

# Joint Task Force on End of Life Issues

Arizona Medical Association // Arizona Osteopathic Medical Association  
Annual Report  
May 15, 2017

## Report

This Task Force was established in the spring of 2016 by both organizations' governing bodies and via resolutions. Members (about 25 MDs and DOs) were recruited based on experience and interest in end of life care from around Arizona in both practice and academic settings.

The **rationale for a Task Force** was based on a number of important recent developments including:

1. Institute of Medicine's Report on *Dying in America* (2014)
2. Atul Gawande's *Being Mortal* (2014)
3. JAMA's Jan 2016 issue entirely devoted to issues related to End of Life care
4. Medicare's authorization to pay for end of life counseling (2016)
5. Legislation in Colorado (2016) and California (2015) legalizing Medical Aid in Dying and corresponding change by their State Medical Associations' position of opposition to such laws to a position of neutrality.

The Task Force defined its **Mission**:

***To review care for individuals with serious, life limiting illness along with those at end of life. The Task Force will identify strengths, unmet needs, and make recommendations that provide practical solutions to improve care for these individuals in Arizona.***

The **Task Force met monthly** from Oct 2016-May 2017 both in person and via telephone. Its **Steering Committee** met monthly before each Task Force meeting. The Task Force heard testimonials from its members based on their experience, and created three workgroups based on the priorities identified:

- 1) Education for physicians and public
- 2) Access to Palliative Care
- 3) Policy (such as POLST and Medical Aid in Dying )

We heard reports from each of these **workgroups** on:

1. Status of education in Medical Schools and Residency programs
2. A comprehensive community / physician / hospital initiative in Northern Arizona to implement POLST (Physician Orders for Life Sustaining Treatment)

3. Pro and con views from prominent physicians on Medical Aid in Dying.

We issued a **publication, communication vehicle and grant application**:

1. Article about Task Force activities in the new statewide medical journal, *Arizona Medicine*, that reaches all 18,000 physicians in Arizona (March 2017)
2. Web page and blog as part of ArMA's website (<http://www.azmed.org/page/endoflifecare>)
3. Lovell Foundation grant application in partnership with the Arizona Healthcare and Hospital Association (AzHHA) for a comprehensive statewide education effort for both providers and the general public across Arizona over a four (4) year time frame (notification expected in July 2017).

We surveyed allopathic and osteopathic **medical schools** in Arizona and **primary care residency programs** in Maricopa County:

1. A survey of curricula at Arizona's Medical Schools found that most contained substantial training on end of life issues.
2. A survey of primary care residency programs in Maricopa County suggested that most do **not** have specific curricular objectives or time allotted to end of life care issues.

The Task Force has the following **future plans**:

1. Another year of meeting to deepen the discussion of key issues identified and to **research further** for **relevant statistics** to benchmark Arizona's experience in end of life care with national data, before making recommendations to ArMA and AOMA.
2. Conduct a **survey** of physicians in Arizona regarding:
  - a. Their views of end of life care in Arizona.
  - b. Their confidence and satisfaction in providing such care.
  - c. Their perceived need for training to improve their skills in end of life care.
  - d. Their perceived access to palliative care services for their patients.
  - e. Their views on Medical Aid in Dying.
3. The Task Force will engage a qualified **pollster** to conduct this survey and has raised funds for this purpose held in the ArMA Foundation. The Task Force will conduct this survey over the summer and analyze results in the fall of 2017. It will base further efforts at education and policy based on the findings of the survey.
4. The Task Force will explore ways of encouraging and providing **training** on end of life care in **residency programs** around the state and through **CME**

- programs for practicing physicians**, including sponsoring a conference on end of life care and trying to engage with physicians in primary care and specialties like oncology, cardiology, nephrology, emergency medicine, hospital medicine, and critical care medicine through their respective specialty organizations.
5. The Task Force is recommending that ArMA /AOMA provide **fiscal support** for its activities in their budgets for 2017-2018. The Task Force has submitted resolutions for ArMA/ AOMA:
    - a. One regarding fiscal support for its planned activities.
    - b. Support for implementing POLST in Arizona.
  6. The Task Force will continue to look for ways to encourage and develop greater **access** to Palliative Care Services to all patients across Arizona in both inpatient and outpatient settings.
  7. The Task Force will also request ArMA **Ethics Committee** to reconvene to revisit prior positions (1996) on Medical Aid in Dying.
  8. The Task Force will continue to reach out to physicians around Arizona who are engaged in activities related to **improving care** to patients near the end of life and engage in collaborative efforts to improve professional and public education on issues related to end of life care.

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## MEMBERS OF TASK FORCE:

Ron Fischler, M.D.*	Pediatrician, Scottsdale, Chair
Dan Aspery, M.D.	VP/Medical Director, Blue Cross Blue Shield, Phoenix
Jeanette Boohene, M.D.	Palliative Medicine, Scottsdale
Carla Denham, M.D.	Psychiatry, Phoenix
Tim Fagan, M.D.*	Internal Medicine, Survey Committee chair, Tucson
Chip Finch, D.O.*	Emergency Medicine, Education workgroup chair
Tom Fitch, M.D.	Oncology /Palliative Care, Mayo Clinic, Phoenix
Danny Hintze	Medical Student, UA COM Tucson
Emmalee Kennedy, M.D.	Palliative Medicine, Flagstaff, POLST pilot head
Evan Kligman, M.D.	Geriatrics, Palliative Medicine, Tucson
Rama Kunkle, D.O.	Palliative Medicine, Honor Health /JCL, Phoenix
John Manfredonia, D.O.	Hospice, regional Medical Director, Tucson
Greg Mayer, M.D.*	Palliative Medicine workgroup chair, ASU Ctr for Science of Healthcare Delivery, Phoenix
Patty Mayer, M.D.	Palliative Medicine, Banner, Phoenix
Alan Molk, M.D.*	Emergency Medicine, Banner, Phoenix
Tom Neumann, M.D.	Nephrology, Cottonwood

Heather O'Toole, M.D.	Family Medicine, Honor Health / Lincoln, Phoenix
Gobi Paramanandam, M.D.	Hospice and Palliative Medicine, HOV, Phoenix
Bruce Peek, M.D.	Cardiology, Cottonwood
Stacie Pinderhughes, M.D.	Palliative Medicine, Banner, Phoenix
Michael Powers, M.D.	Neurology, Phoenix
Akash Shah, M.D.	Family Practice, Resident, St. Joe's Phoenix
Paul Stander, M.D.*	Internal Medicine/Geriatrics/Palliative Medicine Policy Workgroup chair, VA, Phoenix
Lisa Stearns, M.D.	Pain Management, Scottsdale
Jud Tillinghast, M.D.	Pulmonology /ICU, retired, Scottsdale
Sarah Wypiszynski	Medical Student, UA COM Phoenix
Mandy Weaver*	Project Mgr (retired Exec Dir, AOMA)

\* denotes member of Steering Committee

## Appendix

This section includes documentation of testimonials regarding end of life care in Arizona as offered by members of the Task Force that speak not only to the problems they see, but also to possible solutions. They will form the basis for next year's discussions and for the planned survey of Arizona physicians. Additionally, the reports on POLST in Arizona, on education for students and residents, and a compilation of the best articles on end of life care are included as well as the article from [Arizona Physician](#) regarding the Task Force activities.

**Recommendation: The Task Force recommends that additional efforts and grant funds be used to compile additional relevant statistics on end of life care in Arizona that can be used as a comparison with U.S. data and as a benchmark for efforts to improve care to this population.**

# **Dying in Arizona: Testimonials from Members of the Task Force**

**All too many patients with chronic debilitating diseases do not have the conversation about advanced directives with their families and doctors and wind up in a crisis in the ER.**

**Alan Molk, M.D. ER Physician Banner system**

*I am saddened by how many terminally ill patients (an everyday occurrence in my ER) wind up in a medical crisis in the ER when they would be far more humanely served in a palliative or hospice setting.*

**The ICU is also a common place where terminally ill patients are sent because families have not yet dealt with the terminal nature of the illness and discussed a treatment plan and advanced directives. It is costly and invasive, adding to a patient's suffering.**

**Jud Tillinghast, M.D. retired critical care /pulmonary physician Scottsdale**

*Addressing the difficult questions surrounding end of life is a daily problem in the ICU. I have seen family members divided and agitated, demanding aggressive care even if it only prolongs a patient's suffering. We need more physicians (primary care, hospitalists, specialists and critical care specialists) to communicate clearly and sensitively with patients facing a terminal condition, with assistance from the palliative care team, to help families honor the wishes their loved ones and ideally to do this before a crisis occurs that results in an ICU admission.*

**The view of a neurologist who deals with a variety of terminal scenarios. What remains to be clarified is whether patients achieve a "good death" in each?**

**Michael Powers, M.D.**

*The scenarios confronting neurology are quite diverse. In the acute setting, we see the families of those with severe strokes or with cardiac arrests and severe hypoxic brain damage. There the family needs the intervention and the family often determines the level of support, especially in the absence of advance directives.*

*For the more gradually progressive conditions I would divide them between those such as Alzheimer's disease and severe Parkinson's disease where cognitive function is quite impaired vs conditions such as ALS where the body is failing but cognitive function is relatively preserved. There the patient can*

*direct the level of their intervention. If they decline long term ventilation (which is common) then we can usually be successful in utilizing hospice services to keep them from suffering due to ventilatory failure. This typically requires use of sedatives or opioids to eliminate air hunger.*

*Sometimes the issue of tube feeding arises, such as in ALS or other disorders where swallowing is impaired. Most will accept PEG placement to prevent starvation with the understanding it does not artificially prolong life in that setting.*

*Brain tumor patients can be diverse depending on the extent physical and cognitive function is impaired. In my general experience it is possible to provide comfort measures to prevent suffering for most who are dying from neurological disorders.*

**Palliative care-- if started earlier-- could avoid needless suffering and hospitalization and procedures at the end of life.**

**Rama Kunkle, D.O. Palliative Care Specialist Honor Health / Lincoln**

*I was recently taking care of a patient that was end stage heart failure. She had been struggling with shortness of breath and required paracentesis for fluid management with increasing frequency. Although followed by her PCP and Cardiologist, she was admitted to the hospital for respiratory distress the day before she was to meet with hospice. Her daughter said to me that she wished that her mother had palliative care services earlier in her disease process for support and symptom management. Patients and their families often want this support. The presence of outpatient palliative care services is growing and can provide a valuable service to our patients.*

**Counseling patients honestly is a big part of providing care for patients with chronic and ultimately terminal illnesses and revising/ updating prognosis and treatment options with input from the patient and family as the disease progresses.**

**Bruce Peek, M.D. Cardiologist, Cottonwood**

*How we assist patients and their families during the dying process is just as important as how we assist them to prolong life. Educating patients and families regarding the nature and prognosis of their disease throughout the course of their illness, and eliciting their goals and preferences along the way is essential to what we do.*

**Palliative care is a relatively new specialty now available in many larger hospitals to assist physicians and patients make the transition to comfort based care; outpatient palliative care is more limited in availability.**

**Stacie Pinderhughes, M.D. Banner Palliative Care**

*Palliative care is team based, specialized medical care for people with serious illness. A team of doctors, nurses and other specialists provide patients relief from symptoms, pain, and stress of any serious illness. The goal is to improve quality of life for patient and family during any stage of serious illness.*

**Jeannette Boohene, M.D. Palliative Care, Cancer Treatment Centers of America®, Goodyear**

From the most recent Center to Advance Palliative Care (CAPC) report on this for 2015 (four years of data from 2011 to 2015)

*One-third of U.S. hospitals report no palliative care services of any kind, and access to palliative care in community settings (home, nursing home, assisted living) is limited for people who are not hospice-eligible. Additionally, the presence of a palliative care program in a hospital does not necessarily mean that seriously ill patients needing palliative care actually receive palliative care services. As a result, most people with serious illness are unlikely to receive the care they need throughout their course of illness. Making palliative care available to the much larger population of the seriously ill who are neither hospitalized nor hospice-eligible is perhaps the single largest opportunity to improve value in the U.S. health care system*

*Palliative Care penetration is highest in New England, Pacific and mid Atlantic states >75%, and lowest in West South Central (Arkansas 32%) and East South Central states (Mississippi 29%). **Arizona is 68% and moved from a grade C in 2011 to a grade B in 2015.***

**Hospice referrals happen too late; palliative care is often not available outside of a hospital.**

**John Manfredonia, D.O. Regional Hospice Medical Director, Kindred, Tucson**

*Palliative Care has made considerable progress in the last several years, but the palliative model has been predominately hospital rather than community based. There have been a few successful community models but they usually require financial supplementation. Overall, the work force is inadequate to handle the growing need/demand and reimbursement has been inadequate Hospice: About 1/3 of patients entering hospice die in less than a week, insufficient time to achieve a "Good Death." The barriers to early referral*

*include physicians and patient / family perceptions and poor communication within the healthcare system*

*What can be done? Physicians, patients and their families need to better understand the consequences of their decisions. Look at all possible scenarios, the good and the bad. The old adage of living longer does not always equate with living well...in hospice it is about attempting to live (well) until the time of death.*

**CME: Overcoming Doctors' reluctance to having conversations with patients about end of life planning.**

**Patty Mayer, M.D. Palliative Care, Banner, Mesa**

*There is much criticism that doctors can't or won't have these conversations with patients. What I have observed is doctors do want to have end of life conversations but can be uncomfortable doing so simply because they lack training in this area. This is why I hear: "I'm no good talking about death!" My response is: "I can teach you! Just as you could teach me to sew a laceration, administer chemotherapy, or adjust a ventilator. All these things are learned skills; they do not come without training."*

*Most of our medical training emphasizes curing patients, not assisting them with options when they are seriously, critically or even terminally ill. Having difficult conversations is a teachable skill, and most physicians and medical students are eager to learn. As a group they are bright, inquisitive, hard-working quick studies.*

*I have personally taught these skills to many professionals over the years with overwhelmingly positive responses. Imparting these tools to doctors improves their comfort and satisfaction, which in turn enhances the patient experience.*

**For some patients, Medical Aid in Dying offers an important end of life option.**

**Evan Kligman, M.D. Family Physician and Geriatrician, Tucson**

*In my 15 years providing palliative and hospice care, I have experienced situations where such care was insufficient and for which medical aid in dying would have given certain terminally ill patients and their loved ones a degree of comfort and sense of being in control with dignity.*

**Living wills can't for see all events and need provisions for revision as a disease progresses.**

**Lisa Stearns, M.D. Cancer Pain specialist, Scottsdale**

*My mother was diagnosed of lung cancer a year before her death. She suffered from hyponatremia, cachexia and severe pain from vertebral compression fractures. When I went to see her one day, I discussed her condition and the obvious suffering she had endured. I gave her permission to quit to which she replied "really?" and then "thank you." She had dinner with her friends, called in my sisters and died peacefully in her sleep two weeks later. Following her death, my father was distraught and lost. He developed progressive dementia and died eight years after her death. I had to ask a psychiatrist to evaluate his competency after several distressing events. He moved to Montana into a skilled nursing facility to be near my sister. The year of his death, when my sister was out of town for an extended period, he was beaten by a caregiver on several occasions and had boiling water poured on his legs because he "was naughty." Following the burning episode, another caregiver notified us by text of what was happening and shared pictures of his bruises and burns. Upon moving him to a new facility, he withdrew and became more confused. He suffered two falls with subdural hematomas, resulting in aspiration pneumonia and finally death. As MPOA communication was poor and disjointed. It was difficult to get the whole story unless my sister was in town to evaluate his condition. His physician was reluctant to follow his living will and requested that he be transported to the hospital on several occasions. I had to remind him that my father was terminal in the sense that he was living a life which he had stated was without quality and purpose. Hospice care was supportive but sparse when it came to the actual caregiving. Had my sister not been a nurse and her husband a physician, it would have been difficult to stop the interventions from trying to save my father's life. I had to remind his physician and nurses that it was his wish not their personal beliefs which should guide his care.*

*Even though I navigate death scenarios for a living, doing it for family, has been one of the hardest challenges I have encountered as a physician.*

*In a study published in Community Oncology: we found that 86% of patients who came to our office for pain related to cancer, never had an end of life discussion with their physician. Of those, 95% were happy to have the conversation with the provider and completed a medical power of attorney and advanced directives.*

*Today, we discuss end of life planning will all patients and require a medical power of attorney be established at the first visit.*

**Families that come together and have good communication with the medical team and each other can create a "good death" experience.**

**Tim Fagan, M.D, retired palliative care internist Tucson**

*My mother was active with no significant chronic medical issues at age 86. She lived in Prescott, Arizona which has very good to excellent medical care. We had not discussed end of life issues and she had no advance directive, but the family knew how she had lived her life.*

*She called me in Tucson one morning at about 6:30 AM. She had a sudden onset of severe shortness of breath, and she asked me what to do. I advised her to go to the ER immediately.*

*In the ER, her chest X ray revealed a near whiteout. A transthoracic echo revealed previously unknown mitral regurgitation, but the quality did not allow a good assessment of severity. She was severely hypoxic and was presumed to have pneumonia. She was treated with IV antibiotics, intubated, sedated and hospitalized in the ICU, where she was connected to the usual 10 or so tubes.*

*She lived with her husband, and my wife and I drove to Prescott that day. Her other two children and their spouses live in Prescott. All of her grandchildren arrived within the next two days.*

*She did not improve, and a transtracheal echo revealed that she had ruptured her chordae and had a flail mitral leaflet. Thus, she had overwhelming pulmonary edema, rather than pneumonia.*

*The only option for effective treatment was transportation to Phoenix, open mitral valve replacement, with a high risk of operative mortality, and prolonged rehabilitation.*

*Due to sedation, she was unable to speak to us, but we all spent most of several days at her bedside and talked to her. The entire family agreed, that, knowing my mother, even in the absence of an advance directive, that she would not want the transportation, operation and rehabilitation.*

*All of her tubes were removed and she died peacefully within a few minutes.*

*In many respects this was a good death. She suffered minimally, her dying was not prolonged, the entire family had the chance to say goodbye. The family all agreed on what she would want, and she died surrounded by her husband and family.*

*An advance directive, particularly one that specified no intubation or artificial ventilation, would have simplified her death, but the family would not have had a chance to say goodbye.*

**A big problem continues to be resistance by patients to considering palliative care until they are worn down by the ravages of their disease; but a powerful therapeutic relationship with a primary physician can be helpful to families.**

**Akash Shah, M.D., FP PGY 3 St. Joseph's Hospital Phoenix**

*My story revolves around a patient I first saw on my surgery rotation the day after he had an SMA dissection and resultant colectomy. Soon after he developed short gut syndrome and was resigned to being on IVF almost 14 hours a day to stay ahead of the volume loss. Because the patient did not have a doctor and there were no GI specialists who specifically saw post colectomy pts, I volunteered to start seeing him in clinic. I saw almost every 1-2 weeks and I was able to build a very strong relationship with him and his wife. He had follow up with surgery but the only treatment option for him was a full bowel transplant and that required a move to the East Coast and family did not want to consider that option. Therefore, I saw him and helped manage his pain/anxiety/depression/stomach cramping/short gut on a weekly basis with sporadic follow up with specialists. I tried numerous times to bring up the topic of hospice or palliative care and patient abjectly refused every time. After months of this back and forth and continued deterioration of pts physical and mental health, we got a point with his pain management that our clinic was no longer comfortable managing the amounts of benzos/opioids he was getting and we had to send him to pain management as they were still refusing a palliative/hospice evaluation. Then I find out about a week later that the family accepted hospice and the pt finally passed away within a few days. This experience taught me the value of establishing a relationship with pts beyond just their medical issues and delving into their personal story. I learned first hand the kind of difference I could potentially make in pts and their families lives doing palliative type medicine.*

**One of the major problems in the current health care system is that patients lose contact with their primary physicians when they become very ill and enter the hospital and enter the world of hospitalists, intensivists and specialists. Whose role is it to counsel them regarding prognosis, and options and elicit their wishes and address fears and concerns?**

**Heather O'Toole, M.D. Family Physician Honor Health**

*As an FP, I often lose contact when patients are at the end of life. If they enter a long term care facility, they may switch to the primary care doc at the facility. If they go on hospice, they usually switch to hospice for all their needs.*

*The impact that I can make is when they are battling with chronic diseases early on when we can discuss advanced care planning and also if they have a new terminal diagnosis, such as cancer. I see oncologists pushing for treatment*

*that seems futile to me, so it is helpful to have a conversation with patient and family in my office to let them know it is okay if they don't want everything proposed to them. Palliative vs curative is important to discuss. We spend a lot of time discussing quality of life as well and what their goals are. Patients don't often understand the options given by a specialist, so I will see them back, review the consult notes and explain things in a manner that is easier for them to understand. Patients may get into a spiral of multiple specialists, conflicting treatments with potential side effects, and confusion about their diagnoses and I can help to view the big picture and make sure that their treatments are not causing more harm than good.*

*I do a lot of Medicare Annual Wellness Visits, where we do discuss their wishes. I would like to see more education of the primary care physicians and providers on the best way to go about these discussions though.*

**Overcoming resistance by patients' families and doctors to having a conversation regarding end of life wishes in a culturally sensitive way is being demonstrated in a pilot program in Northern Arizona. POLST (AZ MOST) codifies and makes available end of life choices to those that need to know.**

**Emmalee Kennedy, M.D. Medical Director NAH Palliative Care - Flagstaff  
Co-Chair Thoughtful Life Conversations program**

*As a practicing palliative care specialist, I see many patients and families struggle with the unforeseeable choices they face during a serious illness. Medically and functionally frail people are admitted to the hospital, seeming to have no insight into how sick they are or what they may face in the near future. Patients in the ICU are very frequently confused and unable to make decisions. Not uncommonly, we see families struggle with what the patient would want. Without having a conversation about what is important to their loved one or considered a good quality of life, these families can be torn apart with blame and anger. Advance directives (health care powers of attorney and living wills) are very helpful, but they are often filled out when a person is in good health. It is difficult to predict choices in future situations.*

*AzMOST is a helpful tool for people with advanced illnesses to help communicate health care choices pertaining to their current situation. AzMOST stands for Arizona Medical Orders for Scope of Treatment. It is a bright pink form that is a medical order signed by both a health care provider and the patient after a conversation about the medical situation. The conversation gives patients the information they want and need to make important choices about treatment they may need in the near future. These forms are considered the standard of care for communicating a patient's choices in more than 38 states. They allow a patient and their provider to work together to make a treatment plan that is right for what is important to that patient. It also helps everyone involved know the right thing to do in a medical crisis, from the*

*patient's primary care doctor, nursing home, or hospital to EMS or an ER doctor. When the person's health has a change, the form helps start a new conversation and may be updated or changed at any time. Arizona has tried to fill this communication gap through the Prehospital Medical Care Directive, commonly known as the Orange Form. Unfortunately, this form still leaves gaps, especially when patients want to specify in more detail their level of hospital transfer, invasive or noninvasive ventilatory support, or artificial nutrition.*

*As the principal investigator for the main AzMOST pilot, I have seen a high level of engagement, with patients filling out the form about 75% of the time when offered. We serve a large population of Native American patients, primarily Navajo. We often hear physicians decline to have code status or goals of care discussions with patients because it is culturally taboo to discuss end of life care or DNR. However, we have shown that when the conversation is done in a culturally sensitive way, our Navajo patients (in fact all Native patients) engage in this conversation as often as non-Native patients, and a significant number choose to set future limits on care, such as a DNR order. We have also found major issues remaining with communication of these forms (infrastructure and patient understanding) as well as health care knowledge gaps. In order to improve end of life care, we must first have high quality conversations with patients and their families and the best possible access to palliative care. We must ensure wide spread access to palliative care education for all providers, including education specifically on the communication skills needed to have these discussions.*

**Models for early palliative care are emerging that are well accepted by patients and providers alike.**

**Gobi Paramandaram, M.D. Hospice of the Valley Out Patient Early Palliative Care Pilot**

*A recent Kaiser/Economist Survey showed that 71% of Americans say that they would prefer to die at home than in a hospital or nursing home but a smaller share (41%) expect to do so, demonstrating gaps between their wishes and expectations. Early Palliative Care interventions could help in diminishing that gap by eliciting conversations about death and dying prior to a crisis situation. At Hospice of the Valley we've developed a home Palliative Care program where a trained team meets patients in their own environment with the goal of developing a relationship and eliciting people's end-of-life wishes and documenting those over time.*

*We've even seen patients that are not specifically on a dying trajectory, but instead living with chronic illness and yet finding themselves lost in the current medical milieu of doctor visits, frequent medical testing and recurrent*

*hospitalizations. Our interdisciplinary team conducts home visits to educate patients about their disease process, coordinate communication, and elicit goals that allow them to stay at home and out of the hospital and/or nursing home.*

## **Current Status: Education for Physicians in End of Life Care in Arizona**

(Education workgroup: Chair Chip Finch, D.O., Jeanette Boohene, M.D.; Carla Denham, M.D.; Alan Molk, M.D.; Tom Neuman, M.D.; Akash Shah, M.D.; Jud Tillinghast, M.D.; Sarah Wypiszynski, MS IV)

### **Education for Medical Students on End of Life Care in Medical Schools in Arizona** (survey by Sarah Wypiszynski MS IV UACOMP)

Both allopathic and osteopathic medical schools in Arizona were surveyed for curriculum devoted to end of life care issues.

All had substantial educational components across all 4 years, including communication of difficult situations, advanced care planning, medical ethics and hospice/palliative care. All utilized professional patients to simulate difficult communications with patients and families.

### **Training in Residency programs (Maricopa Co.)**

Survey by Akash Shah, MD PGY-3 FP St. Joseph's Hospital, Phoenix.

I reached out to 7 programs in the Valley (five Family Medicine and two Internal Medicine). Only two programs indicated that they have formal curriculum time allocated to end of life issues. All residents do receive varying degrees of training and exposure but few programs have specific milestones that are tied to existing competencies in this particular area. Most have geriatrics rotations.

There are no formal requirements for residency training per the Residency Review Committee milestones in this specific area. Each year residents and their faculty mentors fill out milestones for the ACGME. The six core competencies for residency per the ACGME are: Patient Care, Medical Knowledge, Practice-Based Learning and Improvement, Interpersonal and Communication Skills, Professionalism, Systems-Based Practice. Under each of these areas, there are sub milestones which can address more specific markers of resident training, some of which can be program specific. While going through the Family Medicine milestones, I have realized that sub milestones can be added to any of the core competencies. For example, family meetings at the end of life (usually done during the ICU rotation) can be used as a sub milestone under the Interpersonal and Communication Skills, as well as Patient

Care. Another program utilized Objective structured clinical examinations to practice giving patients and their family bad news and then tied that to the Medical Knowledge, Professionalism, and Interpersonal and Communication Skills milestones. These are a few examples of what can be done to improve end of life training throughout the Valley to improve resident training and education in this vital area.

### **Training for practicing physicians (CME)**

Arizona Academy of Family Medicine (AAFP) included topics on end of life at this year's annual conference, as did the Arizona Osteopathic Medical Association's Annual Convention.

**Recommendation: Greater efforts should be made to encourage medical associations of the various specialties to include topics on care at end of life and to publicize these on ArMA website/ e-news.**

Recent Surveys (Hartford Fdn 2016) indicate that although most physicians believe that conversations with patients regarding end of life wishes are important, most do not have them. A number of barriers have been identified (lack of time, lack of training, personal discomfort, fear of upsetting patients, lack of payment). Effective training modules have been developed elsewhere and local palliative care physicians are available and willing to provide training to colleagues. Medicare now authorizes payment for end of life counseling.

**Recommendation: Training should be offered to all physicians who encounter patients nearing the end of life including; by primary physicians, hospitalists, ER, ICU, specialists. Efforts should be made to find ways to overcome resistance by physicians (and patients) to having these conversations.**

## **Policy Changes to Improve End of Life Care**

Policy change workgroup: Paul Stander MD, Chair; Jim Dearing, D.O.; Ron Fischler, M.D. Emmalee Kennedy MD; Heather O'Toole, M.D.; and Bruce Peek, M.D.

### **1. POLST (Physician Orders for Life Sustaining Treatment/ AZMOST)**

Presented by Emmalee Kennedy, MD Palliative Care Flagstaff and member, Thoughtful Life Conversations (AzHHA)

## **AZ Statutes Today**

Arizona Statutes Related to Health Care Directives

Living Will (A.R.S.§ 36-3261 et. seq.)

Health Care Power of Attorney (A.R.S.§ 36-3221-2)

HC Directive Conflicts (A.R.S.§ 36-3209)

A Mental Health Care Power of Attorney

Pre-Hospital Medical Care Directive (A.R.S.§ 36-3221-2)

## **National POLST Update on Names**

### **Arizona Legal Review & National POLST Recommendations**

Statutory Changes

Seek amendment of A.R.S. § 36-3209(B)

Seek amendment of A.R.S. § 36-3205(C) to grant providers immunity from civil and criminal liability and disciplinary action if the provider makes decisions based on the patient's known wishes

Add reciprocity language

Regulatory Changes

Work with ADHS to address concerns regarding order authentication.

Request a rule change to permit hospital employees to accept AzMOST/POLST form that is not signed by a medical staff member so orders can be implemented without delay

### **Defenses of POLST**

Ensures patient autonomy

Standardizes documentation

Optimizes communication (to diminish anxiety and disputes among families)

Minimizes the use of unwanted interventions

Simplifies decision making

Promotes consistency of care across care settings

Decreases interventions and cost of care at the end of life

### **POLST Success**

**Oregon Study: Location of Death and POLST Orders**

**58,000 deaths reviewed, 31% had POLST in Oregon registry**

**Patient treatment choices honored, including avoiding dying in hospital**

### **Why POLST/ AzMOST?**

People value autonomy (supports PSDA 1990)

Many fear death that comes too slowly and too late

Patient wishes often are not known.

The Advance Directive (AHCD) may not be accessible.

Wishes may not be clearly defined in AHCD

The AHCD is not a physician order

Allows healthcare providers to know and honor wishes during serious illness

### **POLST Benefits**

Promotes informed patients & surrogates

Gold Standard

Promotes quality care through informed end of life conversations and shared decision making

It's voluntary

It is an interactive process with patient/family and/or surrogate and HCP

Concrete medical orders that must be followed by HCP

Transportable orders that follow patient from care setting to care setting

Complements the AHCD

Provides guidance for treatments and triggers additional conversations

Addresses legal concerns when patient is incapacitated and provides clarity for providers and families

Encourages completion of POA

Can be nulled, reversed, updated

Incorporates the importance of comfort

### **POLST Opportunities**

POLST Tool has limitations

Complex, needs provider education and time to review and complete with patient/family or surrogate

Patient must be appropriately selected and medically informed, as well as surrogate

Misconceptions of POLST and frank opposition in Arizona

Will require change in legislation

Will require structure and process development

**Recommendation: Task Force recommends ArMA's legal/ advocacy staff explore the feasibility of moving POLST legislation forward for Arizona.**

## **2. Medical Aid in Dying**

The Task Force heard an ethics panel presentation held at ASU (Ethics at Twilight: Medical Aid in Dying) and from Rebecca Thoman, MD (Minnesota) and David Grube, MD (Oregon) with Compassion and Choices, an advocacy group in favor of this option; it also heard from Zuhdi Jasser, MD, who is opposed to physician involvement.

**Recommendation: At this point the Task Force recommends surveying AZ physicians on their attitudes and recommending that the ArMA Ethics Committee reconvene to review old policies (1996) regarding this topic.**

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# End of Life Care in Arizona - Where Do We Go from Here?

## The Joint ArMA/AOMA Task Force on End of Life Issues

*D was a 69-year-old male who developed renal cell carcinoma with lung and bone metastases at the time of diagnosis. He was treated with chemotherapy and radiation therapy with partial response and many complications, including serious, and ultimately intractable, pain. I visited every other week and we discussed life, death, and choices. He pursued chemotherapy and other efforts to extend life as long as possible, fully aware of the complications, and made the choice to endure them. He used his time well, but when he could no longer function, and pain was particularly difficult to manage, he enrolled in hospice and died peacefully shortly thereafter with family at his side, approximately two years from original diagnosis. His last question to his oncologist was, "Why didn't you tell me it would be this bad?"*

Ron Fischler, MD

Despite his incurable illness and untimely death, Ron's friend was fortunate compared to many Americans who succumb to life-limiting illnesses. He had a friend with medical expertise to help with the complex and confusing choices that patients face at the end of life; however, he died wishing he had better communication with his oncologist. He maintained a large degree of control over the type, amount and settings in which his care was provided, and ultimately died peacefully at home surrounded by loved ones.

Sadly, many Americans experience circumstances where their choices for care at the end of life are unheard or overlooked and often end up dying with poorly controlled symptoms in hospitals or nursing homes. Why does this happen and what can we as physicians in Arizona do to improve end of life care for our patients?

By the late twentieth century the impression that technology could stave off dying became very powerful and

to many in the medical establishment, death became equated with failure, rather than as a natural inevitable part of the life experience. Discussing death or providing a negative prognosis became virtually taboo under the false premise that providing honest information would destroy hope for both patients and their families.

The American health care system remains heavily focused on sophisticated acute inpatient care and is woefully inadequate to address the needs of frail elderly patients with multiple chronic conditions who comprise a majority of those who die in the United States, particularly as the Baby Boomer generation ages. "As an Emergency Medicine physician, I am saddened at how many patients end up in the [Emergency Department] when they would be far more humanely served in a palliative or hospice care setting," states Alan Molk, MD.

A substantial percentage of Medicare spending continues to occur in the last six months of life, often on interventions

that provide little or no benefit, which is neither clinically appropriate nor financially sustainable. There are myriad reasons for this, including “perverse” financial incentives that favor more care, regardless of the chance of benefit; perceived legal risks for physicians who do not acquiesce to “do everything,” even when they believe such efforts are futile; avoidance of advance care planning; and lack of understanding by both patients and physicians alike of the role and benefits of palliative care and hospice and/or the availability of such services.

Jud Tillinghast, MD, a retired critical care specialist reflects, “Addressing the difficult questions surrounding end of life is a daily problem in the ICU. I have seen family members divided and agitated, demanding aggressive care even if it only prolongs a patient’s suffering. We need more physicians (primary care, specialists, hospitalists and critical care) to communicate clearly and sensitively with patients facing a terminal condition, with assistance from the palliative care team, to help families honor the wishes of their loved ones and ideally to do this before a crisis occurs that results in the ICU admission.”

Many of the deficiencies in end of life care in the United States, and possible solutions, were highlighted by the Institute of Medicine in its 2015 report, *Dying in America*. A key message for physicians was to initiate advance care planning discussions as early as possible for individuals with serious illness. This is a role that most physicians fail to address, most often citing lack of time, inadequate reimbursement and inadequate training. Furthermore, when they do conduct such discussions and prognosticate regarding survival, physicians tend to be overly optimistic and overestimate life expectancy in order to not decrease their patients’ hope, which may be well-intentioned but is usually counter-productive.

Cottonwood cardiologist Bruce Peek, MD, states: “How we assist patients and their families during the dying process is just as important as how we assist them to prolong life. Educating patients and families regarding the nature and prognosis of their disease throughout the course of their illness, and eliciting their goals and preferences along the way is essential to what we do.”

The increase in palliative care programs and the recent emergence of hospice and palliative medicine as a recognized medical specialty have been beneficial. “Palliative care is specialized supportive care for people with serious illnesses and is provided by a team of doctors, nurses and other specialists. Unlike hospice care which is indicated for patients with a life expectancy of 6 months or less, palliative care is focused on providing comfort and appropriate at any stage of a patient’s illness to help with symptom management, address psychosocial and spiritual aspects of illness, and define and meet patients’ and families’ goals of care,” explains Stacie Pinderhughes, MD, Director of Palliative Care at Banner Health. “Numerous studies have demonstrated that the involvement of Palliative Care teams can increase patient and family satisfaction with their care and a landmark study in the *New England Journal of Medicine* demonstrated that Palliative Care services reduced the incidence of depression and actually prolonged survival

in patients with advanced lung cancer.”

Still, major gaps in end of life care persist. Many patients today also want more options as they face the end of life. This has fueled efforts and passage in numerous states of so-called “Medical Aid in Dying” or “Death with Dignity” legislation that provides a legal framework for physicians to prescribe medications by which patients with terminal illness can end their lives.

The Task Force on End of Life Care created by the Arizona Medical Association (ArMA) and the Arizona Osteopathic Medical Association (AOMA) is a multispecialty group of physicians from around Arizona. The mission of the Task Force is to assess the state of end of life care in Arizona and offer practical options to improve care for patients across our state. The group initially prioritized three areas:

- 1. Education.** How can provide effective, convenient and accessible educational efforts for both physicians and the public, and to help physicians increase their skills in end of life care? We also want to determine the level of interest of primary physicians, hospitalists, and specialists in Arizona if such training were made available.
- 2. Access to Palliative Care.** How can we assist to increase the availability and accessibility to hospice and palliative care services for patients across Arizona, and to enable advance care planning to occur earlier when it may be more beneficial?
- 3. Policy.** Assess Arizona physician attitudes regarding Aid in Dying legislation and other end of life care issues which may be subject to legislative efforts.

The first goal of the Task Force is to gather as many physician views as possible on these issues. To that end, the Task Force will send a survey to as many Arizona physicians as possible. Your feedback will help us transform the care our patients receive at their most vulnerable time in life. As Carla Denham, MD, a psychiatrist and member of the Task Force, observed, “I was not really surprised to learn that conversations about death and dying are often rewarding to patients and their families, since they frequently help to reduce fear and clarify treatment goals. What was surprising was how those same conversations alleviated my own fears as well.”

To learn more about the Task Force and its members, view article references, or to sign up for updates from the group, please visit [www.azmed.org/general/custom.asp?page=endoflifecare](http://www.azmed.org/general/custom.asp?page=endoflifecare). ■

*Paul E. Stander MD, MBA, FACP is Associate Chief of Staff for Geriatrics at the Phoenix VAMC and was Chief Medical Officer at Banner Good Samaritan and has worked with Hospice of the Valley for many years. He is Clinical Professor of Medicine at the University of Arizona - Phoenix College of Medicine.*

*Ron Fischler, MD, is a pediatrician in Scottsdale who has developed a strong personal interest in end of life issues. He has held leadership roles at Scottsdale Healthcare and in the Arizona Academy of Pediatrics and Arizona Medical Association. He is an Associate Clinical Professor at the University of Arizona College of Medicine.*