

Survey Examines Sources of End-of-Life Care Information Advance Directive Research Now Underway

All four Monterey County hospitals are participating in an advance directive research project led by CCA board member Dr. Marc Tunzi of Natividad Medical Center.

The study explores where individuals get advance directive information and who guides them to complete forms and initiate related discussions. By understanding how people learn about advance directives, study administrators can then determine how to better inform patients, their families and the medical and legal professionals who serve them.

Research began in July, and Tunzi says the team has already made one surprising observation: Fewer people than expected have completed advance directive forms. That makes data gathered in the study even more valuable for shaping future educational programs.

Finding out where those with advance directives get their information is particularly important.

"If we know where people are getting them, we can decide how to improve that process and make the education around it stronger. We can also determine additional places to distribute information," says Tunzi.

Researchers also are finding that patients with advance directives haven't necessarily made all the arrangements they should.

"Even when patients have an advance directive, a very small number know what it really means," says local admissions nurse Kim Chappell. "Many people keep their forms in a safe deposit box, but their surrogate decision maker might not have access to that box. Others have a living will or trust completed by their attorney, but when asked for details they'll say it's for financial matters only—it doesn't indicate their health care wishes or designate a surrogate decision maker."



Professor John Berteaux of CSUMB leads a discussion of ethical issues involved in advance care planning with Summer Health Institute students at Salinas Valley Memorial. The students helped facilitate the survey process for the Advance Directive Research Project.

One unexpected result of this project has been the awareness it raises among participating health professionals, explains Tunzi.

"Even at Natividad, where very few patients have advance directives, I've had the opportunity to talk to social work staff, admitting staff and a handful of nurses about this project," he says. "When I talked to admitting staff, almost everyone knew someone who had faced issues related to end-of-life care or advanced planning. So, they're all really interested in this. Even though Natividad is going to generate few surveys, we've already actually accom-

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Sessions Target Professionals and the Public

CCA Begins Local POLST Training

A Place for Mom eldercare advisor Katrina Valliant helps patients and families consider long-term care and housing options. All too often, she sees loved ones argue when someone falls ill.

"More often than not, they haven't discussed what to do if a parent gets sick," she says. "The family is left in turmoil. They just don't understand. They're guessing at what Mom or Dad wanted, and then this big rift can develop."

Thankfully, a new tool can help families avoid those challenges. The Physician Orders for Life Sustaining Treatment (POLST) form documents an individual's wishes regarding treatments such as pain management, resuscitation and feeding procedures. Instead of taking the place of a living will or durable power of attorney, POLST remains with patients wherever they travel or receive care. The form is completed with the approval of the patient and his or her physician.

Legislation requiring that providers honor the form in good faith took effect in California in January. More than 20 states have or are developing similar programs.

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Message from the Executive Director



A few months ago, an Associated Press article explored the popularity of Twitter, Facebook and other social networking sites. While millions regularly use these tools, the piece noted something surprising: A Pew Internet & American Life Project study found 48 percent of respondents indif-

ferent to, overwhelmed by and sometimes steering clear of online social networks. The article then cited research underlining a preference for face-to-face interactions and meaningful exchanges.

Meaningful exchanges and personal connections are central to Compassionate Care Alliance's outreach. Yes, we provide relevant resources through our Caring Resources website, but our workshops, *Healing Through the Arts* programs, public forums and research projects draw the most response.

CCA is also capitalizing on important connections with the California Coalition for Compassionate Care (CCCC), which received a grant from the California HealthCare Foundation to develop and promote best practices related to end-of-life care in nursing homes. The goal is to reduce hospital transfers at life's end; the recommendations will be based on conversations with practitioners and then endorsed by the state. Because we partner with CCCC, CCA representatives will be observing the creation and implementation of curriculum and using that information in our own programs.

On the national stage, some of the country's most significant conversations currently revolve around health care reform. Of particular concern are misconceptions about advance care planning consultations. As consumers are targeted with inaccurate information, it becomes increasingly important that CCA provide timely, relevant facts on such topics. Thankfully, we're learning how to better inform Monterey County residents through ongoing advance directive research led by CCA board member Dr. Marc Tunzi.

We'll also address some common misconceptions in our advance care planning workshops, which resume this fall and continue through 2010. In addition to adding health care reform to those workshop discussions, we're introducing *Physician Orders for Life Sustaining Treatment* (POLST) to the general public. The POLST seminars we've offered for local medical professionals since August have been well received, and those practitioners will help educate the public, as well.

Because so much is changing as leaders debate health care reform, we've decided to postpone this year's CCA fall forum. We'll wait until the spring, when more details should be available, to convene a large discussion on changes to health care and the related impact on end-of-life issues. In the meantime, we'll continue to focus our energy on small-group workshops, arts programs and ongoing outreach.

Finally, I'm happy to report that CCA continues to be supported by all types of community members. Whether in the form of dollars, time, connections or otherwise, this assistance is crucial to our success. We're a small organization but, thanks to your partnerships, we're able to accomplish big things even in challenging economic times. Thank you for your interest in our work!!!

—Vicki Nelson, Executive Director

Art is the Heart of Healing Reaches New Audiences Two Programs Address Loss Through Art

This summer, CCA's *Healing Through the Arts* committee launched two projects designed to help participants address end-of-life emotions, decisions and challenges.

The first, an intergenerational mural project at Monterey's Classic Residence by Hyatt (formerly The Park Lane), was a response to the *CCA Art is the Heart of Healing* traveling exhibit. Facility residents who viewed the collection of paintings, photos and other works inspired by illness and death were encouraged to discuss their own life experiences. Motivated by residents' reactions, organizers fashioned a new on-site art program—and the result is a mural created by Classic Residence by Hyatt community members and students from Monterey High School Arts Academy.

As they collaborated on the design and painting, participants shared stories about relationships, aging and living life to the fullest.

"Art has been a pleasure throughout my life, starting in high school in Glendale. I was inspired seeing the young people doing the same thing I did in high school, and I admired their skill," says resident Evelyn Bindel. "The mural is a lasting gift and will always give the residents pleasure."

Sue Ann Hillyer directed the mural project. Monterey Bay Women's Caucus for Art, which collaborated with CCA on last year's *Art is the Heart of Healing* outreach, donated the paint.

CCA's second major arts project stems from last year's successful production of *Legacy*, a play that touched upon end-of-life issues as it followed the interactions between a young woman and her grandmother. Audience members participated in dialogue sessions following each performance, and several completed a subsequent survey about the play and its lessons.

"We wanted to know who was there, because that tells us who is already in tune with these topics," says survey creator Carol Galginaitis, who studied qualitative research at the doctoral level and also worked on CCA's *Healthy Aging* television program. "From there, we can learn why they're in tune and what more they want to know."

Respondents praised how *Legacy's* characters handled the difficult discussions surrounding death and dying, and many noted a desire to bring up advance care planning and end-of-life issues with



Residents of Classic Residence by Hyatt as well as students from Monterey High Arts Academy worked together to create a mural in their crafts room.

their own loved ones. Others said the play reminded them to enjoy each moment and communicate more openly.

This type of audience research can help shape future CCA outreach, believes Galginaitis.

"If CCA, and all of us, can continue to have these conversations and ask these questions, we can be a real force in encouraging dialogue," she says.

A new CCA production is scheduled to open in October, 2010 at Carl Cherry Center for the Arts in Carmel. *Exit Strategy*, also written by *Healing Through the Arts* committee chair Cindy Gum, tackles end-of-life challenges from a new perspective. The play will share the story of BJ, a homeless woman, and Jerry, a widowed family physician, who meet at a Lake Tahoe cabin under unusual circumstances. Throughout the production, these two characters address everything from grief and healing to paranormal experiences at life's end to health care delivery and our medical system.

While *Legacy* chronicled the relationship of two close family members, *Exit Strategy* spotlights the communication between two strangers. Their interactions, however, are no less powerful.

"Over the course of a few days, family secrets are exposed and events challenge our characters to dig deeper and reexamine the power of love and heartfelt connections. This is a story about the brilliance of the human spirit," says Gum.

"What a good play does is mirror back experiences that we can relate to," she adds. "The various issues faced by these characters motivate audience members to examine their own feelings about health care and end-of-life issues. This is really the mission of CCA: to create opportunities for education, dialogue and discussion."

Thank You to All Compassionate Care Alliance Supporters

Compassionate Care Alliance thanks all who have donated time, money, professional expertise and personal connections in support of our organization. During the past year, we've educated the community through discussions, workshops, art programs and live performances, plus we've embarked upon research

projects and statewide initiatives designed to keep residents and professionals alike informed about end-of-life issues.

In the words of anthropologist Margaret Mead, "Never doubt that a small group of thoughtful, concerned citizens can change the world. Indeed, it is the only thing that ever has." As a small non-

profit, CCA's ability to raise awareness and inspire change depends on our collaborations with like-minded businesses, partner organizations and individuals.

In our Champions List, we introduce you to these special individuals who have so generously given their time to our projects.

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Community Artists Exhibit

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Susie Berteaux
Jennifer Colby
Kira Carrillo Corser
Michele Faia
Carol E. Galginaitis
Joel Gambord
Ted Hill
Sue Ann Hillyer
Maria Kostelas
Emy Ledbetter
Carmen Leon
Cat Malone
MarthaElin Mountain
Barbara Nelson
Cathy White
Tom Wolver

Community Mural at Classic Residence by Hyatt—Monterey
High Arts Academy Students
Lesley Spowart
Vala Hall

Gina Puccinelli
Eleanor Bindel

Legacy

Carol Galginaitis
Cindy Gum
Stan Gum
Maria Kostelas
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Patrice Parks
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Theatrical

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POLST OUTREACH AND EDUCATION

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Valliant was among nearly 20 individuals who attended CCA's "Train the Trainer" event in August. Participants discussed the history of POLST, heard success stories and learned how to educate others about the form. Additional training sessions have targeted professionals in skilled nursing facilities, residential care facilities and home health agencies, as well as attorneys, first responders and hospital staff members. Attorney outreach is in collaboration with the Monterey County Bar Association.

During her session, Valliant realized the wide-reaching value of POLST.

"It's not really just for the elderly. This POLST form needs to get out to more people, especially those in dangerous jobs—like firefighters and police officers and EMTs. It allows their spouses and their families to understand what they want," she says.

In fact, Valliant had a similar conversation with her own son before he was deployed to Iraq earlier this year. The discussion was difficult, but she felt it was important to understand his wishes, should something happen.

"We all want dignity at the end of our life," she says, "but unless we develop a plan, no one is going to know what we want."

To be carried out effectively, that plan should be understood by patients' families as well as their doctors. CCA's first POLST sessions included medical professionals and members of bio-ethics committees from area hospitals.

"CCA presented an overview of POLST to physicians and our bio-ethics committee members. They were impressed with the



Members of POLST Core work group participate in a training session. The participants will be involved in community outreach on POLST for CCA.

format of the form and saw that it can easily be incorporated into our system," says Dr. Sandra Montijo, clinics medical director of King City's Mee Memorial Hospital.

Carmel Valley attorney Barry R. Harrow, who attended the August POLST training, hopes to work more closely with the medical community in promoting the document.

"It's really up to all of us to educate people about how important these forms are," he says. "Once in a while, public awareness increases from cases like that of Terri Schiavo in Florida, but then people's memories fade. It doesn't translate into an awareness of how important advance directives are to avoid that kind of result."

He also highlights the importance of making POLST work in conjunction with advance directives.

"The important thing is that this be consistent with the advance health care directive that hopefully has been previously

executed. That will cover more ground than the POLST," he says. "But, what I like about POLST is that it's simple and it's something that can follow the patient around."

ADVANCE DIRECTIVE RESEARCH

(continued from page 1)

plished something just by educating staff members as we have."

Salinas High School statistics students, led by Cynthia Hess, and students from Salinas Valley Memorial Hospital's Summer Health Institute are involved in the research, as well. The project presents a "wonderful opportunity for students," according to Lynn Brooks, director of volunteer, health career and spiritual care services at Salinas Valley Memorial.

"We knew we were including an ethics piece into their curriculum this summer, so this was a perfect fit. We were able to address ethics while also using CCA's expertise in presenting the survey parameters and exploring an entire spectrum of end-of-life issues," she says. "We were very fortunate that one of our students, Gus Hernandez, wanted to continue with the project after the Institute ended. He has been instrumental in the study's success."

Partnering with Tunzi on the study are Mike Hutchinson of Salinas Valley Memorial Healthcare System, Dr. Sandra Montijo and Graciela Navarro of Mee Memorial Hospital, and Mary Brusuelas, CCA board president.

To Resume in October

Advance Care Planning Workshops

Compassionate Care Alliance opens a new series of advance care planning workshops this fall, expanding last year's curriculum to include discussions of POLST and health care reform. Sessions are free to the public and also include information on legal, financial and estate considerations, hospice and palliative care, surrogate concerns, grief and recovery.

Two workshops are currently scheduled: one on Saturday, October 17, at Sally J. Griffin Senior Center in Pacific Grove, and another on Saturday, November 14, at

the Carmel Foundation. Thanks to a new partnership with Mee Memorial Hospital in King City, additional events will take place in south Monterey County by mid-2010.

"The people who gather at these community centers often have questions or concerns about advance care planning, so it makes sense to kick off our latest workshops in these locations," says CCA board president Mary Brusuelas. "We want to make it simple for interested individuals to learn about such important topics."

Advance Health Care Planning Workshops

Saturday, October 17 10 a.m. – Noon

Sally Griffin Senior Center — 700 Jewell Avenue, Pacific Grove

Saturday, November 14 10 a.m. – Noon

Carmel Foundation — southeast corner of 8th & Lincoln, Carmel

Workshops are free and reservations are required.

Reserve your space online at www.ComCareAlliance.org or call 655-9506.

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