A publication of the National Association of Catholic Chaplains

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Spiritual care helped this son say goodbye

By David Lichter
Executive Director

After my mother was diagnosed with a severe hemorrhagic stroke, we decided to move her from one hospital system to another. The main reason was the lack of communication and the way we were treated at the first location. At the system we left, the physician talked quickly with us at the bedside of our mother, as if Mom were not there, and was pretty dismissive of her outlook, providing us just basic information and not engaging us in the treatment process.

But when we arrived at Mom’s new hospital, the physician quickly ushered my brother and me into an office, asked how we were doing, expressed empathy at what Mom and we were going through, showed us a computer image of Mom’s brain, and sketched on a piece of paper exactly what had happened to her — and what would occur in the coming hours. Then he explained that anything we wanted to do at that point for Mom would be for our benefit, not hers.

This physician, who was of the Muslim faith, was also aware of our Catholic faith. We felt relief at knowing the facts, comfort at the physician’s concern for Mom and what she was going through, and confidence in the palliative care treatment that could be provided. We were at peace with moving her to a palliative care floor, where she lived another 24 hours. Over that time, our family was visited by a volunteer, who brought a prayer shawl. A chaplain stopped by to see how we were doing and offered to have us exchange memories of Mom. A priest stopped to see if we wanted the Sacrament of Anointing for her. Every time the palliative care nurse stopped in, she commented, “Gee, I am so sorry your mom and you have to go through this,” as she stroked Mom’s head and arms. With Mom’s final breath, we were deeply appreciative of having moved her to this healthcare facility.

This issue of Vision is dedicated to ministering to the needs of families of patients and residents. When the 2001 White Paper on Professional Chaplaincy was published, the fourth section was titled, “The Benefits of Spiritual Care Provided by Professional Chaplains,” with the fifth subsection on “Caring for Families.” It offered insights, based on research at the time, and a conclusion:
• Often family members experience similar or more intense distress than their hospitalized loved ones. In some studies, patients have indicated that one of the most important chaplaincy functions is helping their family members with feelings associated with illness and hospitalization (Carey, 1973; Carey, 1985).
• In one study, 56 percent of the families identified religion as the most important factor in helping them cope with their loved one’s illness (Koenig, Hover, Bearon, & Travis, 1991).
• In another study, family members rated spiritual care from chaplains more highly than did patients (Vandecreek, Thomas, Jessen, Gibbons & Strasser, 1991).

Conclusion: Families rely on religious and spiritual resources to cope with the high levels of distress during a loved one’s illness. A chaplain’s care for family members has a positive impact.

Certainly, our family experience of the physician, nurse, and spiritual care staff during those final hours of Mom’s life left an indelible impression on us. They helped us chose the best care possible, and supported us and our extended family as we said our goodbyes. As chaplains, we can’t underestimate what the family is going through, whether it’s the intensity of strained family dynamics during tough decision-making or the quiet letting go of a loved one.

We are deeply grateful for all the ways chaplaincy ministry tends to the needs of family members in vulnerable times. Thank you for your ministry.
Creating a culture of patient- and family-centered care: The role of chaplains

By Beverley H. Johnson and Deborah L. Dokken

In 2001, Christina Puchalski wrote, “Compassionate care calls physicians to walk with people in the midst of their pain, to be partners with patients rather than experts dictating information to them.

In that excerpt from The Role of Spirituality in Health Care, Puchalski, a leading advocate for integrating spirituality into the practice of medicine, aptly describes the essence of patient- and family-centered care. PFCC is defined as:

An approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families. It redefines the relationships in healthcare by placing an emphasis on collaborating with people of all ages, at all levels of care, and in all healthcare settings. This collaboration assures that healthcare is responsive to the priorities, preferences, and values of individual patients and their families.

In patient- and family-centered care, patients and families themselves define “family” and determine how they will participate in care and decision-making. A key goal is to promote the health and well being of both individuals and families and to maintain their dignity and control (Johnson and Abraham, 2012, p. 4).

Patients and families are experts about their own lives, experiences, and health. As a result, they can be essential allies for quality and safety — not only in direct care but also in quality improvement and other healthcare redesign initiatives.

Within hospitals and health systems, chaplains can play an important role in advancing those core concepts by interacting directly with patients and families. Often clinicians and staff are uncomfortable discussing spirituality or religion. Yet “most Americans consider themselves either religious or spiritual ... many view spirituality as a vital aspect of the illness experience.” (Feudtner, 2003). Various studies have shown that patients want clinicians to understand their spiritual beliefs (Puchalski, 2001).
Understanding spirituality in the lives of patients and families is an important step in building partnerships that benefit both care and decision-making. Chaplains are uniquely qualified to raise this issue and, as a result, can:

- Help patients and families identify and articulate their values and beliefs, especially related to illness, suffering, and even dying.
- Work with patients and families to communicate those values and beliefs to clinicians and staff.
- Support patients and families in decision-making about treatment options, consideration of withdrawal of treatment, and other complex ethical questions.
- If necessary, with end-of-life care, facilitate rituals and meaning-making that support the spiritual values and beliefs of families.

Just as chaplains have an important role with patients and families related to PFCC and its core concepts, they also can be very helpful in working with staff, clinicians, and trainees. They can offer support in difficult or complex cases, or educate them about spirituality and its importance to many patients and families, and help them feel comfortable discussing it. They can also introduce tools like Puchalski’s FICA questions, adapted by George Fitchett, to use in taking “spiritual histories” of both patients and families.

F: What is your faith or belief?
I: Is it important to you?
C: Are you a part of a religious community?
A: How would you like me to address these issues with you?
(Fitchett, 2002)

For many healthcare organizations, a commitment to patient- and family-centered care represents a profound change in organizational culture — a shift from expertise being held solely by clinicians to sharing expertise and decision-making in partnerships with patients and families. In addition to their direct work with patients and families and staff, chaplains have knowledge, skills, and insights that can be applied more broadly within hospitals and health systems as they advance the practice of patient- and family-centered care.

At a number of hospitals and health systems, chaplains actually lead PFCC initiatives. For example, at SSM Health Wisconsin, NACC member Austine Duru, MDiv, MA, BCC, is the regional director of mission, ethics, and pastoral care. He also serves as co-
facilitator for the Patient and Family Advisory Council and on a steering committee that promotes patient- and family-centered care at SSM Health St. Mary’s, Madison.

Patient and family-centered care is based on four core concepts:

- Dignity and respect. Healthcare practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into care.

- Information sharing. Healthcare practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

- Participation. Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

- Collaboration. Patients, families, practitioners, and healthcare leaders collaborate in policy and program development, implementation, and evaluation; in facility design; and in professional education and research, as well as in the delivery of care (Adapted from Johnson and Abraham, 2012).

Even if they do not lead the initiative, chaplains can also serve on patient and family advisory councils or nominate potential patient and family advisors. They can serve on teams charged with changing policies that restrict the presence of families (visiting hours) and implementing welcoming policies and practices. Chaplains often are sensitive to people’s emotions and to the relationships within groups. When quality improvement or safety teams are trying to advance PFCC, chaplains can help address fears, concerns, and discomfort of staff about working in new ways — in partnership with patients and families.

For example, as members of teams changing policy and practice about family presence during resuscitation, chaplains can bring new insights about supporting both families and staff and clinicians involved in codes.

Less formally, chaplains can be actively involved in patient/family meetings, especially
at the time of discharge and other transitions in care, and help identify and contact community supports for patients and families, including religious communities.

Patient- and family-centered care, and its emphasis on building authentic partnerships with patients and families, requires the commitment of every member of the interdisciplinary team. Chaplains can play an invaluable role in supporting patients, families, and staff but also in advancing institution-wide PFCC initiatives.

Beverley H. Johnson is president and Deborah L. Dokken is family consultant of the Institute for Patient- and Family-Centered Care (www.ipfcc.org), which provides national and international leadership to advance patient- and family-centered care in all healthcare settings.

References:


Ministry to Families at End of Life: Chaplaincy 360

By Maggie Finley

During a recent visit, friend and former colleague Rev. Charlotte Keyes of Providence Hospice of Seattle and I talked about ministry to families as the rule rather than the exception in hospice care. Charlotte agrees with me that when someone is sick, in a manner of speaking, the whole family is sick. Illness is a crucible experience for families, making members vulnerable, bringing out the best and the worst in everyone. Charlotte remarked, “When it comes down to it, hospice chaplaincy is being present and aware of family dynamics.”

Charlotte makes no assumptions about whom she is actually there to support in any given visit. During one initial assessment, although the patient’s daughter had requested a chaplain referral for her father, she was the one who ultimately needed support. Meanwhile, the patient slept soundly throughout. The daughter led with the belief that her father “is having trouble letting go.” Charlotte listened intently while the daughter shared a family history fraught with verbal and physical abuse, the scope of which included her mom and two sisters. She still wanted to care for dad, convinced he loved them as much as he could. Since coming to grips with his powerlessness to control his temper, she found it in her heart to forgive him because he was a good provider. Near the end of the visit, the daughter was surprised to feel “a burden had been lifted.” Charlotte remains open and accessible to her as well as anyone else who might enter into the patient’s narrative.

Our conversation also reminded me that hospice ministry is about kinship, since we may begin to see part of a patient’s legacy in its multi-generational dimension. One family with whom I grew into a genuinely pastoral relationship over the course of about 2 1/2 years, spanned four generations. Initially, my bimonthly visits were divided between the nonagenarian patient, Greta, and her caregiver son, Dale (all names have been changed). Protestant and Canadian, they were without formal faith affiliation in Washington. I became something of a pastor figure. Having built a trusting relationship, Dale approached me about the funeral when his eldest son died unexpectedly. It gave me an opportunity to meet other family members of whom I’d previously only heard. My follow-up bereavement
visit included Dale as well as his adult children, along with their spouses and children.

Only six months later, Dale disclosed his wife’s newly diagnosed cancer. Since Dana was admitted to a Providence-aligned hospital for surgery, at the couple’s request, I made a post-op visit, on a day otherwise dedicated to hospice admits. Dale, along with extended family from both sides of the border, arranged their visit to coincide with my time on the floor. A good number were assembled, so I chose to introduce myself via ritual, in response to Dana’s request for shared prayer while incorporating the loved ones’ healing touch and storytelling into our time together.

I don’t know how long it was after Dana’s discharge that Greta, my matriarchal patient, died. I kept my promise to her and her family to preside at her funeral. I was honored to be the one to help these people whom I’d come to know begin the process of mourning the loss of beloved Mum.

During Greta’s last few months, Dale expressed his own health concerns. Neither of us anticipated that merely a month after his mother’s death, during what was simultaneously my last and only bereavement visit, he would discover that his own cancer, in remission for years, had returned. This wasn’t an easy context to end our formal relationship.

But there’s a postscript to the story. Dale stayed in touch by mail, so we exchanged occasional notes and holiday cards. Once I retired, he said he’d welcome a visit, so I did. He processed feelings about the outcome of cancer treatment and said, “I’m not sure I’ll make it.”

I didn’t hear anything for a while. Then a chaplain acquaintance in another healthcare system tracked me down: Dale wanted to reconnect if possible. In a phone call, his son and daughter let me know that he was only expected to live another 72 hours. “Dad would want to see you before he dies,” they said. “Your presence would mean a lot to the whole family.” Acting on my intuition, I visited immediately. On arrival, Dale was fairly unresponsive, although he’d been awake and oriented less than an hour before. His breaths were barely perceptible, some far apart. I called his name, held his hand and talked to him. He knew I was there.
He managed to open his eyes momentarily and drew a few more breaths — then tranquilly, his last. I was moved to silence.

Finally, I said, “What more can I do?” Dale’s children asked for bedside prayer, and I began with lines from Greta’s favorite childhood prayer. I moved us into spontaneous prayers and storytelling. I encouraged the family to bless him in their own words or with loving gestures, to “prepare Dale for the next chapter in his journey.”

I’m forever humbled by what seemed his willingness to wait for me (see the book “Final Gifts”) before making his transition: dying peacefully, surrounded by many loved ones. His parting gift to me was not only the privilege of midwifing his death, but a sense of having come full circle in my hospice ministry to four generations of the same family. I won’t forget.

Maggie Finley, BCC, is a retired chaplain from Providence Hospice of Seattle.
Young caregivers need to be recognized

By Melinda Kavanaugh

Walking into Rick’s house, I saw his wife struggling with his hospital bed in the living room, looking drained. I was the social worker doing an in-home visit to assess care needs.

When I sat down to talk to her about the stress of caregiving and what kinds of support she needed, I noticed their son carrying several cans of liquid over to Rick. Having worked with many patients who are unable to swallow on their own, I knew these were going to be given to Rick via the feeding tube inserted into his abdomen.

“Do you need help?” I asked.

“No, I know how to feed him and clean the tube on my own,” he said. He was 10 years old.

I realized at that moment he was also a caregiver. I also guessed that no one recognized this, or the specific ways it could be affecting him.

How many times have you seen the difficulties of caregiving? Walked into a home and thought, “How does this family do it?” Like me, you may have assumed the role of caregiver fell only to the adult in the home — unaware that children and youth are often extremely involved in day-to-day care. Yet it is estimated that 1.4 million children and youth ages 8-18 exist on the fringes of caregiving with little acknowledgement or support even from those most engaged with the family during this time — social workers, nurses, and chaplains.

We are still learning about caregiving youth — the caregiving experience through their eyes, what they do, and how it affects them. There is astonishingly little attention paid to them. Recently, after completing a review of the literature, I discovered that only 22 research papers have been published on youth caregivers; this is in comparison to thousands of research papers that address adult caregivers.
Here is what we know thus far about youth caregivers. Their school performance suffers. They feel socially isolated. Adults tend to misunderstand their behaviors, such as falling asleep at school because they were up all night with a parent. And they have few supports.

So, where does spiritual care come in? How can chaplains engage and support these youths and their families? Here are two ways to begin adding these youths to the range of supports and services provided by your organization:

First, simply acknowledge they exist. It sounds simple, but often the best thing one can do is see the life of another and bring attention to their needs. It’s very likely that you have met caregiving youth. In fact, approximately 3.2 percent of households with children include a child tasked with caregiving duties. These duties can be intense and extend over years, including bathing, dressing, getting in and out of beds and chairs, toileting, and feeding.

These caregivers receive little to no acknowledgement in caregiving policy, either national- or state-based, and unlike their adult counterparts, have no established rights as a caregiver. Their voices are rarely heard.

Acknowledge them by noticing the youth in family meetings or in hospice settings. Let them know they can talk to you if they are caregiving. Remember, many families who rely on youth caregivers feel shame, guilt, or a concern for child welfare if they discuss the role their child plays, so they may not bring it up or ask for support.

Caregiving often represents intense love and support family member feel for each other. Many families and the youth themselves feel not only responsibility but pride in the care they provide. However, youth still need time away, interaction with peers, and, in many cases, clear education and skills to better perform the tasks they are given. By spending time with these families, you let them know you care, are interested, and will help them process or brainstorm ways to balance the care needs with youth education, social, and emotional needs.

Second, make your institution a youth caregiver-friendly community. Sixty percent of youth caregivers in my studies said caregiving affects their school performance and attendance. Many felt isolated from peers and adults. They had
lost friends who didn’t understand what they were going through in the after-
school or weekend hours. How can your institution provide respite and care
support for these isolated youth?

We know youth involved in caregiving grow up faster and have fewer outlets than
non-caregiving youth. Take the opportunity to ask about caregiving, acknowledge
the role youth may play, and seek out ways to provide respite and youth support
programs, while creating an atmosphere of support for the family as a whole.

Several organizations are starting to take notice of these youths and may serve as
important resources for you and caregiving youth. The American Association of
Caregiving Youth (aacy.org) has established numerous school-based programs and
can be a crucial resource for clergy across the country. Also, many diseases-based
organizations are developing youth supports for caregivers, including the ALS
Association (www.alsa.org), the Huntington’s Disease Society of America
(hdsa.org), and the MS Association (mymsaa.org).

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University of Wisconsin-Milwaukee.
Home care ministry includes family caregivers, too

By Connie McGregor, RSM

“One size fits all?” Anyone who has been involved in chaplaincy quickly learns that that is not the case. I believe that this is particularly true in home care, where ministry to patients and families demands a constantly shifting focus.

As a home care chaplain, I travel regularly throughout Erie and Niagara counties in western New York. My mileage reimbursements are significant, but the drive time between patients offers the opportunity to reflect on the visit and to think about the next encounter.

My travels may take me to a patient who is trying to cope with bad news, or to someone who is recovering from a stroke and is aphasic or has lost her/his independence. The spouse or family may be caring for a loved one who suffers from dementia. Perhaps the patient does not desire spiritual care services and it is the spouse or family who requests it.

In family meetings, we offer the patient and family the forum to share their concerns and their hopes, and we share our thoughts regarding possible options, such as an adult day program for the patient or supportive counseling for patient and/or family members.

Our challenges include those patients who, after a hospital stay, have had to relocate to the home of an adult child or another relative. Many times, families are unaware of the challenges they may face in meeting the various needs of their loved one. Their routines are altered. If they are members of the “sandwich generation,” they are also caring for younger family members. Although they are well-intentioned, their efforts to care for their parent or relative may result in a lack of opportunities for socialization by the patient.

As a chaplain, I try to familiarize families with the ramifications for the patient and for themselves of a decision to bring a patient into their home. This calls for not only our expertise but also for bringing in other members of the healthcare team, in a case conference, a family meeting, or both.
Patients and family members also struggle with treatment. Perhaps the patient decides to forego treatment and opts for palliative care. If the family does not agree with this decision, that is obviously a challenge. As chaplains or healthcare personnel, we cannot make that decision. All we can do is try to help those involved to understand the pros and cons and to help them see each other’s point of view. The decision rests with them. We can and do assure them of our prayers that their decisions about the future will be decisions that benefit the patient.

My bottom-line question for caregivers trying to reach decisions about their loved one is, “Whose needs are you meeting”? As always, I offer continuing support for all involved.

I have met numerous family members who share feelings of guilt that they do not do enough for their loved one. Sometimes they are inclined to literally relinquish their lives. I see the necessity of affirming them in their efforts but also helping them recognize their own needs (self care) and making provisions to meet those needs.

Many times, patients and families state that their faith is helping them to cope. I encourage them to reflect on how their faith has seen them through those stressful times in their lives. I encourage them to continue to access their faith for strength and comfort during their current challenges.

Family members are involved to varying degrees and in some cases, live great distances away. Again, our ministry is one of listening presence and support. We acquaint the patient and family with possible resources in the community that would offer opportunities to interact with others. If a patient is connected to a particular church, with the patient’s consent, we contact the church. Our patients are appreciative when their parish sends a Eucharistic minister or when their pastor and/or church members visit.

Regardless of the great diversity we encounter, our ministry is always one of presence, support and encouragement for our patients and their families. They are asking, “Why me?” which we can’t answer. But we can help them identify their strengths and what helps them to cope during their difficult days. We can assure them of our prayers and continuing visits.
Above all, we can assure them of God’s presence and unconditional love for them.

Often, those who are seriously ill and have lost so much independence question their own value. They ask, “Why doesn’t God take me?” And I reply, “You still have work to do.” I attempt to relate to them what they and others teach me as I carry out my ministry — how to deal with illness, faithfulness, perseverance. I make them aware that in their illness, they are teaching those around them — their families and friends and others with whom they come in contact. That is their ministry.

Our visits with patients may be only with the particular individual or they may include a family member/caregiver. At other times, there may be grandchildren in the home. I leave it to the patient to make the determination about their presence during the visit.

The four-legged creatures who are my patients’ faithful companions bring them comfort and demonstrate an undying loyalty. Some of these furry companions are protective and initially eye me with suspicion. Later, they may find their way onto my lap (no problem for someone who loves animals).

Each day, as I set out, I ask God, “What opportunities will you offer me today?” Each day, as I return home, I reflect on what I learned from those with whom I ministered. Did I learn about perseverance? Faith? Devotion to a spouse? I offer gratitude to God for the many ways my patients have ministered to me. Countless.

Sr. Connie McGregor, RSM, BCC, is a chaplain for Catholic Health Home and Community Based Care in Buffalo, NY.
Rituals help patients and family mark turning points

By Linda F. Piotrowski

Rituals serve many purposes. Foremost is to remind us that God does not abandon us. Rituals also help us to step out of chronos time to enter into kairos time. Rituals are defined as a stylized prescribed manner of marking a religious ceremony. They remind us, as Ecclesiastes states, “there is a time for everything.”

To the Preacher’s list, we could also add that there is a time for patients and a time for families. Using a basic template, with room for variation, can greatly help families process the loss of a loved one.

At the bedside, I’ve found that most people are not disposed to a long, involved ceremony. Keeping in mind the spiritual/religious beliefs of the patient and loved ones, a simple template is: statement of purpose, opening prayer, short reading, symbolic action, perhaps a song/hymn, and closing. I try to involve everyone present if that is at all possible.

One evening I was called in to the bedside of an elderly man. The patriarch of the family was in the process of dying. He was no longer awake or alert. Several of his children and grandchildren were present, as well as his second wife. (His first wife was deceased.) They asked for prayers of farewell. After listening to them talk about him, I invited them to gather around his bedside. I invited everyone present to place a hand on him. His wife and eldest son stood on either side of him and placed a hand on his face. Speaking to him by name, I explained that the people who loved him wanted to help him on his journey by praying.

I briefly prayed for all of us to remember God’s presence with us. I then invited those present to come forward to speak into his ear some message they wanted him to take with him. I carefully explained that this was not required but if they felt confident doing so they were welcome to. Each one present came forward and spoke in a quiet whisper into his ear. Some kissed him. There were lots of tears and expressions of love and some of forgiveness, while one asked for forgiveness. I asked if they had a hymn or a song that was his favorite. His eldest son said that his dad always liked “Danny Boy.” He began to sing, and the others joined in. I prayed a blessing to end the service.
A more formalized ritual is the ceremony celebrated weekly by the palliative care team. Wanting to care for ourselves, as well as the families we serve, led me to develop two ceremonies (one for staff and one for loved ones) to honor the lives of the deceased.

Preparation includes setting out a large glass bowl with colored glass beads the color of water. First, an index card with the name of a deceased patient, along with a star, is put at places around the meeting table. When the staff is all gathered the presider recites, “The time has come for us to remember and celebrate the lives of the people we’ve been privileged to serve.”

Ring a singing bowl. When the sound ceases, the presider recites an Eskimo saying: “Perhaps they are not stars, but rather openings in the heavens where the love of our lost ones shines through to let us know their souls are at peace.” One by one, staff members come forward, read aloud the name, place the star in the bowl, stand in silence for a moment, and then return to their seat. When all the stars have been placed and names read, the service ends with a moment of silence.

This simple ritual was expanded to include all the families of the deceased patients when we held quarterly family services of remembrance. Family members of patients who had died within the previous four months are invited, and the service is publicized throughout the medical center. Members of the palliative care team are involved. Some read texts, some sing, some read names. The service takes place in a hospital meeting room. A staff member plays the harp as people gather, during the reading of names, and after the service. Staff and members of the volunteer program also play guitar and sing. Volunteers help to set up, welcome, mingle, serve refreshments, and clean up.

This is the template for the quarterly family service of remembrance.

**Welcome** by the director of palliative care

**Gathering prayer** by presider

**Opening Song**

**First Reading** (Hebrew Scriptures, usually Psalm 23, read by staff member)

**Silence**

**Litany of Remembrance Reflective Song/Music**

**Second Reading** (suggested and read by a staff member)
Ritual of Remembrance (This is the same ritual described above and used for the team. The presider explains how the ritual is used on a weekly basis to remember and celebrate their loved ones. Staff members read the names. Family and friends are invited to come forward to place a star in the bowl when they hear their loved one’s name read.)

Final reading Selected and read by a staff member.

Blessing and Sending Forth (includes invitation for everyone to remain, share refreshments, and speak with staff)

Most of the time, keeping a simple template in mind while allowing for spontaneity is the best way to minister to a family that needs the comfort and support of a ritual ceremony. As every chaplain knows, we do ongoing assessment of what will best serve the patient and family. Remembering their religious/spiritual beliefs helps us to minister with compassion, giving them and us a kairos moment that can comfort. And although rituals may be formal and complex, they may also be as simple as holding hands while the chaplain prays.

Linda Piotrowski, BCC, is a retired palliative care chaplain at Dartmouth Hitchcock Medical Center in Lebanon, N.H.
Chaplains can help families make difficult decisions

By Daniel Waters

Don (not his real name) was on a vent in the ICU. He had arrived in the emergency department just a few hours earlier in severe respiratory distress. He had been a frequent patient in the ED, sometimes able to discharge home and sometimes being admitted. But this time, things were worse. The intubation was emergent and his family was distraught. As with each of his past trips to the ED, the staff asked if Don had an advance directive.

The Federal Patient Self Determination Act of 1990 (www.congress.gov/bill/101st-congress/house-bill/4449) allows adults to express their desires regarding medical treatment in advance. The act does not require anyone to have an advance directive, and medical facilities cannot refuse treatment to those who do not have one.

Don’s significant other, Mindy, was in tears. She explained that they had several uncompleted booklets sitting on the dining room table. They kept meaning to get to it. Don’s visits to the emergency department had increased as his metastatic lung cancer progressed, but they just never got the document done.

Many families are overwhelmed by the thought of making decisions for a loved one, and there are many misconceptions. But a chaplain who has developed a relationship with a family can be a key support in walking this journey with them.

Hospitals must ask, maintain policies, document, comply with state law, provide care even if there are no directives, handle complaints, and provide staff with education. A patient in any unit of a hospital can find themselves unable to express their wishes regarding medical treatment, and the decision-making responsibility goes systematically to family. Many states have a hierarchy of decision-makers, e.g. legal guardian (if there is one), spouse, majority of adult children, etc. It is important to check state law and communicate with risk management when it is difficult to determine a decision-maker.

Working with Mindy, our spiritual care team contacted a 21-year-old daughter, a 17-year-old daughter, and a sister. We found that Don had been married and had separated from his wife more than 15 years earlier, but they never legally divorced.
Mindy said this was another thing that Don just never got around to. The estranged wife was found — she did have a working cell phone, but was homeless, living in another state 900 miles away. Because there was a warrant out for her arrest, she was afraid to travel even if the team could make travel arrangements. Via her cell phone, the estranged wife became the decision-maker. Mindy was distraught at Don’s critical condition, but the difficult emotions were compounded by the fact that she had no say in what was going on and that she could not get any direct information. Luckily, Don’s oldest daughter was mature beyond her years and provided information to Mindy.

Chaplains often wade directly into the midst of very difficult family dynamics. We don’t impose solutions, but our tools of active listening, spiritual presence, and challenging (to name a very few!) can help families navigate experiences that they never thought they would have to face. A loved one’s critical illness often serves to heighten the anger, hurt, and fear that are present in a severely dysfunctional family. The interventions provided by a spiritual care team can mitigate the worst situations and help a family work together, even if it is done grudgingly.

There was concern among the team that Don’s estranged wife would make decisions based on some path to her own financial gain, or to impose additional emotional hurt on her older daughter. One conversation between her and the daughter ended with a cell phone crashing against a wall in ICU.

After over a week in ICU, with many other ups and downs, Don was terminally extubated. Don’s sister and her family were Catholic and active in their parish. Don grew up nominally Catholic and had recently talked to Mindy about his Catholic faith and the comfort that he had unexpectedly found in that background. The family in town gathered at the bedside before the extubation. We shared scripture, prayers, stories, and a blessing. We prayed together after Don expired. Don’s immediate family was heartbroken, but drew closer in this deep loss.

Chaplains can have a key role in sorting through details by working with a family around medical decision-making. Chaplains’ real work is in dealing with the varied emotions and spirituality that are present in these experiences. Our ability to assess, intervene, and affect outcomes are invaluable to families as they make medical decisions.

*Daniel Waters, BCC, is spiritual care coordinator at Mercy Health in Oregon, OH.*
Ceremonies let families say goodbye after miscarriage

By Kathy Mattone

“All life has inestimable value, even the weakest and most vulnerable ... are masterpieces of God’s creation, made in (God’s) own image, destined to live forever, and deserving of the utmost reverence and respect.” — Pope Francis (engraved quote on crypts where infants are interred)

All life does have inestimable value. In recognition of the sacredness of all life and in the attempt to bring healing to grieving families, St. Joseph East and the Women’s Hospital in Lexington, KY, now offers burial of miscarried infants. Miscarriage is the spontaneous loss of a pregnancy before the 20th week. About 10 to 20 percent of known pregnancies end in miscarriage, and almost one in four families experiences this loss. Over seven years ago, a small group of folks came together from our Women’s Hospital, the Catholic Diocese of Lexington, and the Catholic Cemetery to pray and discern what could be done to honor the lives lost through miscarriage and offer some healing and hope to families. In February 2015, the first burial of miscarried infants took place at Calvary Cemetery in Lexington, KY. Over 300 infants have been interred at the mausoleum since that first burial.

Every other month, hospital and diocesan staff gather with families of miscarriage for a prayer service at Calvary Cemetery. At the service in November 2016, more than 70 people attended. It is a time to mourn, not only the loss of an infant, but the loss of hopes and dreams unfulfilled. Parents, siblings, grandparents, extended family, and friends gather to sing, pray, cry, and laugh. Families can write their baby a note to be included in the casket, there are tiny feet pins, pocket prayer quilts, and vigil candles to take home. At one point in the ceremony, parents can share their baby’s name or have a staff member read the family name. Each burial has between 25 and 35 infant remains, which are gathered and prayed over at the hospital and then brought to the cemetery.

Nurses and doctors at the hospital have begun to see miscarriage patients differently. Their loss is honored and respected. Several patients who have been overwhelmed at the compassionate care they received have paid it forward by bringing gift bags/boxes and making pocket prayer quilts for other families who experience miscarriage. The burial dates are announced in local parish bulletins, and often families who experienced miscarriage years ago will come and grieve
their loss. One brave woman spoke at one of the burials, sharing her story of miscarriage 25 years ago. She said, “I have never had closure, until today.”

Family reconciliation has also taken place at the burials. Last summer, grandparents attended the burial service and were able to speak to, hold, and hug a 3-year-old grandson (who was the older sibling of one of the infants) for the first time in over a year. A family argument had caused a rift that wouldn’t heal. The mother of the miscarried infant decided to invite her parents to the burial. “I just realized how foolish it was to be fighting. We wanted to share our sadness and loss with them. We hoped it would heal the hurt between us.”

We have been overwhelmed at the healing that has rippled outwards from the burial of miscarried infants. Patients are often in a state of shock about their loss when they arrive at the hospital. They have trouble hearing what the staff is sharing with them about the burial. Debbie Gibbons, the bereavement coordinator for the Women’s Hospital/Labor and Delivery nurse and I try to see every patient who miscarries. We provide training for staff in the emergency room, outpatient surgery department, and physician office staff. Patients who are unsure about burial receive a phone call the week or so after their hospital stay to assess their mental, physical, and spiritual status. The nurses in outpatient surgery have recently adapted their follow-up calls to evaluate how patients are coping with their loss.

This outpouring of compassion and reverence has brought healing not only to patients and their families but to our hospital staff as well. God’s love continues to flow outward. It is an honor to be involved with bringing wellness, healing, and hope to all.

*Kathy Mattone, BCC, is a chaplain at St. Joseph East and Women’s Hospital in Lexington, KY.*
Ministry to families: What the research tells us

By Austine Duru

The importance of family support and presence in the healing process is not disputed. Family caregivers are often referred to as “hidden patients” (Kristjanson L., et al, 2011) because of the adverse effects of the burden of caregiving. Understanding the broader impact of disease, hospitalization, incarceration, mental illness, and transition to long-term care or hospice care becomes crucial when evaluated from the perspectives of family members and support persons. Such a perspective offers better insight into how chaplains can effectively support individuals and their families through major life-changing circumstances.

The term “patient-centered care” was coined in 1988 by the Picker/Commonwealth Program for Patient-Centered Care (now the Picker Institute) to call attention to the need for clinicians, staff, and healthcare systems to shift their focus away from diseases and back to the patient and family, (Gerteis M., Edgman-Levitan S., Daley J., Delbanco T., 1993). The term was meant to stress the importance of addressing patients’ needs within an increasingly complex and fragmented healthcare delivery system, a system that also includes the family and support persons. “Professional Chaplains in Comprehensive Patient-Centered Care” featured in the Rhode Island Medical Journal (2014), by Richelle C. Russell, a hospice chaplain, introduces readers to three case studies that illustrate the role of professional chaplains in mediating the complex relationships involved in caring for patients and their families. Although written for clinicians, this work underscores the role of chaplains in advocating for and encouraging person- and family-centered care.

Perhaps nowhere is family involvement more crucial than when children are the patients. Parents of sick children are often very vocal and passionate about advocating for their children, and everyone benefits from a well-coordinated care. This much is clear in the article published in 2014 titled Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems. This article says that understanding care coordination framework, its functions, and its effects on children and families is critical for patients and families themselves — as well as for pediatricians,
pediatric medical subspecialists, and anyone providing services to children and families. It does not specifically call out the role of chaplains. But it describes chaplaincy as part of the support structures that benefit patients and families across care settings, leading to decreased healthcare costs, reduction in fragmented care, and improvement in the patient/family experience.

Often those who are overlooked in healthcare feel powerless to advocate for themselves, leading to increasing health disparities among segments of the population. Public policies are therefore needed to protect the interest of the community. A recent study by Kristin L. Carmen, et al., (2013) shows that patient and family engagement could address disparities in access and quality of healthcare for patients. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies offers a promising pathway toward better-quality health care, more efficient care, and improved population health. The study also explores the implications of a multidimensional framework to support patient and family engagement, and offers a research agenda to investigate how such engagement improves outcomes.

Molter (1979) paved the way for an extensive study of the needs of families of patients in the ICU, leading to the Critical Care Family Needs Inventory (CCFNI, Molter and Leske, 1983), which has been used in various forms in subsequent research projects. Family needs are often categorized into five domains: assurance, proximity, comfort, support, and information (Leske, 1992). Two fairly recent studies that built on some of these earlier successes provide a recent view of this practice. Supporting families in the ICU: A descriptive correlational study of informational support, anxiety, and satisfaction with care, Joanna J. Bailey, et al., (2010) showed that “Informational support provided to family members of ICU patients has significant potential for reducing their psychological distress, enabling them to better cope and support the patient. This cross-sectional descriptive correlational pilot study collected data from a convenience sample of 29 family members using self-report questionnaires. 22-bed medical-surgical intensive care unit of a 659-bed university affiliated teaching hospital in Montreal, Quebec, Canada.” Findings suggest a significant positive correlation between informational support and overall satisfaction with care.
In a related study, Jeffrey R. Johnson et al. (2014) evaluate the association of spiritual care to patients and families in the ICU and family satisfaction with ICU care. The prospective cohort study, “The association of spiritual care providers’ activities with family members’ satisfaction with care after a death in the ICU,” co-authored by NACC chaplain and CPE supervisor Sean Doll O’Mahoney, surveyed about 275 family members of ICU patients and 57 spiritual care providers. “Spiritual care providers commonly reported activities related to supporting religious and spiritual needs (>=90%) and providing support for family feelings (90%). Discussions about the patient’s wishes for end-of-life care and a greater number of spiritual care activities performed were both associated with increased overall family satisfaction with ICU care (p<0.05). Discussions about a patient’s end-of-life wishes, preparation for a family conference, and total number of activities performed were associated with improved family satisfaction with decision-making in the ICU (p<0.05).” The findings suggest that spiritual care interventions improve family satisfaction with ICU care, and show how chaplains can enhance intervention in the ICU by increasing their guidance for families making decisions for critically ill patients. This also provides valuable insights for chaplains working in the medical intensive care settings.

NACC Executive Director David Lichter produced the article CHA Chaplaincy Surveys Offer Key Insights (2014), based on a survey of Catholic healthcare executives, clinicians and colleagues. The 2012 survey, conducted by a joint CHA and NACC Pastoral Care Advisory Committee, used CHA’s vast database of executives and clinicians. Regarding the purpose and value of professional chaplaincy, and what executives and clinicians want from chaplaincy support, responses consistently ranked high the following elements: providing a supportive presence for patients and families; offering prayer/ritual for patients and families; offering support for ethical questions and concerns; and providing staff support and attention to treating the whole person. This survey provides meaningful feedback for chaplains and chaplain educators who work with Catholic healthcare systems or organizations.

Austine Duru, BCC, is regional director of mission, ethics, and pastoral care at SSM Health in Madison, WI.
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What awaits you at the NACC conference?

We hope that you are marking your calendars and making your plans to attend the NACC’s annual national conference April 28-May 1 at the Tamaya Resort in New Mexico. Below are some reflections from members of the planning task force who visited the resort in October.

Where is this place, Tamaya?

By Rich Bartoszek
Liturgy Chair

This is my third year on the Conference Planning Task Force as liturgy chair, and as in the past years, we scheduled a site visit to the conference hotel. It is the first time we all meet in person, as the majority of our work is done by conference calls. This year, the weekend we all came together was in mid-October, and I traveled with a friend to New Mexico, so that after the planning weekend we could visit in the area for a few days. If you haven’t been to this part of the country before, you may want to consider doing the same.

We drove from the airport, and we learned the hard way that Google Maps works better than MapQuest. Without getting lost, it’s a 25-minute drive. I had visited the website for the conference hotel (tamaya.regency.hyatt.com/en/hotel/home.html), so I had an idea of what it might be like — but let me say the pictures do NOT do this place justice. I have been to many conferences near airports and in downtown areas, but this place is out in the wilderness, and it is like no other place where the NACC conference has been held before.

There is so much to do at the Hyatt Regency, but it is also so peaceful and relaxing. You will indeed feel like you are at a resort and won’t want to leave. The mountain views are breathtaking, and the Rio Grande is an easy 15-minute walk away. There are great trails for walking and hiking, the resort has bikes available at no charge, and there are two large pools and a large whirlpool tub under the stars. The outside patios have fire pits that are lit each night so people can sit outside and enjoy nature (make sure you bring a sweater or a jacket for the evening), and every room has a balcony/patio. There are three restaurants onsite and a small store for coffee, snack items, and souvenirs. All the food we
sampled during our visit was delicious.

The Stables at Tamaya house horses and other animals. Over half of the horses are rescue animals from the Tamaya Horse Rehabilitation Program, and those interested in riding can schedule a time. The resort also has a spa and a world-class golf course. If you still need more excitement, or are looking for a different place to dine, the Santa Ana Star Casino (www.santaanastar.com) is only a few minutes away, and the hotel offers a free shuttle service.

Now, this oasis of relaxation is a bit of a drive from the airport, but trust me, it is well worth it, and I can’t wait to go back. It really is a very peace-filled place. I hope if you have any concerns about attending the conference, this will help reassure you. As I said, we have never had an NACC conference at a place like this.

See you in April!

Kiva Time

By Mary Catherine Casey
Local Arrangements Co-Chair

In the Southwest, especially New Mexico, we have communities of Native Americans who are considered part of the Pueblo. Each community stands on its own and has its own name, but may share a language that has common roots. What is unusual about the various Pueblo communities is that the people have lived on that land since their beginnings. The village almost always features a physical structure called a kiva that is used for religious and political needs. This sacred space is often a circular structure that is either underground or partly above ground. One enters the kiva by a ladder (if it is underground) or through a smaller door that a person must bend down to access. The rules for the use of the kiva are very specific and vary according to the particular Pueblo.

As you prepare to attend the NACC national conference, put a red-flagged note on your calendar and under it, place a note: “Explore inner kiva.” Next make a mental or physical list of specific stories that you hold, shelter, or push away. You
may designate some times during the conference as kiva time. In your own inner kiva, take the opportunity to discover how you have walked the road to Emmaus and with whom you have walked.

The landscape surrounding Tamaya is anointed with mountains, scattered mesquite, and juniper trees. There is a simplicity of colors that allow one to be present with oneself on several levels; choose that place that deepens and widens your inner kiva. Climb down the ladder or bend down in order to enter. Be ready to meet Jesus as he waits to break the bread and share wine with you. Invite your eyes to be opened as he reveals himself through the new and old stories that will be stirred by the wisdom and challenges of our plenary speakers and workshop presenters.

See you in April 2017. The road has been prepared, and the inner kiva awaits you, your stories, and what is to be revealed.

The spirituality of Tamaya

By Tom Chirdo
Plenary Speaker Chair

The 2017 National Conference will take place at the Tamaya Resort and Spa, located on the Tamaya Indian Reservation in Santa Ana Pueblo, NM. More than 800 tribal members call the Pueblo of Tamaya home. As a member of the Planning Committee Task Force, I visited the resort in October. The moment I first traversed the winding road, I began to get a sense of the deep spirituality embodied within the Tamaya resort, the land, and the people.

Tamaya, the ancient name of the Pueblo of Santa Ana, means a quiet and peaceful place. The winding road intentionally symbolizes an invitation to cast aside our worries and concerns as we enter this beautiful place. The spoken and unspoken message of Tamaya is: “We invite you to come and take care of yourself.” I reflected upon how this concept connected with the Emmaus journey.

Having lived mostly on the East Coast, I had little idea of what New Mexico living was like. The clear sky and dry climate were refreshing. The strong sun mixed with
cool air was delightful. I saw no potholes. The New Mexico cuisine was a delight to the senses. In short, I saw nothing in New Mexico that wasn’t awesome.

Walking the path that led to the Rio Grande was a touching experience as well. I discovered that entering into the Tamaya experience with an attitude of openness led to unexpected delights and meaningful insights. It led to deeper connection to self, others, and God. I felt a new enthusiasm to follow my call.

I hope that you, too, will be able to experience Tamaya this coming April!

Southwest Native American Art

By Eve Corcoran
Local Arrangements Co-Chair

Southwest Indian art is probably the most distinctive and best-known of Native American artistic traditions. Most southwestern tribes have remained in or near their ancestral lands, suffering less interruption of their traditions than the eastern tribes.

Southwestern Indian art forms not only influence the popular culture of the region at large, they also remain as thriving, unbroken artistic traditions of the native people who first created them.

The Tamaya Resort hallways are galleries in and of themselves. Beautiful paintings, weavings, and sculptures adorn the resort. Come and enjoy a taste of the Southwest’s creative heart.

The arts and crafts that Southwest Indian artists are best known for include the kachina dolls of the Hopi and sandpaintings of the Navajo; beautiful pottery, particularly by Pueblo Indian artists; woven blankets and rugs, particularly by the Navajos; and many different styles of fine basketry and silver and turquoise jewelry.

While Christianity has heavily influenced their religious practices, many Pueblo and tribal communities have reclaimed their traditional celebrations. Their traditions are honored at various feast days and calendar times throughout the
year. The ceremonies are not open to non-native persons but may generally include dance, drumming, chanting, playing the flute, and sacred song. Most of the traditions are oral, so the art of storytelling is sacred to many of the native people.

The following photos depict examples of the art created by native artisans, and the particular artist or gallery where the art is on display/for purchase.

For more information, a helpful link might be:
www.native-languages.org/southwestern.htm

**Kachina House**
Southwest silver and turquoise jewelry, pottery, and kachina dolls from [Hopi](http://www.kachinahouse.com/) and [Pueblo](http://www.canyonart.com/) Indian artists.

**Canyon Country Originals**
Navajo rugs, Pueblo pottery, and other Native Southwestern crafts for sale online. (http://www.canyonart.com/)

**Yazzie's Indian Art**
Classic and contemporary Southwest jewelry designs by an award-winning [Navajo](http://www.navajo-indian.com) silversmith.

**D.Y. Begay's Navajo Weaving Studio**
Southwestern rugs by an award-winning [Navajo](http://www.navajo-indian.com) weaver.
Spiritual Care in a Public Healthcare System

Jonathan Pye, Peter Sedgwick and Andrew Todd (editors), *Critical Care: Delivering Spiritual Care in Healthcare Contexts*. Jessica Kingsley Publishers, 2015. 280 pp. $34.95

By Dan McGill

During the 2012 presidential campaign, Barack Obama’s healthcare reform received an emotional boost when the London Olympics commenced with a depiction of British history that specially highlighted their National Health Service, founded in 1948. While the British celebrate their publicly funded system, politicians in the United States threatened then and still do to dismantle “Obamacare.”

While large differences remain between British and American approaches to public health, *Critical Care: Delivering Spiritual Care in Healthcare Contexts* (containing chapters from 16 contributors, including the book’s three editors) shows that negotiating spiritual care in a public health system presents very similar challenges on both sides of the Atlantic.

The first part, “Constructing Spiritual Care,” makes clear that medicine has operated in a sacred space since time immemorial. Not just modern-day chaplains but all medical personnel, from modern doctors and nurses to ancient healers, have trod upon holy ground whenever they tended to the embodied person. But in a world where the disciplined and often mechanical practice of science has been so effective in treating many diseases, the sacred domain of the human can easily be profaned. For example, pain-control strategies often take scant regard for human suffering, dismissing it as a mechanical problem to be quickly remedied by painkillers or antidepressants.

Yet, as the second part, “Negotiating Spiritual Care in Public,” points out, even though spiritual care can provide an essential element in healthcare, negotiating how it does so presents real challenges. For example, public healthcare tends to operate out of a much more general theology than any one denomination or
religion might possess. Politics, limited economic resources, and massive cultural changes are reshaping spiritual care inevitably in the public sphere.

The same political, economic, and cultural pressures, as well as the dominant rational/medical model of care, make spiritual care research necessary, not only to sustain the role of chaplains and other spiritual caregivers, but also to enlighten the path forward. The essays of the third section, “Researching Spiritual Care,” focus on research to make spiritual care visible in three particular areas: mental health; managing volunteers and their own beliefs; and critically observing spiritual care in an acute setting.

The final section highlights “Critical Issues in Spiritual Care” focusing in particular on suffering and the spiritual self; assisted suicide in the context of incurable mental illness; the effect of spiritual care upon mild cognitive impairment (related to dementia); and spiritual care in a children’s hospice.

Taken as a whole, this book presents the opportunity to reflect with spiritual care colleagues in Great Britain, who in turn are likewise reflecting on spiritual care in the United States.

Dan McGill, BCC, is staff chaplain at Dignity Health Marian Regional Medical Center in Santa Maria, CA.
Finding the spirituality in all of life


**By Martin Folan**

“Spirituality,” writes Christina Puchalski, director of the George Washington Institute for Spirituality and Health, “is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature.”

Charles W. Sidoti’s second book, *Simple Contemplative Spirituality*, presents a treasure chest of golden spiritual nuggets, as you mine through 22 stories of how to view all of life as spiritual.

Sidoti, a member of the NACC, walks through his stories in the sandals of Jesus, and offers truer and richer glimpses of life. His stories invite you to discover a new awareness of God’s presence in museums, through neurologist Sigmund Freud, the Wizard of Oz, the wisdom of Confucius, and the popular 1960s game show *Let’s Make a Deal*, where contestants could risk their cash in hand for what remained hidden behind doors 1, 2, or 3. Risk could yield grand prizes or a gag prize.

“The need to let go of something, risking what we already have for the possibility of obtaining something better, often gets played out in our real lives,” he said. “It happens when we agonize over important choices. We may need to decide whether to leave our current job to take another that we have been offered.

“The struggle we often face in making important life choices is that we must let go of something, trade it away in the hope of trading up, with the ever present fear of getting ‘Zonked.’”

While what’s past is past and cannot be changed, *Simple Contemplative Spirituality* offers new frameworks in which to place past experiences — ordinary, simple and practical — so that past wounds may be healed, new avenues to joy may be traveled, and deeper meaning may be discovered.
In Chapter 20, *God’s Presence in the Here and Now*, Sidoti writes this about the meaning of life, “[I]t will always fail us. We will never think our way to inner peace.”

Who we are and who God is “will require a fundamental shift in the way we approach life. Until this happens, the struggle to discern what our responsibility is and what is God’s responsibility, a kind of role confusion, can wreak havoc upon our inner lives.” To prevent such havoc, he tosses us a life preserver of eloquence and wisdom of playwrights, philosophers and songwriters, and leads us down new pathways to discover joy, inner healing, love, and our true selves.

At the end of each story, you will find the “Contemplative Connection,” a soul tool to integrate into your own life the meaning of stories; they include prayers, reflections, questions, and quotes by saints.

Sidoti’s prose wraps your heart in a warm blanket of comfort story after story. Unwrapping the blanket at the end, you will find yourself basking in a warm, golden glow of deeper meaning.

*Martin Folan, BCC, is director of mission and spirituality at Mercy Hospital and Medical Center in Chicago.*