

Interview with Susan Del Pesco, Esq.

Elizabeth Healy, MPH

Judge Susan Del Pesco (Figure 1) was the first woman elected as President of the Delaware Bar Association and the first woman appointed to the Delaware Superior Court. She championed the opening of a Women's Work Release and Treatment Center, the creation of a chapel at Baylor Women's Correctional Institute (BWCI), and has led two book drives for residents at BWCI. Judge Del Pesco led an effort to identify and raise awareness about issues of gender-bias in the courts, as well as initiating the Superior Court's Project Rightful Owner, which is an effort to assist persons whose property has been sold at sheriff's sale to claim excess funds remaining after all mortgages and liens were paid. Finally, she has played an active role in the creation and enactment of the DMOST statute.

Figure 1. Susan Del Pesco, Esq.



LH: Can you tell me a bit about your background and how you first gained an interest in end-of-life issues?

SDP: I was on the superior court for 20 years, retiring in 2008. Shortly after I retired, I took a position in the Department of Health and Social Services as the Director of the Division of Long Term Care Residents Protection. Through that position, I became aware of many issues affecting people living in long term care facilities. One of those issues was how best to understand and respect each resident's end-of-life choices.

LH: Have there been any individuals or any specific experiences that may have led you to become more passionate about end-of-life decisions and medical orders?

SDP: There was a conference in 2009 at the Delaware Law School which I attended. Pat Bomba, a very effective advocate from New York, spoke at the conference about end-of-life medical orders, and how they differ from and are better than advance directives. That was my first introduction to the concept. It was directly relevant to the work I was doing, and of personal interest as a senior! Later, I became involved in the effort to have an end-of-life medical order

available in Delaware—the effort that ended with the enactment of DMOST, the Delaware Medical Orders for Scope of Treatment.

LH: What do you think makes end-of-life decisions so complex, and this process so challenging?

SDP: Like many things, once people understand the goal and the process, it is not complex, and the biggest challenge has been overcome with the enactment of the statute. DMOST is about a conversation. The conversation takes place at a time when the patient has reached that time when his or her provider would not be surprised if he or she died within the year. That timing is critical as it provides the best context for the decisions. The patient's actual health challenges are discussed so the decisions are made in the context of that patient's prognosis.

The decisions are then recorded on a prescribed form so that any health care provider will have easy access to clear directions. The form is portable, which means it travels with the patient to various care settings—hospital, nursing home, hospice, or home. And the law requires that providers give care as directed.

Health care providers who have had experience with end-of-life orders in their state say that having a process that invites people to participate in guided conversations so that each patient's desires can be known is a critical step forward. The patient's right to specify their end-of-life care has long been acknowledged by the law and medical ethics. The challenge has been providing a way to know those preferences.

Death is a very difficult subject for the patient, for families, and for care providers. That's why there have been so many times when family members are left struggling to make decisions, or there are situations where there are no available family members, so surrogates struggle to figure out what care a patient would have chosen.

If people, be they children, spouses, or legal agents, know end-of-life preferences, decision making is much easier on everybody. Conflict is avoided, and—most importantly—the patient's desires are respected.

LH: In your experience, have you seen any particularly impactful changes in processes or attitudes?

SDP: The baby boom generation is now getting to the age where this issue matters, and there are many, many of us. Thus, the need to provide a process for knowing end-of-life medical preferences has taken on a greater urgency.

Delaware's law allowing advance health care directives was a new idea when it was enacted in the 1990's, and it was an important first step. But advance directives have proven to provide little assistance in many circumstances because the decisions, made in a lawyer's office or elsewhere without medical input, sometimes were medically illogical—such as wanting CPR but not wanting ventilation.

And, more importantly, those decisions, made out of the actual context of a patient's condition and prognosis, often were stale—they no longer reflected the patient's preferences. The absence of a standardized form also made advance directives difficult to interpret, thereby limiting their utility. And, of course, an advance directive is just a piece of paper until it becomes a medical order. DMOST creates a medical order that is immediately actionable.

The most important thing is teaching patients that they are entitled to make decisions about their own care, and enabling medical providers to honor those decisions.

LH: What are your hopes for how these conversations will continue to be had with family members and loved ones?

SDP: My hope is that every person approaching the end of their life will have an opportunity to engage in a really meaningful conversation - more than once, if that is what they want - so that they can make informed decisions while they have the capacity to do so, with the comfort of knowing that those decisions will be respected.

There is reason to believe that's going to happen since CMS has recently authorized reimbursement for the conversations. Having the financial piece in place enables providers to allocate time so that trained personnel will be able to talk with the patients and, if desired, their family.

Certainly, a challenge lies ahead as many people need to be trained about the law, and how it is meant to work.

LH: How did you get involved with the DMOST statute?

SDP: Well, this began when the Academy of Medicine convened a group of interested parties in January of 2013. I was one of those people. I had just retired from the Division of Long Term Care, but was certainly interested in working on for the sake of everybody in the State of Delaware. A subgroup was created to draft the legislation. I had been involved in other legislative endeavors before so this was a good fit for me, along with a number of the other lawyers who participated in the effort.

LH: That leads into my next question, actually, what other projects or initiatives have you been involved in?

SDP: While with DHSS, and with the goal of protecting people - often seniors - from financial exploitation, I was involved in writing and enacting legislation which updated the Delaware Durable Personal Power of Attorney Statute. Delaware's statute now conforms to best national practices.

LH: You have been quoted saying you feel end-of-life issues are intertwined with civil rights issues, can you expand upon that at all?

SDP: I actually learned that from an ACLU document. The ACLU describes end-of-life medical orders as a civil rights issue, and when one reflects on the fact that there is a legal and ethical obligation to respect people's end-of-life preferences, and at the same time plenty of evidence that many times such preferences are ignored, it is easy to agree with that statement. People have a right to make those decisions for themselves, but without a process for capturing that information, it was an empty promise.

LH: What are some of the things you would like our readers to take aware from this issue?

SDP: I think the most important message is don't be afraid to talk about end-of-life issues when the time is appropriate. We have in our society an aversion to discussing death.

People, including many physicians, are very uncomfortable talking about it, and yet, if there is no conversation, everything is more difficult when the time comes. Providing the DMOST process, talking at a time when it doesn't feel frightening, is a very healthy step forward.

I also would like your readers to know that without the leadership of Kathleen McNicholas MD, John Goodill, MD, and the Academy of Medicine in gathering like-minded people to draft and support DMOST, and the work of Secretary Rita Landgraf and Debbie Gottschalk, Esq. of DHSS in getting the legislation passed, DMOST would not soon be available. I offer them my thanks.

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