HOSPICE MATTERS

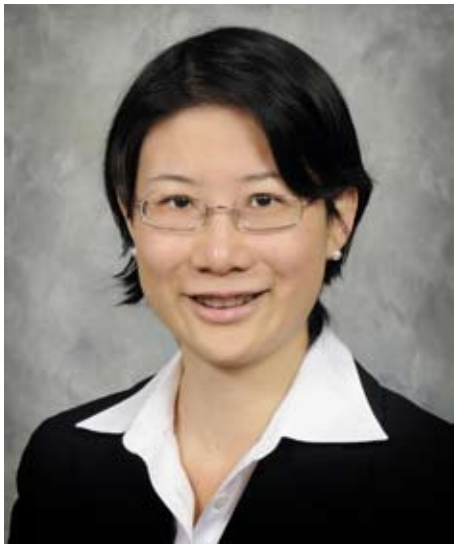
A Newsletter for Family and Friends of Hospice

Spring - 2013

Montgomery HOSPICE

Hospice Discussions with Asian Patients

by Dr. DongMei Wang



Montgomery County, Maryland is known for its rich and diverse culture and heritage. We have a large Asian community along with a growing Asian patient population. From nationwide data, we know that Asian patients use hospice care less often, as compared to other races. How can we help these patients in need to maximize their benefit from hospice? Here are some thoughts based on my experience in my oncology private practice.

Let's first look at the barriers to utilization of hospice service by Asian patients:

1. Many people from Asian cultures think death is a bad thing, and that anything linked to death is bad luck. They do not want to talk about death among family members.
2. Respect for the elderly is an important part of many Asian cultures. As part of this respect, it is not uncommon for Asian adult children to hide a terminal illness diagnosis from their parents.
3. Most Asian patients are not familiar with hospice care, as it is so rare in their country of origin.
4. In general, Asian patients have less knowledge about the American medical system.
5. Dying in a hospital is considered acceptable or the norm in Asian culture.
6. Many Asians expect to receive medical treatment until they die. They may want to try anything and everything to help when there is a poor prognosis.
7. Language barriers exist for many Asian patients and families.

When facing these challenges, here are some tips that I have found helpful when I talk to patients and families about hospice care:

1. Do not rush. Set up a time and sit down with the patient and his or her family.
2. Use an interpreter if you don't speak their language.
3. Get the family's permission first before releasing a bad diagnosis to the patient.
4. Emphasize quality of life rather than quantity of life.
5. Learn about the family's attitude towards hospice. Understand and respect a different culture's approach towards end-of-life issues.
6. Explain the benefit of pain control.
7. Explain the benefit of getting service at home.
8. Explain the benefit of stress relief for family members.
9. Explain that the patient can keep his or her current doctor.
10. Be open to alternative types of medicine.

I have been in a private oncology practice for 5 years, and face many of the same challenges every practitioner faces. I sincerely hope that my tips will help others to discuss hospice services with their patients.

Dr. DongMei Wang is Board Certified in Oncology and in Internal Medicine, and practices at Montgomery Oncology Care and Hematology in Rockville, MD.

Asians in Montgomery County

Asian Americans comprise a fast-growing and diverse segment of Montgomery County.

percentage of total MC population:
- 11.3% in 2000
- 14.4% in 2011

subgroups include:

Asian Indian	Laotian
Bangladeshi	Malaysian
Burmese	Nepalese
Cambodian	Pakistani
Chinese	Sri Lankan
Filipino	Taiwanese
Indonesian	Thai
Japanese	Vietnamese
Korean	

73.7% are foreign born

83.8% speak a language other than English at home

36.9% speak English "less than very well"

information from the US Census Bureau and the Asian American Health Initiative

ColellaPhoto.com

From Ann's Office

Hospice: Improved Quality and Lower Costs

These are uncertain times for healthcare and its providers. The bottom-line effects of the Affordable Care Act are not yet fully known. Fundamental changes to Medicare are being discussed as long-term solutions to the national debt issue. More immediately, sequestration cuts will decrease revenue by 2 percent for those of us serving Medicare patients. Montgomery Hospice continues to fight against being arbitrarily considered outside of the Washington metropolitan area by Medicare and thus receiving lower payments for the services we provide.

We are excited, however, by new research that continues to support what we already know about the value of hospice. The latest research, which was funded by the National Institute of Aging (and published in the March 2013 issue of Health Affairs), shows that hospice both improves the quality of care for patients and saves money for the system. The researchers found Medicare savings of $2,561 to $6,430 per patient (depending on how long the patient was enrolled in hospice), and also showed that these patients spent fewer days in hospitals and were much less likely to die in a hospital setting. The study found particular reductions in time spent in intensive care units and in hospital readmissions for patients who had enrolled in hospice months before death, rather than waiting until the last weeks or days. Building on other studies that have shown high patient and family satisfaction, the researchers conclude that "Medicare should seek to expand access to hospice services so that hospice can contribute to its full potential to the overall value of care."

We remain immensely grateful to all of our community supporters, whose donations allows us to continue providing the quality care that we are known for, easing the burdens of our seriously ill and grieving neighbors. We thank so many of you who have donated to our Gentle the Journey Campaign. In this, the last year of the campaign, we are more motivated than ever to do the work needed together to allow Montgomery County residents access to the services of Montgomery Hospice.

Ann Mitchell

Ann Mitchell
President & CEO

Paul Brenner: a "persevering pioneer"

The hospice community lost one of its early advocates when Paul Brenner died on February 22, 2013. The "Montgomery Hospice Society" benefited from his wisdom and passion when he served as Executive Director from the mid 1980s through 1994. Carol Whitney, a nurse who has worked for Montgomery Hospice since the early days in the basement of St. John's Episcopal Church, remembers him clearly as having "the hospice heart." When the organization outgrew the borrowed space in the church, Mr. Brenner deliberately chose offices on a higher floor in order to move "beyond the basement mentality." Former Congresswomen Connie Morella described him as "a persevering pioneer," after she learned of his death and reflected on his role in growing Montgomery Hospice. Martha Flory, Director of Finance, was hired by Mr. Brenner in 1989; she described him as "congenial, with a good sense of humor, and very dedicated to causes that he believed in – hospice was his main cause." Mr. Brenner was also instrumental in the organization's first steps toward achieving the vision of a hospice house, working with Mrs. Eugene B. Casey and accepting her generous donation of land and funds, given in memory of her late husband.

Paul Brenner accepting donation from Congresswoman Connie Morella

With gratitude for his service to our community, Montgomery Hospice extends condolences to Paul Brenner's family.

Quality End-of-Life Care

by Mei Ching Lee, PhD

A Life Journey

Going on a trip requires planning. Likewise, a good life journey requires thought, effort and preparation so that it may be concluded with quality. This article discusses barriers to quality of life at the end of life, and provides suggestions in planning for a peaceful journey.

Quality End-Of-Life Care

People face serious illness with different approaches. Some choose to battle with it to extend the quantity of life, often intending to complete unfinished business or wishes. Others may choose quality over quantity of life, choosing comfort and to avoid burdensome treatments and medications. The purpose of quality end-of-life care is to treat patients according to their wishes and their goals, not over-treating or undertreating them. Knowing an individual's treatment goal is crucial in providing quality end-of-life care. When the cure of illnesses becomes unrealistic, most people desire to complete their life's journey with no pain or suffering, to die with peace and dignity. Unfortunately, many people struggle at the end of life in opposition to their wishes; they go through painful treatments and procedures, suffer from unrelieved symptoms, burdened by multiple trips to the emergency room, and die in the intensive care unit with various life support medications and medical equipment around them. Surveys of family members with their loved ones in intensive care units revealed that many of them were dissatisfied with the care because of frequent pain and anxiety, poor communication and conflicting treatment goals. An executive summary by the Robert Wood Johnson Foundation in 2003 described barriers to quality end-of-life care and suggested that these barriers can be categorized according to patient and healthcare provider factors.

Dr. Lee earned her PhD at the University of Maryland School of Nursing, where she serves as an Assistant Professor. Dr. Lee was an NIH-funded Post-Doctoral Fellow in Bioethics at Johns Hopkins University.

Patient Factors

Advance directives

Lack of advance directives is one of the major barriers in providing quality end-of-life care to patients. Patients and their families have the tendency to wait for someone other than themselves to initiate the discussion. Some terminally ill patients have never had a discussion of their preferences for end-of-life care with their family. When these patients lose the capacity to participate in making treatment decisions, the tremendous responsibility of healthcare decision-making falls to the family members who have no knowledge of what their loved ones would prefer. This situation creates confusion around the treatment goal and greatly affects the quality of end-of-life care. Family members often have to make stressful healthcare decisions such as whether to withdraw life-support or to continue every possible treatment. These are difficult decisions when there is no clear direction from the patient, and often family members are left to ponder if they are making the best decisions for their loved ones. Therefore, it is important that the details of individuals' end-of-life preferences are acknowledged so that others can honor and respect their wishes.

Autonomy and the decision maker

Culture plays an important role in the quality of end-of-life care. The value placed on autonomy and individual rights in American culture may be regarded differently in other cultures. When applied to situations involving people of other cultures, the placing of individual rights first may not be beneficial but can create difficulties and distress to patients and their family members. The Patient Self-Determination Act was passed in 1991, recognizing the rights of patients to make treatment decisions. This act included the right for patients to participate in and direct their own healthcare decisions, the right to accept and refuse medical treatment, and the right to prepare an advance directive. Under this law, healthcare providers must respect that patients have the ultimate right to be informed of the diagnosis and prognosis of even a terminal illness, and that the individual is to direct the decision making, including accepting or refusing treatment, curative or palliative care.

From a cultural standpoint, the issues of full disclosure or truth-telling and healthcare decision making may be viewed quite differently. For many Asians and Pacific Islanders, their cultural values include observing filial piety, wherein family members are expected to take over the decision-making role for seriously ill elderly family members. A collective decision-making method that involves family members in healthcare decision making is more important than the

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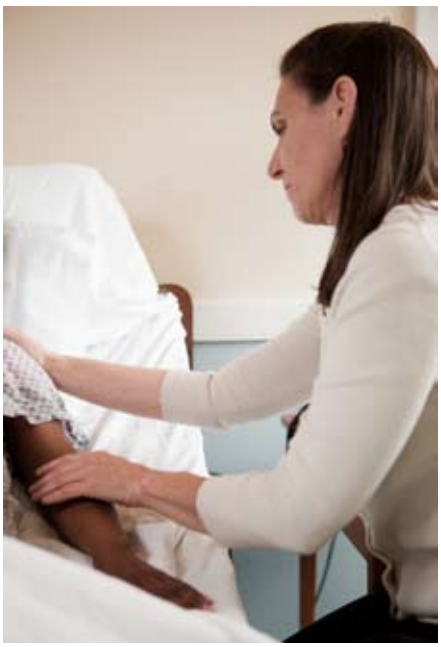
Complementary Therapies

"A massage calms my breathing; it is very valuable, very beneficial. I am amazed by how much it helps me." A life-long runner and exercise enthusiast, 52-year old Judy has been an advocate for herself throughout her years living with cancer. She continues this advocacy, taking advantage of Montgomery Hospice's Complementary Therapy Program. She relies on support from her family, traditional pain medications – and massage. *"Sandy's massages help with pain and discomfort, and breathing. This is absolutely what I want as part of my hospice care."*

"Sandy's massages" refers to the work of Sandra Lavengood, Montgomery Hospice's Complementary Therapies Manager. Montgomery Hospice created this manager position in 2010, making a serious commitment to the use of complementary therapies and becoming one of the few hospices in the nation with a staff member dedicated to creating a complementary therapy program. Building on ideas and visions of other staff members, and partnering with Director of Volunteers Christiane Wiese to maximize the use of volunteers, Sandy has worked to establish a clinically sound foundation for the program, always focusing on the very clear goal of providing comfort for dying patients.

Although the term "complementary therapies" can mean many different things, one definition describes the Montgomery Hospice philosophy well: Complementary therapies are noninvasive, non-pharmacologic adjuncts to mainstream treatment. Complementary therapies are rational, evidence-based practices delivered or taught by trained practitioners.* Montgomery Hospice chooses therapies that have been effective, and introduces them after consulting with other end-of-life experts, and establishing protocols, policies and trainings to ensure patient safety.



Massage is one therapy that works well with patients, specifically gentle touch techniques tailored to patients at end of life. Montgomery Hospice staff and volunteers have been trained to provide Lavender Oil hand massages since 2007. This simple, effective offering combines touch and aroma to bring comfort and relaxation to patients and families. In 2010, Montgomery Hospice took touch therapies to a new level by establishing a volunteer massage therapy program. Licensed massage therapists with at least 2 years of experience have been recruited to volunteer their professional services. In addition to completing Montgomery Hospice's volunteer training, these therapists are further trained in Comfort Touch®, a type of massage specifically designed for patients who are elderly or very ill. The care the volunteer therapists provide is supervised by Sandy Lavengood, herself a licensed massage therapist. In 2012, a second licensed massage therapist, Diana Goroff, was hired. Her availability on staff has been essential to meeting the growing demand for massage services, and to further integrating this work into ongoing patient care. Together Sandy, Diana and the ten volunteer licensed massage therapists visit patients in homes, facilities and at Casey House, making more than 600 patient visits in 2012 (up from 236 in 2010).

Music has also been shown to have many benefits for hospice patients, including a decreased perception of pain, reduced anxiety and heightened relaxation. Montgomery Hospice worked with a professional with a specialized college degree in Music Therapy to develop the use of music with patients. Volunteers and staff have access to an extensive library of music, available on CDs and iPods. One patient, a former saxophone player in a jazz band, asked the volunteer who plays jazz for him: *"What do people do without music?"* A soothing, stringed instrument called a Reverie Harp has been very popular with patients and family members. At Casey House, CD players and iPod speakers are available in patient rooms. Patients at Casey House also have the benefit of a volunteer violinist and another volunteer who is a certified music practitioner, who plays a hammered dulcimer. A family member thanked this musician: *"The part you played in my mother's journey was truly breathtaking. She was sick but she was at peace and relaxed enough to completely connect with you and the gift you gave her of the beauty of music. You truly have a special gift."*

A third complementary therapy increasingly supported by research is aromatherapy, the use of essential oils from plants for therapeutic benefit. Described as "nature's pharmacy," essential oils have been shown to be effective for a range of physical and emotional conditions including many hospice-specific uses, for example anxiety, respiratory issues and wound care. Montgomery Hospice has invested in developing in-house expertise in this area, with three staff nurses recently completing a 310-hour clinical certification program. Plans are underway to begin a pilot program at Casey House utilizing these natural products in patient care protocols.

Going forward, Montgomery Hospice plans to continue to explore and integrate complementary therapies into ongoing patient care. Complementary therapies are well received by patients and families and growing in demand. They fit well with the holistic aspects of hospice care, and are being integrated into the team approach to serving patients and their families. They are proving to be particularly compelling with the new Montgomery Kids program, with several of the children benefitting from Comfort Touch® massages and musical interventions. Generous foundations and donors have come forward to provide funding to support different aspects of the program. Montgomery Hospice is grateful for these forward-thinking supporters of this effective, innovative program.

* *The Complete Guide to Complementary Therapies in Cancer Care* by Barrie R. Cassileth, MS, PhD. ©2011 by World Scientific Publishing.

***Sandra Lavengood, MHSA, LMT**, is Montgomery Hospice's Complementary Therapies Manager. A licensed massage therapist, Sandra graduated from the Potomac Massage Training Institute in Washington in 2003, and specializes in palliative massage and energy modalities including Comfort Touch® and Reiki. She holds a masters degree in health services administration from the University of Michigan. She is active nationally as a member of the NHPCO Allied Therapy Section Steering Committee.*

complementary therapies resources:

National Center for Complementary and Alternative Medicine (NCCAM)
National Institutes of Health (NIH)
nccam.nih.gov

American Massage Therapy Association
www.amtamassage.org

American Music Therapy Association
www.musictherapy.org

National Association of Holistic Aromatherapy
www.naha.org

Donor Spotlight

Thank you, Lou and Kim Fiorentino. Your donation has made a difference in the lives of Montgomery Hospice families.

Kim and I support the Montgomery Hospice Complementary Therapies Program. Our support stems from different perspectives. Kim has viewed, both personally and professionally (as an attorney who works with many families confronting end-stage illness), the challenging process of losing a loved one. Whether it was a progressed dementia or a terminal illness in a younger person, Kim has also seen how Montgomery Hospice assists during these difficult moments.

My experience with pain management issues came when my first wife Helen was experiencing "break-through pain" as a result of metastatic cervical cancer. As a patient, Helen employed many unique approaches to ameliorate her pain. Transcendental meditation, acupuncture and yoga played major roles. In addition, as an artist, Helen used her canvas to express her feelings and to assist her in managing the complex path her disease took. At a late stage in Helen's life, I called Montgomery Hospice to help us manage this very difficult problem. They quickly put together a team of highly qualified professionals to develop a pain management program. Their treatment protocols made a big difference in Helen's quality of life.

When Kim and I discussed some of our charitable giving goals, we were intrigued with the new Complementary Therapy Program that Montgomery Hospice wanted to add to the therapies available to its clients. While Montgomery Hospice always took a holistic approach to treating people and their families, the complementary therapies added a new component that further dignifies the patients and also gives them comfort in a very human and touching way. Complementary therapies add an important dimension to the outstanding standard of care -- in the task of pain management and in the process of "gentling the journey" for all of those whose lives Montgomery Hospice touches.

Lou Fiorentino

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individual patient's rights. Family members may prefer to have health information given to them first and then decide when to reveal the news to patients. This practice may create conflict between family members and the healthcare providers. In addition, some cultures expect physicians to have the ultimate authority; questioning or voicing opinions about medical treatments is viewed as disrespectful. These cultural differences prevent patients, family members and healthcare providers from having effective communication, affecting symptom management and resulting in poor end-of-life care.

Healthcare Provider Factors

Discussion of end-of-life care

Lack of discussion of end-of-life care between physicians and patients is another major barrier to quality end-of-life care. Physicians are trained to cure and treat diseases. The discussion of end-of-life care may be viewed as a symbol of failure in medicine and the sense of defeat may make it difficult for physicians to initiate the discussion. Furthermore, it is hard to predict life expectancy and not easy to determine the proper timing for an end-of-life discussion. Physicians struggle to balance between being honest about the prognosis and keeping patients' hope intact for the success of the treatment regimens.

End-of-life education and training

Lack of education and training is also a major barrier in quality end-of-life care. Most of the healthcare providers agree that the discussion of end-of-life care needs to be initiated sooner and that it is important, but many stumble in the conversation and do not feel confident to carry out the discussion. Some health institutions have special palliative care or hospice care teams for end-of-life care consultation. The professionals in the team are well trained with knowledge and skills to manage the health challenges at end of life, aiming to manage symptoms and improve the quality of life. It is a great resource for patients with serious illness. However, not all institutions have the resources for these services.

Prepare For The Journey

People neglect to prepare for end-of-life issues because death is a sensitive topic. It is thought to be a matter that needs to be addressed only when someone has a terminal illness. In fact, the best time to prepare is when someone is healthy, without the burden of disease. To plan for end-of-life care decisions, think about what is important in your life, what are your values and goals. Consider how you feel about using life-support measures and what kind of care you want at end of life. Carefully prepare a living will that reflects your preferences for end-of-life care. Because it is not possible to document all possible health scenarios in a living will, you will need someone you trust to make healthcare decisions for you when you may be unable to do so for yourself. This person should have a good understanding of your values and be capable to act on your behalf. A discussion of your preferences for end-of-life care will help your decision-maker to have comfort in making these decisions for you. Share your preferences for end-of-life care with your healthcare providers and provide them with a copy of the advance directives to keep in your medical record. Do not wait for them to initiate the discussion. If you or your loved one is diagnosed with a serious illness, communication is the key to achieving quality end-of-life care. An open and honest discussion with healthcare providers will help to explore the different treatment options, including hospice or palliative care, and establish a realistic treatment goal that reflects the patient's wishes.

Everyone will face the destination of end of life. It could be stressful and hectic. However, appropriate planning and open communication can help individuals to prepare, plan and ensure a quality and peaceful journey.

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Montgomery Hospice is grateful to our 2013 Corporate Partners.

Gold Level

The **Pettit Family Charitable Foundation** was started in 1989 and is operated by five trustees from the Pettit Family. The Foundation works mainly in the areas of food, health, housing and shelter.

Several of the Foundation's trustees are active members in the community, serving as volunteers with area non-profit organizations. Mr. Dick Pettit was a Montgomery Hospice board member for many years, also serving as Chairman of the Foundation Board. He currently serves as a volunteer on the Corporate Gifts Committee for "Gentle the Journey," the 3-year comprehensive fundraising campaign to raise $8 million for Montgomery Hospice.

Silver Level

Family & Nursing Care, family owned and operated since 1968, has long been the leader in compassionate, progressive and complete care for older adults. Family & Nursing Care is the area's most trusted resource for home care andalso the nation's first provider of in-home therapeutic massages for older adults. We are your resource for in-home care aides to assist with daily living activities for an aging parent, companionship or hospice care. RNs and LPNs are also available for skilled needs.

Our licensed massage therapists provide older adults with relief, wellness and better quality of life through therapeutic massage. Massage therapy is an increasingly common component of hospice care because it brings great comfort and relaxation. We have given thousands of families peace-of-mind, knowing that their loved ones are being cared for by dependable, respectful, compassionate professionals.

Family & Nursing Care proudly supports Montgomery Hospice in its mission to gentle the journey through serious illness and loss with skill and compassion. We applaud Montgomery Hospice's commitment to ease the burdens of patients and their families and provide them with dignity and comfort throughout their difficult time. Furthermore, we appreciate all the volunteer services offered, especially the bereavement care support services Montgomery Hospice offers to anyone in the community coping with loss.

Visiting Angels, America's Choice in Homecare, is uniquely qualified to provide homecare services to those in need of assistance with the activities of daily living. We are experts in homecare. Every potential client receives a personalized care plan based upon their unique situation and needs. Our caregiving is custom designed to be competent and caring. Whether we are in your home for a few hours, or around the clock, our dedicated, experienced and certified caregivers are there to ensure comfort, safety and well-being. Homecare by Visiting Angels enables clients to remain within the comfort of their home while receiving the level of care they require.

Visiting Angels is a proud sponsor and partner of Montgomery Hospice. Each of our organizations meets people where they are and provides loving, experienced, and personalized service and care. Montgomery Hospice "gentles the journey." Visiting Angels cares every day in every way.

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Reynaldo Medina
Leslie & Frances Meil
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Christopher Phelan
The Psotka Family
Pat and Bruce Rider
Bobbie and Ken Seidelmann
Walling Family
David Walsh
Carol Whitney

Please accept our apologies if we have omitted any names from these lists.

Montgomery HOSPICE

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Hospice Matters is a newsletter for family and friends of Montgomery Hospice, a non-profit organization serving residents of Montgomery County, Maryland who are bereaved or terminally ill.

educational opportunities

Montgomery Hospice Center for Learning presents

Dr. Joan Teno: *Policy Implications of the Dementia Tsunami*
May 3, 11:45 am–3:00 pm, Silver Spring Civic Building, CEUs

Dr. Christina Puchalski: *Spirituality and Palliative Care*
Aug 30, 8:30 am–5:00 pm, Universities at Shady Grove, CEUs

Bereavement Care: free grief education for Montgomery County residents

Remembering Mom and Dad workshop May 7, 7:00-8:30 pm, 1355 Piccard Drive, Rockville
Afternoon Grief Support Group May 14, each Tuesday, 1:00-2:30 pm for six weeks, Bethesda
Parent Loss Support Group May 21, each Tuesday, 6:30-8:00 pm for six weeks, Silver Spring
Evening Grief Support Group May 22, each Wednesday, 6:30-8:00 pm for six weeks, Olney
Loss of a Child Support Group May 22, each Wednesday, 6:30-8:00 pm for six weeks, Rockville

Volunteer Training

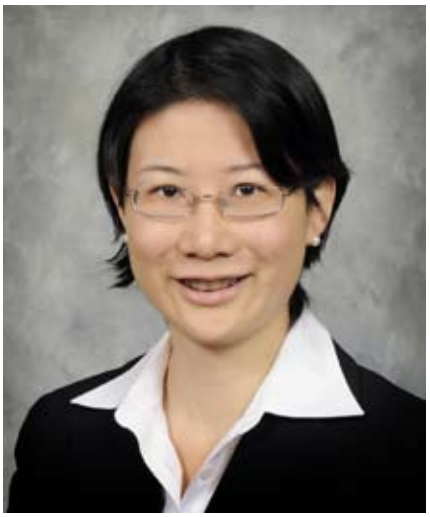
June 7, 14, 21, 8:30am–3:30 pm, Rockville

more info: www.montgomeryhospice.org

Montgomery HOSPICE

inside this issue

serving the Asian community



Dr. DongMei Wang discusses cultural sensitivities in end-of-life decision making among the growing Asian population in Montgomery County.