from each other. This forum allows providers to develop competencies and skills for ongoing process improvement efforts while offering CEU credits to nurses and social worker/counselors who attend.*

## F. Use Culturally-Appropriate Language

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If you are working with a largely immigrant community, it is essential to focus on using culturally appropriate language, both in written communications and in the healthcare setting. Documents should not just be translated, but trans-created. In other words, they should be made easily understandable and appropriate for the community they are for, using correct terminology and not just a direct translation. Efforts should be made to have trained interpreters available when providing healthcare services. Interpreters can play a crucial role in facilitating the delivery of quality healthcare to Chinese-Americans, and the best interpreters will understand cultural considerations as well as language skills. Often family members will serve as interpreters which is not ideal. Studies have shown that untrained medical interpreters, including family members, often fail to accurately convey information between the patient and healthcare practitioners. That is why it is so important to have properly trained medical translators on staff, as volunteers or available through contract agencies. See Section V for translation and interpretation resources.

As noted in Section I, it is important to understand the diversity of Chinese languages. A large majority of people from mainland China and Taiwan speak Mandarin Chinese, while others speak dialects such as Cantonese. Cantonese and Mandarin share a common written language—most Chinese characters are understandable by all. However, there are important differences between written language in mainland China and in Taiwan. Since the 1950s, mainland China has used “simplified” characters, a way of writing characters with less detail while Taiwan uses only “traditional” characters.

*HomeReach Hospice translated some of its hospice information into a Chinese brochure tailored to meet the cultural concerns of the community. It was very important to develop these materials and to use them at health fairs and other community events, in addition to being useful for families and staff. However, because hospice is a new concept for many Chinese-Americans, and one that can have many misconceptions, ensuring that these brochures are adequately distributed is an ongoing effort. Hospice staff use these educational resources while providing care in the community.*

*Another collaborative initiative for HomeReach Hospice was working with the OhioHealth organization and community interpreting agencies to clarify roles and expectations for providing quality care. Betty Tom-Denzer, Valerie Huang, and OhioHealth’s interpreting services manager met with interpreting agencies, including Chinese-speaking staff, to understand perspectives in working with families, patients and providers dealing with end-of-life issues. All Asian interpreters employed by AACCS were offered education on hospice and palliative care services as well as advance care planning. Bridging the gap between healthcare staff and interpreters remains an on-going priority.*

## G. Build Trust

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One of the most important things that any organization must do when working with a cultural community for the first time is to build trust. Gaining the trust of a community takes time. Developing trust needs to 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 Chinese-American community.

*Betty Tom-Denzer and Valerie Huang made a conscious decision to engage the faith communities for Chinese-Americans very slowly. They felt it was essential to take the time to establish a good relationship with these important and influential organizations in order to develop a sound reputation throughout the Chinese-American community. The time that they have invested has helped religious leaders understand the goals of hospice and dispel common myths.*

*First, a structured meeting was held with Christian and Buddhist clergy, soliciting their input as experts on their community and discussing strategies for engaging their members, as well as their feedback on a presentation about the fundamentals of hospice. There will be a long-term follow-up meeting with these leaders later in 2007 to get additional feedback, share experiences, hear from the Medical Director of HomeReach Hospice, and tour the in-patient facilities.*

*Local leaders of the Tzu Chi Foundation, a Taiwanese Buddhist organization with hospice experience and many chapters throughout the United States, were very interested in the HomeReach Hospice project after the first clergy meeting. Several individuals mentioned they had previous hospice volunteer experience. Soon after, they requested an advance care planning presentation just for their clergy. Betty and Valerie incorporated materials from Caring Connections' It's About How You LIVE campaign and Respecting Choices™ into this training, which was done at the local Tzu-Chi Service Center.*

For more information about the Link, Learn, and Support End of Life Project of HomeReach Hospice of OhioHealth, go to [www.aacsohio.org](http://www.aacsohio.org).

## IV. Outreach Strategies

### *Featuring the Chinese-American Coalition for Compassionate Care (CACCC)*

This section offers outreach strategies and activities that can be used to engage Chinese-Americans in your community. The Chinese-American Coalition for Compassionate Care (CACCC) and the work of CACCC founder Sandy Chen Stokes, RN, is used as a model for hospices and coalitions educating and reaching out to the Chinese-American community about end-of-life issues.

This section will discuss the following specific outreach strategies with practical examples from CACCC on how to:

- ◆ A. Form a Community Advisory Committee or Coalition
- ◆ B. Assess Healthcare Providers
- ◆ C. Provide Education and Training About End-of-Life Care
- ◆ D. Develop and Distribute Helpful Resources
- ◆ E. Cultivate Volunteers
- ◆ F. Engage the Chinese-American Media

#### ***A. Form a Community Advisory Committee or Coalition***

The formation of a coalition is an excellent way to bring together a wide variety of professionals to accomplish a common goal. Many areas of the United States have a relatively small Chinese-American population and there may be few professionals who work exclusively with this community. It is important for professionals interested in improving end-of-life care for Chinese-Americans to come together to share resources and expertise.

Developing a community advisory committee or coalition provides a formal structure to bring people and professionals together to collaborate. This structure will help professionals learn more about initiatives in different parts of the community, communicate regularly, and serve as a network for those committed to better serving the Chinese-American community. A coalition structure can help to generate momentum as individuals and organizations work towards a common goal.

*The Chinese-American Coalition for Compassionate Care (CACCC) is the only coalition in the US devoted to end-of-life care for Chinese-Americans. Founded in California in late 2005 to address the lack of linguistically and culturally appropriate information about end of life available to the Chinese-American community, in its first year CACCC grew to more than 100 people representing over 40 organizations including the American Cancer Society, Alzheimer's Association, California Transplant Donor Network, and Tzu Chi Foundation USA.*

*CACCC is a combination of bilingual Chinese volunteers with an interest in end-of-life care and aging and end-of-life care professionals from different backgrounds committed to improving culturally-competent care for this community. CACCC emphasizes the importance of bringing as many people to the table as possible— diverse professionals, community members, and organizations that serve Chinese-Americans— and dedicates portions of its meetings to educating coalition members as well as planning projects.*

*Sandy Chen Stokes, RN, MSN founded CACCC and serves as its chair. She also serves on Caring Connections' National Advisory Committee. Sandy, a geriatric nurse specialist, has a wealth of experience in end-of-life issues, as well as expertise in advance care planning, resource development and community partnership. Born and raised in Taiwan, she is familiar with the taboos and discomfort people have discussing death in Chinese culture. CACCC is the culmination of her years of work advocating for end-of-life care in the Chinese-American community.*

## **B. Assess Healthcare Providers**

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Assessing the needs of the Chinese-American community regarding end-of-life issues can be useful in designing outreach strategies as discussed in Section III. In addition, assess healthcare providers who work closely with Chinese-Americans, especially Chinese-American medical professionals, since it is likely they will care for Chinese-American patients. These providers can also offer insight into different attitudes towards Traditional Chinese Medicine and modern medicine in relation to end-of-life care. Whether it is through interviews, focus groups or a survey, the views of providers who serve Chinese-Americans will provide valuable insights for your community outreach initiatives.

*The California Coalition for Compassionate Care (CCCC) completed a needs assessment that sought to elicit Chinese-American community attitudes towards end-of-life care. Sandy Chen Stokes, who was the lead consultant on that project, conducted focus groups with patients and families as well as with Chinese-American doctors who practiced both Eastern and Western medicine. Physicians said one barrier to good end-of-life care is that many Chinese still believe that talking about death will result in an earlier death. Read a summary of the results in Section II.*

### **C. Provide Education and Training About End-of-Life Care**

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One need your assessments are likely to identify is a significant need for education about end-of-life care. Consumers need to know about advance care planning, pain management and hospice services, whereas providers need to understand how they can better serve the end-of-life care needs of the Chinese-American community.

Advance care planning is perhaps one of the most direct ways to begin outreach with any community. While advance care planning in other communities may begin with family discussions that lead to completing advance directive forms, the reverse process may take place in the Chinese community. There is emphasis in Chinese culture on doing things ‘the right way’ and following the rules of the healthcare system. This may offer an opportunity to introduce advance directives as ‘the right thing to do’ when thinking about illness and death.

*The Chinese-American Coalition for Compassionate Care has held many events in different California communities on a wide range of end-of-life topics including making medical decisions and meeting the religious and cultural needs of the community, in addition to advance care planning.*

*One of the first ways Sandy Chen Stokes engaged Chinese-Americans in California in end-of-life care issues was by conducting advance care planning presentations for local elders at community and cultural centers which were very well attended. In order to assist all who wanted to complete an advance directive, it was necessary to train bilingual Chinese volunteers to assist others, since many of the elders could not read the English language California Advance Healthcare Directive. To encourage family involvement, each presentation was followed by a second one within a week, to give audience members the opportunity to bring the person named as their healthcare proxy to the presentation.*

### **D. Develop and Distribute Helpful Resources**

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It is essential to give people helpful information and specific tools that can be used to engage communities with end-of-life care. Your hospice or coalition may find it is important to develop culturally-relevant materials that explain who you are and what services you offer. The feedback you receive from the community that you have already gathered can be very helpful, and can guide the development of these materials.

To fill a need for end-of-life materials in Chinese, Sandy Chen Stokes has contributed to the development of many resources.

*Sandy and two others translated the California Advance Healthcare Directive to Chinese and modified it to better-fit Chinese cultural norms. In addition, she helped the American Cancer Society-Northern California Chinese Unit develop the first end-of-life related Chinese resource booklet, “Quality of Life Handbook: A guideline for patients with terminal cancer or long-term illness and their families” Go to [www.caccc-usa.org](http://www.caccc-usa.org) for more information.*

*Next, Sandy wrote and narrated a DVD presentation in (Mandarin) Chinese with an accompanying 50-page booklet in Chinese. “Advance Healthcare Directives and Hospice,” has had four printings for a total of 11,000 copies.*

*The results of the Chinese-American needs assessment led to the development of “Mrs. Lee’s Story: Medical Decisions Near the End of Life” with Sacramento Healthcare Decisions. This 16-page booklet is appropriate for patients, families, and clinicians. Written in Chinese and English it tells the story of a Chinese elder and includes basic information on advance care planning, pain management, and hospice care.*

*(Note: For more information about the resource mentioned above, see Section V of this Guide.)*

## **E. Cultivate Volunteers**

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The important role of volunteers in end-of-life care for Chinese-Americans cannot be understated. It will rarely be possible for any hospice or healthcare organization to hire enough bilingual or bicultural staff to meet the needs of all of Chinese-American patients and families. Generally, there are not enough Chinese-American health professionals in most communities to meet the needs of all healthcare providers. Therefore, training volunteers is a key way for hospices and coalitions to link with their communities and improve services.

Coalitions are sustained by volunteers, ideally representing the community or groups that the coalition hopes to serve. In addition to cultivating attention to end-of-life care in their community and helping form new relationships, Chinese-American volunteers can disseminate information, translate documents and serve as interpreters in healthcare settings or for community outreach programs. Chinese-American coalition members will also enhance the credibility and likely success of your efforts. If you are perceived to be an outside group seeking to “do something to” a diverse community, you are less likely to succeed.

In hospice, the role of volunteers is a broad one, from patient care to administrative tasks. Chinese-American volunteers should not be used only with patients and families from the Chinese-American community. Since many hospices don’t serve large numbers of Chinese patients and families, it severely limits the opportunities of volunteers if they do not also serve patients and families with other backgrounds. Giving them as many opportunities to use their skills as they would like is important to feel fully part of the hospice community.

Consider offering a volunteer training in a place connected with the Chinese-American community. Partnering with a Chinese-American community center or Buddhist temple may be a good way of demonstrating your commitment to respecting Chinese-American culture and building further bridges with the community.

*In August 2006, CACCC organized a training for volunteers who offer respite to care-giving families at the request of the American Cancer Society Northern California Chinese Unit (ACSNCCU). It was a tremendous success with 99 attendees, almost double the anticipated number, demonstrating the significant interest in and need for end-of-life care in this community. It was conducted in Mandarin with simultaneous English interpretation (only 6 attendees did not speak Chinese). One third of the audience was associated with ACSNCCU and the rest were associated with CACCC, including volunteers from faith communities and other community organizations, and family caregivers. Conducting this training proved to be wonderful opportunity for CACCC to recruit new volunteers.*

## ***F. Engage the Chinese-American Media***

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To continue to raise awareness in and engage the Chinese-American community about end-of-life issues, cultivate relationships with the Chinese-language media. Develop ads and public service announcements, approach local journalists, radio shows and television programs. Often these outlets are eager for new content and new story topics.

There are a number of Chinese-language newspapers that have national distribution in the US, as well as regional papers in Florida, California, New Jersey, Chicago and Seattle. There are radio stations that broadcast in Chinese in New York, California, Washington, D.C. and Philadelphia. Finally, there is local television programming in Chinese in New York and California.

*The California Coalition for Compassionate Care hired Sandy to provide editorial oversight of the Chinese translation of the newspaper series “Finding Our Way” for the World Journal, the largest Chinese language newspaper in North America with a circulation of 350,000. For 15 weeks, the World Journal national Sunday magazine ran a different article and the series successfully raised awareness about end-of-life issues in the Chinese-American community.*

**For more information about translation and other services the Chinese-American Coalition for Compassionate Care may be able to offer your organization or coalition, see Section V of this Guide or go to [www.caccc-usa.org](http://www.caccc-usa.org).**

## V. Resources for Community Engagement

### A. HelpLines

NHPCO's HelpLine: 800.658.8898

Multilingual HelpLine: 877.658.8896

Trained HelpLine staff are available to help people find information including:

- ◆ Locating a hospice, palliative care program, or other end-of-life care organization
- ◆ Free state-specific advance directives
- ◆ Brochures
- ◆ Information about state and community end-of-life coalitions
- ◆ Identifying local, state and national resources

### B. Educational Tools

#### Caring Connections

Caring Connections, a program of the National Hospice and Palliative Care Organization, has educational brochures on end-of-life care topics available in Chinese to download at [www.caringinfo.org](http://www.caringinfo.org) or purchase at [www.nhpco.org/marketplace](http://www.nhpco.org/marketplace).

#### Mrs. Lee's Story: Medical Decisions Near the End of Life

This 16-page booklet in Chinese and English was developed by Sacramento Healthcare Decisions. It tells the story of 91-year old Mrs. Ming Lee and includes basic information on advance directives, advance care planning, pain management and hospice care. Preview and order Mrs. Lee's Story at [www.sachealthdecisions.org/publications.html](http://www.sachealthdecisions.org/publications.html).

#### Hospice and Advance Directives (DVD & Booklet)

In 2003 the Amitabha Buddhist Society of the USA partnered with Sandy Chen Stokes to produce a DVD presentation and accompanying 50 page booklet on hospice and advance directives. It is available for free. For more information and to order, email: [info@amtb-usa.org](mailto:info@amtb-usa.org).

#### The Chinese Hospice (Video/DVD)

This documentary, sponsored by the American Society on Aging, was filmed at a Beijing hospital in 2000. It portrays hospice care available to a few in mainland China, and tells the story of a few patients whose lives reflect the many changes China has undergone in the last century. Go to [www.filmmakers.com](http://www.filmmakers.com) for more information.

### ***C. Professional Organizations***

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#### **Chinese-American Coalition for Compassionate Care - [www.caccc-usa.org](http://www.caccc-usa.org)**

The only organization in the United States dedicated to improving end-of-life care for the Chinese-American community. Read about successful outreach strategies of CACCC in Section IV. Currently, CACCC's efforts are focused on the San Francisco Bay Area due to its concentration of Chinese-Americans. As CACCC grows, it hopes to work with organizations throughout California, the United States and internationally to foster successful outreach to other Chinese-American communities, and assist with strategic planning and possibly healthcare professional training. Visit [www.caccc-usa.org](http://www.caccc-usa.org) for more information about consulting and training services.

#### **Tzu Chi Foundation, USA - [www.tzuchi.org](http://www.tzuchi.org)**

With offices in over twenty countries, the Tzu Chi Foundation is a Buddhist organization that provides services for those with medical, educational and disaster relief needs of any cultural or religious background. Nearly all services are provided by foundation member volunteers. In the US, there are four regional offices and two free health clinics. To locate a list of regional offices, visit [www.tzuchi.org/global/offices/index.html](http://www.tzuchi.org/global/offices/index.html).

#### **Asian Pacific Islander American Health Forum (APIAHF) - [www.apiahf.org](http://www.apiahf.org)**

This national organization is dedicated to promoting policy, program and research efforts to improve the health and well-being of all Asian- American and Pacific Islander communities. APIAHF advocates coalition-building and developing capacity within local API communities on health issues, conducts community-based technical assistance and training, and analysis of health and US Census data.

#### **Chinese-American Medical Society (CAMS) - [www.camsociety.org](http://www.camsociety.org)**

The Chinese-American Medical Society, founded in 1963, has nearly 1,000 physician and medical student members, most of whom are in the New York-New Jersey area, with others from around the country. Their Web site provides in-depth information about health issues in the Chinese-American community.

#### **The Asian Liver Center - [www.liver.stanford.edu](http://www.liver.stanford.edu)**

The Asian Liver Center at Stanford University addresses the high incidence of hepatitis B and liver cancer among Asians and Asian-Americans. Its Web site has in-depth information about hepatitis B and liver cancer, the impact on the Asian-American community, and community outreach materials in multiple Asian languages are also provided.

#### **Buddhist Lotus Hospice Care Foundation - [www.lotushcf.org.tw/english.htm](http://www.lotushcf.org.tw/english.htm)**

A Buddhist society in Taiwan dedicated to promoting hospice care. It is likely that Chinese-Americans originally from Taiwan are familiar with this organization.

#### **Hospice Foundation of Taiwan - [www.hospice.org.tw](http://www.hospice.org.tw)**

The English portion of this site is under construction.

#### **American Cancer Society Northern California Chinese Unit - [www.acs-nccu.org](http://www.acs-nccu.org)**

This site is an excellent resource for Chinese-speaking people who are looking for information about cancer in Chinese.

## D. Publications

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In addition to the references listed in Section I, below are other useful publications:

Crawley, L., Kagawa Singer, M. (2007). *Racial, Cultural, and Ethnic Factors Affecting the Quality of End-of-Life Care in California*. San Francisco: California Healthcare Foundation. Available at [www.chcf.org](http://www.chcf.org).

Hsiung, Y. Y., Ferrans, C.E. (2007). *Recognizing Chinese-Americans' Cultural Needs in Making End-of-Life Treatment Decisions*. *Journal of Hospice and Palliative Nursing*, 9(3):132-140.

World Journal - [www.chineseworld.com](http://www.chineseworld.com)

*World Journal* is the largest Chinese language newspaper in North America, and it is published daily, with its distribution over 350,000. Their Web site is in Chinese and English.

## E. Language and Translation Assistance

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Chinese-American Coalition for Compassionate Care - [www.caccc-usa.org](http://www.caccc-usa.org)

One important goal CACCC has is to help make end-of-life care language more consistent by popularizing particular terms and establishing key words and common messages. The end-of-life care glossary available in the Appendix was compiled by CACCC. CACCC can offer translation services, done by nurses familiar with end-of-life issues. Go to [www.caccc-usa.org](http://www.caccc-usa.org) for more information about translation services.

National Asian Pacific Center on Aging (NAPCA) Multi-Lingual HelpLine - [www.napca.org](http://www.napca.org)

This toll free multilingual helps elders obtain Medicare and other benefits that they are eligible for: English 1-800-336-2722; Chinese 1-800-582-4218; Korean 1-800-582-4259; Vietnamese 1-800-582-4336.

Family Caregiver Alliance - [www.caregiver.org](http://www.caregiver.org)

Family Caregiver Alliance has information available in Chinese covering a variety of topics such as Alzheimer's disease, assisted living, caregiving, stroke, and advance care planning. For more information, go to [www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=529](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=529).

### SPIRAL:

*Selected Patient Information Resources in Asian Languages* [spiral.tufts.edu](http://spiral.tufts.edu). This site is a large multi-lingual database at Tufts University that provides downloadable PDF files on a range of health issues including cancer, aging, and pain management. Health information is provided in Chinese, Korean, Cambodian, Vietnamese, Thai, Hmong and Laotian.

Language Access Network - [www.languageaccessnetwork.com](http://www.languageaccessnetwork.com)

Language Access Network provides real-time translation services in over 40 languages using phone and video conferencing. Project Coordinator Betty Tom-Denzer of Ohio Health HomeReach Hospice conducted an end-of-life care education program with Language Access Network.

## ***F. Advance Directives\****

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Five Wishes™ - [www.agingwithdignity.org/translations.html](http://www.agingwithdignity.org/translations.html)

Five Wishes™ is an advance directive document available in Chinese (simplified or traditional), Korean, Hmong, Vietnamese and Japanese. Please note that the English version of the document is legally valid in 40 states.

California - [www.caccc-usa.org/forms/ChineseAdvanceDirectivesForm.pdf](http://www.caccc-usa.org/forms/ChineseAdvanceDirectivesForm.pdf)

Chinese, complex characters.

New York State - [www.health.state.ny.us/professionals/patients/health\\_care\\_proxy/intro.htm](http://www.health.state.ny.us/professionals/patients/health_care_proxy/intro.htm)

Chinese, complex characters.

Maryland - [www.mccelc.org/useful\\_links.html](http://www.mccelc.org/useful_links.html)

Chinese, complex characters.

*\*Note: Please check whether the documents listed above are legally valid in your state since some state statutes do not recognize translated versions of advance directives.*

## VI. Acknowledgements

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## VII. Appendix

To download the Appendix documents, visit [www.caringinfo.org](http://www.caringinfo.org), and click on “Community.”

### A. Community PowerPoint Presentations

- a. *Making End-of-Life Decisions* (English ppt)
- b. *Making End-of-Life Decisions* (Chinese ppt)
- c. *Hospice Can Help You and Your Family* (English ppt)
- d. *Hospice Can Help You and Your Family* (Chinese ppt)

### B. Glossary of End-of-Life Care Terms (Chinese) 美華慈心關懷聯盟生命末期療護詞彙

#### The Chinese American Coalition for Compassionate Care

Addiction	上癮
Advance care planning	事前療護計劃
Advance Health Care Directive	醫療照護事前指示
Anorexia	厭食症
Antibiotics	抗生素
Antidepressant	抗憂鬱劑
Anxiety	焦慮
Aromatherapy	芳香療法
Art therapy	藝術療法
Artificial nutrition and hydration	人工營養及水份補充
Artificial ventilation	人工呼吸
Autonomy	自主權
Bedsore/pressure sore	褥瘡/壓瘡
Bereavement	哀傷；傷慟；喪慟
Bioethics	生命倫理
Biofeedback therapy	生物反饋療法
Brain death	腦死
Cardiac arrest	心搏停止

Cardiopulmonary resuscitation (CPR)	心肺復甦術
Caregiver	照顧者
Comfort care	安適療法
Communication	溝通
Competent	決定能力
Constipation	便秘
Death and dying	死亡及瀕死
Delirium	譫妄
Depression	憂鬱
Diarrhea	腹瀉
Do Not Intubate (DNI)	不做氣管內插管
Do Not Resuscitate (DNR)	不做急救
Drug tolerance	耐藥性
Durable power of attorney	預立醫療代理人
Dysphagia	吞嚥困難
Dyspnea	呼吸困難
Edema	水腫
Empathy	同理心
End-of-Life care	生命末期療護
Ethical dilemma	倫理兩難困境
Euthanasia	安樂死
Fatigue	疲倦
Grief	悲傷
Healthcare Proxy/power of attorney	醫療代理人/法定代理人
Hematuria	血尿
Hemorrhage	出血
Hospice care	安寧療護
Informed consent form	同意知會書
Insomnia	失眠
Intubation	氣管內插管
Jaundice	黃疸
Kidney dialysis	洗腎；腎透析
Life-sustaining treatment	維持生命醫療

# 安寧療護 Chinese-American

## OUTREACH GUIDE

Living will	生(前)預囑
Long term care	長期療護
Medicaid/Medi-Cal	州/加州醫療保險
Medical decision-making capacity	醫療決定能力
Medical futility	醫療無效
Medicare	聯邦醫療保險
Mercy killing	仁慈殺人
Mourning	哀悼
Music therapy	音樂療法
Natural death	自然死
Nausea	噁心
Occupational therapy	職能療法
Pain management	疼痛處理
Palliative care	緩和療護
Paralysis	癱瘓
Physical therapy	物理治療
Prolonging dying	延長瀕死期
Quality of life	生命品質
Registered nurse	註冊護士
Rehabilitation medicine	復健醫學
Relaxation technique	放鬆技巧
Respiratory arrest	呼吸停止
Respite care	喘息療護
Social worker	社工人員
Short of breath	呼吸短促
Spiritual care	靈性療護
Titration	給藥時的劑量控制
Total pain	整體疼痛
Urinary retention	尿滯留
Urine incontinence	小便失禁
Vomiting	嘔吐
Weakness	虛弱
Withholding or withdrawing life-sustaining treatment	不做或撤除維持生命醫療





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