## July 15, 2018 - Hospice and Palliative Care meeting

**MaryCarol Reeder, FNP-C** (Certified Family Nurse Practitioner), Palliative Care Integration Director for Scripps Hospitals.

MaryCarol read her advance directive, which included specific prohibitions, such as "I do want to be resuscitated. I do not want to be dialyzed," as well as conditional wishes such as "if not too burdensome to my family, my wish is to die at home."

She emphasized that the first critical step to dying with dignity is to write down and write personal wishes.

The World of Health definition of palliative care is:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

MaryCarol said the intent is to help give you strength to carry on your daily life, but most importantly the goal is to improve your quality of life by addressing emotional, spiritual and social needs.

At Scripps there are 5 teams at 5 Scripps hospitals. Teams consist of a doctor, a nurse practitioner, social worker, and chaplain. Inpatient and outpatient work differently.

About 80% of the people they see have cancer.

She gave an example of a sample in-patient visit. A patient's cardiologists asked the palliative care team to see the patient.

The team discussed with the patient the trajectory of his disease and what it looks like. They listened and answered questions. In this case, a Left Ventricular Assist Device (LVAD) had been recommended by the cardiologist. The team discussed what life would be like with and without the device. They listened and documented the patient's goals.

Outpatient side – there are 2 right programs now, one at Mercy and one in La Jolla. Typically the patient is seen in this type of situation 3-5 times. The patient is told what to bring to the meeting in terms of records. The team goes over medications; usually the doctor has previewed the chart. The beginning is similar to a doctor's appointment, your vital signs are taken. After that you are taken to a conference room setting, you can bring your family and the team talks to you and asks questions to understand what your understanding of your disease is. They ask the patient if they are ready to hear their prognosis; sometimes their own doctor has not explained it to them. If the patient is not ready, they do not tell the patient. The team explains the available options to the patient. At Scripps, they do not mention the End of Life Option Act as an option. If the patient asks about it, they are given a flyer describing what the patient needs to do.

Some patients improve and are taken off of palliative care. In the case of dementia, resources are offered to the family. Scripps does not offer hospice anymore. Medicare Plan B pays for palliative care for those eligible.

**Stephen Poses, MD**, private practice, Carlsbad. He has an almost 4 year waiting list. He specializes in house-call based geriatrics and palliative care. He is board certified in internal medicine and hospice and palliative medicine. He is Associate Medical Director of Lightbridge Hospice and Medical Director of Dependable Home Health. He is a voluntary clinical faculty at UCSD medical school. He is very involved in teaching palliative medicine to the fellows in both geriatrics and geriatric psychiatry.

Dr. Poses explained the default philosophy of modern western medicine is "full steam ahead," (do everything possible), and good luck stopping it. He said that as a physician he needs to be aware that every single thing he orders has

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potential side-effects. He considers it a part of his job to determine if the potential benefits of a particular test or procedure outweigh the possible risks. He encourages us to ask our health care providers this same question; patients need to take some ownership to make sure that they do not fall victim to knee-jerk medicine.

One thing that started Dr. Poses along this line of thinking was his stint on Admiralty Island in Alaska as a 4<sup>th</sup> year medical student. A particular case made clear that community standards of care can vary a lot. On Admiralty Island there are more bears (grizzlies) than people. His first day in the clinic the faucet was stopped up. The pediatrician took the faucet off and a leech came out. One healthy 15-year old came in with a badly sprained ankle, swollen to the size of a small cantaloupe. If Dr. Poses had been in his own community hospital, chances are someone would have already made the knee jerk reaction to order an x-ray of the ankle. On Admiralty Island, where the ferry ran only twice per week, getting an x-ray would have entailed an 8-hour ride one way, an overnight stay and another 8 hours to get back. It was a pivotal moment in his medical education and started him habit of asking of himself "Do I need this test or do I want this test?" Ever since then he takes a few seconds to think about every test he orders.

During residency in San Francisco during the 1990's he had a lot of exposure to people pre and post-transplant, a lot of AIDS and ICU patients. He observed a lot of codes where the patient was doing his best to die and the doctors were doing their best to prevent it. He noted the incredibly low percentage of people that were successfully resuscitated at the moment and the even lower percentage that were able to walk and talk again.

Since 1999 he sees all of his patients in their home because they are home bound. Under Medicare's definition a home-bound person is someone for whom it is an unreasonable and taxing effort to get to a physician's office. It doesn't mean they can't drive. It means they have "end-stage," whatever. It is a person who is going to take a full half day out of their lives and then another whole day to recover from that in order to get 10-20 minutes of face time with a nursing assistant or physician. The medicine he practices is person and family-oriented. He notes that a hospital is neither of those, a hospital is doctor-centered care.

## Goals for his practice:

- -To avoid unnecessary hospitalizations, ER visits, surgeries, and especially ICU visits
- To get all of his patients enrolled in hospice before they die, and not just a day or two before, but at least several months before. He noted there are some people who do not have severe symptoms at end of life. It is rare, but it happens. Even in those circumstances, hospice is such a benefit to the patient's family and their surviving loved ones; it is still very worthwhile to get them enrolled.

He is not successful in either goal, but he does strive for them.

## Courtney Sniderman, Certified Hospice and Palliative Care Registered Nurse

Courtney works for Pacifica House - Hospice of the North Coast. It is the only short-term in-patient hospice in North County. It has six beds and operates under skilled nursing facility licensing. It is only for patients who need acute management, whose symptoms are out of control and require 24-hour care; things like extensive wound care - nausea, vomiting, severe agitation, things that family cannot manage. They also accept patients whose caregivers need respite care, a benefit that Medicare provides for 5 nights every few months. These patients do not have to have those out of control symptoms in order to stay at Pacifica House. In-patient Hospice can be done at any nursing or board and care facility. Board and care facilities do have to have a waiver in order to take a hospice patient, but a lot of them do.

Courtney said if you are interested in a hospice that will support California's End of Life Option Act, you need to call various hospice facilities to find out their position. She advised careful questioning is in order to determine what level of support they might provide, because "support" to many hospices means they will hand you a phone number for Compassion and Choices, as opposed to assisting you in meeting the strict requirements of the End of Life Option Act, or having a nurse or doctor available when you ingest the life-ending drug.